Factors Influencing Self-Medicating with Codeine in Pain Management - An Exploratory Cross-Sectional and Longitudinal Qualitative Research Study

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Thesis submitted to the Department of Psychology, Faculty of Science and Engineering, in fulfilment of the requirements for the degree of Doctor of Philosophy, National University of Ireland Maynooth.

October 2023

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Table of Contents

Table of Contents .... **i**

Acknowledgements .... **vii**

Abstract .... **viii**

List of Tables and Figures .... **x**

Glossary of Terms .... **xi**

List of Abbreviations .... **xii**

Chapter 1: Introduction **1**

1.1 The codeine epidemic 1

1.2 Codeine 2

1.3 Misuse of codeine 3

1.4 Codeine legislation 6

1.5 Codeine use in Ireland 8

1.6 Chronic pain management and OTC codeine use 10

1.7 Irish health system 11

1.8 Rationale for the current study 12

1.9 Thesis outline 14

Chapter 2: Literature Review **17**

2.1 Introduction 17

2.2 Chronic pain definition and epidemiology 17

2.3 Types of chronic pain and intensity 19

2.4 Current understanding of chronic pain 21

2.5 Psychological models of chronic pain 22

2.5.1 Behavioural model 22

2.5.2 Cognitive-Behavioural model 23

2.6 Management of chronic pain 28

2.7 Challenges of managing chronic pain 30

2.7.1 Diagnostic uncertainty 30

2.7.2 Uncertainty in illness theory 31

2.7.3 Common-sense model of self-regulation 32

2.8 Self-management of chronic pain 33

2.9 Self-medicating in self-management of chronic pain 35

2.9.1. Risks in self-medicating 36

2.9.2 The role of the pharmacists in self-medicating 37
2.10 Barriers and facilitators of chronic pain self-management 41
2.10.1 Health status 42
2.10.2 Personal/Individual factors 44
2.10.3 Health system factors 48
2.10.4 Resources 55
2.10.5 Environmental factors 58
2.11 Current study 59
Chapter 3: Overview of study 61
3.1 Introduction 61
3.2 Study aims 61
3.2.1 Phase one objectives 61
3.2.2 Phase two objectives 62
3.3 Study design 62
3.4 Philosophical foundation of study 64
3.4.1 Pragmatism 64
3.5 Qualitative research 66
3.5.1 Intra-paradigm qualitative research 66
3.5.2. Compatibility in intra-paradigm qualitative research 67
3.6 Triangulation 68
3.7 Reflexivity in qualitative research 69
Chapter 4: Phase 1 – Pharmacy Professionals Cross-Sectional Research 72
4.1 Introduction 72
4.2 Research aim 72
4.2.1 Research objectives 73
4.3 Reflexive thematic analysis design 73
4.3.1 Participants 75
4.3.1.1 Sampling 75
4.3.1.2 Recruitment 76
4.3.1.3 Participant sample 77
4.3.2 Data collection 80
4.3.2.1 Development of interview guides 80
4.3.2.2 Piloting the interview questions 81
4.3.3 Conduct of interviews 81
4.3.4 Ethical considerations 82

4.3.4.1 Consent 82
4.3.4.2 Anonymity and confidentiality 82
4.3.4.3 Debriefing 83
4.3.5 Data analysis 83
4.3.6 Reflexivity in qualitative research 88
4.4 Findings of cross-sectional analysis of pharmacy professional interviews 90
4.4.1 Summary of findings 90
4.4.2 Theme 1: Unintended consequences of codeine regulations 91
4.4.2.1 A hindrance to providing support 92
4.4.2.2 Conflicts of interest 97
4.4.2.3 ‘It’s emotionally draining’ 103
4.4.3 Theme 2: Systemic failures 106
4.4.3.1 Classification of analgesics 107
4.4.3.2 Inadequate health services 113
4.4.4 Theme 3: Social influences 117
4.4.4.1 Evolving information sources 118
4.4.4.2 Lifestyle choices 120
4.4.4.3 Social norms 121
4.4.5 Summary of findings 123
4.5 Discussion 124
4.5.1 Unintended Consequences of codeine regulations 125
4.5.2 Systemic failures 129
4.5.3 Social influences 133
4.6 Conclusion 134
Chapter 5: Phase 2 - Longitudinal Qualitative Research 135
5.1 Introduction 135
5.2 Research aim 136
5.2.1 Research objectives 136
5.3 Longitudinal Qualitative Research Design 137
5.3.1 Time in Longitudinal Qualitative Research 139
5.3.2 Change in Longitudinal Qualitative Research 140
5.3.3 Iterative nature in Longitudinal Qualitative Research 142
5.3.4 Challenges of Longitudinal Qualitative Research 142
5.3.5 LQR approach in current study 143
5.3.6 Participants 144

5.3.6.1 Sampling of participants ... 144
5.3.6.2 Inclusion and exclusion criteria ... 145
5.3.6.3 Recruitment ... 146
5.3.6.4 Participant sample ... 147
5.3.7 Data collection ... 150
5.3.7.1 Development of interview guide ... 150
5.3.7.2 Evolution of the interview guide for subsequent interviews ... 151
5.3.7.3 Conduct of interviews ... 151
5.3.8 Adaptations due to COVID-19 pandemic ... 154
5.3.9 Ethical considerations ... 156
5.3.9.1 Ongoing consent ... 156
5.3.9.2 Anonymity and confidentiality ... 157
5.3.10 Data analysis ... 157
5.3.10.1 Longitudinal analysis ... 159
5.3.10.2 Across cases longitudinal analysis ... 166
5.3.10.3 Within cases longitudinal analysis ... 171
5.3.11 Reflexivity in qualitative research ... 173
5.3.11.1 Different selves ... 175
5.3.11.2 Reflexive data collection and interpretation ... 176
5.4 Summary of findings from longitudinal analysis across cases ... 179
5.4.1 Through-line: “Just managing” ... 179
5.4.2 Theme 1: Feeling disregarded ... 180
5.4.2.1. Trajectory 1: Continuity in feeling disregarded ... 195
5.4.2.2. Trajectory 2: Increases in feeling disregarded ... 199
5.4.3 Theme 2: Feelings of being misunderstood ... 202
5.4.3.1 Trajectory 1: Continuity in feelings of being misunderstood ... 206
5.4.4 Theme 3: OTC codeine is my enabler ... 207
5.4.4.1 Trajectory 1 – Increases in use of codeine as an enabler ... 214
5.4.4.2 Trajectory 2 – Decreases in use of codeine as an enabler ... 215
5.4.4.3 Trajectory 3 - Decreases and increases in use of codeine as an enabler ... 218
5.4.5 Summary of Section 2 ... 221
5.5 Findings from longitudinal analysis within cases ... 222
5.5.1 Introduction ... 222
5.5.2 Case History 1: Peter’s chronic pain journey ... 223
5.5.2.1 Theme 1: Feeling disregarded ... 224

5.5.2.2 Theme 2: Feelings of being misunderstood ... 229
5.5.2.3 Theme 3: OTC codeine is my enabler ... 231
5.5.3. Summary of Peter's case history ... 235
5.5.4 Case History 2: Amy's chronic pain journey ... 236
5.5.4.1 Theme 1: Feeling disregarded ... 237
5.5.4.2 Theme 2: Feelings of being misunderstood ... 243
5.5.4.3 Theme 3: OTC codeine is my enabler ... 245
5.5.5 Summary of Amy's case history ... 250
5.5.6 Concluding remarks ... 251
5.6 Longitudinal Qualitative Research Discussion ... 252
5.6.1 Introduction ... 252
5.6.2. Overview of key findings ... 253
5.6.3 Environmental factors influencing self-medicating habits ... 255
5.6.4. Social factors influencing self-medicating habits ... 260
5.6.5 Individual factors influencing self-medicating habits ... 263
5.6.6 Conclusion ... 269
Chapter 6: Synthesis Chapter ... 270
6.1 Introduction ... 270
6.2 Triangulation ... 271
6.2.1 Triangulation protocol in current study ... 273
6.2.2 Weighting of phases ... 274
6.2.3 Analysis ... 275
6.3 Reflexivity in qualitative research ... 278
6.4 Synthesised findings ... 280
6.4.1 Convergence ... 280
6.4.2 Complementarity ... 283
6.4.3 Silences ... 284
6.4.4 Dissonance ... 286
6.5 Discussion of key findings in the current study ... 289
6.5.1. Phase one and two findings ... 289
6.5.2. Synthesised findings ... 290
6.6 Environmental factors ... 292
6.6.1 Access to healthcare ... 292
6.6.2 Quality of healthcare ... 292
6.6.3 Classification of OTC analgesics ... 293

    - 6.6.4 Relationships with healthcare providers 294
- 6.7 Social factors 295
    - 6.7.1 Socio-economic status 295
    - 6.7.2 Psychosocial support 296
    - 6.7.3 Social influences 296
- 6.8 Individual factors 297
- 6.9 Study limitations 298
- 6.10 Original contributions of the study 300
- 6.11. Implications of current study 302
    - 6.11.1 Codeine provision implications 302
    - 6.11.2 Policy implications 303
    - 6.11.3. Research implications 304
- 6.12 Concluding remarks 306

References 308

Appendices 344

Acknowledgements

Firstly, I would like to thank my supervisor Professor Deirdre Desmond for believing in me, guiding, and challenging me to push boundaries, and for being a source of inspiration throughout this research project. I am sincerely grateful for your unwavering support. Your encouragement and knowledge transformed my vague research ideas into this thesis.

To my family and friends, thank you for supporting and encouraging me throughout this journey. To my husband, children, and brothers, despite the long and often frustrating journey, your love, patience, care, encouragement, prayers, advice, and sacrifices gave me the strength to keep on going even at times when I felt like giving up. I am eternally grateful to you for standing with me.

To my parents, even though you did not live to see this, my heartfelt appreciation goes to you for instilling in me the values of faith and self-belief despite the barriers and challenges of life. The completion of this journey is a testament of how all things are possible.

Finally, this research would not have been possible without the participants who gave up their valuable time to be part of this study. To the community pharmacy professionals who took part, thank you for taking time out of your busy schedules to share your experiences in what is a challenging aspect of your role. To all the participants who shared their chronic pain journey, thank you for sharing your very personal and painful experiences with me. I sincerely hope this thesis gives a voice to the untold stories central to self-medicating with OTC codeine-based analgesics.

Abstract

The use of over the counter (OTC) codeine-based analgesics in Ireland is high despite codeine's known misuse and abuse potential. Codeine misuse and abuse is an internationally recognised problem but quantifying the scale is challenging due to its availability without a prescription. The effects of codeine that lead to its misuse and abuse are typically initially discovered through legitimate pain management. However, the factors that influence positioning and transitioning on the continuum of codeine use in pain management within the general population are unclear. The aim of the current study was to explore the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. The study consisted of two phases: 1. a cross-sectional study with community pharmacy professionals (n=25), to explore their views and experiences on their interactions with codeine consumers in pain management; 2. a longitudinal qualitative research study consisting of four interviews, at 6-months intervals, with individuals living with chronic pain (n=10), to explore their experiences of self-medicating with codeine overtime. Phase 1 identified three themes: unintended consequences of codeine regulations, systemic failures, and social influences as issues at the interface between community pharmacies, and OTC codeine consumers in self-medicating. Phase 2 identified the through-line "just managing" as the driver of self-medicating with OTC codeine overtime across three emblematic themes; feeling disregarded, feelings of being misunderstood, and 'OTC codeine is my enabler'. Overall, the emblematic themes highlighted how; 1. environmental factors (access to healthcare, quality of healthcare, classification of OTC analgesics and relationships with healthcare providers), 2. social factors (socio-economic status**,** psychosocial support, and social influences) and 3. individual factors (health status**,** knowledge and experience**,** psychological stability, and motivation and beliefs) pose as risk or protective factors to self-medicating on the continuum of OTC codeine use in pain management. The findings have significant implications for codeine provision, and healthcare policies going forward. The availability of codeine as an OTC analgesic has implications to its misuse and abuse in pain management. Upscheduling of OTC codeine to prescription only can minimise the misuse and abuse of codeine in pain management in Ireland. In addition, there is immediate need to provide adequate accessible care through primary and secondary care services informed by a national model of care in pain management services in Ireland. The current organisation and delivery of care has significant gaps that can influence elevated self-medicating with over-the counter codeine-based analgesics in pain management.

List of Tables and Figures

Table 1: Demographic Characteristics of Phase 1 Participants.. 79

Table 2: Summary of Phase 1 Themes and Sub-themes 91

Table 3: Characteristics of Phase 2 Participants 148

Table 4: Engagement of Phase 2 Participants 149

Table 5: Overview of themes and subthemes from cross-sectional analysis………………165

Table 6: Questions to guide the analysis of LQR data. Adapted from Saldana (2003) 170

Table 7: Questions to guide the analysis of Case Histories. Taken from Neale (2021)....... 173

Table 8: Factors Influencing Positioning and Transitioning on the Continuum of OTC Codeine Use in Pain Management 291

Figure 1: Factors Influencing Self-Medicating with OTC Codeine-based Analgesics in Chronic Pain Management **.. 254**

Glossary of Terms

Term	Definition
Analgesic	A drug used to achieve relief from pain.
Chronic pain	Pain that persists for more than the expected healing time of typically 3 to 6 months in the absence of structural abnormalities or progressive disease.
Codeine	A short-acting opiate analgesic derived from morphine used for its analgesic, antidiarrheal and antitussive effects.
Codeine abuse	Codeine use outside the recommended guidelines including for recreational purposes.
Codeine misuse	Legitimate medical use of codeine at significantly higher and more frequent doses than recommended in-order to manage pain.
Emblematic theme	Broad representations linking thematic and process analysis in capturing patterns or relationships within a data set.
Over the counter	Medication that can be purchased without a medical prescription.
Pharmacy hopping	Sourcing of pharmacy restricted over the counter medicines by moving from pharmacy to pharmacy.
Self-management	The active role that individuals suffering with chronic pain take to manage pain and minimise pain interference with everyday life, mood, and relationships.
Self-medicating	A self-management strategy that provides an opportunity to administer medications without the need to seek medical intervention or supervision.
Through-line	The common thread which captures change, continuity, and processes at play through time.

List of Abbreviations

ACT	Acceptance and Commitment Therapy
CBT	Cognitive Behavioural Therapy
CCM	Chronic Care Model
CDSMP	Chronic Disease Self-Management Programme
CLP	Chronic localised pain
CSM	Common-Sense Model
CWP	Chronic widespread pain
EU	European Union
FA	Fear-Avoidance
GP	General Practitioner
HL	Health literacy
IASP	International Association for the Study of Pain
ICCC	Innovative Care for the Chronic Conditions
IFSMT	Individual and Family Self-Management Theory
IPA	Interpretive Phenomenological Analysis
LDN	Low Dose Naltrexone
LQR	Longitudinal Qualitative Research
MBCT	Mindfulness-based cognitive therapy
MBI	Mindfulness-based interventions
NSAID	Non-steroidal anti-inflammatory drugs
OTC	Over the counter
PF	Psychological flexibility
PHI	Private Health Insurance
PMP	Pain Management Programme
PSI	Pharmaceutical Society of Ireland
RTA	Reflexive thematic analysis
SE	Self-efficacy
SES	Socio-economic status

SFMF	Self and Family Management Framework
TA	Thematic Analysis
UK	United Kingdom
US	United States
WHO	World Health Organisation

Chapter 1: Introduction

1.1 The codeine epidemic

The use of non-prescription medicinal products containing codeine is a significant public health concern due to codeine's widespread misuse and abuse potential (Cooper, 2013; Richards et al., 2022; Van Hout & Norman, 2016). Codeine is the most accessible widely used opiate and its misuse is an internationally recognised problem that is well documented in most countries including in Ireland, Australia, United States, United Kingdom, France, Germany, Spain, India, Nigeria, and South Africa (Anil et al., 2017; Cooper, 2013; Ishola et al., 2022; Nielsen, 2018; Roussin et al., 2013; Van Hout, et al., 2017; Wells et al., 2019).

Quantifying the scale of the problem is challenging as analgesics containing codeine can be sold over the counter (OTC) without a prescription in most countries. In addition, access to OTC sales data is limited due to lack of robust data collection (Richards et al., 2022). Furthermore, based on the 1961 Single Convention on Narcotic Drugs, it is not mandatory to report consumption data of OTC codeine as it is classified as a schedule III drug which according to the convention are "not liable to abuse and cannot produce ill effects" (United Nations, 1961).

In research carried across 31 countries in Europe, Africa, Asia, America and South America, Ireland had the second-highest sales per person for OTC codeine-based analgesics. Datasets covering between April 2013 to March 2019 show that Ireland sold 30 dosage units per person and was only exceeded by South Africa which sold 36 dosage units per person. The Irish population buys more than twice as much OTC codeine as compared to the United Kingdom and six times more than Poland (Richards et al., 2022).

1.2 Codeine

Codeine is a short-acting opiate analgesic derived from morphine used for its analgesic, antidiarrheal and antitussive effects (Roussin et al., 2013). For OTC use, it is typically combined with other analgesics such as paracetamol and non-steroidal anti-inflammatory drugs (NSAID) such as ibuprofen which have greater efficacy than codeine on its own (Hockenhull et al., 2022). A systematic review on the efficacy of low-dose codeine in combination with analgesics that included 10 randomised controlled trials reported small to moderate added pain relief for acute and chronic pain conditions (Shaheed et al., 2019). The added analgesic effect of low-dose codeine in pain management is minimal. Low dose codeine, is nonetheless associated with various side effects (Frei et al., 2010; Labianca et al., 2012; Parry et al., 2015).

Common side effects of codeine include constipation, vomiting, dizziness, stomach pain and itchiness. Serious side effects include dependence, seizures, slow heart rate and shortness of breath. Despite codeine's adverse side effects, it also has side effects that have been implicated as the cause of its misuse and abuse e.g., relaxing effects, feelings of euphoria, feelings of drunkenness and altered consciousness (Frei et al., 2010; Hockenhull et al., 2022). With prolonged use, physiological and psychological dependence can occur, and the levels required for dependence vary significantly from individual to individual. This is due to the varying rates of metabolism per individual as the breakdown of codeine in the stomach is dependent on the speed of metabolism to achieve maximum effect (Van Hout, 2015). In addition, adverse side effects of codeine dependence are related to excessive or long-term use of non-opioid analgesics like paracetamol and ibuprofen typically combined with codeine for OTC use. Associated risks include gastric and peptic ulcers, gastrointestinal haemorrhaging, hypokalaemia, and renal failure (Frei et al., 2010; Labianca et al., 2012).

Codeine tolerance levels can quickly build up resulting in the need for higher and more frequent doses to achieve the desired effect. Once physiological and psychological dependence is reached, withdrawing can cause opiate withdrawal symptoms like headaches, restlessness, nausea, muscle aches, stomach cramps, insomnia, and mood swings (Foley et al., 2017; Frei et al., 2010; Van Hout, 2015).

1.3 Misuse of codeine

Misuse of codeine involves legitimate medical use at significantly higher and more frequent doses than recommended in-order to manage pain. Abuse involves use outside the recommended guidelines for recreational purposes (Van Hout, 2014). On the continuum of codeine use, there is: 1. consumption within recommended doses; 2. consumption that does not exceed recommended doses but meets criteria for misuse based on frequency of use; 3. consumption of higher doses than recommended for therapeutic or non-therapeutic use; and 4. consumption of doses significantly higher than the recommended doses in the context of elevated codeine dependence (Casati et al., 2012; Cooper, 2011). Once dependence occurs in codeine use, cravings associated with codeine withdrawal reinforces continuous use (Van Hout, 2014; Foley et al., 2017; McDonnell, 2019). The availability of codeine as an OTC medicine contributes to its misuse as OTC medicines are generally perceived as safe. The options to buy from multiple suppliers also significantly adds to the potential for misuse (Roussin et al., 2013). Detoxification requires opioid substitution treatment comprising of similar regimes as those used for heroin addiction whereby suboxone or methadone are used as a safe opioid replacement therapy to counteract withdrawal symptoms. Sedatives and intense therapy can also be employed in the detoxification of codeine (Joint Formulary Committee, 2022).

Codeine misusers present a unique clinical profile that deviate from other opiate misuser profiles. They include misusers of all age groups and gender, misusers with no history of substance abuse or co-occurring conditions, patients with chronic pain and alcohol and illicit drug users (Cooper, 2011; Nielsen et al., 2013; Van Hout, et al., 2017). The potential for iatrogenic dependence in codeine use is typically not initially realised and misusers view themselves as different from other substance abusers (Cooper, 2011; Nielsen et al., 2018). Addiction models can illustrate the cognitive and behavioural concepts underlying the use of codeine in this unique and distinct clinical profile of opiate misusers (Bechara et al., 2019; Beck & Haigh, 2014; Van Hout et al., 2017). According to the cognitive model of addiction, substance misuse like codeine emerges from the interplay between situations, beliefs, and behaviours (Beck & Haigh, 2014). To illustrate the role of these cognitive and behavioural concepts in codeine use, Van Hout et al. (2017) applied the cognitive developmental model of substance abuse by Liese and Franz (1996) to the trajectory of codeine use moving from pain management towards misuse, abuse, and dependence. The sample included 46 adults living in Ireland and South Africa who were accessing treatment for misusing and abusing codeine and had developed psychological dependence. Findings reported how codeine misuse and dependence was maintained through physiological determinants such as pain, withdrawal and tolerance, and psychological influences such as therapeutic need, relief from anticipated pain, emotional distress, and the sedative effect of codeine. Environmental influences such as availability of codeine were highlighted as mediators for progression of misuse. Concept mapping of codeine misuser's experiences to the cognitive developmental model of substance abuse highlighted seven interacting factors that influenced use, misuse, and dependence on codeine (Van Hout, Norman, et al., 2017):

1. Early life experiences, schemas, exposure and experimentation with addictive behaviours, and development of perceived benefits of codeine, were all highlighted as influential to initial consumption of codeine before continuous use.
2. Activating factors that predispose individuals to risk of codeine misuse included internal and external factors. Internal factors included physical pain, depression, anxiety, and psychological trauma. External factors included adverse life experiences like unemployment, divorce, reduced social interactions and social isolation. These activating factors were situated in a context where availability of codeine as a legitimate OTC analgesic for pain management enabled use.
3. Beliefs activated. Beliefs on codeine are activated based on the benefits of consuming codeine to activating factors and subsequently influence the use of codeine. These include anticipatory beliefs that focus on the efficacy and benefits of codeine and automatic beliefs that focus on the relief and expectations associated with codeine use.
4. Automatic thoughts. These result as a consequence of beliefs activated due to use of codeine and associated anticipatory and automatic beliefs. Automatic thoughts associated with codeine will mirror the beliefs held about the benefits of using codeine. For example, ‘feel better’, ‘improved life’, ‘take one’.
5. Transitioning to misuse and dependence. Continuous use due to activating factors, beliefs and automatic thoughts has the potential to lead to elevated use. Lack of awareness of dependence potential, use for legitimate therapeutic reasons and OTC availability can all contribute to continuous use.
6. Enabling beliefs. These reinforce the continuous use of codeine through justifying codeine use as a coping mechanism for physical and psychological distress as well as life stressors.

7. Instrumental strategies. Once individuals have transitioned to misuse and have developed enabling beliefs, their focus centres on acquiring and developing strategies to obtain codeine supplies through legitimate sourcing.

The cognitive behavioural approach to substance abuse brings understanding of the underlying concepts in codeine use. However, from a neurobehavioral approach Bechara et al. (2019) implicated the overlap between the analgesic and the reinforcement effects of opioids as influential to continued use due to the overlap in brain structures that process pain and reward. Based on the cognitive behavioural approaches and neurobehavioral approaches to addiction, the misuse of codeine cannot be attributed to a single factor. Codeine misuse and abuse is initiated and maintained due to a complex interaction of biological, psychological, and social factors.

1.4 Codeine legislation

Codeine supply legislation approaches differ internationally and are determined by each individual country. Some countries restrict quantities sold, others require addiction potential information included on packaging, others restrict advertising and public displays of products, whilst others restrict the sale of any codeine sales without a medical prescription (Foley et al., 2015; Richards et al., 2022). Australia, Germany, Italy, France, Finland, Greece, and Portugal are among some of the countries that require a prescription to supply any strength of codeine. Contrarily, Ireland, United Kingdom, Denmark, and South Africa are among countries that can supply codeine without a medical prescription albeit with varying degrees of restrictions associated with supply. Within the European Union (EU), there has been no attempt to unify codeine regulation approaches to date (Foley et al., 2015; Hockenhull et al., 2022).

The Pharmaceutical Society of Ireland (PSI) introduced regulations in 2010 in the supply of OTC medicines containing codeine. In Irish law, codeine is classed as Schedule 5 under the controlled drug regulations meaning that it can be supplied to patients over the counter under the supervision of a pharmacist (Pharmaceutical Society of Ireland, 2019). Current codeine regulations (Pharmaceutical Society of Ireland 2019, pp. 5–6) state that:

1. “Codeine containing medicinal products must not be made available to the public for self-selection and should be stored where they are not visible to the public, ideally in the dispensary where pharmacists can monitor supply. Supply of codeine medicines can only be made by or under the personal supervision of a pharmacist”.
2. “Codeine should only be supplied when a pharmacist deems such a supply to be necessary and only when a non-opioid analgesic, e.g., paracetamol, aspirin, or ibuprofen, has not proven sufficient to relive the patient’s symptoms”.
3. “Medicines containing codeine should be used for the shortest time possible and for no longer than three days without medical supervision. Where symptoms persist after the three days, the patient should be referred to a medical practitioner”.
4. “Pharmacists must also ensure that patients are advised of the importance of adhering to the recommended dosage and duration of use as well the addictive potential associated with overdose and or/prolonged use. Patients should also be counselled in respect of potential adverse reactions or side effects”.
5. “Where misuse or abuse is suspected, pharmacists can decline sales”.

Despite the implementation of regulations at point of sale, international research on the use of codeine shows an association between availability of codeine as an OTC product and overuse (Richards et al., 2022; Wells et al., 2019). A comparison study found the prevalence of codeine use eight times greater in Spain and four times greater in the UK where codeine is available OTC with some regulations than in Germany and Italy where codeine is only available on prescription (Hockenhull et al., 2022). A survey of 300 UK-based GPs found that 87% believed the availability of codeine OTC was associated with misuse. In addition, they believed that patients were not fully aware of the risks associated with OTC codeine consumption (Foley et al., 2016). Following the ineffectiveness of codeine supply regulations similar to the current Irish regulations, France and Australia up-scheduled codeine to prescription only in 2017 and 2018 respectively (Bruno & Nielsen, 2018; McCoy et al., 2022). In Australia, during the first year after the upscheduling of codeine, first line analgesics use increased significantly whilst codeine prescriptions slightly increased. In addition, the number of codeine-related calls to Poisons Information Centres substantially decreased (Schaffer et al., 2020). Further research in Australia with individuals who reported regular OTC codeine use prior to the upscheduling found a significant reduction in codeine use three years post upscheduling (McCoy et al., 2022).

1.5 Codeine use in Ireland

Despite, the strict regulations on the supply of OTC codeine-based analgesics, codeine is a highly used opiate in Ireland. Misuse and abuse of codeine in Ireland is relatively under documented in research studies despite the problem being termed an ‘emerging epidemic’ (McDonnell, 2019). There are limited screening methods to detect codeine misuse and likewise limited treatment options for misuse. Ireland has more pharmacies per capita in comparison with United Kingdom but has a lower number of pharmacists per pharmacy possibly making it difficult to achieve pharmacovigilance required in effectively implementing codeine regulations (Pharmaceutical Society of Ireland, 2016). Despite General Practitioners (GPs) being aware and concerned about codeine misuse, they are unaware of the extent of OTC codeine misuse due to its availability without the need of a medical prescription and have limited resources to intervene where misuse is detected (Foley et al., 2017).

In 2016, a study carried out in Ireland (n=1023), revealed that 43% of participants indicated codeine-based analgesics as the preferred choice of painkillers for individuals suffering from headaches (O'Sullivan et al., 2016). The sample included individuals requesting analgesics for headaches from a mixture of 158 urban, sub-urban and rural community pharmacies in the Munster region of Ireland. In addition, a study of the lived experience of codeine misusers undergoing treatment or in recovery in Ireland reported that most participants did not initially realise the risks involved with codeine use, despite receiving advice from pharmacies, as it was sold without requiring a prescription for pain management. However, as the euphoria effect was discovered, an awareness of dependence was there but most were in denial that they could be opioid addicts. Physical pain, emotional stress, codeine's pleasurable effect, the ease of availability through multiple pharmacies, dependence, adverse withdrawal effects and stigma in seeking support were all highlighted as contributory factors to misuse and abuse of OTC codeine (Van Hout et al., 2018).

There is an awareness among the population of the problematic use of codeine in Ireland. Various media reports have reported pharmacy hopping as influential to the codeine epidemic in Ireland whereby individuals obtain huge quantities of codeine by moving from pharmacy to pharmacy. The ease with which individuals can get a supply of codeine-based analgesics in Ireland has been heavily criticised (Foley et al., 2015; McDonnell, 2019). In

May 2022, an investigative reporter obtained 10 boxes of codeine-based analgesics in pharmacies located around Dublin City with minimal caution given on the addictive potential of the medication (Higgins & Farrell, 2022). Similarly, to test the effectiveness of the codeine regulations, in October 2022, a researcher obtained 408 codeine-based analgesics in 18 pharmacies situated in 3 counties over 3 days. None of the 18 pharmacies involved adhered to all the codeine regulations surrounding the supply of OTC codeine (McMorrow, 2022).

In addition, the problematic use of codeine in Ireland has been a prominent topic of discussion in Dáil Éireann (Irish House of Representatives). This has resulted in the Minister for Health, Minister of State at the Department of Health, and Tánaiste (Deputy Prime Minister) providing written responses on parliamentary questions posed on the extent of codeine addiction in Ireland and the government's approach in addressing the problem. However, to date there have been no further steps taken to address the regulation of codeine sales in Ireland (Oireachtas, 2022).

1.6 Chronic pain management and OTC codeine use

Individuals living with chronic pain are at higher risk of transitioning into OTC codeine misuse and abuse due to the need to frequently self-medicate to find symptomatic relief from pain (Cohen et al., 2021; Perrot et al., 2019). In Ireland, the burden of chronic pain is substantial, with approximately 1 in 3 adults experiencing moderate to severe pain constantly or intermittently (Breivik et al., 2006; Raftery et al., 2011). The risk of transitioning into codeine misuse is high as management of chronic pain is associated with elevated self-medicating (Perrot et al., 2019; Rogers et al., 2020). In the case of Ireland, this risk may be further exacerbated due to the lack of adequate chronic pain management services in publicly funded hospitals (Purcell et al., 2022). To date, there is no national strategy for chronic pain management in Ireland and there is a shortage of specialist practitioners required to deliver an effective meaningful multidisciplinary chronic pain management service. The Irish health service is characterised by unequal distribution of services, long waiting lists, and limited chronic pain management services, it cannot compare with services provided in other jurisdictions in chronic pain management (Purcell et al., 2022).

1.7 Irish health system

Ireland does not have a universal health services entitlement system. Rather it has a 2-tier public and private system (Burke et al., 2018). Eligibility on the public system is mainly based on low income and entitles those who qualify a medical card. A medical card is a card that entitles recipients to free medical care and selected medical services in Ireland. Approximately one third of the population have a medical card and receive GP, inpatient, and outpatient hospital care for free with a modest dispensing fee charged by pharmacies for prescriptions. Approximately two thirds of the population are on the private system and must pay for GP care, public hospital emergency department care without a GP referral, statutory charges for public hospital stays and prescription charges with a maximum threshold per month. In addition, around 10%, of the population qualify for a GP visit card which provides only free GP care (Central Statistics Office, 2019). However, Ireland has a private health insurance (PHI) market accessible to both public and private patients. PHI is supplementary in nature and affords faster access to services and more opportunities and choices of health providers both in public and private health services (Murphy et al., 2020; Whyte et al., 2020). There are shorter waiting lists for both outpatient appointments and inpatient admissions for individuals accessing services under PHI than those accessing publicly (Whyte et al., 2020).

The current organisation and provision of care In Ireland means level of access and quality of care for individuals living with chronic pain is dependent on the health scheme they are eligible to and affordability of PHI instead of need. The literature on the influence of health systems on self-medicating in chronic pain management will be discussed in detail in the next chapter.

1.8 Rationale for the current study

Over the counter pain medications can be effectively used to self-medicate to alleviate short-term mild to moderate pain and in chronic pain management. Appropriate use in self-medicating has significant potential to reduce the burden of illness on healthcare systems (Cooper, 2013b). However, inappropriate use of OTC codeine-based analgesics has been reported to have adverse effects that include dependence, addiction, cooccurring conditions and fatalities (Hopkins et al., 2018; Mill et al., 2018). The fact that codeine is legally supplied by pharmacists in the legitimate self-management of pain makes the subsequent transitioning to misuse and iatrogenic dependence potentially insidious. Despite pharmacy professionals being well-positioned and trained to advise on safe self-medicating in pain management, research has shown that the conceptualisation and perception of risk differs between pharmacy professionals and consumers (Hibbert et al., 2002; Traulsen, 2004). This is problematic as codeine consumers may choose to disregard the advice of pharmacy professionals. Pertinent to this discrepancy in perceptions of risk is the emergence of a new phenomenon of the ‘new consumer’ in consumer behaviour trends (Chan & Tran, 2016; Traulsen, 2004). Research on consumer behaviour trends in pharmacies has identified a shift in consumer behaviour from the more traditional passive pharmacy professional led consumer to a new consumer. The new consumer is described as information strong, increasingly demanding, willing to challenge pharmacy professionals’ authority and more autonomous (Chan & Tran, 2016; Traulsen, 2004). The emergence of an autonomous new consumer has potential for risks to be overlooked in OTC medications as consumers often have a misplaced sense of confidence in self- diagnosis and self-medicating (Chaar & Kwong, 2010). In a comparative exploration of community pharmacists views on the management of OTC and prescription codeine across Ireland, United Kingdom and South Africa, Carney et al. (2016) highlighted the need for further research on the central role of community pharmacies in the first-line management and reduction of codeine misuse in Ireland. In consideration of the elevated use of codeine in Ireland despite the supply regulations (Richards et al., 2022), there is need for research to explore the issues at the interface between community pharmacies and codeine consumers in OTC codeine supply to understand the factors that influence codeine consumption in Ireland.

In addition, the effects of codeine that lead to its misuse and abuse are typically initially discovered through legitimate pain management (McDonnell, 2019; Van Hout et al., 2018). With the prevalence of chronic pain in Ireland, the risk of codeine misuse and dependence is elevated (McDonnell, 2019; Purcell et al., 2022; Van Hout et al., 2018). Despite research suggesting that the effects of codeine are initially discovered through legitimate pain management before transitioning into misuse and subsequently abuse, transitioning from recommended use to misuse and abuse is not inevitable. Research in Ireland so far has concentrated on the experiences, behaviours and treatment of codeine misuse and abuse with participant samples typically comprised of codeine misusers seeking help, referred to specialist management services, and recruited through medical settings (Cohen et al., 2010; Kimergard et al., 2017; Van Hout et al., 2018; Van Hout et al., 2017). The current evidence is insufficient to understand the processes that subsequently lead to help-seeking or referrals for codeine misuse treatment in the general population. There is need for research to explore the factors that influence the positioning and transitioning on the continuum of codeine use with samples from the general population self-medicating for pain management. Understanding these factors will contribute knowledge that can inform policy and practice in safe codeine provision and consumption. Therefore, the overarching aim of the current study was to explore the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management.

1.9 Thesis outline

This thesis describes two related studies that explore the factors influencing OTC codeine use in pain management from the perspectives of both pharmacy professionals tasked with safe supply of OTC codeine and individuals self-medicating with OTC codeine in chronic pain management within the general population. Exploring the views and experiences of pharmacy professionals and the lived experiences of individuals self-medicating with OTC codeine provided a multidimensional interpretation of the factors influencing self-medicating with OTC codeine-based analgesics.

Following on from this introduction, Chapter 2 presents a literature review. The purpose of this chapter is to situate chronic pain as a condition experienced within multiple, complex interacting individual, social, economic, and environmental contexts that influence the management of pain. Self-medicating is discussed as a self-management strategy in chronic pain highlighting inherent benefits and risks. The review concludes by focusing on the barriers and facilitators to self-management strategies to better understand the issues that have potential to influence level of codeine use in the self-management of chronic pain.

Chapter 3 presents an overview of the methods used in the study. It details the aims and objectives of the study, design of the study, philosophical assumptions underpinning the study, the qualitative research approaches adopted and a reflexive discussion.

Chapter 4 presents qualitative cross-sectional research with community pharmacy professionals. It details the methods used and the themes identified from analysis of interviews conducted with pharmacy professionals. It concludes with discussion of the key findings from the interviews with pharmacy professionals.

Chapter 5 presents longitudinal qualitative research conducted with individuals living with chronic pain. It details the longitudinal qualitative methodological approach adopted. Findings from longitudinal across case analysis of semi-structured interviews with individuals living with chronic pain conducted at four timepoints over a period of 18 months are discussed first. These are presented in the form of a through-line, represented by emblematic themes and corresponding trajectories that represent the experiences of participants over the duration of the study and demonstrate processes that influence change or continuity in self-medicating with codeine-based analgesics. Findings from longitudinal analysis within cases (two case histories) are then discussed to complement the longitudinal across case findings by capturing and highlighting distinctive aspects of participants' experiences in self-medicating that could not be captured with across cases analysis. The chapter concludes with a discussion of key findings from the longitudinal qualitative research with individuals living with chronic pain.

Chapter 6 presents the synthesised findings from the qualitative cross-sectional research and the longitudinal qualitative research. It details the methodological approach adopted in synthesising phase one and two of the study, then discusses the synthesised findings of the study and critically discusses the factors associated with positioning and transitioning on the continuum of OTC codeine use in pain management. The chapter concludes by outlining the original contributions and implications of the research.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents the literature review that informed the study. It contextualises the study by presenting chronic pain as a health condition and describes its underlying mechanisms. Key models of chronic pain are presented before discussing the management of chronic pain and associated concepts and theories that influence the challenges in chronic pain management. Self-medicating as a specific strategy to chronic pain management and its inherent benefits and risks are considered before focusing on the role of pharmacists in the self-management of chronic pain. The chapter concludes by focusing on the barriers and facilitators of self-management strategies that may influence self-medicating in chronic pain management.

2.2 Chronic pain definition and epidemiology

The International Association for the Study of Pain (IASP) defines pain as “an aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury” (Raja et al., 2020). This definition encompasses both acute and chronic pain. Acute pain is defined as pain that has a short duration lasting less than 6 months, is generally related to tissue damage and serves as a warning sign of threat to the body or disease. Pain is diagnosed as chronic when it persists for more than the expected healing time of typically 3 to 6 months in the absence of structural abnormalities or progressive disease (Treede et al., 2015). Unlike acute pain, chronic pain has no adaptive purpose and cannot be typically modelled as a physiological response to tissue damage as it can occur without tissue damage, exist in areas where tissue damage no longer exists and does not always respond to medical intervention (Mifflin & Kerr, 2014). Chronic pain frequently presents as secondary to an underlying condition termed as chronic secondary pain. Examples include chronic cancer-related pain, chronic posttraumatic and postsurgical pain, chronic secondary headache and orofacial pain, chronic neuropathic pain, chronic secondary visceral pain, and chronic secondary musculoskeletal pain. However, despite chronic pain frequently presenting as a result of a condition or injury, it can present in its own right as a condition known as chronic primary pain. Examples include fibromyalgia and non-specific low back pain (Mills et al., 2019; Treede et al., 2019).

Chronic pain is associated with reduced quality of life (Cho et al., 2012). It is associated with high prevalence of physical and psychological comorbidities which impact daily living (Kato et al., 2006; Kleykamp et al., 2021). Chronic pain interferes with a range of daily activities including sleep, mobility, employment status, independence, exercising, social roles, and social life (Breivik et al., 2006; Dansie et al., 2014; Elfving et al., 2007)). The association between chronic pain and disruption of daily activities is a result of interactions between physiological, psychological, and social factors (Bevers et al., 2016; Gatchel, 2013). For example, the relationship between quality of sleep and intensity of chronic pain is reciprocal and therefore poor sleep may exacerbate intensity of pain overtime. Depression, emotional responses to chronic pain, and pain related cognitions before sleeping can contribute to poor quality of sleep. In addition, other behaviours associated with chronic pain like decreased activities and resting during the day may play a role in sleep disturbances (Husak & Bair, 2020; Mathias et al., 2018). Furthermore, chronic pain is associated with reduced social roles therefore reducing social interactions (Lempp et al., 2009; Slade et al., 2009). Collectively the interaction of all these factors can exacerbate chronic pain and impact quality of life (Cho et al., 2012).

The World Health Organisation (WHO) recognises chronic pain as a global public health problem adversely affecting quality of life of a significantly high percentage of the world population (Elzahaf et al., 2012). It is a recognised major health concern in most Western countries, but it is difficult to estimate its prevalence. For example, in the United States (US), a national health survey estimated the prevalence of chronic pain as 20.4%, 1 in 5 adults (Pitcher et al., 2019). In the United Kingdom (UK), a meta-analysis estimated chronic pain prevalence between 38.4% and 48.6% in adults (Fayaz et al., 2016). In Ireland a prevalence, impact and cost of chronic pain study found a prevalence of 35.5% meaning 1 in 3 adults experience moderate to severe pain constantly or intermittently (Raftery et al., 2011). Older adults were more affected in comparison with younger adults in all 3 studies. In the UK and US studies, chronic pain was more prevalent in females than males but in the Irish study there were no gender differences in chronic pain prevalence. However, population-based studies have found that chronic pain tends to affect more women than men (Fillingim et al., 2009; Ruau et al., 2012) and can also affect children (Greenspan et al., 2007). Chronic pain adversely impacts quality of life by negatively affecting physical and psychological functioning and consequently working and social lives (Andrews et al., 2017). In addition, chronic pain places an ongoing substantial economic burden on healthcare systems, patients, and societies. The financial cost of managing chronic pain per annum is estimated at €200 billion in Europe alone (Van Hecke et al., 2013).

2.3 Types of chronic pain and intensity

Chronic pain can be classified into two forms: chronic widespread pain (CWP) and chronic localised pain (CLP). CWP is a more severe type of chronic pain presenting in several body areas that include the right and left side of the body, upper and lower parts of the body and the axial skeleton (Andrews et al., 2017; Viniol et al., 2013). Risk factors for development of CWP include female gender (Mansfield et al., 2016), excessive body weight (Arranz et al., 2014), smoking, anxiety and depression (Mundal et al., 2014), lack of social support and low socioeconomic status (Bergman, 2005). CWP is associated with cooccurring conditions for example, gastro-intestinal problems, diabetes, asthma, chronic obstructive pulmonary disease, kidney disease, arthritis and depression. Sufferers experience long lasting pain that can potentially lead to disability classifications and have worse health status (Andrews et al., 2017). Contrarily, CLP is chronic pain confined to one or a few body areas characterised by periods of pain and pain-free periods (Viniol et al., 2013).

Pain intensity in chronic pain is typically measured by use of numerical pain rating scales, visual analog scales, and verbal rating scales to assess and monitor pain (Langford et al., 2022; Robinson-Papp et al., 2015). The numerical pain rating scale is a unidimensional pain scale where respondent selects a number that best interprets pain intensity on a scale where 0 represents no pain and 10 extreme pain. A visual analog scale is a straight horizontal line with ends representing the extreme limits of pain intensity (no pain on one end and extreme pain on the other end). Verbal rating scores can also be used whereby individuals are asked to choose the best adjective that best represents pain from a list (Chiarotto et al., 2019; Chien et al., 2013).

Measuring pain intensity in chronic pain is complex due to its subjectivity, multi-dimensionality, and temporality. The validity and reliability of pain intensity measuring scales in chronic pain have been criticised for their simplicity that do not consider and capture the complex physical and emotional experiences associated with chronic pain (Langford et al., 2022; Robinson-Papp et al., 2015). The interpretation of pain intensity in chronic pain is intrinsically linked to functional capacity, quality of life, and coping with pain and as such these cannot be all captured with measurement tools (Chiarotto et al., 2019). However, despite their criticism, pain intensity measurement tools provide a summary of how individuals interpret pain and a practical approach in measuring pain intensity (Chiarotto et al., 2019; Langford et al., 2022).

2.4 Current understanding of chronic pain

Over the past five decades, the biopsychosocial model of chronic pain has supplanted the historical scientific conceptualisation of chronic pain as dependant on a direct linear relationship between identifiable pathology and symptoms (Gatchel, 2013; Meints & Edwards, 2018; Moayedi & Davis, 2013). Initially introduced by Engel in 1977 and subsequently applied to pain by Loser in 1982, the biopsychosocial model of pain postulates that psychosocial factors become of influence on illness as the illness becomes chronic. The biopsychosocial model of chronic pain conceptualises pain as a subjective interactive experience unique to each individual whereby biological, psychological and social influences interact bidirectionally (Bevers et al., 2016; Gatchel, 2013). In chronic pain, biological changes, psychological status and social contexts are linked and interact to determine how individuals perceive and respond to it. This is central to the variability among individuals living with chronic pain. For example, the psychological state of an individual can influence their physiology through stress response mechanisms as well as their appraisal and perception of pain (Gatchel, 2013).

Based on the biopsychosocial model, chronic pain cannot be understood by breaking it down to distinct biological or psychosocial components but requires a multi-disciplinary approach in understanding its aetiology (Alonso, 2004; Lea et al., 2004). By the same token, effective assessment of chronic pain requires a multi-disciplinary approach that besides the physiological symptoms, assess psychological symptoms for example depression and anxiety, personality traits and social factors (Adler, 2009; Bevers et al., 2016). The social factors that can influence chronic pain outcomes include environmental stressors, interpersonal relationships, family environment, social support and expectations, cultural and religious factors, work life and medical intervention access and affordability (Lea et al., 2004). Similarly, chronic pain management requires an interdisciplinary approach that identifies and addresses each factor in chronic pain (Gatchel et al., 2014).

2.5 Psychological models of chronic pain

2.5.1 Behavioural model

Early models of pain adopted classical and operant conditioning principles in their explanation of pain behaviours and coping (Keefe et al., 1986; Vlaeyen & Crombez, 2020). The behavioural models of pain assumed that pain behaviours, for example complaining, develop through positive and negative reinforcement whilst avoidance behaviours, for example inactivity, were associated with fear (Keefe et al., 1986; Vlaeyen & Linton, 2000). Based on the models, pain appraisals and beliefs acquired during pain experiences were influential to behaviour associated with efforts to return to normal activity. When behaviours initially triggered by nociception for example inactivity or guarded movements become associated with fear of pain, based on operant and classical conditioning, returning to normal activities can be problematic resulting in decreased activity overtime (Keefe et al., 1986; Turk & Okifuji, 2002). However, due to their focusing on motor pain behaviour and lack of consideration of the underlying emotional and cognitive aspects of pain, the behavioural models have been heavily criticised (e.g.) (Gatchel et al., 2007; McCracken & Morley, 2014; Sharp, 2001; Vlaeyen & Crombez, 2020).

2.5.2 Cognitive-Behavioural model

Cognitive-behavioural models of chronic pain include the cognitive aspects of pain that the behavioural models did not take into consideration (Vlaeyen & Crombez, 2020). Pain related cognitions are associated with the incorporation of adaptive or maladaptive coping strategies in chronic pain management (Linton & Shaw, 2011). The cognitive behavioural model of pain posits that an individual’s appraisals and beliefs regarding their pain symptoms influence their behavioural and psychological functioning and can directly influence the levels of emotional and physical disability experienced (Gatchel et al., 2007; Linton & Shaw, 2011). Based on the cognitive behavioural model, thoughts, mood, and physiological processes are all linked and reciprocally influence each other. Within this context, behaviour can be triggered by thoughts and can influence thought processes, whilst being simultaneously influenced by the individual and the environment (Turk, 2003).

From a cognitive behavioural model perspective, pain behaviours are a reaction of idiosyncratic understandings of reality informed by knowledge and beliefs shaped mostly by previous pain experiences (Linton & Shaw, 2011). This perspective is further supported by the Fear-Avoidance (FA) model which posits that the fear of pain can lead to individuals with chronic pain avoiding movement which then further exacerbates both pain and fear (Leeuw et al., 2007; Vlaeyen & Linton, 2000). Typically, fear is an adaptive response to real threat but based on the FA model can develop into anxiety for presumed future threats in chronic pain (Leeuw et al., 2007). The fear of experiencing increased pain informs preventative and protective behaviours for example avoidance of movement and hypervigilance for pain. Subsequently, this can generate disability, anxiety, depression and lowers pain threshold in future pain experiences (McCracken & Morley, 2014; Vlaeyen & Linton, 2000).

The main components in the FA model are pain severity, catastrophising, attention to pain, avoidance, vulnerabilities, deterioration of an individual's muscle due to disuse and disability (Leeuw et al., 2007). A meta-analysis on the association of components of the FA model found evidence that catastrophising, fear of pain and pain hypervigilance were associated with anxiety, depression, and pain related disability. More specifically, pain catastrophising was found to be strongly associated with pain intensity, anxiety, depression, and pain related disability (Rogers & Farris, 2022). Pain catastrophising can be defined as a negative cognitive affective response to actual or anticipated pain. It is characterised by an exaggerated negative orientation towards pain associated with pain magnification, rumination, and feelings of hopelessness. In the treatment of chronic pain, there is strong evidence that pain catastrophising is linked with increasing risk of developing persistent pain and disability (Andersen et al., 2016; Rogers & Farris, 2022), difficulties in achieving effective treatment (Linton & Shaw, 2011), and elevated self-medicating with analgesics (Jacobsen & Butler, 1996; Valdes et al., 2015; Vlaeyen et al., 2004).

Further evidence on the impact of catastrophising to pain outcomes can be found in the effectiveness of Cognitive Behavioural Therapy (CBT) in coping with pain (Gilliam et al., 2021; Turner et al., 2016). CBT is a treatment approach that focuses on behavioural and cognitive change to address pain-related maladaptive coping behaviours (Okifuji & Turk, 2015). The aim of CBT is not to eradicate pain, but it focuses on reduction and frequency of pain through targeting the components associated with pain intensity and disability for example, catastrophising, fear, avoidance, anxiety, and depression. Consequently, pain catastrophising is commonly targeted in CBT for chronic pain management as it is a predictor of pain outcomes (Gatchel, 2009; Valdes et al., 2015). Targeting catastrophising in CBT is associated with improved pain outcomes (Gilliam et al., 2021; Turner et al., 2007, 2016).

In addition to improving catastrophising, CBT has been found to improve self-efficacy in chronic pain management (Jackson et al., 2014; Nash et al., 2013; Turner et al., 2007, 2016). Self-efficacy is a construct that refers to an individual’s perception to execute behaviours required and judgements of their capacity to execute those behaviours to produce a desired outcome (Cheng et al., 2020; Turner et al., 2005). In chronic pain management, functional self-efficacy refers to an individual’s confidence and ability to execute specific physical activities to achieve improved pain outcomes. A meta-analysis to evaluate overall strengths of relation between self-efficacy and pain severity, functional impairment, affective distress found that self-efficacy was associated with positive outcomes in chronic pain and related functional outcomes (Jackson et al., 2014).

CBT can be effective in improving physical functioning, anxiety, depression, and quality of life in pain management (see review by Knoerl et al. (2016) on chronic pain and CBT). However, in their last updated Cochrane review on psychological therapies for pain management, Williams et al. (2020) reported short term effects evidence of CBT. Effectiveness for pain and distress six to twelve months post-treatment as well as for disability is minimal. There is also insufficient evidence to determine the risks of CBT for treating chronic pain indicating limitations for individuals managing chronic pain (Williams et al., 2020). In addition, access to CBT, beliefs on the superiority of pharmacological therapies, lack of trained professionals and stigma associated with psychological therapies can pose as further limitations of CBT in chronic pain management (Knoerl et al., 2016).

The Psychological Flexibility (PF) model further advances the cognitive behavioural approach. PF can be defined as a process focused cognitive behavioural model that facilitates the capacity to change behaviour by focusing on the present moment, change or persistence in behaviour to serve valued ends (Karayannis et al., 2023; McCracken & Morley, 2014; McCracken & Vowles, 2014). Central to this model is the concept that by changing attitudes to pain through being open, accepting, living in the present, awareness of thought patterns without judgement or detachment, and by focusing on valued ends, PF can develop which facilitates adaption to living with pain (Hayes et al., 2011; McCracken & Morley, 2014). PF includes 6 interrelated processes, acceptance, cognitive defusion, flexible present focused attention, self as observer, values and committed action (Hayes et al., 2006; McCracken & Vowles, 2008). These interrelated processes form the core dimensions of PF; awareness, acceptance and engagement which influences the coping strategies that an individual employs when faced with chronic pain (Karayannis et al., 2023).

Awareness is related to thoughts and patterns that bring non-judgemental attention to the present moment and is used in mindfulness-based interventions (MBIs) to increase sensitivity to the salient features of the environment and one's reactions therefore enhancing coping with pain (Forsyth & Hayes, 2014; Leça & Tavares, 2022; McCracken & Vowles, 2014). MBIs helps to prevent ruminating or worrying about pain and therefore minimise maladaptive cognitive processes (Hayes et al., 2011; Karayannis et al., 2023). This approach has been incorporated in various MBIs for example, Mindfulness-based cognitive therapy (MBCT) which has gained popularity as a self-management chronic pain technique (Marikar Bawa et al., 2015; Pei et al., 2021). MBCT incorporates key elements of CBT and mindfulness-based stress reduction and has been reported as beneficial to chronic pain (Dalili & Bayazi, 2019; De Jong et al., 2018). A recent meta-analysis on the efficacy of MBCT in chronic pain reported a significant effect on depression (Pei et al., 2021), similar to previous meta-analyses that included MBIs (Hilton et al., 2017; Veehof et al., 2016). However, the findings also reported minimal effect on pain intensity, pain inference and pain acceptance between group differences. Nevertheless, research on specific chronic pain conditions have reported benefits of MBIs for example: improved pain interference in primary headache

(Namjoo et al., 2019), improved illness perception, and levels of depression, anxiety, and stress in rheumatoid arthritis (Dalili & Bayazi, 2019).

Acceptance involves a behaviour pattern of continuous engagement in activity whilst pain is present. It is associated with willingness to experience pain and pain related stress without disengaging with activity (McCracken & Vowles, 2008). Pain acceptance is associated with reduced pain intensity and improved emotional and physical function in pain management (Gillanders et al., 2013; Kratz et al., 2018; Veehof et al., 2016). It is associated with adaptive coping and minimal need for pharmacological interventions (Esteve et al., 2021; Lin et al., 2015).

Engagement involves the ability to persist with actions guided by goals in a way that embraces the difficulties involved to achieve desired outcomes (Karayannis et al., 2023; McCracken & Morley, 2014). In chronic pain management, this involves engagement in valued activities like goal directed physical activities to manage chronic pain. An overview of Cochrane reviews of adults with chronic pain found that involvement in goal directed physical activities to manage chronic pain was associated with decreased pain intensity and improved physical functioning (Geneen et al., 2017).

Acceptance and Commitment Therapy (ACT) is a treatment approach that targets the 6 interrelated processes involved in PF, acceptance, cognitive defusion, flexible present focused attention, self as observer, values and committed action (Hayes et al., 2006). By targeting the processes required to develop PF, ACT’s approach is to teach individuals to stop denying, avoiding or struggling with negative emotions associated with pain and instead accept these feelings as appropriate responses that with commitment to make necessary changes they can move forward with their lives despite the pain (McCracken & Vowles, 2014). There is evidence that this approach of developing PF to improve coping strategies is effective in pain management (Godfrey et al., 2020; Luciano et al., 2014). Indeed, a review of the meta-analytic evidence of ACT found that ACT was efficacious for pain including anxiety and depression (Gloster et al., 2020). However, the impact of ACT can be condition specific and the benefits can vary overtime depending on condition. For example, Luciano et al. (2014) reported that ACT significantly improved functioning status of individuals with fibromyalgia post treatment, and this improvement was maintained at post-treatment follow up and after 6 months. However, Godfrey et al. (2020) reported a small improvement in the functional status of individuals with chronic low back pain and this was not maintained at 12 months follow up. In a review on status of ACT, Feliu-Soler et al. (2018) reported further limitations of ACT as; lack of specific evidence of its mediators and moderators resulting in limited individual-level characteristics that can be used to predetermine benefit potential for potential candidates; lack of treatment providers; barriers to access, and long waiting lists for most chronic pain populations.

2.6 Management of chronic pain

Management of chronic pain is complex and requires a multi-dimensional approach for optimum outcomes (Gatchel et al., 2014; Okifuji & Turk, 2015). Overtime, treatment of chronic pain has evolved from biomedically informed approaches only to include cognitive-behavioural approaches (Gatchel et al., 2014). In a recent Delphi study, Sharpe et al. (2020) reported a consensus on the necessary and desirable psychological intervention strategies for chronic pain management. The study findings state the necessity for psychoeducation strategies to increase activity and cognitive approaches as a first line of interventions and 24 other desirable strategies that could be included if required. However, McCracken (2020) argued for an evidence-based individualised and modularised treatment approach that only includes required components of psychological treatments for best outcomes in chronic pain management.

In recognition of the need for dedicated care in chronic pain management, Pain Management Programmes (PMPs) have been developed (British Pain Society, 2013; Turk, 2002). PMPs are chronic pain treatments guided by cognitive behavioural principles delivered by a team of interdisciplinary health professionals. The aim of PMPs is not to cure pain but to help individuals better manage chronic pain (Gatchel et al., 2014; Williams et al., 2020). Pain education and training in active self-management strategies that focus on individual factors are usually substantial components of PMPs, participants are taught exercise, attention diversion, activity pacing, goal setting, self-monitoring, deliberate exposure to pain, adherence to treatment plans, meditation, sleep management, thought management and communication skills (Du et al., 2017; Nicholas & Blyth, 2016). The efficacy of PMPs in improving health status, knowledge, and experience of managing chronic pain, psychological stability, motivation to adopt effective self-management strategies and beliefs on perceived control over chronic pain is well established (see Wilson (2017) and Williams et al. (2020) for reviews of the efficacy of chronic pain treatments guided by cognitive behavioural principles incorporated in PMPs).

Despite the evolving treatment approaches, the effective management of chronic pain remains complex. Indeed, the findings of a systematic review on the treatment of non-cancer pain reported a reduction of pain of only 30% for the best treatment outcomes out of all the different treatment modalities that included pharmacological, interventional, physical, psychological, and rehabilitative approaches in treating pain (Turk et al., 2011). Similarly, in a review of practices and advances in chronic pain management, Cohen et al. (2021) highlighted the limited efficacy of integrative medicine that incorporates holistic approaches in the treatment of chronic pain. Therefore, effective management of chronic pain is difficult to achieve and at best, optimum treatment outcomes are minimal.

2.7 Challenges of managing chronic pain

Research has shown that managing chronic pain is complex and challenging (Cohen et al., 2021; Turk et al., 2011). In addition to the physiological and psychological impact and limitations of chronic pain, other interacting factors can exacerbate the complexity of managing chronic pain. Some of the challenges can be attributed to key factors inherent in chronic pain experiences such as the unpredictability of chronic pain and lack of clarity in its aetiology (Wright et al., 2009), issues around credibility and legitimacy of experiences (Slade et al., 2009), and lack of consensus and effective treatment (Kleykamp et al., 2021; Wright et al., 2009).

2.7.1 Diagnostic uncertainty

Diagnostic uncertainty is associated with chronic pain conditions that have no agreed aetiology like fibromyalgia, rheumatoid arthritis, pelvic pain, and nonspecific chronic low back pain (Baastrup et al., 2016; Costa et al., 2023; Wright et al., 2009). Diagnostic uncertainty is a perception that healthcare providers are unable to provide accurate explanations of health problems and is associated with increased emotional distress, maladaptive pain related cognitions, disability, and efforts to exert control with actions perceived as helpful but that can be maladaptive in the long-term (Costa et al., 2023; Pincus et al., 2018; Serbic et al., 2016). Typically, receiving a medical diagnosis provides a structure which can attenuate uncertainty and help direct focus on health prognosis and associated management strategies (McKoane & Sherman, 2022)**.** The lack of a clear diagnosis associated with some chronic pain conditions has the potential for individuals experiencing chronic pain to lose confidence with healthcare professionals and in some cases disengage from health services (McGowan et al, 2007, Pincus et al., 2018). Management of chronic pain without clear knowledge of what is happening, no plan of action to focus on, and lack of clarity on future outcomes is challenging within this context (Costa et al., 2023; McKoane & Sherman, 2022).

2.7.2 Uncertainty in illness theory

Based on uncertainty in illness theory (Mishel & Braden, 1988; Mishel, 1990), management of chronic pain is challenging and is associated with maladaptive coping, psychological distress, and reduced quality of life (Costa et al., 2023; Slade et al., 2009; Wright et al., 2009). Uncertainty in illness theory can be defined as "*the inability to determine the meaning of illness-related events that occurs where the decision maker is unable to accurately predict outcomes due to insufficient cues*" and accurately anticipate or predict health outcomes (Mishel, 1990). It is characterised by four key factors namely: ambiguity concerning illness, complexity of treatment in health services, lack of information about diagnosis and the unpredictability of illness trajectory (Mishel & Braden 1988).

In chronic pain management, aetiology is often unknown and symptoms are often unpredictable and incongruent with diagnostic findings, whilst treatments vary in their efficacy (Wright et al., 2009). For example, fibromyalgia is one such chronic pain syndrome with an unknown aetiology and is associated with illness uncertainty which can originate due to the dichotomy between psychological experiences and somatic experiences, the issue of credibility and legitimacy of experiences, and lack of consensus and effective treatment that targets all symptoms (Baastrup et al., 2016; Kleykamp et al., 2021; Wright et al., 2009).

Indeed, research on the experiences of individuals living with fibromyalgia indicates illness uncertainty impacting mood, identity, social life, relationships with health professionals and coping behaviours (Johnson et al., 2006; Lempp et al., 2009; Reich et al., 2006). Other examples of chronic pain conditions that are unpredictable with no agreed cause include rheumatoid arthritis, endometriosis, and nonspecific chronic low back pain (Costa et al., 2023; Handelsman et al., 2023; Slade et al., 2009; Wright et al., 2009). Similar to experiences of fibromyalgia, research on experiences of individuals living with low back pain where aetiology, prognosis and interventions required were unknown revealed illness uncertainty leading to hopelessness, frustration, and challenges in how to effectively manage pain (Costa et al., 2023). Within this context, ambiguity concerning chronic pain conditions with no agreed cause, complexity of treatment in health services, lack of information about diagnosis and the unpredictability of illness trajectories raises challenges at multiple levels in the management of chronic pain.

2.7.3 Common-sense model of self-regulation

According to the Common-Sense Model (CSM) of self-regulation, when faced with a condition like chronic pain, individuals are typically problem solvers who will respond to the threat by finding strategies to manage it. The CSM of self-regulation is an information processing model that posits that, a health threat results in individuals relying on past cognitive and emotional illness representations to better understand and manage the threat. Through these illness representations, individuals develop coping strategies to manage the threat and associated negative impacts (Leventhal, Meyer, & Nerenz, 1980). Illness representations consists of five core dimensions namely: identity (beliefs of what the threat is), timeline (beliefs about duration of threat and whether it is acute, chronic, or cyclical), cause (beliefs about origin and reason for threat), consequences (belief about the physical, psychological, social, and economic outcomes of the threat), and controllability (beliefs about responsiveness to treatment) (Leventhal, Meyer, & Nerenz, 1980).

Based on the CSM of self-regulation, chronic pain is interpreted as an illness/threat, that results in individuals relying on past cognitive and emotional pain representations to better understand and manage chronic pain (Hagger & Orbell, 2022). Within this context, the early stages of chronic pain can be problematic as existing pain representations will be based on acute pain experiences. Beliefs informed by acute pain experiences that pain is typically associated with a few symptoms, presents for a short time with limited consequences, and is curable can inform adaptive behaviours during the early stages of chronic pain (Leventhal et al., 2016b). However, the longevity of chronic pain can challenge these acute pain representations and there is potential for continuation of adaptive behaviours based on acute pain interventions which when executed on a long-term basis may become maladaptive leading to negative outcomes overtime (Hale et al., 2007; Leventhal et al., 2016a). For example, the continuous use of OTC analgesics in pain management has been found to have detrimental effects to wellbeing overtime (Frei et al., 2010; Labianca et al., 2012).

2.8 Self-management of chronic pain

Literature defines self-management in several ways with most definitions focusing on the dynamic and interactive way that individuals manage ill health (Grey et al., 2015; Lorig & Holman, 2003). It has also been defined as the ability an individual, in conjunction with healthcare professionals, family and community, has to manage all aspects of a health condition (Richard & Shea, 2011). In chronic pain, self-management has been defined as “the active role that individuals suffering with chronic pain take to manage pain and minimise pain interference with everyday life, mood, and relationships” (Nicholas & Blyth, 2016). According to Lorig and Holman (2003) self-management involves problem solving, decision making, resource utilisation, the formation of a patient–provider partnership, action planning, and self-tailoring.

Effective self-management of chronic pain involves decisions related to maintenance of physiological and psychological stability and recognition of and response to symptoms (Bair et al., 2009). For optimum outcomes, it is characterised by daily individual decisions that include medication, diet, physical activity, symptom monitoring and seeking intervention when required (Thorne, 2003). Richard and Shea (2011) highlighted the importance of the involvement of family, community, and healthcare professionals to self-management. Effective management of chronic pain requires self-management approaches that include building effective relationships with health-care providers, support from friends and family, incorporating cognitive and behavioural strategies to cope with pain, maintaining normality in daily life and roles, and self-medicating appropriately (Bair et al., 2009; Büssing et al., 2010; Mann et al., 2013; Peres & Lucchetti, 2010). Self-efficacy (Jackson et al., 2014; Turner et al., 2005) and health literacy (Mackey et al., 2019; Rogers et al., 2020) are also critical to effective self-management.

Self-management strategies in chronic pain can be broadly classified as including active coping and passive coping. Active coping strategies include: seeking information and support, distraction and engaging with exercise, whilst passive coping includes relying on medical interventions and avoidance of physical activity (Blyth et al., 2005; Büssing et al., 2010; Peres & Lucchetti, 2010). Active coping is associated with increased physiological functioning and decreased functional impairments and depression levels whilst passive coping strategies are associated with increased pain intensity, higher depression levels, decreased levels of physical activity and feelings of despair (Brown & Nicassio, 1987;

Büssing et al., 2010; Carroll et al., 2002). For example, in a population-based study on self-management of chronic pain, Blyth et al. (2005) reported an association between active coping and reduced levels of pain-related disability whilst passive coping was associated with high levels of pain-related disability. A systematic review and meta-synthesis of what works in self-management interventions for people with chronic pain highlighted that self-management interventions are most effective when participants adopt active coping strategies and feel empowered, develop self-awareness, and are immersed in a supportive environment (Devan et al., 2018). However, in a review on the effectiveness of self-management strategies, Nicholas and Blyth (2016) highlighted the limitations and complexities inherent in self-managing chronic pain in consideration of the challenges and barriers. Findings highlighted how chronic pain experiences and trajectories are condition specific meaning that there is no single universal approach. Self-management strategies must be tailored to suit different circumstances and contexts which is not always cost-effective and attainable. In addition, chronic pain occurs in different social and economic contexts, and health settings that must provide optimum support for effective self-management which poses further limitations in chronic pain management (Nicholas & Blyth, 2016).

2.9 Self-medicating in self-management of chronic pain

Within self-management, self-medicating is a strategy that enables individuals with chronic pain to manage pain within everyday contexts outside health systems which is where most individuals are situated throughout their chronic pain experience (Blyth et al., 2005; Perrot et al., 2019). This makes self-medicating worthy of specific inquiry in the self-management of chronic pain.

Self-medicating is defined as a self-management strategy that provides an opportunity to administer medications without the need to seek medical intervention or supervision (Pineles & Parente, 2013). Indeed, a review conducted by an established expert multi-disciplinary group on self-medicating in pain management highlighted that OTC analgesics are widely used as a self-management strategy without prescription all over the world (Perrot et al., 2019). Different countries have different legislative guidance on what medications and at what doses and forms are available for self-medicating but generally paracetamol, ibuprofen, aspirin, and low-dose codeine are the main non-prescription medications available for self-medicating in pain management (Cooper, 2013; Perrot et al., 2019; Terrie, 2013). In comparison with prescription medication, OTC pain medications are less restrictive in what they can be used for, how often they can be used and at what doses they can be used (Cooper, 2013b). OTC pain medication represents the largest market of OTC drugs and used at recommended doses in the self-management of pain they can be effective in alleviating symptoms (Perrot et al., 2019; Pineles & Parente, 2013).

2.9.1. Risks in self-medicating

There is vast literature documenting the overuse of OTC analgesics worldwide in the self-management of pain (Cooper, 2013; Kawuma et al., 2021; Perrot et al., 2019). Indeed, in a systematic review on self-medicating for pain, Rogozea et al. (2020) highlighted the need to address overuse of analgesics in self-medicating from a much wider multidimensional public health perspective due to its prevalence. In comparison with prescription analgesics, individuals self-medicating for pain tend to perceive OTC medications as safer than prescription medications due to their availability in non-healthcare settings. The fact that analgesics can be purchased in supermarkets, service stations and pharmacies that are housed in large retail shops is influential to this perception (Cooper, 2013a).

Notwithstanding the overuse of general OTC analgesics worldwide, OTC analgesics combined with the opioid codeine are among the highest and most common misused analgesics in self-medicating for pain, as highlighted in the preceding chapter. Codeine is implicated as the driving force behind this overuse (Bruno & Nielsen, 2018; Van Hout, 2018). Whilst countries like Australia, Germany, Italy, France, Finland, Greece, and Portugal require a prescription to supply any strength of codeine, countries like Ireland that supply OTC analgesics combined with codeine without a prescription have varying degrees of restrictions that require the involvement of pharmacists (Foley et al., 2015; Hockenhull et al., 2022). Therefore, the role of pharmacists in self-medicating warrants particular discussion in the self-management of chronic pain.

2.9.2 The role of the pharmacists in self-medicating

The role of pharmacists has evolved from the traditional focus of dispensing medication to becoming a focal point in the provision of primary healthcare (Khaira et al., 2020; Silcock et al., 2004). Community pharmacies now provide patients with convenient access to initial and ongoing medical intervention therefore reducing strain on healthcare systems (Cooper, 2013). In consideration of the temporal dimension of chronic pain and the ongoing burden, pharmacists are key to providing the first point and ongoing access to primary healthcare, drug information and education, pain management and provision of OTC analgesics (Hahn, 2009; Strand et al., 2016). Within this context, the relationship between individuals with chronic pain and pharmacists is key in facilitating self-management (Schulman-Green et al., 2016).

In-order to develop a relationship that maximises the services provided by community pharmacies, relationships between individuals with chronic pain and pharmacists must be characterised by shared decision making and a collaboration that supports patient-centred approaches (Worley et al., 2007; Yong et al., 2020). Role theory encapsulates concepts and theories that can be theoretically used to explain respective roles (Thakur & Chewning, 2020). It posits that dyadic relationships have expectations of roles and of the other member of the dyad (Guirguis & Chewning, 2005). Based on role theory, the effectiveness of the patient/pharmacist relationship is dependent on how clear the role expectations are between patients and pharmacists (Thakur & Chewning, 2020; Worley et al., 2007). Research on the nature of the patient/pharmacist relationship incorporating role theory, proposed role dimensions vital for a conducive relationship. In a study investigating patient/pharmacist relationships, Worley-Louis et al. (2003) highlighted the following vital role dimensions, for pharmacists, role dimensions included information sharing, responsible behaviours, creating a patient-centred relationship and interpersonal communication. For patients, role dimensions included information sharing, responsible behaviours, active communication to related healthcare and interpersonal communication.

However, research incorporating both role theory and patient/pharmacist role dimensions suggest that patients and pharmacists were not in agreement on the roles that each should play in the relationship. In a study on pharmacists and patient roles Worley et al. (2007) reported that both patients and pharmacists had similar views on the pharmacist's role of information sharing but differences on; responsible behaviours, creating a patient-centred relationship and interpersonal communication. Views were also different on all the patient roles. In addition, research has shown an unawareness of the evolving role of the pharmacists among patients (Keshishian et al., 2008). The effectiveness of the pharmacist role can be diminished due to patients choosing not to acknowledge the role of pharmacists as they may view the role as inappropriate to meet their needs (Banks et al., 2007; Schommer et al., 2006).

In self-medicating for chronic pain, there is well documented literature on the conflicts arising between pharmacists and individuals with chronic pain involving the sale and supply of OTC codeine-based analgesics (Nielsen et al., 2013; Sansgiry et al., 2016; Van Hout, 2015). These conflicts arise from the efforts of pharmacists to deter OTC codeine-based analgesics use through implementation of codeine regulations, opioid risk communications and refusal of sale. Research has indicated that pharmacists face ethical dilemmas in their involvement in educating patients about opioid misuse that may be influential in codeine misuse. Fleming et al. (2019) highlighted how pharmacists were reluctant to engage with patients in opioid misuse communications due to the potential for patient conflicts, loss of patients to other businesses, time constraints due to conflicting demands and lack of remuneration for the engagements. In a review of factors affecting community pharmacist work, Yong et al. (2020) reported on the multifactorial transitional environments contributing to ethical dilemmas for pharmacists. Findings reported tensions between management expectations and pharmacist’s roles in clinical work as problematic especially around the issue of the existence of key performance indicators and sales targets. This resulted in conflicting clinical and business priorities in their roles. In addition, tension associated with patient conflicts resulting in psychological distress was also highlighted as problematic. Furthermore, pharmacists reported that some patients perceived them as shopkeepers, and this was problematic in their efforts to assert their clinical role in interactions (Yong et al., 2020).

Notwithstanding the conflicts between individuals managing pain and pharmacists, self-medicating is a specific strategy in the self-management of chronic pain with inherent benefits albeit with associated risks (Perrot et al., 2019; Rogozea et al., 2020). However, the effective self-management of pain not only requires self-medicating but requires daily decisions that maintain physiological and psychological stability and recognition and response to symptoms (Bair et al., 2009; Devan et al., 2018; Turk et al., 2011). These include but are not limited to exercise, attention diversion, activity pacing, goal setting, self-monitoring, deliberate exposure to pain, adherence to treatment plans, meditation, sleep management, thought management and communication skills (Du et al., 2017; Nicholas & Blyth, 2016).

There is a dearth of information on the relationship between engagement with self-management strategies and OTC codeine consumption in chronic pain management (see review by Axon et al. (2019) on use of multidomain management strategies and opioids consumption). However, there is some evidence that suggest lack of engagement with self-management strategies in chronic pain management is associated with increased prescription opioid use (Eaton et al., 2018; Rogers et al., 2020). For example, a comparison study in opioid use in pain management identified higher use in patients living in rural settings characterised with low use of self-management interventions than those living in non-rural settings characterised with high use of self-management interventions (Eaton et al., 2018). In addition, Wilson et al. (2018) reported a reduction on prescription opioid misuse after patients engaged with an online medication assisted behavioural pain self-management programme. Furthermore, a study on health literacy and chronic pain management reported an association between poor self-management of chronic pain and prescription opioid misuse. This association remained evident over and above other relevant covariates including depression, anxiety, age, gender, income, and education (Rogers et al., 2020). However, in a review on management strategies and use of opioids, Axon et al. (2019) highlighted the need for further research on the relationship between the use of opioids, management strategies and level of pain. Based on the available evidence, engagement with self-management strategies is associated with reduced opioid use in chronic pain management (Eaton et al., 2018; Rogers et al., 2020; Wilson et al., 2018). Within this context, the barriers and facilitators to self-management strategies warrant particular focus to better understand the issues that have potential to influence level of OTC codeine use in the self-management of chronic pain.

2.10 Barriers and facilitators of chronic pain self-management

Different self-management models and theories have been adopted in understanding the risk and barriers to self-management in chronic illness (Jaarsma et al., 2020; Riegel et al., 2021). The Individual and Family Self-Management Theory (IFSMT) is a biopsychosocial model that assumes the individual living with a chronic condition, or their family members take responsibility for self-management and may include healthcare providers as collaborators (Ryan & Sawin, 2009). The IFSMT considers risk and protective factors, components of the physical and social environment and unique individual and family characteristics that influence self-management. It addresses the contextual factors that influence self-management, the process of self-management that can impact knowledge and beliefs, self-regulation skills and social facilitation. In addition, it highlights the proximal and distal outcomes of self-management and the outcomes of self-management (Ryan & Sawin, 2009).

Similarly, the revised Self and Family Management Framework (SFMF) adopts a biopsychosocial approach in the self-management of chronic illness in collaboration with family and healthcare providers (Grey et al., 2015). Health status, personal/lifestyle, health systems, resources, and environment are considered risk and protective factors to self-management which exist on a continuum of negative (barriers/risks) to positive (facilitators/protective) and continuously interact to influence self-management (Schulman-Green et al., 2016). Similar to the IFSMT, it addresses the processes that facilitates self-management and proximal and distal outcomes (Ryan & Sawin, 2009). However, the SFMF expands on the self-management processes that facilitate self-management and include the emotional management necessary in the self-management of chronic conditions (Schulman-Green et al., 2012), as well as enhancing knowledge and beliefs, regulation of skills and abilities and social facilitation (Grey et al., 2015). Since its inception, the SFMF has been used widely in research. A recent review reported 126 citations of the original 2006 framework and 37 of the revised 2015 framework (Schulman-Green et al., 2021). The review further reported the use of SMFM in 35 health condition studies including chronic pain. The applicability of SMFM to different health conditions (Modi et al, 2012), articulation of evidence-based processes underlying self-management (Ryan et al., 2020), the emphasis of contextual factors to self-management (Archer & Aria, 2019), and highlighting the complexity of chronic illness (Bernhard et al., 2017), have all been acknowledged as strengths of SMFM in self-management research. The SFMF will be used to guide the discussion on the barriers and facilitators to self-management in the current study: health status, personal/lifestyle, health systems, resources, and environment.

2.10.1 Health status

In the self-management of chronic pain, the health status of an individual is influential to the execution and maintenance of self-management initiatives (Grey et al., 2015; Schulman-Green et al., 2016). Severity of pain and its trajectory is associated with the level of self-management strategies and approaches adopted and maintained by individuals living with chronic pain (Viniol et al., 2013). The variance of pain across different conditions and how pain presents is influential to the incorporation of self-management strategies to manage pain. In comparison with CLP, CWP is typically associated with less self-management initiatives due to its association with decreased health related quality of life (Cho et al., 2012), disability (Øverland et al., 2012), high prevalence of physical and psychological comorbidities (Kato et al., 2006; Kleykamp et al., 2021) and increased mortality rate (Sarcon et al., 2019).

For example, fibromyalgia is a CWP condition associated with both physical and psychological comorbidities resulting in poor health status. Physical characteristics of fibromyalgia include unpredictable widespread musculoskeletal pain, tenderness, fatigue, stiffness, sleep disturbances and other associated conditions like migraines, joint disorders, irritable bowel syndrome (Baastrup et al., 2016; Kato et al., 2006; Kleykamp et al., 2021). Within this context, the incorporation of self-management strategies like physical activity known as beneficial in fibromyalgia treatment is problematic. Physical activity in fibromyalgia can be associated with exercise induced exacerbation of pain which can lead to disengagement in exercising (Dansie et al., 2014). The unpredictability of how pain presents in fibromyalgia is also associated with inconsistent efforts in self-management strategies like physical activity leading to reduced fitness levels and sedentary lifestyles (McBeth et al., 2010).

In addition, the psychological impact of fibromyalgia is associated with poor health status and therefore reduced self-management efforts. Psychological characteristics of fibromyalgia include depression, anxiety, bipolar disorder, and panic disorder. These can all pose as barriers to self-management strategies (Schulman-Green et al., 2016). Psychological distress and pain-related fear in fibromyalgia negatively influence self-management abilities in pain management (Dansie et al., 2014; Luciano et al., 2014). The association between physical and psychological distress and self-management efforts can also be evidenced in cooccurring musculoskeletal conditions (Bair et al. 2009; Elfving et al. 2007; Krein et al., 2002). Co-occurring conditions contribute to health status and add complexity to self-management as they can interfere with efforts to manage pain and minimise pain interference with everyday life (Lea et al., 2004; Schulman-Green et al., 2016). Within this context, the general health status of an individual can be a risk or protective factor to effective self-management highlighting how individual contexts can add to the complexity of self-managing pain.

2.10.2 Personal/Individual factors

In addition to health status, other individual factors can act as barriers or facilitators in the self-management of chronic pain. In a meta synthesis of factors affecting self-management, Schulman-Green et al. (2016) highlighted how level of knowledge, understanding of health conditions and how to manage them, self-management experience, health beliefs, motivation, psychological distress, and life patterns were all associated with self-management.

Knowledge and understanding

Health literacy (HL) is associated with health outcomes in the self-management of chronic pain (Edward et al., 2018; Rogers et al., 2020). HL can be defined as the ability to obtain, understand, and use health information to promote and maintain good health (Nutbeam, 2000). The ability to obtain knowledge and understanding of chronic pain and how to manage it, is critical in the self-management of chronic pain. A systematic review of health outcomes indicated an association between low HL and greater frequency of hospitalisation, poor medication adherence and overall health status and higher rates of morbidity and mortality (Berkman 2011). Indeed, in a study with 445 adults living with chronic pain, Rogers et al. (2020) found that low levels of HL were associated with pain severity, pain disability, maladaptive self-management behaviours and opioid dependence. Similarly, in a study of health outcomes in individuals with chronic pain, Mackey et al. (2019) reported an association between inadequate HL and poor disease related knowledge, poor beliefs about pain, increased comorbidities, and reduced use of non-emergency health services and allied health services. A systematic review on HL and chronic low back pain reported an association between HL and health information seeking behaviours (Edward et al., 2018). Level of knowledge and understanding of chronic pain and how to manage it, can pose as a risk or protective factor to self-management.

Beliefs, self-management experiences and motivation

Within individual contexts of managing chronic pain, beliefs, self-management experience and motivation can also act as barriers or facilitators of self-management (Brooks et al., 2017; Jackson et al., 2014; Singh et al., 2014). Individual beliefs on perceived control over chronic pain and associated symptoms are an important facilitator of self-management. Perceived control can be defined as an individual's ability to exert control over a situation (Schulman-Green et al., 2016). Perceived control and perceived consequences of previous self-management behaviours are influential to the continuity of self-management approaches. For example, Brooks et al. (2017) found an association between self-management engagement and perceived behavioural control and experiences, in exercise behaviour in chronic pain management. Findings reported an association between previous benefits of exercise and continuous engagement with physical activity. Similarly, Singh et al. (2014)

reported how improvements brought on by physical activities influenced exercise adherence in chronic pain management. In a review of motivation in pain and pain relief, Navratilova and Porreca (2014) highlighted the association between behaviour and achieving pain relief. Past experiences informed future behaviours in achieving improved pain outcomes (Navratilova & Porreca, 2014). When engaging with exercise is associated with improved pain outcomes and disengaging with negative consequences, individuals tend to exert more effort to achieve exercise adherence. However, when exercising is associated with negative consequences, this poses a barrier to meeting exercise goals (Brooks et al., 2017; Hwu & Yu, 2006).

Motivation is also influential to adhering with self-management activities. The level of motivation an individual has can be a barrier or facilitator to self-management in chronic pain management. Self-efficacy is closely linked to motivation and contributes to the level of engagement in self-management activities (Grey et al., 2015). Self-efficacy (SE) refers to an individual's perception to execute behaviours required and judgements of their capacity to execute those behaviours to produce a desired outcome (Cheng et al., 2020; Turner et al., 2005). High levels of SE can be a determinant of the motivation and effort exerted to engage with self-management activities in the face of physical limitations and associated obstacles and challenges of chronic pain (Jackson et al., 2014). Low SE is related to low motivation and can be a barrier to self-management. For example, in a 2-year longitudinal self-management study of 452 individuals with arthritis, increased SE was associated with increased attendance to PMPs and increased health related behaviours such as aerobic exercise (Osborne et al., 2007). A systematic review of the role of SE in chronic musculoskeletal pain reported an association between higher SE levels and physical activity participation, greater physical functioning, and lower pain intensity (Martinez-Calderon et al., 2018). Within this context SE is influential to the motivation an individual has which depending on the level can be a risk or protective factor to self-management in chronic pain management.

Psychological distress

Depression, stress, pain related fear and impaired mood are all barriers of self-management (Schulman-Green et al., 2016). For example, in a qualitative study with primary care patients with co-occurring musculoskeletal pain and depression, Bair et al. (2009) found that depression interferes with a patient’s ability to incorporate self-management efforts in managing chronic pain. Similarly, Elfving et al. (2007) found an association between low levels of exercise and pain related fear in participants with back pain. Psychological distress influences the ability to self-manage chronic pain. For example, in a study of chronic pain with older patients, Krein et al. (2002) found an association between depression and failure to maintain recommended diet. Indeed, a systematic review and meta-synthesis on facilitators and barriers in the self-management of chronic pain reported that stress, anxiety, and depression negatively influenced self-management abilities following cognitive behavioural interventions (Devan et al., 2018).

Individual life patterns

The social contexts that individuals manage chronic pain in are complex and contribute to the capacity to self-manage pain. From an individualistic perspective, daily schedules, disruptions to routines and life transitions can all contribute to influence the level of engagement with self-management activities. Development of a daily self-management routine has been reported to facilitate and maintain consistent self-management (Hwu & Yu, 2006). However disruptions to routines can occur due to weather, special occasions, traveling, as well as life transitions like employment or parenthood (Schulman-Green et al., 2016). Disruptions of these routines can result in inconsistent engagement with self-management activities. Indeed, in a longitudinal qualitative study of self-management patterns, Audulv (2013) highlighted how individuals living with rheumatism performed self-management behaviours in an episodic self-management pattern due to routine challenges, weather, pain interference to routines and life transitions. Similarly, bad weather and time conflicts with doctor’s appointments were reported as barriers to self-management in a study of chronic pain management with older persons (Austrian et al., 2005). The individual contexts that chronic pain is managed in are complex. Level of knowledge, understanding of health conditions and how to manage them, self-management experience, health beliefs, motivation, psychological distress, and life patterns are all linked and interact overtime to determine the level of engagement with self-management behaviours in chronic pain management.

2.10.3 Health system factors

The relationship between health care and chronic pain management is crucial in achieving optimal self-management care. Following on from self-management, primary care and secondary care provide the support required in the management of chronic pain (Gatchel et al., 2014). The SFMF highlights the importance of these health system structures in supporting and enabling individuals living with chronic pain to engage with self-management activities (Grey et al., 2015). The Chronic Care Model (CCM) elaborates on the importance of; 1. healthcare systems and their payment structures; 2. community resources and policies; and 3. health care organisation in chronic care (Bodenheimer et al., 2002). Based on the

CCM, the efficiency and cohesion of these 3 structures that chronic pain is managed in determine the 6 essential elements for optimal care. These include community resources and policies, health care organisation, self-management support, delivery system design, decision support for healthcare providers, and clinical information systems (Bodenheimer, 2016). In addition, the WHO Innovative Care for Chronic Conditions (ICCC) model, provides greater emphasis on the broader policy environment that influence self-management of chronic pain. The ICCC model highlights the importance of integrated care centred on the patient and family to increase efficiency in health services and to promote self-management (Grover & Joshi, 2015).

The importance of health systems to self-management for individuals living with chronic pain is clear as elaborated in the CCM and ICCC model. In addition to providing interdisciplinary care, health care systems play a role in the educating and training of evidence-based self-management strategies in chronic pain management. For example, the Stanford Model or Chronic Disease Self-Management Programme (CDSMP), is used in health care settings to enhance self-efficacy and skills required to optimally manage chronic pain (Grover & Joshi, 2015). Numerous studies have demonstrated the effectiveness of CDSMP in improving self-management through improvements in self-efficacy, exercising, medication adherence and health literacy (Ory et al., 2013, 2014; Ritter et al., 2014). In addition, cognitive behavioural model informed interventions like CBT and ACT are also delivered through health systems to enhance self-management in chronic pain management. The benefits of CBT and ACT to self-management in chronic pain are well established and health systems play an important role in facilitating these (Gloster et al., 2020; Knoerl et al., 2016). Based on the SFMF, health system factors influential to self-management include 1. access to health care services, 2. the ability to navigate the healthcare system to ensure ongoing care and 3. relationships with healthcare providers (Grey et al., 2006; Schulman-Green et al., 2016).

Access to health services

Access to health services is critical in establishing and maintaining effective self-management strategies (Gatchel et al., 2014). Based on the CCM, the organisation and delivery of health services must include interdisciplinary teams that provides physicians to treat chronic pain and other allied health professionals to support self-management and follow up (Bodenheimer et al., 2002). Indeed, in a qualitative study including GPs, physiotherapists, occupational therapists, practice nurses, community pharmacists and patients there was consensus for self-management education to be included as part of chronic pain treatment (Gordon et al., 2017). In addition, healthcare professionals highlighted the need for early integrated approaches of promoting self-management to ensure it was not associated with abandonment and negative experiences of failure in finding a cure. A study on the effects of patient-professional partnerships in chronic back pain management found a positive association between engagement with health professionals and stimulating and maintaining patients' internal resources to self-manage pain. Self-management was a mediator between health-related quality of life and engagement with health professionals (Fu et al., 2016b). Findings of a systematic review of patients and professional partnerships identified access to health services as influential to self-management in chronic back pain (Fu et al., 2016a). However, despite access to health services being beneficial to the establishment and maintenance of self-management activities in chronic pain management limitations have been identified. Structures in health systems have been implicated in these limitations. For example, lack of direct access to pain management programmes in the event of flare ups or reviews with physiotherapists to adjust self-management strategies were highlighted as a limitation in the maintenance of self-management activities in patients with low back pain (Cooper, 2009). In addition, long waiting lists to pain management programmes were identified as detrimental to self-management despite having access to health services (Gordon, 2017).

Navigating the healthcare system and maintaining continuity of care

The ability to navigate the healthcare system and ensuring establishment and continuity of care is influential to self-management. Long waiting lists, seeing different healthcare providers each time can be problematic and can negatively impact self-management (Gordon et al., 2017; Schulman-Green et al., 2016). For example, in a study on patient views of primary care management of chronic pain, Upshur et al. (2005) highlighted how participants experienced barriers in accessing prompt and continuous care during break through pain episodes and around prescription renewals and this was detrimental to continuing with self-management activities whilst experiencing flare-ups. In addition, access to comprehensive documentation of their treatment history was also problematic in maintaining continuity in the decision-making of self-management strategies when they had to see alternative healthcare providers within the same settings but who had no access to previous interventions (Upshur et al., 2005).

Research has shown that navigating healthcare systems and maintaining continuity can be problematic due to the fragmented care approaches inherent in health systems. Indeed, in a systematic review on fragmented care and chronic illness patient outcomes, Joo (2023) found an association between care fragmentation and ongoing adverse effects in patient outcomes. Establishment and maintenance of self-management activities was problematic within this context as there was no coordination of care among healthcare providers and biomedical approaches were adopted in providing care (Joo, 2023). However, experiences of navigating chronic pain management in an integrated healthcare system also highlighted lack of continuity in care as problematic in establishing and maintaining self-management strategies in collaboration with healthcare providers. Participants in the study revealed how they felt they were always going through a reacquaintance process due to a high proportion of medical trainees and each visit felt like starting again (Driscoll et al., 2018).

In addition to the challenges and constraints inherent in health systems, navigation in healthcare systems occur at the intersection of biomedical, psychosocial, economic, and environmental conditions that are distinct to each individual (Sofaer, 2009). Based on the behavioural-ecological model of health access and navigation, individual characteristics shape the process of navigation and responses to opportunities and constraints in the healthcare environment (Ryvicker, 2018). Individual characteristics include, education level, health literacy, social status, communication skills and level of SE (Davidson et al., 2002; Ryvicker, 2018). For example, an individual with a higher level of education and a high level of HL maybe more confident to navigate the health system to achieve optimal care in the absence of supports for individuals with HL challenges within the health system (Gwynn et al., 2016; Paasche-Orlow, 2011). In addition, individual psychological factors for example: depression, a common cooccurring condition in chronic primary pain (Andrews et al., 2017), has been shown to hinder effective health care system navigation and engagement with self-management strategies (Bayliss et al., 2007). Interacting individual characteristics as well as health system constraints influence the navigation of health systems to achieve optimal support to establish and maintain self-management strategies in chronic pain management.

Relationships with healthcare providers

Healthcare professionals are the primary facilitators of self-management in primary care settings (Lukewich et al., 2015). Positive patient-healthcare provider relationships are crucial in establishing and maintaining self-management in chronic conditions (Grey et al., 2006). From the patient's perspective, these relationships need to be characterised by good communication, support, trust, empathy, competence confidence, valuing of subjective illness experiences, adequate time to share concerns and practical advice for self-management. From the healthcare provider's perspective, relationships need to be characterised by honesty, proactiveness in seeking self-management information, sharing opinions and making suggestions regarding self-management approaches (Gordon et al., 2017; Grey et al., 2006; Ploughman et al., 2012; Schulman-Green et al., 2016). In essence, to achieve optimum self-management approaches, a collaborative approach is required between patients and healthcare providers, that is characterised by shared problem solving and decision making to achieve agreed goals in self-management. However, collaborative and conducive relationships can be challenged due to concerns of opioid abuse resulting in refusal to prescribe or being treated suspiciously, lack of trust, diagnosis uncertainty, being judged and credibility on the self-reports of severity and adverse effects of chronic pain (Upshur et al., 2005).

Whilst health professionals are experts in providing support, chronic pain and its impact can only be experienced by patients making them experts of the lived experience of pain (May, 2010). For optimum self-management of chronic pain, there is need for partnership and collaborative approaches that realise each party's expertise and integrate complementary knowledge and skills (Fu et al., 2016b). The CCM suggests that good collaborative partnerships between health professionals and patients enhance patients' ability to manage their condition (Bodenheimer et al., 2002). Indeed, a study on the effects of patient professional partnerships reported a direct positive impact on patients' self-management abilities and good partnerships between health professionals and patients in chronic back pain management (Fu et al., 2016b).

However, despite recognition that self-management is achieved in collaboration between health professionals and patients, challenges have been identified in interactions. For example, health professionals have been identified as focusing on increasing patients' knowledge and self-management skills through prescribed health behaviours resulting in directive approaches in interactions with patients (Franklin et al., 2019; Thille et al., 2014). In addition, uncertainty in how best to support patients has been identified in healthcare professionals due to multiple competing priorities in managing complex conditions (Entwistle et al., 2018), limited training in supporting self-management and constraints around appointment durations (Gordon et al., 2017). From the patients perspective, self-management support can be perceived as an approach to compensate for the gaps in healthcare provision due to diagnostic uncertainty, long waiting lists and untimely referrals (Gordon et al., 2017). In addition, failure to engage with self-management strategies can make patients feel blamed within interactions with health professionals resulting in tensions (Lewis et al., 2022). Furthermore, within the individual and social contexts chronic pain occurs, self-management is embedded and constructed based on past histories, present realities (Audulv, 2013), socially situated time (Lewis et al., 2022), and psychological states (Bayliss et al., 2007). From the patient's perspective, self-management is complex and is embedded in their own experiences which may not align with the linear approach which healthcare professionals adopt in supporting self-management (Manderson & Warren, 2016).

Within these contexts, achieving collaborative partnerships between patients and health professionals in reality is problematic. Indeed, in a study on patient and health professional interactions in chronic conditions, Lewis et al. (2022) reported a disconnect between patients and health professionals in how they interpreted the influence of individual contexts (past histories, present realities, and future realties) to self-management. Health professionals adopted linear approaches to self-management that did not take into account the layered past, present and future temporalities of individual contexts in self-management. Patients' complex realities were embedded in past and present challenges that hindered progress-oriented futures envisaged by health professionals (Lewis et al., 2022). Within these contexts, despite the importance of collaboration being well-documented, in practice fostering positive patient-healthcare provider relationships can be problematic and this can subsequently negatively impact self-management in chronic pain management.

2.10.4 Resources

The resources that an individual living with chronic pain has can influence self-management in chronic conditions. These include financial resources and psychosocial support. Limited resources pose as barriers whilst adequate resources pose as facilitators to self-management (Grey et al., 2006; Schulman-Green et al., 2016).

Financial resources

Chronic pain occurs and is experienced within economic contexts that can exacerbate and perpetuate the impact of chronic pain (Maly & Vallerand, 2018). Limited financial resources, financial instability and lack of private health insurance are significant barriers to self-management whilst adequate financial resources facilitate self-management (Tan et al., 2019). Financial instability and limited financial resources are associated with reduced or cessation of self-management efforts due to the costs associated with self-management, for example, purchasing healthy food and cost of alternative therapies and non-pharmacological medication. Similarly, lack of health insurance is associated with reduced or cessation of self-management efforts due to costs associated with continuously accessing health care services and acquiring medications (Fink et al., 2023; Prego-Domínguez et al., 2021; Schulman-Green et al., 2016)

The socio-economic status (SES) of an individual living with chronic pain has a bearing on self-management and quality of life (Bonathan et al., 2013; Tan et al., 2019). The relationship between SES and chronic pain is complex and can create a vicious cycle of negative outcomes in chronic pain management. Indeed, a review on SES and chronic pain reported an association between low SES and higher prevalence of chronic pain and severity, CWP, chronic primary pain, and other comorbidities like depression, and obesity (Prego-Domínguez et al., 2021). In addition, the review also reported on the association between low SES and manual jobs associated with musculoskeletal chronic pain conditions, ineffective coping strategies and unhealthy lifestyle factors such as low physical activity and unhealthy diets (Prego-Domínguez et al., 2021). Low SES has also been associated with low HL (Rogers et al., 2020), opioid addiction (Fink et al., 2023), low SE and minimal self-management activities (Bonathan et al., 2013). Combined, these factors can perpetuate the development of chronic pain and mediate the severity of chronic pain.

Based on the CCM, the payment structures in health systems can create a barrier to self-management support for individuals with low SES (Bodenheimer et al., 2002). Indeed, in healthcare systems where patients pay for care, low SES is associated with inadequate treatments due to limited financial resources, and lack of private health insurance resulting in limited health care utilisation and opportunities to effectively engage with self-management strategies (Maly & Vallerand, 2018; Tan et al., 2019). For example, the 2- tier public and private health system provision in Ireland means level of access to care, quality of care and opportunities to develop self-management strategies in conjunction with healthcare providers are dependent on the health scheme an individual is eligible to and affordability of private health insurance instead of need (Burke et al., 2018). High SES within the Irish health system affords private health insurance affordability and therefore more opportunities to access continuous care and development and maintenance of self-management strategies. The lack of financial resources in chronic pain management can create multi-faceted issues that impact self-management.

Psychosocial support

Chronic pain occurs and is experienced within social contexts that may act as barriers or facilitators of self-management. The psychological and physical limitations associated with chronic pain can result in reduced social life, loss of valued activities and interactions resulting in difficulties in building and maintaining close supportive social relationships (Lempp et al., 2009; Slade et al., 2009). However, psychosocial support is a factor that can be a barrier or facilitator of self-management. Support from family and friends is critical in establishing and maintaining self-management (Grey et al., 2006; Schulman-Green et al., 2016). Indeed, in a study on barriers to self-management, Bayliss et al. (2003) highlighted the need for social and emotional support to facilitate self-management. Similarly in a qualitative study exploring how family and friends influence chronic illness management, Gallant et al. (2007) highlighted how family and friends exerted positive influences on self-management by providing functional support. However, support in coping with the psychosocial impact of chronic illness and its management was difficult. Participants in the study highlighted how difficult it was for family and friends without the lived experience of pain to understand its impact and provide psychological support. However, participants were reluctant to discuss their experiences all the time (Gallant et al., 2007). This finding echo other studies (Holloway et al., 2007) whereby participants felt the need to conceal their true experiences to avoid being burdensome and being stigmatised.

Despite the clear need for psychosocial support from family and friends to facilitate self-management, research has shown that this can be problematic due to issues around lack of diagnosis, legitimacy, and pain invisibility in chronic pain (Koesling & Bozzaro, 2021; Newton et al., 2013). For example, in a study on fibromyalgia experiences, participants highlighted how pain invisibility and lack of a clear diagnosis contributed to lack of understanding from social networks and family. They felt their experiences of chronic pain were constantly challenged within familial and social relationships (Lempp et al., 2009). Similarly, experiences of individuals with nonspecific chronic low back pain highlight how the validity of their pain was consistently questioned by family and friends due to pain invisibility and diagnostic uncertainty resulting in lack of understanding and judgemental attitudes (Slade et al., 2009). Furthermore, experiences of individuals with degenerative spinal pain highlighted denial and underrating of pain from family members due to lack of identified pathology (Ojala et al., 2015).

2.10.5 Environmental factors

The interplay between a health condition and the environmental context an individual lives is crucial in shaping self-management behaviours (Grey et al., 2015). Environmental constructs that can be facilitators or barriers to self-management include home, work, and community (Grover & Joshi, 2015; Ryan & Sawin, 2009). Within the home, competing demands with family members can inhibit self-management activities. Maintenance of role identities within the home can interact with self-management (Audulv, 2013). Similarly, responsibilities imposed by work can be a barrier to self-management (Schulman-Green et al., 2016). However, work environments with supportive structures and are understanding of the impact of living with a chronic condition can facilitate self-management (Dickson et al., 2008; Steenstra et al., 2009).

From an environmental context, the community an individual lives in is also influential to self-management. Based on the CCM, the community an individual lives must have resources that support self-management for optimal chronic illness management (Bodenheimer et al., 2002; Grover & Joshi, 2015). Indeed, lack of adequate transportation (Austrian et al., 2005), exposure to unhealthy food (Ann & Renee, 2010), and inadequate physical activity enabling environments (Maly & Vallerand, 2018), act as barriers to self-management whilst availability of these are facilitators of self-management.

2.11 Current study

The literature describes chronic pain as a chronic condition with profound and far-reaching consequences. It elaborates on the complexity of managing chronic pain within individual, social, economic, and environmental contexts that influence self-management. The SFMF elaborates on risk and protective factors that influence self-management in chronic pain. It identifies health status, personal/individual factors, health systems, resources, and environment as the factors influential to self-management. These factors can pose as risk and protective factors and may inadvertently influence self-medicating in chronic pain management (Grey et al., 2006; Schulman-Green et al., 2012, 2021).

The importance of self-management to managing chronic pain is well established (Bair et al., 2009; Nicholas & Blyth, 2016; Thorne et al., 2003). Within self-management, self-medicating is a specific strategy with inherent benefits in pain management (Cooper, 2013b; Perrot et al., 2019). However, the misuse of codeine typically occurs through legitimate pain management highlighting the risk of self-medicating in self-management (Hopkins et al., 2018; Mill et al., 2018). The fact that codeine misuse occurs within self-medicating – a recognised and legitimate self-management strategy in pain management, warrants an exploration of the processes that lead to misuse. The current study will explore the issues at the interface between community pharmacies and individuals self-medicating with codeine-based analgesics for pain management. In addition, it will explore the lived experiences of individuals self-medicating for pain management to identify the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management.

Chapter 3: Overview of study

3.1 Introduction

This chapter presents the overview of the methodological approach used in the study. The study aims and objectives are presented followed by the design of the study. The chapter then discusses the philosophical foundation of the study before discussing the qualitative research approaches adopted. Triangulation is then presented before concluding the chapter with a reflexive discussion.

3.2 Study aims

The overarching aim of the study was to explore factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. This was achieved in two phases. Aims pertinent to each phase of the study were:

1. To qualitatively explore the views and experiences of community pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with over-the-counter medication.
2. To qualitatively explore the lived experiences of individuals living with chronic pain with specific focus on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain overtime.

3.2.1 Phase one objectives

The specific objectives of this phase of the study were to explore:

1. The healthcare advice provided in community pharmacies on pain management.
2. The influence of the community pharmacy structure to the service provided on pain management.
3. The relationship between pharmacy professionals and patients/consumers in pain management.
4. The issues surrounding the sale of over-the-counter (OTC) medication for pain management with specific focus on OTC codeine-based analgesics.

3.2.2 Phase two objectives

The specific objectives of this phase of the study were to explore:

1. The lived experiences of individuals living with chronic pain overtime and how these experiences influence self-medicating habits with specific emphasis on OTC codeine-based analgesics.

2. The psychosocial factors that influence choice and use of medication for pain management, focusing on change or stability overtime and the causes and consequences of change.

3. The relationships between individuals living with chronic pain and pharmacies in the self-management of pain.

3.3 Study design

The current study consisted of two phases: Phase 1 adopted a reflexive thematic analysis (RTA) design for the cross-sectional research. Phase 2 adopted a longitudinal qualitative research (LQR) design for the longitudinal research involving four time points. The cross-sectional research involved interviewing community pharmacy professionals to explore their views and experiences on their interactions and relationships with codeine consumers in the management of pain with OTC medication. The longitudinal research involved interviewing individuals living with chronic pain at four timepoints to explore their lived experiences with specific focus on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain overtime. The methods, findings, and discussion of each phase of the study will be presented separately in Chapters 4 and 5, respectively.

Following on from the two study phases, findings from phases 1 and 2 were synthesised to achieve the overall aim of the study that is to explore the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. Effective management of chronic pain recognises the expertise of pharmacy professionals in providing self-management support and individuals living with chronic pain as the experts in the lived experience of pain (Fu, et al., 2016b; Gordon et al., 2017; Morgan et al., 2017). Understanding the perspective of pharmacy professionals who are experts in providing support in self-medicating and have been tasked as gatekeepers to implement codeine supply regulations highlighted the issues at the interface between community pharmacies and codeine consumers in OTC codeine supply and self-medicating. In addition, understanding the perspective of experts in the lived experience of pain highlighted the lived experiences and the contextual, individual, social, and environmental issues that influence patterning of OTC codeine use in chronic pain management. Synthesising both findings presented a comprehensive, multi-dimensional, and higher-level interpretation of the factors influencing self-medicating both from the perspective of community pharmacy professionals and individuals self-medicating for chronic pain.

3.4 Philosophical foundation of study

Every researcher is guided by beliefs, perspectives or world views and patterns of interaction with the environment. This subsequently influences the choice of methods used to answer research questions, the knowledge produced and its meaning (Creswell & Creswell, 2007; Denzin, 2009). These sets of beliefs guiding researchers in the choice of methods used can be defined as research paradigms (Mertens, 2017). Research paradigms serve as a guide in disciplined enquiry and are identified by ontological, epistemological, methodological approaches and by theoretical perspectives underpinning the research methodology used (Creswell & Creswell, 2007; Denzin, 2009). The following section contextualises and serves as a guide on the beliefs, perspectives and worldviews underpinning the current study.

3.4.1 Pragmatism

Pragmatism is a philosophical paradigm that acknowledges reality both from constructivist and positivist paradigms therefore accepting the existence of singular or multiple realities (Creswell & Creswell, 2007). Instead of focusing on specific epistemological and ontological assumptions, pragmatism is based on the premise that methods are selected based on their relevance and capability to address and solve real world problems (Johnson & Onwuegbuzie, 2004). This ensures that research produces actionable knowledge that is of benefit to addressing complex issues. For example, in health research, pragmatism has been adopted in patient-oriented research (Allemang et al., 2022), paediatric research (Thompson et al., 2022), and implementation science (Ramanadhan et al., 2021). Pragmatism recognises that knowledge is both constructed and is based on the reality it is experienced in therefore lending itself to multi-methods and mixed methods research. Though typically adopted in mixed-methods (qualitative and quantitative) research, (Johnson & Onwuegbuzie, 2004; Morgan, 2014), pragmatism provides opportunities to strategically combine established qualitative approaches to address complex phenomena in qualitative research (Kelly & Cordeiro, 2020; Ramanadhan et al., 2021; Thompson et al., 2022).

Pragmatism was adopted as the philosophical foundation of the current study. It was deemed suitable given the complexity of exploring the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management and the need to produce actionable knowledge that is of benefit to addressing the codeine epidemic in Ireland. More specifically, from a philosophical perspective it was deemed the most suitable for phase 2 of the research which adopted a LQR design (see section 5.3). LQR designs are flexible and do not have distinguished epistemological and ontological standpoints allowing researchers to develop suitable research designs for each study by combining diverse qualitative data collection and analytical techniques (Audulv et al., 2022; Thomson, 2007; Tuthill et al., 2020). In response to criticism of LQR due to the lack of a clear epistemological and ontological standpoint, Saldaña, (2003), highlighted his position as "*My own paradigmatic assumptions and pragmatic ways of making meaning in qualitative inquiry boil down to a research orientation that suits" (*Saldaña, (2003 p xi)). Similarly, Neale (2021) highlighted the need to embrace different analytic approaches to uncover complexities and nuances inherent in longitudinal qualitative data. Pragmatism allowed the researcher to strategically combine established qualitative analytic approaches to best explore the lived experiences of individuals living with chronic pain focusing on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain overtime. Detailed methodological approaches for each of the phases are presented in Chapters 4 and 5.

3.5 Qualitative research

Qualitative research has been described as an inductive, interpretive, and naturalistic approach used to understand how individuals experience the world (Braun & Clarke, 2013; Yilmaz, 2013). Addo and Eboh (2014) defined qualitative research as an approach to the scientific inquiry which is primarily concerned with exploring human experiences in personal and social contexts to gain an in-depth understanding of factors influencing those experiences. Qualitative research is grounded in a constructivist paradigm where things exist as constructions of reality and there is no fixed or static objective truth waiting to be discovered as posited by the positivist paradigm (Creswell & Creswell, 2007; Denzin, 2009). A qualitative research methodological approach was deemed most suitable for the current study due to its congruence to the underpinning philosophy of qualitative inquiry with the aims and objectives of both phases of the study.

3.5.1 Intra-paradigm qualitative research

Within qualitative research, different research methodologies and methods can be used to explore a phenomenon in what is referred to as intra-paradigm research whereby all aspects of research are drawn from the same paradigm with the same ontological foundation that allows epistemological congruence (Morse, 2009; O'Reilly et al., 2021; Thomson, 2007). Intra-paradigm qualitative research can include mixed methods designs and multi-method approaches in qualitative studies. Mixed methods involve the use of multiple qualitative methods of data collection (e.g., interviews, focus groups and document analysis) and/or multiple qualitative data analysis approaches (e.g., identification of themes, case histories, analysis of discourse) in a specific study (Anguera et al., 2018; O'Reilly et al., 2021). The use of mixed qualitative methods in intra-paradigm qualitative research can allow for a better understanding of complex phenomena by adopting best suited qualitative methods of exploration for data collection and analysis (Audulv et al., 2022; Tuthill et al., 2020). It allows researchers to incorporate multi-dimensional qualitative analytical approaches that provide unique strengths to address and explain complex issues in qualitative research (Calman et al., 2013; Holland et al., 2006). Multiple method involves the use of different qualitative methodologies in studies whereby each methodological component of the study is conducted separately to ensure rigour before synthesis of findings (Morse, 2009; O'Reilly et al., 2021). The use of multiple methods in intra-paradigm qualitative research can allow researchers to expose insightful aspects from different perspectives that one method could not expose before synthesising findings to reach a more comprehensive interpretation of the studied phenomena (Briller et al., 2008; Heale et al., 2016; Noble & Heale, 2019).

The current study adopted an intra-paradigm qualitative approach in its design. A multiple method approach was adopted for the overall study. Phase 1 adopted an RTA design (see section 4.3.5) and phase 2 a LQR design (see section 5.3) before synthesising the findings through triangulation. In addition, Phase 2 adopted a multiple methods approach in its analytical roadmap. Details of the analysis are discussed in section 5.3.10. This allowed a more balanced and nuanced explanation of the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management.

3.5.2. Compatibility in intra-paradigm qualitative research

Pertinent to intra-paradigm qualitative research is the need for compatibility of qualitative methods and methodologies used in a study (Briller et al., 2008; O'Reilly et al., 2021). The current study adopted a constructivist paradigm approach to explore the socially constructed and dynamic realities for pharmacy professionals in their experiences of supplying of OTC codeine and individuals' lived experiences of self-medicating for chronic pain (Adom & Ankrah, 2016; Creswell & Creswell, 2007). It adopted a social constructivist epistemology where there is no objective truth waiting to be discovered but through individuals interacting with the world, knowledge is constructed (Crotty, 1998; Macleod et al., 2022). The methodological approaches chosen throughout the study (RTA and LQR), have a constructivist orientation that allowed compatibility in constructing and interpreting the multiple realities to understand the factors that influence OTC codeine use based on individual contexts, experiences, knowledge, attitudes, and beliefs (Macleod et al., 2022). In addition, the synthesis of findings allowed a higher-level interpretation of experiences both from the perspectives of pharmacy professionals and the lived experiences of self-medicating for chronic pain using the same constructivist world view (McMillan, 2022). Within the current intra-paradigm qualitative research, epistemological congruence ensured compatibility in data collection methods, analytical approaches adopted, and in the synthesis of findings through triangulation. (Cleland, 2022; McLeod et al., 2022; Mcmillan, 2022).

3.6 Triangulation

Triangulation was used to synthesise the data from Phase 1 and Phase 2 of the study. Triangulation refers to the use of either multiple data sources, methods, theories, or observers in qualitative research to develop an enriched comprehensive understanding of a phenomena (Patton, 1999). It helps explore and explain complex phenomena through the use of multiple approaches therefore offering a balanced explanation and interpretation (Carter et al., 2014; Guion et al., 2011). The primary goal of triangulation is to explore convergence, complementarity, silences, and dissonance to achieve the overall goal of enhancing validity, credibility, and dependability of research (Farmer et al., 2006). Convergence refers to the consistency or agreement of findings leading to the same conclusion whilst complementarity refers to different perspectives on the same phenomena which can relate in building a more comprehensive understanding from individual findings. Silence refers to the absence of a theme in other findings whilst present in one finding. Dissonance refers to when two or more sources of data addressing the same phenomena produces unexplainable divergent explanations which can be as equally important in bringing a more nuanced understanding of a phenomenon or provide a point of departure for different theory development (Farmer et al., 2006; Heale & Forbes, 2013). By using information from different sources and methods to interpret the same phenomena, in addition to exposing convergence, triangulation can expose multi-dimensions of the same phenomena through the complementarity of multiple data sources. In addition, it can expose unexplainable divergences through dissonance in findings (Carter et al., 2014; Golafshani, 2015). Triangulation was adopted in the current study. It facilitated synthesis of multiple data sources (pharmacy professionals and individuals living with chronic pain) and methods (RTA and LQR designs) to offer a more comprehensive understanding and interpretation of the factors that influence OTC codeine use. Triangulation enhanced validity, credibility, and dependability of the research (Carter et al., 2014; Farmer et al., 2006; Johnson et al., 2017).

3.7 Reflexivity in qualitative research

Macleod et al. (2022) highlighted the interconnectedness of both researcher and participants in social research and therefore the importance of reflexivity. From a constructivist epistemological standpoint, the researcher is the key primary data collection and interpretation tool. The researcher’s relationship with participants is inextricably linked and influential to the knowledge produced (Braun & Clarke, 2013; Creswell & Creswell, 2007). Therefore, my role as researcher warrants further discussion as my position, personal values, assumptions, and prejudices may have influenced methodological design, conduct, analysis of data and findings presented (Morse, 2015; Patton, 2014).

I qualified as a Pharmacy technician and had previously worked in community pharmacies for 15 years prior to commencing the current study. At the time of Phase 1 data collection, I was working in a community pharmacy, and I was involved in the supply of OTC codeine. However, I moved from community pharmacy to a health promotion role a year after commencing the study. The motivation to embark on this study arose from my professional experience of interacting with individuals self-medicating with codeine-based analgesics and the complexity of implementing codeine regulations within these interactions. Throughout the study, I wrestled with my identity as a pharmacy technician and my identity as a researcher. As a pharmacy technician, I started the research with assumptions of why individuals misused codeine analgesics coming from a place of frustration having been involved in implementing codeine regulations. As a researcher, I knew there was more to the issue of codeine misuse that went further than my understanding from a community pharmacy perspective. Throughout the research process I reflected on each stage of the study. I continuously engaged with my research supervisor to seek views, comments, and opinions at all stages to ensure that the process of reflexivity was enhanced (Patton, 2014). I specifically used bracketing as a way of mitigating the influence of preconceptions (Tufford & Newman, 2012). These took the form of strategically timed meetings with my supervisor conducted throughout the study.

The purpose of reflexive practice is to ensure transparency, trustworthiness, and accountability in the research process and therefore researchers need to be clear in their motivations to ensure an accurate representation of research findings (Doucet, 2008; Morse 2015). In terms of my own stance, I had to be clear about my background of being a pharmacy technician at the beginning of the study before moving on to a health promotion role for the remainder of the study. It is from this position that I conducted, analysed, and interpreted this current study. Reflections pertinent to each phase of the study are included in Chapters 4, 5 and 6.

Chapter 4: Phase 1 – Pharmacy Professionals Cross-Sectional Research

4.1 Introduction

This chapter presents phase one of the study: qualitative cross-sectional research with community pharmacy professionals. Firstly, the chapter details the qualitative methodological approach adopted in this phase of the research. The aim of phase one of the study is outlined, followed by the objectives of the research. An overview of the research design, recruitment, sample, data collection and generation, ethical considerations and analysis process are discussed before concluding with a reflexive discussion.

Secondly, the chapter presents the themes identified from analysis of interviews conducted with pharmacy professionals. The themes and sub-themes identified are presented alongside the extracts from the interview transcripts. A summary of the findings is outlined to conclude the chapter.

4.2 Research aim

The aim of this phase was to explore the views and experiences of community pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with over-the-counter medication.

4.2.1 Research objectives

As outlined in Chapter 3, the specific objectives of this phase of the study were to explore:

1. The healthcare advice provided in community pharmacies on pain management.
2. The influence of the community pharmacy structure on the service provided on pain management.
3. The relationship between pharmacy professionals and patients/consumers in pain management.
4. The issues surrounding the sale of OTC medication for pain management with specific focus on OTC codeine-based analgesics.

4.3 Reflexive thematic analysis design

A reflexive thematic analysis (RTA) design was adopted to qualitatively explore the views and experiences of community pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with OTC medication. Thematic analysis (TA) can be described as a qualitative method of identifying, analysing, and reporting patterns (themes) within a data set (Boyatzis, 1998). One of the key tenets of TA is it provides an interpretation of the research topic and themes that capture issues of importance in relation to research questions (Braun & Clarke 2013).

An RTA design approach was considered the most appropriate to explore the views and experiences of pharmacy professionals in pain management interactions within community pharmacies. It facilitated research coherence between the aim to explore the views and experiences of community pharmacy professionals and the constructivist paradigm underpinning the qualitative approach adopted in the study. RTA was incorporated within a constructivist epistemology that allowed the construction and interpretation of the multiple realities of experiences of community pharmacy professionals on their interactions with codeine consumers in the management of pain (Braun & Clarke, 2021a). The RTA design approach adopted in this study provided an opportunity for pharmacy professionals' views to be interpreted based on their own words, the totality of their experiences and the meanings ascribed to subjective experiences when interacting with individuals managing pain and in the sale of codeine-based analgesics (Braun & Clarke, 2013).

Within RTA, interviews, focus groups and self-report qualitative techniques are among data collection methods that can be adopted (Braun & Clarke, 2021a). Interviews were deemed most suitable as a qualitative data collection method within the current study. Proximity and access to GP services, socio-economic status of the population served, prescription dispensing volume and location of pharmacy are all determinants of the level of service provided in community pharmacies (Rogers et al., 1998; Schommer & Gaither, 2014). In addition, the structure of community pharmacies in relation to the healthcare/retail space has an impact on the healthcare advice provided and expected. Big chain pharmacies with an optimised retail space tend to be perceived by patients/consumers as a resource for OTC medicine supply whilst small independent pharmacies with limited retail space are perceived as healthcare advice resources in the self-management of illness (Abu-Omar et al., 2000). Based on the potential of these contextual issues shaping the views and experiences of pharmacy professionals, individual interviews were more suitable to elicit subjective experiences shaped by these different contexts. Semi-structured interviews were deemed most suitable to collect data as they enabled reciprocity between participants and researcher enabling free emergence of topics to expose the participants' perspectives (Kallio et al., 2016). They provided a flexible approach to collecting data whilst enabling the elaboration of information or exploration of ideas of interest, which may not have previously thought about as important (Britten, 2006; Gill et al., 2008).

4.3.1 Participants

4.3.1.1 Sampling

Professionals working in community pharmacies who were directly involved in the sale of OTC codeine-based analgesics were eligible to participate; this includes pharmacists, pharmacy technicians and healthcare assistants. A description of the sample is included in section 4.3.1.3. Firstly, purposive sampling was used followed by snowball sampling using initial participants' networks to recruit more community pharmacy professionals (Heckathorn, 2011).

Braun and Clarke (2021a) suggest researchers provide a sample size range during the design stage in RTA with the final sample size determined during data collection using the concept of theoretical or meaning sufficiency. RTA advocates for pragmatic approaches in determining sample size range pre-data collection. This involves considering what is normative and acceptable in the discipline, time, and resources available to the researcher and the need to provide a sample that will generate adequate in-depth data sufficient to capture a rich, multifaceted, and complex story of patterning on the issues of interest (Braun & Clarke, 2021b; Ogden & Cornwell, 2010; Vasileiou et al., 2018). However previous RTA research approaches have considered data saturation as a guide to sample size (Carlsen & Glenton, 2011; Guest et al., 2020; Vasileiou et al., 2018). Data saturation can be defined as the concept of information redundancy whereby no new information codes or themes can be generated from qualitative data (Braun & Clarke, 2021b). Some research suggests sample size justification of data saturation through quantitative based approaches (Francis et al., 2010; Guest et al., 2020). However, Braun & Clarke (2021) argued the incompatibility between data saturation approaches and RTA. To ascertain the number of participants required to reach data saturation in RTA would require data collection and analysis to be conducted and completed before the number can be determined. In RTA, coding can evolve through the research process and eventually become more refined, interpretive, and conceptual as analysis progresses. Within this context, the concept of data saturation in determining sample sizes is arguable (Braun & Clarke, 2021b).

Sample sizes of between 15 and 30 participants are common in studies using RTA (Braun & Clarke, 2013). Based on the normative and expected sampling size within the psychology discipline, the need to generate in depth data on the issues at the interface between pharmacy and codeine consumers in pain management, and the practical and logistical constraints of the timeframe to complete the PhD study, a pragmatic decision was made to aim for a sample size range of between 25 and 30 participants for the current study. However, during the study, data collection was stopped after interviewing 25 participants as meaning sufficiency was reached at this point (Braun & Clarke, 2021a). The 25 interviews had sufficient data to generate in-depth meanings of the views and experiences of community pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with OTC medication.

4.3.1.2 Recruitment

Approval to approach prospective participants at their workplaces was sought through management of community pharmacies (Appendix C1). Following approval from each pharmacy, to avoid potential conflict of interest between prospective participants and pharmacy management (Mecca et al., 2015), prospective participants were approached in their individual pharmacies and invited to take part in the study. A research information sheet (Appendix C2) was provided to prospective participants and after a cooling off period of at least 24 hours, prospective participants were approached for recruitment. If agreeable, convenient venues and times to conduct interviews were then arranged with participants. Contact details were also requested at this stage to facilitate interview arrangements.

4.3.1.3 Participant sample

Twenty-five participants were recruited for the study. Of the 25 participants, 15 were female and 10 were male. Their experience working in pharmacies ranged from less than 1 year to 26 years. The sample comprised of the following:

Pharmacists (n = 7)

Pharmacists based in one community pharmacy. The sample comprised of both males *(n = 5)* and females *(n = 2)* working in urban community pharmacies in the Leinster region.

Locum pharmacists (n = 7)

Locum pharmacists are employed on a contractual basis by pharmacy agencies, and temporarily fulfil duties of pharmacists in any pharmacy. The sample comprised of both males (*n = 2)* and females *(n = 5)* who were working both in urban and rural community pharmacies located in all the regions of the Republic of Ireland, Connacht, Leinster, Munster, and Ulster.

Pharmacy Technicians (n = 7)

Pharmacy technicians assist in the dispensing of prescriptions and assist on the sale of OTC medication under the supervision of the pharmacist. The sample comprised of a male *(n = 1)* and females *(n = 6)* working in urban community pharmacies in the Leinster region.

Healthcare assistants (n = 4)

Healthcare assistants assist on the sale of OTC medication under the supervision of a pharmacist. The sample comprised of males (n = 2) and females *(n = 2)* working in urban community pharmacies in the Leinster region.

All the names presented throughout the thesis are pseudonyms to ensure the anonymity of the participants in accordance with ethical principles. The demographics of the participants are summarised in Table 1.

Table 1:

Demographic Characteristics of Phase 1 Participants

Participant	Pharmacy Role	Experience (years)	Gender
Ethan	Pharmacist	5	Male
Owen	Pharmacist	2	Male
Nathan	Pharmacist	11	Male
Charlie	Pharmacist	17	Male
Darren	Pharmacist	20	Male
Fiona	Pharmacist	11	Female
Sophie	Pharmacist	10	Female
Ian	Locum Pharmacist	26	Male
David	Locum Pharmacist	6	Male
Emily	Locum Pharmacist	1	Female
Anna	Locum Pharmacist	2	Female
Suzanne	Locum Pharmacist	6	Female
Aisling	Locum Pharmacist	4	Female
Lisa	Locum Pharmacist	17	Female
Lauren	Pharmacy Technician	11	Female
Tracey	Pharmacy Technician	19	Female
Hazel	Pharmacy Technician	10	Female
Rachael	Pharmacy Technician	7	Female
Clara	Pharmacy Technician	6	Female
Lucy	Pharmacy Technician	18	Female
Leo	Pharmacy Technician	10	Male
Seamus	Healthcare Assistant	>1	Male
Connor	Healthcare Assistant	1	Male
Olivia	Healthcare Assistant	>1	Female
Grace	Healthcare Assistant	10	Female

4.3.2 Data collection

4.3.2.1 Development of interview guides

Interview guides were developed informed by literature on pain management in community pharmacies; one for pharmacy technicians and healthcare assistants (Appendix C3) and another one for pharmacists (Appendix C4). The decision to develop two was based on the different roles of pharmacy professionals in the supply of codeine-based analgesics (Pharmaceutical Society of Ireland, 2019). The questions were broadly on the following topics: interactions with individuals managing pain, pain consultations, roles in the sale of over-the -counter pain medication, codeine-based analgesics and retail products in the pharmacy and codeine regulations implementation. The following questions were included:

- Can you tell me about your role in OTC pain management in the pharmacy?
- Can you tell me about your role in assisting and selling of retail products in the pharmacy?
- Can you tell me about the sale of over-the -counter pain medication to patients managing pain?
- Each codeine sale is referred to the pharmacist. How do you feel about that? (For pharmacy technicians and healthcare assistants)
- Each codeine sale is referred to you. How do you feel about that? (For pharmacists)
- How do you feel about recommending codeine-based pain medication?
- Do you have anything else you would like to share of your interactions with patients looking for codeine-based pain medication?

Questions were open ended to ensure they would elicit detailed information and prompts were used to encourage more detailed responses (McIntosh & Morse, 2015). Though the purpose of the interview guide was to provide some structure to the interview, it also proved useful in ensuring that all issues of interest were discussed, interviews did not stagnate and to refocus on issues related to research when discussion veered off topic (Braun & Clarke 2013; Neale, 2021). At the end of each interview, participants were offered to check on identified themes and to receive a final report of the study. One participant opted for theme checking and all participants to receive the final report.

4.3.2.2 Piloting the interview questions

Piloting was conducted with three pharmacy professionals: a healthcare assistant, a pharmacy technician, and a pharmacist. This was to ensure that there were no ambiguities or difficulties with interview schedule, validity of schedule in exploring research objectives and that researcher was familiar with interview method (Pritchard & Whiting, 2012). This proved useful as this facilitated refining of questions and prompts. Pilot data was not included in analysis.

4.3.3 Conduct of interviews

A total of 25 participants were recruited and all interviews were conducted between April 2018 and September 2018. All interviews were conducted face to face and audio recorded. Interviews lasted between 35 and 88 minutes. The mean duration of interviews was 50 minutes.

4.3.4 Ethical considerations

Ethical approval for study was granted by the Social Research Ethics Sub-Committee of Maynooth University between March 2018 and March 2019 (Appendix C5).

4.3.4.1 Consent

Written consent was sought from participants before each interview (Appendix C6). The process of consent involved going through the research information sheet to ensure participants understood all aspects of the research and their role as a participant. Specific ethical issues were also highlighted for example, confidentiality, anonymity, and the right to withdraw before seeking for consent to participate and to audio record the interviews. Consent forms were signed after this process once participants were agreeable.

4.3.4.2 Anonymity and confidentiality

All data were handled in accordance with the principles of confidentiality from the outset of the research. Only the research supervisor and researcher had access to personal information and data collected from participants. The data comprised of demographic information, consent forms, audio-recordings, and transcripts. All audio recordings and transcripts were encrypted and stored on a secure PC and consent forms were stored in locked cabinets with limited access on campus. All audio recordings were collected on a mobile device which was protected with a strong password and were deleted from the mobile device once transcription was completed. All data collected were anonymised to ensure privacy and confidentiality by use of pseudonyms.

4.3.4.3 Debriefing

On completion of each interview session, the welfare of each participant was checked by researcher and participants were reminded to contact their GP, or the National Counselling Service should they experience stress due to participating in the study. They were also reminded of the purpose of the study and were given the opportunity to ask questions. Their right to withdraw up until personal identifiers were disposed of was also reiterated and anonymisation of data, use of pseudonyms and confidentiality.

4.3.5 Data analysis

RTA was used to analyse the data generated through semi-structured interviews (Braun & Clarke, 2006; Byrne, 2022). Different approaches can be used in TA; inductive or deductive. The inductive approach involves qualitative data analysis without any predetermined theories, frameworks, or structures. It uses actual data generated during the study to form the structure of the analysis. Contrarily, a deductive approach involves the use of predetermined theories, structure, or framework. Fundamentally a deductive approach imposes its own theories, or frameworks on the data (Braun & Clarke, 2006). In comparison, the deductive approach is relatively quicker and easier. However, the focus on existing theories, frameworks or structures can potentially bias analysis process and can limit opportunities for theory development. An inductive approach was adopted for the current study.

Within inductive and deductive approaches Braun & Clarke (2020) highlighted 3 variations of TA: coding reliability, codebook, and reflexive. Coding reliability and codebook TA fit within deductive approaches and uses a structured coding framework for developing and documenting analysis. They typically require multiple coders and themes can be predefined and are developed early on during the analytical process. RTA is an inductive approach which uses data generated during the study to form the structure of the analysis. It is a flexible approach which acknowledges researcher's role in knowledge production and does not require multiple coders. Codes are understood as researcher's interpretation of patterns identified within a data set. Themes are not predefined or developed early but through a process of flexible open coding, identification of patterns and interpretation, themes are developed.

Braun et al. (2006) outline six steps involved in RTA which were adopted for this current study; 1) familiarisation with data, 2) generation of codes, 3) construction of themes, 4) reviewing of potential themes, 5) defining and naming of themes and 6) writing of findings.

Step 1: Familiarisation with data

Familiarisation with data corpus marked the first stage of analysis. However, prior to this stage, conducting all aspects of the research had initiated the process of familiarisation with the data during data collection. Developing interview guides, piloting interview questions, and conducting all interviews allowed me to immerse in the data from the outset. Individually transcribing each interview provided me an opportunity to interact with the data for prolonged times listening to each interview and rewinding recordings where necessary to capture all data. Even though transcribing of interviews was time-consuming, it offered me an opportunity to immerse myself in the data and to start making connections within the data. Slowing down interviews during the transcription process allowed me to grasp and process connections that had not been apparent during the interviews. After transcription, I engaged with reading, and rereading of transcripts to further engage with the data. I noted my initial thoughts and connections on the views and experiences of community pharmacy professionals in their interactions in pain management and more specifically with codeine consumers during this process. I reflected and noted the meanings ascribed by participants to their experiences, and it became apparent to me during this stage that participants interpreted their experiences from a personal, professional, and moral perspective.

Step 2: Generation of codes

Manual coding was adopted for this phase of the study. This involved systematically coding each transcript by going through line by line and taking note of anything that jumped out and was potentially interesting in interpreting the views and experiences of pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with over-the-counter medication (see Appendix C7). I used an inductive approach and coded everything I identified as meaningful to the research interest. Initially this led me to semantic coding, capturing of explicit meanings directly linked to participants’ narratives (Braun & Clarke, 2020). However, as I progressed and revisited transcripts, my coding of data became more interpretive which led me to latent coding, capturing of implicit meanings of participants’ narratives (Braun & Clarke, 2020). Some interpretations of data resulted in both semantic and latent coding which is in line with the constructive epistemology adopted in the study. This involved interpreting data based on the participants’ contexts, experiences, knowledge, attitudes, and beliefs (Braun & Clarke, 2019; Byrne, 2022). This was an arduous process which involved stepping away from the process due to the time required to generate codes. However, this proved to be beneficial as this provided an opportunity to reengage with data after reflecting on explicit and implicit meanings. This led to engaging with data with a different mindset which allowed a more nuanced higher-level interpretation of data. During this iterative process my codes became shorter as I moved from semantic coding to latent coding. Generation of codes was an iterative process throughout, that involved revision and refining of codes until I generated final codes that I identified as meaningful to capturing the views and experiences of pharmacy professionals. Eventually most codes were brief but offered sufficient detail to inform patterns identified on the views and experiences of pharmacy professionals in pain management interactions (Braun et al. 2013). During this process I noticed patterns in the different transcripts, and I highlighted corresponding excerpts using different colours for each pattern identified.

Step 3: Generating themes

I adopted a manual approach to organising codes that conveyed the same or similar meanings. I wrote codes with similar meanings and commonalties on the same colour post it notes and grouped each colour separately on sections on a wall. During this process, I identified codes that had shared meanings and combined them to form one code. Some of the codes were a representation of a few codes and started to represent subthemes. This approach enabled me to use codes with common and similar meanings as building blocks in the generation of themes (Braun & Clarke, 2006). The initial organisation of post it notes quickly highlighted how the views and experiences of participants were embedded at 3 levels, 1. at a patient/consumer level; 2. at a systems level, and 3. at a personal level. Once I identified these levels, I started grouping post it notes within each level. However, I identified codes that fitted in more than one level. For example, the meanings ascribed to experiences of interacting with codeine consumers in codeine regulation protocols at a semantic level seemed like they were all personal but from a latent level, I identified there were implicit meanings ascribed at systemic and patient/consumer levels as well. This process further highlighted commonalities within the codes using explicit and implicit meaning and through further iterations I eventually identified coherent patterns within the data. I then generated the initial provisional themes based on the meaning being conveyed by grouped codes (provisional sub-themes).

Step 4: Reviewing themes

I reviewed provisional themes in two ways. Firstly, I reviewed the coherence between data excerpts and codes that had informed subthemes and themes. I returned to the dataset to ensure that the data and associated codes were a representation of sub-themes and themes. Secondly, I reviewed the themes for coherence with the data set and the extent that they were addressing the views of experiences of pharmacy professionals in their interactions with codeine consumers. This involved an iterative process of combining some themes, discarding, or adjusting accordingly until all relevant experiences and meanings represented by the codes were captured and represented in the themes and subthemes. The use of post it notes made it easy to move around codes iteratively whist checking with transcripts to confirm meaning.

Step 5: Defining and naming themes

This involved refining and defining themes and subthemes identified in the data. This was an iterative process that involved a lot of reflection. There were different approaches that I could have adopted in refining and naming the final themes. During this process, I continually engaged with my supervisor and shared ideas and the associations I had identified between themes and research focus. This broadened my perspective in capturing the essence of each theme and associated subthemes. For example, themes and subthemes that were related to the system that inadvertently shaped the way pain interactions went with codeine consumers were named to reflect this. Extracts that were used as part of the report were also identified at this stage based on their capability to elaborate on associated sub-themes and themes.

Step 6: Writing of findings

Writing of findings required further reflection as I articulated the themes and the meanings associated with sub-themes. Through supervisor feedback, I progressed from the initial draft to the final presentation of findings with some further adjustments to themes and sub-themes in a way that addressed the research topic. This also involved further refinement of themes and sub-theme names to capture the essence and provide a complete representation of the experiences and views of pharmacy professionals. This was an iterative process that served the purpose of allowing a higher level of articulation of the issues represented in the writing of the findings.

4.3.6 Reflexivity in qualitative research

During the initial phase of this study, I was working in a community pharmacy as a pharmacy technician. The pharmacy I was working in approved my request to approach and invite pharmacy professionals to participate in the study. Inadvertently, I ended up interviewing five of my work colleagues. This created both a position of strength and weakness. During interactions, I quickly identified an assumption that I knew and understood the issues at the interface between the pharmacy I was working in and codeine consumers. More often colleagues focused on the frustration the regulations had brought on to their roles.

This is something that I had also identified during piloting and as such I was aware of this assumption resulting in some issues not being fully explored. The use of the interview guides ensured that all issues of interest were discussed, and I used prompts to ensure a more in-depth exploration of all issues that participants may have overlooked based on the assumption that I knew them already. On the other hand, due to the pre-existing rapport with participants, I felt participants were very open and free to discuss their experiences with me. However, at analysis stage, I had moved on to a health promotion and research role and I was no longer directly interacting with codeine consumers. This was beneficial throughout analysis as this enabled me to immerse myself in the data without being exposed to codeine interactions. Adopting the six steps involved in RTA (Braun & Clarke, 2006), involved reflexive data generation throughout the process as highlighted in section 4.3.5.

The purpose of reflexive practice is to ensure transparency, trustworthiness, and accountability in the research process and therefore researchers need to be clear in their motivations to ensure an accurate representation of research findings (Doucet, 2008; Morse 2015). In terms of my own stance, I had to be clear about my background of being a pharmacy technician at the time of data collection and the reflexive processes I engaged with during data analysis. Throughout the research process, I continuously engaged with my research supervisor to seek views, comments, and opinions at all stages to ensure that the process of reflexivity was enhanced (Patton, 2014).

4.4 Findings of cross-sectional analysis of pharmacy professional interviews

4.4.1 Summary of findings

Three broad overarching themes and associated subthemes were identified from thematic analysis of interviews: unintended consequences of codeine regulations; systemic failures; and social influences.

Firstly, findings identified unintended consequences of codeine regulations. Tension filled interactions between pharmacy professionals and individuals self-medicating for pain were identified due to the implementation of codeine regulations which were a hindrance to providing support. In addition, implementation of regulations resulted in conflicts of interest due to competing demands for pharmacy professionals. Furthermore, implementation of codeine regulations had personal implications for pharmacy professionals as they described associated tension-filled interactions as emotionally draining.

Secondly, systemic failures that shaped pain interactions in pain management interactions were identified. Classification of OTC analgesics and inadequate health services were found to be influential to how interactions between pharmacy professionals and individuals self-medicating for pain went. Thirdly, social influences were found to be problematic in pain management interactions. Evolving information sources, lifestyle choices and social norms were found to be more influential to self-medicating choices and habits than the advice of pharmacy professionals. A summary of the themes and sub-themes is presented in Table 2.

Table 2

Summary of Phase 1 Themes and Sub-themes

Main Theme	Sub-themes
Unintended consequences of codeine regulations	• A hindrance to providing support • Conflicts of interest • It's emotionally draining
Systemic failures	• Classification of analgesics • Inadequate health services
Social influences	• Evolving information sources • Lifestyle choices • Social norms

4.4.2 Theme 1: Unintended consequences of codeine regulations

The introduction of regulations in the supply of OTC codeine-based analgesics was identified as problematic resulting in conflict and division between pharmacy professionals and codeine consumers in pain management. The implementation of codeine regulations in the sale of OTC medication is contradictory with the expectations of consumers when they seek to purchase OTC medication in pharmacies. The classification of codeine-based analgesics as OTC medication requiring specific criteria to be met before being sold brought on unintended consequences for both pharmacies and consumers. Three sub-themes: a hindrance to providing support, conflicts of interest and it's emotionally draining capture how introduction of regulations has resulted in unintended consequences causing conflict and division between pharmacies and codeine consumers.

4.4.2.1 A hindrance to providing support

Pharmacy professionals reported a distinction between consultations relating to general health issues and those specific to pain management. General health issue consultations were guided by information and support seeking goals from customers creating opportunities for pharmacy professionals to recommend appropriate interventions. Contrarily, pain management consultations typically began with product specific requests and efforts to provide support were not always welcomed.

"In general people that come for pain medication know what they want, they will ask for a specific product" (Olivia - Healthcare Assistant).

"When you ask a patient for example let's say stomach issues, they open almost like a flower, and they give all the gory details and they really kind of want your help. If you make any sort of attempt when its pain related there is almost like an immediate shut-down where the patient, they become taciturn they become a little bit belligerent perhaps a little bit aggressive they almost see it as an interference" (Ian- Locum Pharmacist).

The disparity of expectations is clearly evidenced here. Pharmacy professionals expect and are well-trained to provide support and recommend appropriate interventions in pain management. However, customers do not see the need to involve pharmacy professionals in the decision-making process of the medication required for pain management. Experience and learned histories on the efficacy of pain medication seem to be more influential to the decision-making process than support from pharmacy professionals. This disparity of expectations was highlighted as more evident with codeine-based analgesics consumers.

"I find when people request for products it is the codeine painkillers. I find that the majority of other people they are like there's something wrong with me or I have something

wrong with me rather than like oh I need a decongestant, or I need something to soften wax in my ear, they ask for advice" (Owen- Locum Pharmacist*).*

"They would ask for specific products. Nine times out of ten it is product requests. You would get the odd person coming in to ask to help relieve a certain type of pain. So, nine times out of ten it would be codeine based with paracetamol" (David - Healthcare Assistant).

Conversely, customers realise and engage with the supportive role of pharmacy professionals in seeking advice for other ailments but deviate from this behaviour in pain management. There is a disparity of expectations and goals for the sale of pain medication especially codeine-based analgesics. Both customers and pharmacy professionals experience hindrances in achieving their goals but in different ways. In the context of OTC pain medication, there is an oppositional relationship created and performed resulting in conflict and division within interactions. To achieve their own goals, when specific requests of codeine-based analgesics were made, pharmacy professionals would follow codeine regulation guidelines to further interact with customers. This involved asking questions and advising on the addictive potential of codeine as per codeine regulations protocol. However, this resulted in a question-and-answer session instead of a proper consultation where more advice and support could be provided. Opportunities to further explore the nature of the pain and possible alternative interventions were missed.

"There would probably be more in-depth consultations if the patient indicated that they need advice. In those cases, you could go into much more detail, you can do a more thorough exploration of what the issue might be, is there any obvious analgesic choice that we can give, is there any adjuvant therapy, is it pain from stomach spasms, can we look at dietary lifestyle advice moving away from more traditional painkillers and give something like hyoscine antispasmodic" (Charlie - Pharmacist).

"Unintended consequences of actions around analgesia in Ireland have left patients on one side of the fence and pharmacy maybe on the other side of the fence, you know. Patients come in and they have their own opinion, and they say what they think pharmacists want to hear which might actually hide the root cause of the pain that need treating" (Ian – Locum Pharmacist).

In-order for customers to achieve their goal of purchasing codeine-based analgesics, interactions are steered in a manner that would achieve this goal. From the customer's perspective, the goal of getting the strongest, fast, and effective pain relief takes more pre-eminence than to seek for support. The immediacy of getting pain relief shapes and reinforces behaviour and heightens the disparity between customer approaches and professional approaches. The existence of codeine implementation protocols that need to be followed with each request causes tension between pharmacies and customers.

"They see us as annoying bureaucratic gatekeepers who are effectively and kind of an irritating block to getting what they want" (Ethan - Locum Pharmacist).

The differing of goals hinders the support pharmacy professionals can potentially provide in the management of pain. The importance and relevancy of the professional role that pharmacy professionals have is lost within the tension that differing goals create.

"A lot of patients they think of pain as an illness. I just have pain I need to get rid of it. I encourage them that painkillers are just controlling the pain and not controlling the cause of the pain but a lot of people they just don't want to hear they just want the pain gone" (Fiona - Locum Pharmacist).

"They think if I go to pharmacy and get this, I will be fine, so the next time it comes oh I tried that, and it helped I will go again and get the same thing" (Tracey - Pharmacy Technician).

Participants highlighted the importance of a holistic approach in the management of pain and emphasised the importance of looking further than just symptomatic relief to the root cause of the pain. The need to implement regulations once specific product requests were made did not lend itself into exploring the association of pain and other underlying health issues. It directed and shaped interactions in a manner that is not conducive to shared decision making in self-medicating approaches. The tensions inherent in pain medication interactions shaped the interactions between pharmacy professionals and customers in pain management resulting in an unwillingness for customers to engage further with pharmacy professionals. Underpinning the approach taken by customers to achieve their goal is the perceived efficacy of codeine-based analgesics in comparison with other OTC analgesics.

"Paracetamol and aspirin are very effective painkillers eh, I think familiarity breeds contempt, people don't seem to respect their painkilling power and you get phrases like 'I might as well eat smarties" (Charlie - Pharmacist).

"I have heard the word smarties associated with paracetamol like I am not taking those, that's smarties, give me something stronger" (Emily - Locum Pharmacist).

Despite empirical evidence on the efficacy of codeine-based analgesics suggesting that the amount of codeine in OTC medication is not high enough to provide significant additional pain relief, individuals seeking pain relief prefer them as first line treatment. This preference is in direct contrast with codeine supply regulations. The classification of codeine-based medication as a second line treatment has potential to influence the attitudes of codeine consumers towards first line treatment options.

"Codeine should be used as a last resort and yet having said that codeine-based painkillers are the best painkillers sold in Ireland and are top sellers in OTC medication, that doesn't make any sense that they are bestsellers" (Ian - Locum Pharmacist).

"I suppose that is just human nature, just that people will push as far as they are let. I think people will often jump to second line first, the good stuff (laughs) so you definitely hear those phrases about the good stuff" (Lucy - Healthcare Assistant).

Within this context, the need to get a supply of analgesics perceived as the most effective hinders the potential to receive support from pharmacy professionals. In addition, based on codeine regulations, codeine-based analgesics cannot be stored where consumers can see them. Typically, they are stored in the dispensary where pharmacists can monitor sales. Healthcare assistants and pharmacy technicians must consult and seek authorisation from a pharmacist before selling to consumers. Storing codeine-based analgesics in the dispensary can create subtle dynamics in the expectations and attitudes of consumers.

"If a patient sees you going into the dispensary where the codeine products are stored, they might think from a psychological aspect oh look they are in the dispensary that means they are more effective" (Owen - Locum Pharmacist).

"Some people think oh the pharmacist has to sell it to me, that must be better than what I can get over the counter, they request codeine-based painkillers regardless of whether it is suitable for their condition" (Tracey - Pharmacy Technician).

Typically, prescription only medications are stored in the dispensary. Storing OTC codeine pain medication in the dispensary could have inferred connotations of how strong and effective the medication is from the consumers perspective. The unusual classification of codeine has left it in a liminal space with the potential to foster tensions between pharmacy professionals and consumers. The lack of a clearly defined category is an indication of how complex it can be for consumers to understand the regulations surrounding codeine-based medication. From a consumer's perspective, once medication is not on prescription it is reasonable to expect a pharmacist to supply the medication when requested. Being subjected to extensive questioning hinders the opportunity for more natural and conducive interactions between pharmacies and codeine consumers.

4.4.2.2 Conflicts of interest

The implementation of codeine regulations is complex and has the potential to create multiple competing demands for pharmacy professionals resulting in conflicts at a professional, regulatory, business, and personal level. Pharmacy professionals are expected to manage competing expectations both from employers and from customers when selling codeine. Employers expect pharmacy professionals to provide excellent customer care in a manner that builds a long-term relationship with the customer. Similarly, when customers visit a pharmacy, they expect excellent customer service and do not expect to be refused to buy a product that they perceive as over the counter. These competing expectations leave pharmacy professionals in a precarious position professionally as the codeine regulations demand that they decline selling codeine to consumers who do not meet the codeine regulations criteria.

"This can be very hard say if you refuse to sell the codeine painkillers you hear about it, they complain to head office, 90% of the complaints we get are codeine related" (Tracey - Pharmacy Technician).

"I had a complaint made against me a few months ago over codeine products, somebody wanted to buy them for a cold, and they told me they had not tried anything. I went to get the pharmacist that's all I did, and they put in a complaint against me" (Lauren - Pharmacy Technician).

The above quotes illustrate how the demands of implementing codeine regulations have implications on the customer service provided in pharmacies. Participants perceived receiving a complaint as a negative reflection of their performance professionally despite following the recommended guidelines. They found themselves in a position where their profession could be compromised due to dissatisfied customers complaining directly to management.

Contrarily, not implementing the regulations could also compromise their profession due to not complying to the codeine regulations. The complexity between trying to provide excellent customer service as expected of their role and upholding the codeine regulations results in a complex situation with conflicting demands for pharmacy professionals. They perceived their professions as continuously under threat due to the complaints logged to employers over codeine sales. They reported how a customer is always considered to be right in the retail business and this left them vulnerable.

Furthermore, pharmacists had the added threat of being reported to professional bodies as well as their employer. The risk of being reported to the Pharmaceutical Society of Ireland can open a fitness to practice investigation if a few complaints were logged against the same pharmacist. Pharmacists highlighted how their profession could be threatened by either supplying codeine without implementing the regulations or by refusing to supply codeine to patients.

"I have seen the consequence. I see pharmacists penalised for supplying codeine products and pharmacists being just as penalised for not supplying codeine under the fitness to practice regulations" (Ian- Locum Pharmacist).

"It is always a difficult one to make a call and you are caught right in between wanting to do what is right and wanting to protect yourself" (Owen – Pharmacist).

The role that pharmacists have in codeine sales demands that they make a judgement and risk mitigation call whilst exercising their role as gatekeeper and protecting their own profession. This puts pharmacists in a precarious position and creates conflicting interests with regards to providing the customer service employers expect whilst following codeine guidelines. The precarious nature of the pharmacist role in the implementation of codeine regulations is further emphasised in the case of locum pharmacists. Locum pharmacists perceived that if they implement regulations accordingly this could affect their relationship with that pharmacy and therefore were more inclined to conform with the way the codeine regulations were handled in that pharmacy.

"I feel like as a locum you kind of step into the business and kind of do it as they do but there have been cases where it has been really bad, where you see that this could be a dangerous situation and you have to intervene maybe with a healthcare assistant and a customer and talk to them but as a locum it would be hard to do long term, so you don't want to cause too much upset in the business but it is risky" (David - Locum Pharmacist*).*

"You go in some pharmacies and there is a certain way things are done especially in the small pharmacies where everyone knows everyone. It is difficult to really refuse anyone as you don't want to rock the boat. I have been told before that the normal pharmacist here does not ask me all that and of course you cannot argue with them" (Aisling – Locum *Pharmacist).*

There seems to be no uniformity in the way codeine guidelines are implemented across different pharmacies. For locum pharmacists, there is the added conflict of trying to conform to the way each pharmacy implements the regulations and following the guidelines. In addition, the expectation from the employer is for the business to run smoothly without the regular pharmacist. However, by conforming to the norms of the pharmacy and meeting the expectation of the employer, locum pharmacists are at risk of compromising their professional and ethical integrity. Implementing the regulations differently as a locum pharmacist poses the risk of the employer not hiring them again. This emphasises how the implementation of codeine regulations can create conflicting demands that pose professional threats to pharmacy professionals.

Furthermore, pharmacies operate as businesses whose main aim is to make a profit highlighting the need to sell products in-order for the business to perform well. Of note was, this issue was highlighted mainly by pharmacists and locum pharmacists. This is possibly due to pharmacists and locum pharmacists being the ones who makes the decision on whether to sell or decline codeine sales.

"If you think about how many codeine painkillers we sell in a day, maybe about 4 dozen boxes a day so that is just one pharmacy, think about how much that makes" (Nathan - Pharmacist.

"A pharmacy is a business at the end of the day we have to pay staff, we have a lot of bills to pay. Do you refuse sales whilst you are not meeting the bare minimum you need to survive" (Owen- Locum Pharmacist).

Codeine-based analgesic sales substantially contribute to community pharmacies income. Participants highlighted how pharmacies operated as businesses with set targets to achieve. This presented a conflict of interest whereby the more codeine-based painkillers sold, the higher the chances of achieving sales targets. However, the correct implementation of codeine regulations could result in them refusing sales which in turn reduces chances of achieving sales targets.

"Equally I am backed to do the right thing but if you have a pharmacy whose bills come through the door with staff to pay are you going to try, I am not trying to say this is ethical but are you going to risk not selling? Would there be a pressure to sell there, would there be a pressure there not to obey the regulations?" (Ethan - Pharmacist).

"Sure, go through the motions, tell them that's something for short term use and you have done your bit, you have covered yourself, you are accountable and then give it to them and its money in the till now" (David - Locum Pharmacist*).*

Tension between achieving sales targets, professional integrity and implementing codeine regulations are evident. These conflicting demands create a situation where for pharmacy professionals to meet one demand they may be forced to compromise on the others. In these quotes, pharmacists demonstrate an in-depth understanding of the importance for pharmacies to operate as a profitable business. However, the profitability seems to come at a cost to fulfilling their roles and responsibilities from an ethical and professional perspective. Within the quotes, there is an explicit acknowledgement that generating income for the pharmacy is paramount. Pharmacists seem to navigate interactions involving codeine sales coming from this viewpoint. Concurrently, they handle the codeine interactions in a manner that safeguards their profession and upholds the regulations if scrutinised.

Furthermore, the pharmacy remuneration model was highlighted as a barrier in pharmacies providing holistic support in pain management. Remuneration is a determinant to the level of engagement to services provided in the pharmacy. This was a hindrance and pharmacists felt that if they could engage more with patients and address pain from a holistic perspective, they could assist patients to achieve good pain control in a safe manner by running a proper pain management service involving one on one consultations. However, they reiterated that this would only be achievable if the time spent in pain consultations is recognised and remunerated by the government.

"So currently we have a model that reimburses me for the prescriptions I dispense and that's how I get paid by the government, that's how I get paid by my patients, that's the item I dispense or the product they buy on the healthcare counter but equally I could have a

half an hour pain consultation with someone and get nothing because I have referred them to their GP or I only get €2 because they buy a box of paracetamol. So, I feel that if we are to play a bigger role, we deserve to be reimbursed appropriately by the government like with the emergency contraception service" (Ethan - Pharmacist).

"On any given day I am just constantly preoccupied by getting the prescription medication out, it is always a real challenge to safely clinically check prescriptions and deal with queries. The initiation of the financial emergency measure act in 2010/2011 has had a massive impact on pharmacy reimbursement and there are just no resources for pharmacists to deal with queries" (Charlie - Pharmacist).

The financial emergency measures act in 2010/2011 reduced the markup percentages charged by pharmacies per each item dispensed. Instead, set dispensing fees were introduced per item dispensed under the medical card and other public-funded schemes resulting in a significant loss of income for pharmacies. Due to the lack of remuneration in pain management consultations, pharmacist involvement is limited. Healthcare assistants handle most of the interactions involving pain management over the counter. Pharmacists identify the need to engage with individuals managing pain but prioritise work that brings income to the pharmacy. This creates competing and conflicting demands and responsibilities for pharmacists. A choice must be made between duty of care and running a profitable pharmacy business. Time is of essence and is prioritised for activities that contribute to the profitability of the business.

"Now with codeine sales the line of questioning is pretty much memorised now, you are not even trying to counsel you are just trying to make sure that this thing takes the shortest time possible, it's a ten second conversation just because you are so busy" (Owen - Pharmacist).

"Everyone knows the pace in a pharmacy, sometimes it's only myself in there and it's hard to manage everything, you have prescriptions, people waiting for services like the emergency contraceptive and it's just hard to go on the counter" (Charlie -Pharmacist).

Despite the hectic pace and busy environments described the quotes above infer that despite time being limited, if pain consultations were to be recognised and remunerated, pharmacists could prioritise engaging with individuals managing pain. Pharmacists recognise the need for more engagement and have the expertise to advise on effective and safe self-medicating in pain management. However, the lack of recognition of this service by the government poses a barrier to achieving this level of engagement from pharmacists.

4.4.2.3 'It's emotionally draining'

For pharmacy professionals, implementing codeine regulations daily in consideration of the volumes of codeine-based analgesics sold evoked various emotionally draining feelings. Feelings of frustration, guilt anger, embarrassment, humiliation, helplessness, and nervousness were all expressed by pharmacy professionals.

"It is uncomfortable, it can be nerve wrecking, upsetting you know you don't get any joy at all out of it, if you could just give people what they want life would be easy" (Hazel - Pharmacy Technician).

"It's given us a headache, there's been an awful lot of abuse, controversy you know all the time" (Leo - Pharmacy Technician).

Implementation of codeine regulations alter the typical pharmacy/customer relationship, creating an environment where pharmacy professionals feel frustrated. The emotional impact to pharmacy professionals despite working well within their remit is clear here. This frustration is brought on by initiating enforced interactions that serve the purpose of meeting community pharmacy professionals' goals of going through the protocol questions before selling codeine-based analgesics. These interactions are filled with tension and the responses from customers are not always positive. Despite pharmacy professionals achieving their goal in these interactions, feelings of guilt were highlighted.

"I feel guilty if you are giving them, I know you are going by protocol and that you are covered, you have tried your best but humanly thinking you are also feeling sorry for those who are abusing it" (Olivia - Healthcare Assistant).

"I find it very hard dealing with these people looking for codeine, even handing it out sometimes I feel I hope this person is not going to get addicted to this. I say this in my own mind that's how I feel about it because we have a certain responsibility even though it's the pharmacist's decision, but you do feel responsible for it. I just wish we were not doing it that's just my honest truth" (Grace - Healthcare Assistant).

Pharmacy professionals understand the hidden nature of codeine addiction, the severity of the problem and their role in raising awareness and curtailing misuse and abuse where appropriate. However, despite following the protocols and achieving their goals in interactions going through the protocols with customers, they felt they were contributing to the addiction problem by continuously selling codeine. Feeling responsible for potential addiction demonstrates a duty of care that goes beyond complying with regulations to safeguard their profession. It infers that pharmacy professionals knew the ineffectiveness of following the protocol in curtailing misuse but were helpless to support consumers. As well as frustration, guilt and helplessness, implementation of regulations evoked humiliation and embarrassment for pharmacy professionals.

"Sometimes there is confrontation at the healthcare counter then everyone is involved, and other customers are looking on and you just feel like crap, and it can go on and on and its never ending, you feel like this is not fair when is this going to end and the more they fight the more they get frustrated because you can't just hand it over" (Clara - Pharmacy Technician).

"I have had people shouting at me and that is not right and after that you are just supposed to continue working as if nothing has happened. That is just not fair" (Sophie – Pharmacist).

The implementation of codeine regulations has created a hostile working environment for pharmacy staff. Where customers are not happy or willing to engage with staff, interactions can be confrontational. Deescalating the situation is not always possible without meeting the customer's goal of supplying the medication without following the protocol. The occurrence of these confrontations in an open public space adds another dimension to the tension, embarrassment and humiliation felt. Pharmacy professionals must continue to serve other customers following such confrontations as if nothing has happened whilst aware of the potential for such experiences to occur frequently. This made pharmacy professionals nervous as they went on their day-to-day duties, and they were constantly on alert.

"You know the weird thing now is even before they ask, you just know as they walk up to you. It's there in their face and you can see they are ready for battle, and you just feel your heart rate going up" (Grace – Healthcare assistant).

"You can almost tell even before they ask sometimes. Its either they go overboard being nice to you or they may try to intimidate you" (Olivia – Healthcare Assistant).

"Sometimes you are standing there, and you are not sure how the argument is going to end. You are trying to catch the eye of the security guard in case things get out of hand and

you are thinking I should have just avoided this by giving them without asking much" (Suzanne – Locum Pharmacist).

Despite pharmacy professionals sometimes fearing for their own safety during confrontations, they have no option but to remain calm and professional. In addition to navigating the tension-filled interactions during codeine sales, pharmacy professionals must manage the feelings evoked by the implementation of codeine regulations. Feelings of frustration, guilt, anger, embarrassment, humiliation, helplessness, fear, and nervousness must be supressed in order to maintain a professional front. Contending with such feelings whilst interacting directly with individuals is emotionally draining.

4.4.3 Theme 2: Systemic failures

Systemic failures that contribute to codeine misuse and abuse were identified within the Irish system. The introduction of codeine regulations stemmed from the identification of misuse and abuse of codeine-based analgesics in Ireland. However, the approach adopted to mitigate the risk to consumers does not provide a comprehensive intervention that considers contextual issues leading to codeine misuse and abuse. The current approach to mitigate risks is deficient as it only focuses on controlling codeine purchases at point of sale and therefore is narrow in its focus to fully address the issue. Two themes: classification of analgesics and inadequate health services capture the systemic failures that contribute to codeine misuse and abuse in the Republic of Ireland.

4.4.3.1 Classification of analgesics

The current classification of OTC codeine as a controlled drug that can be supplied to customers over the counter under the supervision of a pharmacist is deficient on its own to deter misuse and abuse. It is a classification that does not counteract the severity of the problem as consumers can still misuse or abuse OTC codeine.

"I think if you as a regulator, more or less know that there is a chronic widespread misuse and abuse of a product that is available without a prescription that long term is going to cause grievous harm to patients how can you sit back and do nothing, that is morally unconscionable" (Ian - Locum Pharmacist).

"I think this no man's land it has been left in is unsatisfactory" (David - Locum Pharmacist)

"They said it is up to the pharmacist whether to sell or not but if you are actually going to control the sale of codeine products put them on prescription because its black and white" (Aisling - Locum Pharmacist).

Participants interpreted the introduction of codeine regulations as a half-measured approach in resolving the issue of codeine misuse and abuse. The unusual classification of codeine puts the consumer and pharmacy professionals in a complex territory that is ambiguous to interpret.

"If we start bringing more and more products off the traditional back wall or off prescription into this kind of grey category of yes, they are over the counter, but they are to be sold under the supervision of the pharmacist based on guidelines from the regulator you kind of feel like you are caught in the middle" (Ian - Pharmacist).

"It is not on prescription control, it is not over the counter, it's an unusual category it's kind of a quasi, it's kind of there in between over the counter and prescription. I am not aware of it in other jurisdictions, why was that required?" (Charlie - Pharmacist).

The unusual classification of codeine has left it in a liminal space that lacks clarity for both pharmacy professionals and consumers. Instead of completely removing access to consumers to mitigate the risks, the classification still enables consumers who are misusing and abusing to purchase codeine albeit by adjusting their narratives to suit the protocols associated with the classification. The complexity of the classification is such that it occupies a space where the onus has been left to pharmacists to manage the supply of codeine without consideration of the efficiency of the associated protocol to mitigate risks.

"Patients know how to answer the questions, they have heard it all before, they have it all rehearsed. The people who are abusing they come up with convincing stories to get the codeine and they get it all the time unless if the same face keep appearing" (Owen - Locum Pharmacist).

"The same people who were buying them over the counter every few days before from us are still coming in they are just more wiser on the way they go about it they know all the right answers" (Tracey - Pharmacy Technician).

As a deterrent, the adjusted classification is ineffective and deficient in curtailing the purchase of OTC codeine. Where consumers are already misusing or abusing, they must contend with withdrawal symptoms if codeine consumption is stopped. Within this context, the adverse effects associated with stopping consumption can underpin the resourcefulness consumers apply in ensuring they have a supply of codeine despite the regulations. In addition, in pain management, the expectation that consumers will stop after 3 days use whilst still in pain is unrealistic and not plausible. Within the context of managing pain, time lapse does not provide a strong rationale to stop a problem-solving mechanism that is effective. Giving the onus of this responsibility to someone who is suffering is not realistic and highlights the deficiency of the classification protocol adopted. The deficiency of the classification can be further evidenced by how easy it is to circumvent the regulations attached to the classification.

"If someone is addicted to codeine, I could refuse them, but they can go to the next pharmacy and potentially have a different consultation which I suppose they would give different responses to the questions and get a box" (Sophie -Pharmacist).

"As a locum, I worked in two different pharmacies two days in a row and came across the same person twice once in Ashbourne and once in Dunboyne on a Saturday and on a Sunday coming in with the exact same spiel, when I told him I had sold him the previous day he just walked away" (Fiona - Locum Pharmacist).

The quotes above highlight the deficiency of the regulations attached to the classification of codeine in deterring misuse and abuse. This raises the question of whether the classification of OTC codeine as a controlled drug and the associated regulations are fit for purpose. Despite pharmacy professionals implementing the regulations, there is an open acknowledgement of fighting a losing battle. To compound the deficiency of the regulations, implementation approaches can differ per pharmacy. Due to varying management styles in pharmacies, competing demands and expectations put on pharmacy professionals, compliance to the regulations can be varied.

"Some pharmacies tend to be absolutely by the book, that is absolutely not the case in all pharmacies. There are definitely a lot of pharmacies where you have a healthcare assistant coming in and collecting a box of codeine painkillers without even actually asking the pharmacist" (Anna -Locum Pharmacist).

"We had a man the other day and he went completely mad; he was asked whether he had used them before and he said no one had ever asked him questions before he then said leave it, I will go down the road where they will not ask me questions" (Clara -Pharmacy Technician).

The lack of uniformity across pharmacies highlights another deficiency of the codeine regulations. Consequently, this variance can distort consumer expectations when they visit different pharmacies. Ensuring compliance in each pharmacy would be problematic even from the pharmaceutical regulator's perspective as they would have to police all pharmacies for compliance. In addition to lack of uniformity across pharmacies, the classification does not facilitate consistence in the supply of codeine. Where misuse or abuse is suspected, pharmacies must refuse sale. However, there is ambiguity on how exactly this can be achieved in a consistent manner.

"It's very difficult you can't refuse a sale if they are answering the questions correctly" (Leo - Pharmacy Technician).

"The extreme ones can keep coming but you can't judge because you have not done any test so I normally just say we don't have the codeine painkillers, you are forced to lie, you can't say I am refusing you for misuse or abuse because you have no proof so it kind of limits you" (Ethan - Pharmacist).

The quotes above give insight to how pharmacy professionals have embraced the regulatory role they have been tasked with. However, the role has afforded them the mandate to decline sales without clarity on how to detect misuse or abuse. The frequency that codeine consumers requested painkillers and behavioural cues during interactions where among some of the techniques reported.

“If you see them coming in two or three times in a week for codeine products you kind of recognise their face then you know they are not using according to regulations, another way is the way they answer the questions, very abrupt and answering questions before you even ask them” (Fiona - Pharmacist).

“Another way you can know that this person is coming for a long time specifically for codeine products is when they bring the exact change of the cost of the painkillers” (Darren - Locum Pharmacist).

Participants were aware of the deficiency of their approaches. They inferred refusing a sale as the equivalent of telling a patient that *‘you are addicted to codeine, and I am not selling it to you’* without the evidence. To an extent, the classification of OTC codeine as a controlled drug without the requirement of a prescription, expects pharmacy professionals to adopt a policing role without the tools or mechanisms to achieve the role. Devising ways of identifying misuse and abuse had led to pharmacy professionals developing attitudes that were inadvertently informing interactions in codeine sales.

“So, there is a defence mechanism from my point of view when I reflect on it, once you hear codeine painkillers your antenna just goes up and I might even try and strike a defence on that ok let me try to see if this person is genuine so I wouldn’t hand it out easily” (Leo - Pharmacy Technician).

“Whenever you see someone coming and you hear them asking for codeine you kind of think I know you try not to judge but you sort of think oh no is this something that I am going to have to refuse, in university you are constantly told about the maximum amount of codeine you can sell its drilled in you and you are just so sceptical when someone asks for it” (Anna - Locum Pharmacist).

The ambiguity of the regulations in their implementation has resulted in pharmacy professionals developing approaches and attitudes that are unhelpful in the already tension-filled codeine sale interactions. A general reluctance to supply codeine was evident in pharmacy professionals' approaches. The approaches leaned more towards controlling and limiting the supply of codeine rather than ensuring codeine was consumed safely.

"Since 2010, I can count on one hand how many times I have recommended codeine-based painkillers to a patient and that's 8 years so we will say that's once a year" (Tracey - Pharmacy Technician).

"The very, very odd time it would usually be if somebody is in with like tooth pain and they can't get to the dentist and they have already tried ibuprofen and paracetamol and they have tried them both together at the same time and the pain is really not going, I will say then maybe codeine painkillers might be advisable" (Nathan - Pharmacist).

There is a power dynamic evident in the approach pharmacy professionals adopt in the supply of codeine. Pharmacy professionals have adopted a gatekeeping role and would rather not be the ones undermining this role by recommending codeine. From the perspective of pharmacy professionals, codeine is linked to misuse, and they would rather not facilitate misuse. The classification of codeine as a controlled drug reinforces this approach.

Further systemic failures were identified in the classification of analgesics. The lack of alternative second-line treatments is problematic and influential to the risk of codeine misuse and abuse. The impact of this limitation is such that codeine-based analgesics provide the only option in second-line treatments for pain management.

"There are choices in brands, strengths and pack sizes but when it comes right down to it you really have 3 choices: ibuprofen, paracetamol and aspirin" (Lauren - Pharmacy Technician).

"OTC pain management in the pharmacy is quite basic at the moment, there are the first line treatments then codeine, otherwise what can you do for the patient?" (Ethan - Pharmacist).

Participants believed deregulation of some prescription only analgesics was necessary in-order to effectively manage pain with OTC analgesics. This approach is consistent with other countries where some prescription analgesics have been classified as OTC medication (Healthdirect, 2023). Reclassification of alternative analgesics from prescription only to OTC medication will increase the second-line treatment options available in Irish pharmacies.

"I think we fall short with our patients. I see people trying to manage arthritis with codeine painkillers. It's a long-term condition that flares up often. If we could give them say naproxen in a low strength, that would be much better" (Lauren - Pharmacy Technician).

"I would like a little bit more armour you know, I would like short-term acting and long-term non-steroidal painkillers like Arcoxia say right 5-day pack of the 90mg in other words short, sharp, very powerful, very good for all muscular pain and not really liable for abuse or a buzz" (Ian - Locum Pharmacist).

The lack of alternative OTC second line treatments can be problematic for individuals who live with chronic pain. The availability of alternative analgesics would provide second line treatments with greater efficacy for specific pain. In addition, these would have the added advantage of having no addictive potential. Broadening of options on OTC pain medication could be one way of reducing the misuse of codeine-based painkillers in self-medicating.

4.4.3.2 Inadequate health services

The lack of adequate health services was identified as a systemic failure that contribute to the misuse and abuse of OTC codeine in pain management. The classification of codeine as a controlled drug and associated regulations cannot in isolation mitigate the misuse and abuse of codeine. The inadequacy of the health system to meet the needs of individuals managing pain leads to self-medicating with what is perceived as the best second-line treatment for pain available in pharmacies. Due to the two-tier system of accessing medical services in Ireland, costs of medical interventions influence self-medicating habits with delays in access associated with exhausting all OTC medication alternatives.

"You tell them to seek medical intervention after 3 days if pain is not resolved but they nearly leave it like a week to 10 days before they do and they tell you it costs €60 to see their GP and they wouldn't pay €60 just on day 3, they would rather just persevere even if it's the wrong course of action" (Ethan -Locum Pharmacist).

"Private patients are happy to self-refer to a pharmacist, they are not going to pay €60 for a limited ailment whereas there are some medical card patients who will go at the drop of a hat for a cold or a sniffle" (Suzanne - Locum Pharmacist).

The inequality brought on by the two-tier system mean individuals who pay for GP access, seeking medical intervention can be a financial decision. Seeking intervention for pain that can be alleviated by codeine-based analgesics may be perceived as unnecessary and more costly. The financial cost involved in seeking medical intervention could be central to deciding if and when individuals should seek intervention in pain management.

In addition, the expectation that patients managing chronic pain should seek medical intervention once flare-ups go beyond the recommended 3 days of OTC codeine use is unrealistic. Experience in the efficacy of analgesics and learned histories inform self-medicating decisions in these instances. Individuals would self-medicate with medication that had effectively controlled pain previously. The prolonged use of codeine-based painkillers was reported as elevated in such cases.

"You hear a lot of oh I have got a stiff shoulder, it happens all the time when the weather is bad and there is no point in getting to the doctor, I might as well use the money to buy the medication" (Hazel - Pharmacy Technician).

Timely access to specialist care was problematic once patients went to see GPs with complicated issues resulting in elevated self-medicating during these waiting periods.

"If they go to a GP with a complicated problem, if they can get a referral in a timely fashion to an expert there will be no need to continuously self-medicate but unfortunately that is not the case" (Darren - Pharmacist).

"Ideally everyone with chronic pain should have access to an expert physiotherapist who deals with that and can establish what the problem is then provide intervention exercises. That would go a long way into helping those with chronic pain. Of course, it doesn't solve your migraines or menstrual issues but again if they can go to the GP and get a speedy referral to a specialist whether it is a gynaecologist or a pain management specialist that would protect people from falling into addiction whist managing pain" (Charlie - Pharmacist).

The above quote highlights the inadequacy of the healthcare system in accessing specialist services in a timely manner. This suggests that individuals waiting for specialist appointments can be left in limbo for a long time. Despite seeking medical intervention, individuals would still need symptomatic relief and codeine painkillers are typically used during these times. Availability of alternative second line OTC treatments with no addiction potential could alleviate this problem. This provides an insight on how systemic failures within the healthcare system contributes to elevated OTC codeine consumption. Within this context, pharmacies do not have the support required within health services to mitigate the risk of codeine misuse and abuse. As a profession, participants felt there had been no support from the regulatory bodies, government bodies and other health professions in jointly addressing the misuse and abuse of OTC codeine.

"I think what we need is sort of an awareness campaign for the public to recognise that actually why is the pharmacist asking me why I need codeine painkillers. I think the regulator needs to do a better job of supporting us and saying actually well these medications are potentially dangerous and that's why we have taken the decision to say the pharmacist can sell at their discretion" (Sophie - Pharmacist)

"The regulation was just dumped on us, for something this serious this should be provided under citizens information because any person will manage pain at some stage in their life. They need to push the information out there for everyone to know the dangers associated the prolonged use of codeine" (Leo - Pharmacy Technician).

Participants felt there was need for a national endeavour to clamp down on the misuse and abuse of codeine. The current regulations were insufficient in educating consumers of the risks involved in misuse and abuse. Educational programmes, media coverages and research on the actual scale of the problem would support the pharmacy profession in getting the message across.

"There need to be more education programmes on codeine like the media coverage programme they did last year of people going to different pharmacies for codeine and taking 96 tablets a day due to addiction. The amount of conversations it generated in the pharmacy was good for educating people" (Leo - Pharmacy Technician).

"The guidelines have been in place now I would say 7/8 years, I think its timely now that a research study should be funded by the healthcare providers and regulators to check if the controls in place are effective. I think there will be an awful lot of information that will come from that" (Nathan- Pharmacist).

There is a recognition within the pharmacy profession that the current regulations are not enough to facilitate the change needed to mitigate misuse and abuse of codeine. Additional interventions from regulators and governing bodies would be beneficial in enhancing and reinforcing risks associated with codeine. In addition, support in the practicalities of implementing the regulation was also insufficient. The lack of a clear referral pathway and support services for codeine consumers misusing or abusing codeine was identified.

"Where can I send them, you have people who have tried to engage with addiction services and get nowhere because well I suppose on the scale of codeine and heroin what's the bigger problem to warrant an intervention" (Ethan - *Pharmacist).*

"It is a massive problem, can these patients identify themselves and eventually go to addiction centres, I don't think there is adequate support in the system" (Charlie - *Pharmacist).*

Refusal to sell codeine without the required detoxification support can cause adverse codeine withdrawal effects. Within this context, systemic failures of not including wraparound services to support pharmacies in the implementation of regulations where misuse and abuse is identified reinforces elevated codeine consumption.

4.4.4 Theme 3: Social influences

Social influences contribute to the misuse of OTC codeine-based analgesics. Three sub-themes: evolving information sources, lifestyle choices and social norms, capture the influence of society on codeine misuse and abuse.

4.4.4.1 Evolving information sources

The introduction and availability of information technology has led to a shift in the advisory role of pharmacies. The availability and easy access to health information online enhances individuals' understanding of managing health conditions and associated healthcare decisions. In addition, the introduction of online shopping provides an opportunity for individuals to independently choose and make decisions in the purchase of some of the products available in pharmacies. These changes were implicated in customers feeling empowered to make their own choices and decisions, without the influence of pharmacists. Individuals have opportunities and easy access to obtain information online prior to coming to the pharmacy and came in knowing what they wanted. Participants felt this had led to a situation where the whole pharmacy concept was being devalued and pharmacies are now being perceived as drug distribution shops.

"There is a shopkeeper mentality among some patients, they look at pharmacy as a place to buy medication instead of a place to seek for advice" (Conor - Healthcare Assistant).

"They know it all now, once they request it you are just supposed to hand it over" (Fiona -Pharmacist).

Within this context, the gatekeeping role that pharmacy professionals have been given in the sale of codeine can be problematic. The traditional pharmacy/consumer relationship is evolving due to information being sourced from alternative sources. Consumers feel empowered to make their own decisions in self-medicating and do not expect pharmacy professionals to override them. Pharmacy professionals are left in a difficult position in situations where they must implement regulations.

"An awful lot of people research and they know what they want, they are looking for a particular medicine. In this world of Google, they research everything and sometimes that can be difficult for us" (Grace - Healthcare Assistant).

Google and online forums were highlighted as common sources for research prior to visiting pharmacies. However, not all consumers would check the reliability of alternative information sources. Participants reported that this posed challenges for them as the information patients brought was at times inaccurate.

"Someone came in looking for maximum strength ibuprofen and they had read that they could take 3 tablets at a time on Google. I had to explain that they would overdose, sometimes your job is about unconvincing them about what they have researched" (Grace - Healthcare Assistant).

Advertisements were also perceived as influential in self-medicating decisions. Patients would come in with product specific requests based on the information given on advertisements.

"If they see it on telly and they think it works, they come in looking for it and its not suitable, it doesn't matter what you say because it was on telly, I don't think there is enough warnings on these television and magazine ads of the dangers, it only tells them how effective it is and how quick it works" (Rachael - Pharmacy Technician).

"*There is heavy advertising at the moment about an anti-inflammatory gel, and how effective it is for muscle pain and a lot of people are coming in looking for it and for some it is not suitable so now it's about it's about stirring them away from it by offering suitable alternatives" (Connor - Healthcare Assistant).*

The quotes above are an indication of some of the drivers in self-medicating decisions and habits. Participants inferred that some customers believe the messages behind adverts more than the advice from pharmacy professionals. In the case of codeine-based medication, adverts are not permitted in Ireland according to codeine regulations. However, consumers can still access adverts from other jurisdictions online. Media adverts would have achieved the same effect, however the increase and ease of accessing digital media seem to have increased the influence. The influence of friends and family was also highlighted as problematic due to providing misleading information.

"People come in and they are like, I'm looking for the one in the red box my friend told me it's a good one and it is difficult to convince them that there might be a better alternative" (Clara - *Pharmacy Technician).*

"They tell a family member I have pain next thing they are given 2 codeine painkillers to try then they come in now looking for them because they have worked but prior to that they had not tried anything else" (Tracey - *Pharmacy Technician).*

Participants perceived that friends and family were deemed more reliable sources of information than themselves. Implementing the codeine guidelines in such cases was problematic. The classification of codeine painkillers as OTC medication facilitates families and friends to recommend them. A prescription only classification would alleviate such problems.

4.4.4.2 Lifestyle choices

Lifestyle choices were highlighted as also driving pain medication use. Participants reported selling increased amounts of codeine-based painkillers over weekends and bank holidays due to hangovers.

"*I find most customers over the weekend saying they just need codeine painkillers, and they will be sorted. It is turning out to be a hangover remedy as well. On a Sunday you* *literally have people queuing asking for codeine painkillers, you can definitely see a difference between weekends and weekdays"* (Conor - *Healthcare Assistant).*

Participants highlighted that patients were not always truthful when they were looking for codeine painkillers for hangovers.

*"People go out for a night out you know, they have a hangover, and they want analgesics for that right? But they never come in and tell you that I am dying of a hangover give me codeine-based painkillers, the stories I have heard when I work weekends" (*Darren - *Pharmacist).*

The quote above highlights the underlying tensions in the pharmacy/consumer relationship. Consumers adapt their approach in-order to get a supply of medication. Pharmacy professionals make their judgement on the suitability of codeine based on the story they have been told regardless of them suspecting hangovers. Within the interactions, pharmacy professionals highlight that they are aware of deceit, however based on the guidelines they still supply codeine in such cases.

4.4.4.3 Social norms

Participants highlighted how social norms were influential to self-medicating habits. Prior to the codeine regulations, codeine was the drug of choice and despite the consultations, participants still find a cohort of patients who feel that it is the only medication that works for them despite getting similar much stronger drugs on prescription.

"You get someone coming in looking for codeine painkillers combined with paracetamol. When they tell you the medication, they are currently taking you realise that they are already taking the same medication but with a much higher dose of codeine than the

OTC codeine. When you try and explain that they will not work as the strength is much lower than what they are currently on, you get told the prescription codeine medication is not working and Mary down the road takes them and they work, and she gave me some and they worked" (Lauren - Pharmacy Technician).

The quote above highlights the psychological aspect involved in self-medicating and the impact of social influence. Empirical evidence on the efficacy of codeine-based painkillers suggests the amount of codeine in over-the-counter medication is not high enough to provide significant additional pain relief. Prescription only codeine-based painkillers typically have 30mg of codeine as compared to 8mg or 12mg in OTC codeine-based painkillers. Despite this, some consumers perceive OTC codeine as more effective in managing pain.

Participants felt self-medicating habits in adults were also influenced by childhood experiences. They reported on how as a society it is has been normalised for painkillers to be administered to babies and children for any minor ailment. Pharmacy professionals felt that adults also mimicked this behaviour in self-medicating. This seems to suggest consumers were not engaging with other alternative non-medical interventions in pain management and had developed an overreliance on medication spanning from their childhood experiences.

"You see parents giving babies and children pain medication for the slightest pain and even anticipated pain, you hear them saying I will just give some medication just in case and they will be grand" (Lisa - Locum Pharmacist).

"Codeine had been so normalised in Ireland for so long that people don't see it as addictive. I even know as a child one of my aunties if you ever had a sore throat or sore head, she would just dissolve one and give you to drink, it was the first port of call" (Lauren - Pharmacy Technician).

Though subtle, social influences are also driving choice of medication in self-medicating. Despite the introduction of codeine regulations, there seems to be a social resistance in using codeine-based painkillers as a second line treatment. In addition, pharmacies are perceived to be there to supply medication once requested and refusal of codeine sales is not received well.

4.4.5 Summary of findings

This section brought together the key findings from the analysis of pharmacy professional interviews. Three broad overarching themes and associated subthemes were presented: unintended consequences of codeine regulations; systemic failures and social influences.

Unintended consequences of codeine regulations were identified. The implementation of codeine regulations did not foster conducive interactions between pharmacies and codeine consumers in pain management. Instead, interactions were tension filled with each party focused on achieving their own goals impeding more meaningful conversations focused on information sharing to achieve the best possible pain management interventions.

In addition, conflicts of interest were identified due to multiple competing demands for pharmacy professionals resulting in conflict at a professional, regulatory, business, and personal level. The complexity between trying to provide excellent customer service as expected of their role and upholding the codeine regulations results in conflicts of interest for pharmacy professionals. Consequently, this inadvertently impacted and informed interactions in pain management interactions. Furthermore, implementing codeine regulations was found to be emotionally draining for pharmacy professionals which further complicated the already tension filled interactions in pain management.

Systemic failures within the Irish system contributed to codeine misuse and abuse. The current approach to mitigate risks is deficient as it only focuses on controlling codeine purchases at point of sale without addressing the contextual issues leading to misuse and abuse. Within this approach, classification of analgesics is problematic in that the regulations associated with codeine regulations are deficient in tackling the issue and seem to undermine the scale of the problem. In addition, classification of OTC analgesics does not provide safe effective second line medications in pain management. Lack of support around efficient implementation of codeine regulations to initially deter misuse and referral services for identified abuse contributed to systemic failures within the Irish system.

Social influences were also found to be problematic in pain management interactions in pharmacies. Health information accessed online, friends and relatives influenced self-medicating decisions more than the information provided from pharmacy professionals. Lifestyle choices and social norms were also found to be influential to the use of codeine-based analgesics more than that advice provided by pharmacies. The next section presents the discussion of the findings.

4.5 Discussion

The aim of this study was to explore the views and experiences of community pharmacy professionals on their interactions and relationships with codeine consumers in the management of pain with over-the-counter medication. The study provides novel findings on the healthcare advice provided in community pharmacies on pain management, the relationship between pharmacy professionals and codeine consumers in pain management, and the issues surrounding the sale of over-the-counter medication for pain management with specific focus on codeine-based pain medication.

4.5.1 Unintended Consequences of codeine regulations

Whilst previous studies in Ireland have explored, codeine purchasing trends (Wells et al., 2019), characteristics of codeine dependence (Van Hout et al., 2018), codeine misusers profiles (Van Hout, et al., 2017), comparative studies of codeine misuse (Carney et al., 2018) and best practices in the management of opioid abuse (Norman et al., 2016), little is known about the issues at the interface between pharmacies and codeine consumers within the general population in pain management. One of the key findings from interviews with pharmacy professionals was the emerging relationship between pharmacies and OTC codeine-based analgesic consumers following the introduction and implementation of codeine regulations. Interactions in pain management typically started with codeine-based analgesics requests and were subsequently directed by the need to implement regulations by pharmacy professionals. This is inconsistent with the typical pharmacy professionals’ role dimensions of, information sharing, creating a patient-centred relationship and interpersonal communication as posited by the role theory (Hermansen-Kobulnicky & Worley, 2008; Schommer et al., 2006; Worley et al., 2007). Responding to pain medication requests from a regulatory and gatekeeping perspective hindered interactions in pain management and subsequently the relationship between pharmacy professionals and codeine consumers. Based on the role theory, patients’ role dimensions in pharmacy interactions are characterised by, information sharing, responsible behaviours, active communication to related healthcare and interpersonal communication (Schommer et al., 2006; Worley et al., 2007). Administration of questions guided by codeine regulations during pain management interactions hindered the opportunity for more natural and conducive interactions between pharmacies and codeine consumers where each party could apply typical role dimensions in interactions. However, these typical patient’s role dimensions were evidenced by pharmacy professionals in other non-pain management interactions.

The implementation of codeine regulations further hindered the opportunity for pharmacies to fulfil their primary care role in pain management as the most accessible healthcare professionals on the front line of pain care (Hahn, 2009; Strand et al., 2016). Consistent with other research (Cooper, 2013; Rogers et al., 1998; Stanos et al., 2016; Takaki et al., 2015), current findings indicate that pharmacy professionals are well-trained to provide holistic support and recommend appropriate interventions in pain management. However, because of the tensions inherent in the pharmacy-patient relationship due to codeine regulation led interactions, the skills of pharmacy professionals were often underutilised. This was due the pharmacy/patient relationship breakdown resulting in tensions that created barriers identified by pharmacy professionals as defensiveness, aggressiveness, non-receptivity in interactions and the fear of being stigmatised for taking codeine from the patient's perspective.

The tension filled interactions brought on by the implementation of codeine regulations can be attributed to the phenomenon of the 'new consumer' in consumer behaviour trends (Traulsen, 2004). The new consumer is information strong, more autonomous and is willing to challenge the authority and advice of pharmacy professionals (Chan & Tran, 2016). Within this context, the existence of codeine regulations challenges the new consumer. According to codeine regulations, there is need for pharmacy professionals to act as intermediaries between consumers and OTC codeine-based analgesics to identify and manage risks associated with codeine consumption. However, based on the new consumer phenomenon, codeine regulations create forced unwanted interactions from the consumers perspective where their autonomy is challenged. To resolve this, codeine consumers reluctantly engage with pharmacy professionals in a way that fulfils their goal to purchase codeine-based analgesics. This underutilisation of pharmacy services is consistent with other studies whereby the role of pharmacy professionals is underutilised due to direct product requests limiting patient assessment and exchange of clinical information (Byrne et al., 2018) and variance of views with pharmacy professionals (Traulsen, 2004). The unintended consequence of the introduction and implementation of codeine regulations is that it has resulted in tension filled interactions between community pharmacies and codeine consumers leading to underutilisation of pharmacy services in chronic pain management.

Previous research does not elaborate on the complexity inherent in decision-making at the point of sale during interactions between pharmacy professionals and codeine consumers. A key finding from the current study was the complexity inherent in implementing codeine supply protocols at the intersection of legal regulations, personal considerations, professional, and ethical integrity. Pharmacy professionals consistently experienced ethical dilemmas due to conflicting values between professional integrity, codeine regulatory protocols and business and personal interests. In some cases, the decision to sell codeine-based analgesics was influenced by whether refusing to sell would result in professional repercussions and financial losses to the business. For pharmacy professionals, the need to provide good customer service, protect their own employment and meeting business targets was of paramount importance. Within this context, selling codeine-based analgesics in circumstances that warranted refusal of sale was justifiable from their perspective. This is consistent with utilitarian ethics whereby an action is judged right or wrong based on consequences rather than deontological ethics whereby an action is judged right based on its conformance to ethical practice according to theories of moral philosophy (Sporrong et al., 2005, Tseng & Wang, 2021). This conflict between deontological and utilitarian ethics further supports research findings on the experiences of other healthcare professionals such as nurses, doctors, social workers in healthcare settings. Finding a balance between deontological and utilitarian ethics is often a challenge within healthcare settings (Babar, 2019.; Lovat & Gray, 2008; Vearrier & Henderson, 2021).

Similarly, in the case of selling codeine-based analgesics it is challenging to reach a balance between consequence-based approaches and legal and ethics-based approaches. The implementation of codeine regulations recommend that pharmacy professionals refuse sales where use is not in line with recommendations therefore following deontological ethics. However, the complex structure of community pharmacies that mixes a commercial retail element and pharmacy regulatory elements makes it challenging to adopt deontological ethics whilst ignoring the need to make profits, provide customer care and safeguard employment. In addition, pharmacies are not reimbursed for consultations but only generate income through sale of products and dispensing prescriptions. The evolving structure of pharmacies and the roles of pharmacy professionals has left it in a liminal space where it is a commercial business, a healthcare setting and both all at the same time (Rosenthal & Rong, 2019; Tabeefar et al., 2020). It is from this perspective that pharmacy professionals approached the supply of codeine-based analgesics in pain management interactions.

The Code of Conduct (Pharmaceutical Society of Ireland, 2019), that governs principles and ethical standards for pharmacists in Ireland addresses the issue of ethical dilemmas and provides an ethical decision-making tool. However, in the case of codeine supply this can be problematic as the tool requires significant information from the patient which the patient may choose not to divulge in consideration of the tension-filled relationships in pain management. In addition, the tool involves different time-consuming stages and does not lend itself to timely decision making as required in over-the-counter sales.

Another key finding was that participants consistently experienced codeine interactions as stressful. The complexity inherent in implementing codeine supply protocols at the intersection of legal regulations, professional and ethical integrity resulted in moral distress (Kälvemark et al., 2004). This was characterised by stress related symptoms described as feelings of frustration, guilt, anger, embarrassment, humiliation, helplessness, fear, and nervousness as pharmacy professionals implemented codeine regulations. This occurred due to pharmacy professionals consistently experiencing ethical dilemmas where they were unable to fulfil codeine protocols, professional and ethical integrity, and business demands. Experiencing moral distress due to ethical dilemmas is consistent with findings of other studies in clinical and community settings (Giannetta et al., 2020; Kälvemark et al., 2004; Molinaro et al., 2023).

4.5.2 Systemic failures

Since the introduction of codeine regulations in 2010 (Pharmaceutical Society of Ireland, 2019), there has been limited qualitative research exploring the effectiveness of the regulations in deterring elevated use of codeine-based analgesics in pain management from a pharmacy perspective. In 2016, one study compared the perspectives of community pharmacists in 3 countries on OTC and prescription codeine misuse (Carney et al., 2016). Findings indicated that codeine misuse was a widespread problem that required more efforts to curtail than current information approaches at point of sale. It highlighted the need for further research on the central role of community pharmacies in the first-line management and reduction of codeine misuse. Recent, studies within the Irish context have focused on sales of OTC products containing codeine (Purcell et al., 2022), overdosing with codeine (Birchall et al., 2021) and guidelines awareness and adherence (O’Brien et al., 2021). A key finding from interviews with pharmacy professionals was the deficiency of the regulations adopted to mitigate misuse and abuse of OTC codeine. At the time of the research interviews, codeine regulations had been in existence for 8 years but based on the participants’ accounts, codeine-based analgesics were among the most sold over the counter products. This is consistent with research identifying Ireland as the second highest country on sales of OTC codeine-based analgesics out of 31 countries between April 2013 and March 2019 (Richards et al., 2022).

The availability of codeine without the need of a prescription was problematic and did not deter acquiring and misuse of codeine-based OTC products. Despite the introduction and implementation of codeine regulations, the availability of codeine without a prescription was associated with increased use. This finding supports previous studies that associated availability of codeine with increased use and misuse in Australia (Cairns et al., 2016; Schaffer et al., 2020), and in Spain and United Kingdom (Hockenhull et al., 2022). Based on the cognitive developmental model of substance abuse by Liese and Franz (1996), availability of codeine as an OTC analgesic without the need of a prescription can act as a mediator for progression to misuse. Once an individual transitions from recommended use to misuse and develop enabling beliefs, focus centres on acquiring and developing strategies to obtain codeine supplies through legitimate sourcing (Van Hout, et al., 2017). Based on the cognitive developmental model of substance abuse by Liese and Franz (1996), the regulations currently in existence do not deter codeine misuse and allow strategies like pharmacy hopping for individuals to source OTC codeine as highlighted by pharmacy professionals in current findings.

Also, of note was, within the Irish context the classification of codeine-based analgesics is unusual leading to ambiguity in interactions with codeine consumers. Typically, pharmacies are trusted sources of information (Carney et al., 2018; Cooper, 2013; Perrot et al., 2019), the dissonance found in codeine supply interactions can be attributed to the ambiguity of the classification of codeine. Codeine classification in Ireland occupies a grey area where consumers fail to understand why a sale can be refused if it is not on prescription. Despite the efforts of pharmacy professionals to deter use outside the guideline recommendations, the current findings suggest continuous misuse of codeine-based analgesics in Ireland. This is consistent with the findings of a Cochrane review that found that despite information provision by pharmacy professionals being effective in increasing public knowledge and informed decision making, it is ineffective in improving compliance (Ryan et al., 2014).

The lack of an evidence-based mechanism within the codeine regulation protocols to detect misuse was highlighted as a challenge for pharmacy professionals. This was problematic as refusal of sale without evidence of misuse intent could be challenged. Frequency of codeine supply and habitual purchasing were not considered to be effective in identifying misuse. This further supports evidence from other jurisdictions on the ineffectiveness of regulations to deter misuse (Carney et al., 2018; Cooper, 2013). In addition, the potential to obtain codeine supply in multiple pharmacies was also problematic. Pharmacy professionals expressed a desire for a real time monitoring system similar to steps adapted with other OTC products with an identified misuse potential (Hamer et al., 2014) if the classification and implementation of codeine regulations were to be effective. With regards to upscheduling codeine to prescription only, the findings indicate mixed feelings among pharmacy professionals. This stemmed from the lack of alternative second line treatments.

Previous studies in codeine misuse within the Irish context fail to elaborate on the contextual issues inherent in the Irish system driving elevated self-medicating in pain management. Another key finding of the current study was the identification of several barriers that impaired the ability for pharmacy professionals to effectively deter use of codeine-based analgesics in pain management. One of the barriers was the disparity in access to primary care due to the two-tier system approach of healthcare delivery in Ireland. This creates an equality gap in accessing health services resulting in delays in health care access and use. This finding further supports previous research on delayed healthcare access and use in other health system jurisdictions due to disparities (Lu et al., 2022; Matranga & Maniscalco, 2022). Within this context self-medicating with OTC codeine-based analgesics may provide symptomatic relief further delaying more appropriate healthcare use.

The problem of limited and delayed healthcare access and use is compounded by the lack of adequate and timely care. Pharmacy professionals highlighted the lack of effective care pathways to refer patients for prolonged pain. Patients had to contend with long waiting times and access services within a fragmented system in pain management. This finding mirrors previous studies that identified lack of a national strategy for chronic pain management, lack of multidisciplinary chronic pain management services, unequal demographic distribution of services and long waiting lists in pain management services as problematic for individuals living with chronic pain in Ireland (Fullen et al., 2006; Purcell et al., 2022; Raftery et al., 2012).

The lack of adequate pain management services in Ireland further compounds the lack of support for pharmacy professionals where misuse is identified. Codeine withdrawal treatment guidelines are encompassed within broader guidelines for all opioid treatments in Ireland. Withdrawal treatment services are characterised with long waiting lists and heroin addiction is given more precedence than codeine addiction (Foley et al., 2017; McDonnell, 2019). Overall, pharmacy professionals felt the need for more comprehensive national efforts in highlighting the addictive potential of OTC codeine. Collectively, the deficiencies of codeine regulations and analgesic classification, the lack of adequate health services and interventions, and lack of national efforts to highlight the addictive potential of OTC codeine contributed to systemic failures resulting in elevated supply of OTC codeine-based analgesics in Irish pharmacies.

4.5.3 Social influences

Another key finding from the study was the impact of social influences on the way consumers self-medicated with OTC codeine-based analgesics. Pharmacy professionals felt that the advice they provided in recommending alternative analgesics in pain management was undermined due to evolving information seeking behaviours. Online sources were deemed more useful and plausible in comparison with pharmacy professional advice in pain management interactions. This finding provides further support for previous quantitative research in Ireland and United Kingdom that indicated that a high proportion of participants preferred to seek advice on self-medicating online, followed by from general practitioners, and lastly pharmacies (Kimergard et al., 2017). The reduced credibility of pharmacy professionals was problematic when conflicting medical information was accessed online or received from friends and family perceived as more trusted sources. Previous studies indicate an association between conflicting medication information and poor medication adherence (Carpenter et al., 2010, 2014). Findings indicated that the more sources of information used the higher the chance of encountering conflicting medication information. In the current study, conflicting medical information was identified around codeine dosages, addictive potential of codeine, self-medicating, and suitability for type of pain.

Another key finding was that lifestyle choices were a driver of self-medicating with OTC codeine-based analgesics. Self-medicating for hangovers was reported as problematic with significant increased demand over weekends and national holidays. This finding further supports previous research in the UK identifying the regular use of codeine to relieve hangovers as instrumental to elevated self-medicating and leading to subsequent misuse and abuse (Lee & Cooper, 2019). Social norms around alcohol consumption and the use of OTC codeine-based analgesic for hangovers were problematic in trying to implement codeine supply protocols leading to consumers adjusting their narratives to obtain supplies.

4.6 Conclusion

Overall, the study presents unique insights on the relationship between pharmacy professionals and codeine consumers in pain management, advice provided in Irish community pharmacies on pain management and the drivers of self-medicating with OTC codeine-based analgesics in pain management within an Irish context. It is the first study to explore the issues at the interface between pharmacies and codeine consumers in pain management within an Irish context. It highlights the deficiency of the regulations adopted to mitigate misuse and abuse of codeine and the complexity inherent in decision-making at the point of sale during interactions between pharmacy professionals and codeine consumers. In addition, it identifies the barriers that impair the ability for pharmacy professionals to effectively deter elevated use of codeine-based analgesics in pain management. Furthermore, it brings to light the impact of evolving information-seeking behaviours and social norms in self-medicating with OTC codeine-based analgesics. Limitations of phase 1 are included in section 6.9.

Chapter 5: Phase 2 - Longitudinal Qualitative Research

5.1 Introduction

This chapter presents phase two of the study: Longitudinal Qualitative Research (LQR) with individuals living with chronic pain. Firstly, the aim of phase two of the study is outlined, followed by the objectives of the research. An overview of the longitudinal qualitative research design, participant sample and recruitment, data collection and generation, study settings and COVID-19 pandemic adaptations, ethical considerations, and analysis, are discussed before concluding the first section with a reflexive discussion.

Secondly the chapter presents the findings from longitudinal across case analysis of semi-structured interviews with individuals living with chronic pain conducted at four timepoints over a period of 18 months. These are presented in the form of emblematic themes and corresponding trajectories of change or continuity alongside extracts from interview scripts before concluding with a summary of the findings.

The chapter then presents findings from longitudinal analysis within cases as two case histories. These complement the longitudinal across case findings by capturing and highlighting distinctive aspects of participants' experiences that could not be captured with across cases analysis. The findings are presented around the emblematic themes identified in across cases analysis before concluding with a summary of the two case histories.

The final section of this chapter presents the discussion of the key findings of phase two of the study. The section is structured around the environmental, social, and individual factors that interact to influence choice of medication and self-medicating habits in the self-management of chronic pain. A summary of the findings is outlined to conclude the chapter.

5.2 Research aim

The overarching aim of phase two of the study was to qualitatively explore the lived experiences of individuals living with chronic pain with specific focus on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain overtime.

5.2.1 Research objectives

As outlined in Chapter 3, the specific objectives of this phase of the study were therefore to explore:

1. The lived experiences of individuals living with chronic pain overtime and how these experiences influence self-medicating habits with specific emphasis on OTC codeine-based analgesics.
2. The psychosocial factors that influence choice and use of medication for pain management, focusing on change or stability overtime and the causes and consequences of change.
3. The relationships between individuals living with chronic pain and pharmacies in the self-management of pain.

5.3 Longitudinal Qualitative Research Design

A Longitudinal Qualitative Research (LQR) design was adopted to qualitatively explore the lived experiences of individuals living with chronic pain with specific focus on self-medicating habits, and choice of medication in the self-management of chronic pain. LQR has been described as a unique methodology used to know and understand the social world through time (Neale and Flowerdew, 2003 , Tuthill et al., 2020)). It has an established role in social sciences disciplines such as psychology, education, social policy, and sociology and has gained popularity in health behaviour research (Calman et al., 2013, Saldaña 2003). LQR focuses on the temporality of phenomena and is driven by the desire to understand experiences across time, turning points, as well as what change happens, how and why it happens in the sociocultural context (Saldaña, 2003; Calman et al., 2013; Holland et al., 2006; Tuthill et al., 2020). LQR can capture the interplay between time and the cultural dimensions of social life and generates in-depth data in comparison with cross-sectional or quantitative data alone. It can facilitate a better understanding of the lived experience of disease, how individuals use healthcare services and why they make specific choices (Grossoehme & Lipstein, 2016).

Historically, longitudinal research designs were typically used in quantitative studies with a few qualitative studies using the approach (McCoy, 2017; Vogl et al., 2018). However, over the last few decades, LQR designs have become more popular with an increasing number of studies using them (Calman, et al., 2013; Cameron et al., 2019; Lewis, 2021; Tuthill et al., 2020). Despite the increased popularity, there has been much debate over whether LQR is a methodology on its own or is more suitable as a design element of a study within long established qualitative methods for example grounded theory, phenomenology or ethnography (Calman et al., 2013; McCoy, 2017). The debate stems from its use as a methodological approach in some studies and as a longitudinal data collection approach in others and the diversity of qualitative data collection techniques and approaches to analysis used within LQR (Audulv et al., 2022). Plano Clark et al. (2015), McCoy (2017) and Bennett et al. (2020) argued that LQR is a design element of studies due to its lack of clear data collection and analysis approaches, its flexibility to be used in mixed methods studies, and the lack of distinguished epistemological and ontological standpoints. For example, McCoy (2017) describes LQR as an orientation which can be combined with other established methodologies such as Interpretive Phenomenological Analysis (IPA) therefore making longitudinal IPA a methodology. However, the lack of clearly defined procedures of data collection and analyses provides an opportunity and flexibility for researchers to develop suitable research designs for each study by combining diverse qualitative data collection techniques (Audulv et al., 2022; Thomson, 2007; Tuthill et al., 2020). It is this uniqueness that allows LQR to be an emerging and distinct methodology that can be applied to understand human experience where other methodologies will not elicit the temporality of phenomena and associated changes within the sociocultural context. For example, LQR has been used to understand human development (Schmidt et al., 2019), progression of chronic illness (Namukwaya et al., 2017), medication adherence (Salter et al., 2014) and aging (Oosterveld-Vlug et al, 2013), using a variety of data collection and analysis approaches.

LQR is distinguished by the incorporation of temporality in its orientation making it suitable in health research where time and change form part of health experiences that determine health status or recovery (Audulv et al., 2022; Calman et al., 2013). Use of data collection and analytic approaches which focus on time and change ensures that LQR may be employed to understand the lived experience of illness, how individuals use healthcare services and why they make specific choices (Grossoehme & Lipstein, 2016a). The main tenets of LQR are time, change, and its iterative nature. Each will be discussed in turn.

5.3.1 Time in Longitudinal Qualitative Research

Saldaña (2003) identified that different periods of time and different points in time are qualitatively distinct, reflecting different experiences. This is also influenced by cultural conditions around an individual`s geographic location impacting the interpretation of time and perceived change across time. Since time is an inherent component of LQR, and experiences can be captured at different periods of time and different points, LQR provides an opportunity to collect individual experiences over a period compared with a one-off interview which may not fully capture the whole experience, particularly as experiences change over time.

According to Saldaña (2003) there is no consensus as to how long a longitudinal study should take or when to generate data, it depends on the context of the study and other factors important to the study. Corden and Nice (2007) supported Saldaña also stating that there is no definitive length of time for a study to be considered longitudinal in LQR. For example, Clermont et al. (2018) studied the acceptability and use of supplements during pregnancy over a period of 6 months; Solomon et al. (2018) studied the trajectories of episodic disability in people aging with HIV over 20 months; Henderson et al. (2014) followed young people for a period of 14 years in the Inventing Adulthood study. The timeframe of each longitudinal study is influenced by research aims, questions, methodology, theoretical framework, and practical and logistical constraints. However, it is important to be cognisant of the fact that the individual`s construction of time is a major contextual factor in influencing the individual`s subjective experiences across time. The synchronised biographical time of both participant and researcher serves the purpose of moving between past and present and creating different timepoints in LQR (Carduff et al., 2015; Thomson and McLeod, 2015).

More specifically in illness experiences, traversing between the present and the past provides an opportunity to better understand and identify changes in illness interpretation and associated responses across time.

5.3.2 Change in Longitudinal Qualitative Research

Another key tenet of LQR is change. Like time, change can only be interpreted through an individual traversing from present to past (Carduff et al., 2015; Thomson and McLeod, 2015). Saldaña (2003) articulated change in LQR as contextual to each study and therefore flexibility is key to allow change to emerge as a study progresses. In practical terms, this involves continuous revision of the definition of change for every LQR study. In addition, Lewis (2007) highlighted the importance of being aware of the four kinds of change that can be identified or exposed through the analysis of qualitative research data in LQR studies:

1. Narrative change which involves how participants' stories unfold overtime. Stories are typically not told in a clear chronological order, but overtime participants go back and forth and through this process the narrative can change. This could be due to:

    - Developing trust and rapport with the researcher and willingness to reveal experiences they may have been uncomfortable with in the beginning.
    - Having previously forgotten to mention some issues.
    - Some issues becoming more relevant as time goes on.
    - Assumptions that they have mentioned these experiences before.

2. Change arising from reinterpretation by participant occurs overtime as participants reinterpret and re-describe stories and experiences in later interviews. Additional experiences and time may evoke different meanings and perspectives on certain issues that participants may have highlighted in earlier interviews (Calman, 2013). As noted by Lewis (2007) LQR provides an opportunity to engage participants in the analysis of change by observing change in their interpretations and thus reflecting on inconsistencies to enhance a collaborative interpretation of participants' account of their stories.
3. Change arising from the researcher's interpretations occurs as a researcher continues to interact with participants and learn more about participants' perspectives and behaviours (Carduff et al., 2015). As participants retell and reinterpret their stories and the narrative and interpretation changes, so does the researcher's interpretation of participants experiences, perspectives, and behaviour (Lewis, 2007).
4. The absence of change is of equal importance in LQR studies. Saldaña (2003) highlighted the importance of noting what remains consistent or constant through time. Absence of change could be a positive and this may depict stability, consistency and maturity allowing explorations of how stability can be promoted or supported. It could also be a negative as it can depict failure of progress (Lewis, 2007).

In addition to the importance of being aware of the different kinds of change, Saldaña (2003) argued that there is need for a flexible approach in classifying change in a study. Whilst change can be defined by research aims, it is important that multiple contextual factors that may inevitably influence change be considered throughout the study (Saldaña, 2003). Furthermore, researchers should confront preconceptions about change and allow the definition of change in LQR studies to emerge without imposition (Pettigrew, 1990; Lewis, 2007).

5.3.3 Iterative nature in Longitudinal Qualitative Research

Another key tenet of LQR is its iterative nature in data generation. This involves drawing on what was learnt in previous interviews to understand what has changed overtime (McLeod and Thomson, 2009; Carduff et al., 2015). Therefore, LQR is characterised by the practice of going back and forth to previously collected data to inform current data and ensure consistency throughout the study. This provides an opportunity for participants to divulge new reflections and interpretations and enables researchers to edit, incorporate or alter previous data (Miller, 2015).

However, Mertens (2015) argued the reliability of going back in time using previously collected data since the passage of time can lead to different reinterpretations and perceptions for both participants and researchers. In other words, it is impossible to truly go back in time. Nevertheless, the secondary analysis of previous data collected alongside the analysis of newly collected data is beneficial for gaining an in-depth understanding of participants' experiences. The iterative nature of LQR, creates an opportunity to gain fresh analytic insights for extending, revisiting and retheorising periods of significant transition in participants' experiences (Calman et al., 2013; Miller, 2015).

5.3.4 Challenges of Longitudinal Qualitative Research

Despite the unique opportunity that LQR provides in accentuating experiences across time, turning points, as well as highlighting what change happens, how and why it happens in the sociocultural context, it has some distinct challenges. Due to its longevity, retaining participants in LQR studies especially in cases where the sample is comprised of participants with chronic illness can be problematic (Tuthill et al., 2020). The process of consent can also be problematic as it requires constant re-negotiation due to the longevity of LQR and different waves of data collection (Holland et al., 2006). In addition, LQR generates a vast amount of data which can be challenging to manage (Calman et al., 2013; Saldaña, 2003). Due to the amounts of data generated, analysis can be complex as it requires a muti-dimensional approach that includes synchronic and diachronic analysis to capture change, turning points and processes that are involved in change (Grossoehme & Lipstein, 2016; Holland et al., 2006; Lewis, 2021). Furthermore, LQR analysis requires rigorous attunement to identify what represents change, the interrelation of different types of change and the processes that influence change before articulating and presenting findings in a coherent manner (Saldaña 2003). In the current study, these challenges were considered and addressed in the design of the study. These will be discussed and highlighted as part of the methodological approach and decisions made in the design of the study.

5.3.5 LQR approach in current study

The current study adopted a LQR approach to capture the experiences of a cohort of individuals living with and self-managing chronic pain over 18 months at 4 time-points: 0, 6, 12 and at 18 months. Saldaña (2003) recommends using prior research evidence to establish a timeline in LQR. Eighteen months was the timeframe selected because Calman et al, (2013) and Tuthill et al. (2020) recommends allowing time to develop a relationship between researchers and participants in-order to elicit a rich narrative of experiences especially on sensitive issues. This timeframe enabled researcher to develop a relationship with each research participant and generated a rich textured in-depth account of participants' lived experiences of self-managing chronic pain and how these experiences influence self-medicating habits with specific emphasis on OTC codeine-based analgesics.

Indeed, the aim was to gain a deeper understanding of the experiences of participants in self-managing chronic pain; what change happens, how it happens and how participants experience and cope with change over-time with specific focus on what influences self-medicating with OTC codeine. Exploring these concepts and lived experiences over a longer period provided an opportunity for the participant to have a stronger voice, limiting the often-power imbalance inherent in the researcher-participant dyad (Saldaña, 2003) and avoiding a biased perspective gained sometimes from one interview at one moment in time (Tuthill et al., 2020). Pragmatically, the timeframe was also determined by the practical constraints in terms of the duration of the PhD programme.

5.3.6 Participants

5.3.6.1 Sampling of participants

Purposive sampling was used in the selection of participants for the study. Purposive sampling is the act of selecting a sample based on characteristics of a specific population and the purpose of the study (Campbell et al., 2020). It allows researchers to match the sample to the objectives and aims of the research, therefore improving the rigour of the study and trustworthiness of the findings. This approach ensured that the sample recruited reflected the phenomenon being investigated. As noted by Silverman (2000) "Purposive sampling allows the researchers to choose a case because it illustrates the feature in which we are interested" (p. 104).

Calman et al. (2013) proposes 10-12 participants as an appropriate cohort for longitudinal qualitative research studies. The relatively small sample allows researchers to develop a relationship than can help manage sensitive topics and emotions in interviews therefore allowing an in-depth exploration of individual narratives and trajectories to capture the processes that influence change. For example, Crouch and McKenzie (2000) recruited a sample of 7 women to explore women's experience of post-mastectomy. Similarly, Lopez et al. (2011) recruited a sample of 10 participants to explore the explanations of patients about the development and coexistence of symptoms and self-managing them. In addition, small samples allow researchers to effectively manage large data sets generated in LQR from data collection to analysis specifically where research data is managed by one researcher. Tuthill et al. (2020) highlighted the challenge of retaining participants in LQR studies especially in cases where the study is occurring over a long period of time. They recommended building rapport and establishing strong relationships from the onset. Progression of illness in participant samples with chronic illness can also pose a challenge in retaining participants over a long period of time (Calman et al., 2013). The current study sought to recruit 15 participants to take into consideration the need to develop relationships with each participant to allow in depth exploration of chronic pain experiences and full engagement with data at interview and analysis stages while also considering possible attrition.

5.3.6.2 Inclusion and exclusion criteria

The inclusion criteria for this study were: adults with chronic pain living in Ireland self-medicating with OTC analgesics, including codeine-based OTC analgesics, with the ability to give informed consent. There was one exclusion criterion namely, individuals currently attending addiction services for opioid addiction i.e., taking medication for opioid replacement therapy.

5.3.6.3 Recruitment

Community pharmacies, and a number of support organisations, including Arthritis Ireland, Migraine Association of Ireland, and Fibromyalgia Ireland, and Maynooth University research participation scheme were all used to recruit participants. Letters seeking for approval to approach membership of support groups and employees (Appendix LQR1), leaflets (Appendix LQR2) and study information sheets (Appendix LQR3) were all used in the recruitment process. The role of the organisations was to make study details available in different fora, prospective candidates had to initiate contact to opt in the study. Digital or copies of research participation leaflet invitations (Appendix LQR2) were provided to prospective participants once organisations approved to approach their employees or members. This included information about the study, duration of study, data collection timelines and my contact information.

Once contacted, study information sheets were sent and after a cooling off period of at least 24 hours, prospective participants were contacted for recruitment. Three prospective participants who made contact to opt in were not recruited as they did not meet research criteria; one was on opioid substitution treatment and the other two were not self-medicating for pain. Ten met the criteria and arrangements were made with participants on convenient venues and times to conduct the initial interviews. Despite using these various channels, recruitment of male participants was problematic. Efforts were made to directly contact organisations who directly support men for example ‘men’s sheds’ to disseminate study information. However, this did not yield further recruitment opportunities.

5.3.6.4 Participant sample

Ten participants were recruited on the study. The geographical spread of the participants included North, South and County Dublin, Counties Kildare, Meath, and Louth in the Republic of Ireland. All the participants were living with long-term illnesses that were linked to persistent chronic pain. Based on self-reported diagnoses, participants were classified as having CWP or CLP. The sample consisted of seven females and three males ranging from 20 – 55 years in age. The employment status of participants at recruitment was varied and did not remain constant during the period of the study. All the names presented throughout the thesis are pseudonyms to ensure the anonymity of the participants in accordance with ethical principles. The characteristics of the participants are summarised in Table 3.

Table 3

Characteristics of Phase 2 Participants

Participant	Chronic illness	Gender	Age range (years)	Education	Health Scheme
Amy	Fibromyalgia and rheumatoid arthritis (chronic widespread pain)	Female	51 -55	3rd level	Private with health insurance
Louise	Ankylosing spondylitis and rheumatoid arthritis (Chronic widespread pain)	Female	51 - 55	2nd level	Private with health insurance
Helen	Migraine and knee pain (chronic localised pain)	Female	21 - 25	3rd level	Private with no health insurance
Jess	Lyme disease and rheumatoid arthritis (chronic widespread pain)	Female	21 - 25	2nd level	Private with no health insurance
Joanne	Multiple sclerosis (chronic widespread pain)	Female	36- 40	2nd level	Public with health insurance
Edel	Ehlers-Danlos syndrome (chronic widespread pain)	Female	46 - 50	3rd level	Private with health insurance
Katie	Migraine (chronic localised pain)	Female	21 - 25	3rd level	Private with no health insurance
Jack	Fibromyalgia (chronic widespread pain)	Male	21- 25	3rd level	Public with no health insurance
Peter	Fibromyalgia (chronic widespread pain)	Male	26 - 30	2nd level	Public with no health insurance
Darren	Arthritis (chronic localised pain)	Male	46 - 50	2nd level	Private with no health insurance

All ten participants completed the time point 1 interview. Eight participants were available for time point 2 six months later, six for time point 3 twelve months later and eight for time point 4 eighteen months later. Due to the burden of living with chronic pain and the challenges associated with the COVID-19 pandemic, three participants were not able to complete all planned interviews in the study. However, all participants except one indicated their desire to continue with the study where practicable. Therefore, the longitudinal findings presented in this chapter represent 9 participants. At timepoint 1, ten interviews were conducted face to face; all the other interviews were conducted via Microsoft Teams except for one participant who opted for telephone interviews. The engagements with participants are outlined in Table 4. A total of 32 interviews were conducted between October 2019 and August 2021.

Table 4

Engagement of Phase 2 Participants

Participant	Timepoint 1	Timepoint 2	Timepoint 3	Timepoint 4
Amy	✓	✓	✓	✓
Louise	✓	✓	✓	✓
Helen	✓	✓	✓	✓
Jess	✓	x	x	x
Joanne	✓	x	x	✓
Edel	✓	✓	✓	✓
Katie	✓	✓	x	x
Jack	✓	✓	✓	✓
Peter	✓	✓	x	✓
Darren	✓	✓	✓	✓
Total	**10**	**8**	**6**	**8**

5.3.7 Data collection

Data were collected using semi-structured qualitative interviews at each timepoint. This enabled six-month intervals between interviews to analyse individual experiences, identify themes to clarify and discuss in subsequent interviews and factor time and change in the research process, key tenets of LQR. Semi-structured interviews provided a flexible approach of generating data through free ranging conversations of research phenomena (Roulston & Choi 2018). Parahoo (2006) highlighted the degree of control that researcher has in the interview process through use of predetermined interview questions and the flexibility of probing for in-depth exploration where needed. This approach facilitated an interchange of ideas in seeking knowledge between participant and researcher. In addition, semi-structured interviews enable the exploration of participants' social, cultural, and political understandings of the research phenomena (Mishler, 1986). Interviews lasted 25 minutes to 90 minutes (mean duration 42 minutes).

5.3.7.1 Development of interview guide

A comprehensive interview guide was developed for timepoint 1 interviews informed by literature on chronic pain management (Appendix LQR4). The questions were broadly on the following topics: pain experience, pain management strategies, interactions with healthcare professionals, self-medicating, and support. Questions were open ended to ensure they would elicit detailed information and prompts were used to encourage more detailed responses (McIntosh & Morse, 2015). Though the purpose of the interview guide was to provide some structure to the interview, it also proved useful in ensuring that all issues of interest were discussed, interviews did not stagnate and when discussion veered off research topic.

5.3.7.2 Evolution of the interview guide for subsequent interviews

The initial interview guide was only used in timepoint 1 interviews. Subsequent interview guides (Appendix LQR5) were tailored to each participant and were designed to expand upon themes that were specific to the participant from previous interviews, one of the strengths of LQR design (Nevedal et al., 2019, Saldaña, 2003). As rapport developed, this approach facilitated a natural flow of dialogue and enabled further exploration of experiences and change overtime. For example, as well as specific issues to be followed up for each participant, each question guide comprised the following questions on:

- Pain experience focusing on what change had happened, how it happened and the impact of the change.
- Interactions with medical professionals.
- Current pain management strategies.
- Self-medicating habits.
- Interactions with pharmacies.

This approach enabled both participants and researcher to reflect on the dynamic changing experiences and facilitated the iterative nature of LQR. All timepoint 2, 3 and 4 interviews were conducted during the Covid 19 pandemic and as such the impact of related changes on chronic pain management experiences were explored.

5.3.7.3 Conduct of interviews

The first interview

Each interview started by asking participants about demographic and socio-economic status related questions in-order to contextualise the data generated. Participants were then asked to share their pain experience story. This encouraged participants to tell their story, in their own words starting at a timepoint that was most appropriate to them. The open-ended question allowed the participants to start either with current experiences, how it started, seeking diagnosis or anywhere in between. This approach facilitated a natural follow up of related issues specific to their story; many of which were part of the interview guide. This enabled natural dialogue and created an opportunity to begin building rapport between the researcher and the participant. At the end of interviews, interview summaries were recorded in the form of voice recordings of some immediate thoughts as they occurred and other possible avenues to explore in subsequent interviews. These proved to be useful in generating interview guides and during analysis.

Subsequent interviews

Interviews two and three similarly commenced with asking participants about participants' pain experiences. Due to COVID-19 social distancing guidelines (Kennelly et al., 2020), more often pain experiences were discussed under the lens of living under these restrictions. This facilitated rapport between researcher and participants as participants typically asked after researcher's well-being and coping strategies as well as they reflected on their own experiences. In addition, researcher made efforts to follow up on personal activities or connections that had been highlighted in previous interviews. This rapport encouraged participants to share experiences they may have felt uncomfortable with at initial interviews especially around the issue of misusing OTC pain medications. Participants were asked to expand on themes identified in analysing previous interviews ensuring an iterative approach rather than a repeat cross-section approach (Smith, 2003).

The final interview

The fourth and final interview, for most participants, was used to probe into issues of interest in the study that were yet to be explored in previous interviews identified at analysis stages. Saldaña (2003) highlighted the need for context-driven approaches in final interviews in-order to address the needs and interests of researchers. In addition, participants were given an opportunity to reflect on their chronic pain experiences and self-medicating patterns starting from the initial interview to current experiences and how they envisioned their future. This generated in-depth discussions which were underpinned by the changes that had occurred overtime and encouraged future planning in coping strategies. To close the interview, all participants were offered the option to check on identified themes and to receive final report of the study. None opted for theme checking and one opted to receive the final report.

Debriefing

On completion of each interview, participants were debriefed by reiterating the following:

- Participants were thanked for taking part and the purpose of the research was reiterated. They were also given the opportunity to ask any questions and to seek clarification pertaining the research.

- Participants were reminded of their right to withdraw from the study up until personal identifiers were disposed of and about the anonymisation of data, use of pseudonyms on transcripts and confidentiality.
- The well-being of participants was checked after interviews in consideration of the sensitive topics discussed and they were signposted to their GP or alternatively the National Counselling Service if further support was required. None of the participants indicated the need for support throughout the study.

5.3.8 Adaptations due to COVID-19 pandemic

All initial interviews were conducted face to face between October 2019 – January 2020. In March 2020 the WHO declared a global pandemic of COVID-19 (Carbia et al., 2022). In-order to contain the spread of the virus, unprecedented measures were adopted which involved lockdown measures that included stay at home measures, prohibition of non-essential travelling and closure of public spaces, schools, and non-essential businesses (Kennelly et al., 2020; Government of Ireland, 2020). As the COVID-19 pandemic evolved, a framework for COVID-19 response that included 5 different levels of restrictions was implemented over the course of this research (Carbia et al., 2022; Government of Ireland, 2020). This affected the recruitment process, study settings and timepoints 2, 3 and 4 of phase 2.

Based on COVID-19 guidelines (Government of Ireland, 2020), face to face interviews were no longer an option and there was no indication of when these could resume. A decision was made to switch to alternative remote data collecting methods such as telephone or video interviews. Historically, face to face interviews have been perceived as the gold standard with other modes considered inferior (Rubin & Rubin, 2011; Hermanowicz, 2002). The underlying concern in this perception is that data quality is compromised when collected remotely and it is more challenging to build rapport with participants. However, Johnson et al. (2021) examined variation in mode effects across in-person, telephone and skype interviews using 306 interviews in the United States, United Kingdom, and India. Findings revealed that face to face interviews are advantageous in producing conversation turns and word-dense transcripts and field notes but there was no significant difference in interview length, subjective interviewer ratings and substantive coding. Concerns regarding building rapport in remote interviewing were partly overcome in this study due to combining face to face interviews with remote interviews. Remote interviewing has gained popularity due to technological advancements, increased internet access and most recently measures brought on by the COVID-19 pandemic. It has been used extensively in health research (e.g., Pang et al., 2018; Saarijärvi et al., 2020), and social research (e.g Gruber et al., 2023; Melis et al., 2022). Remote interviewing facilitated continuation of this LQR study despite the social distancing guidelines set by the government to contain the COVID-19 pandemic (Kennelly et al., 2020).

At the time of the first lockdown, 10 participants had been recruited and initial interviews conducted. Recruitment of new participants was problematic for various reasons; there was a sense of waiting for normality to resume and interactions through participant recruitment channels were hindered due to lockdown measures. In addition, the experiences of living through the COVID-19 pandemic would not have been the typical experiences of living with chronic pain. However, for the 10 already recruited participants, all initial interviews had been conducted prior to the pandemic and provided a reflection of typical experiences of living with chronic pain in day-to-day life. Therefore, this provided an opportunity for subsequent interviews to incorporate and seek to explore the impacts of living through a pandemic into chronic pain management experiences. A decision was made to continue the study with 10 participants similar to other LQR studies (e.g., Crouch & McKenzie, 2000 & Lopez et al., 2011). Timepoints 2, 3 and 4 were all conducted via telephone and video interviews.

5.3.9 Ethical considerations

Ethical approval for the study was granted by the Social Research Ethics Sub-Committee of Maynooth University between March 2019 and August 2021 (Appendix LQR6).

5.3.9.1 Ongoing consent

Ensuring ongoing consent was an important ethical consideration throughout especially considering the longitudinal aspect of the study (Holland et al., 2006). Initially during the recruitment phase, it was highlighted to participants that they had no obligation to participate at all timepoints, they had the right to withdraw from research and decline further participation at any time without providing a reason. Consent was provided in written form before the first interview (Appendix LQR7) and was also confirmed verbally at the beginning of the interview.

Consent to contact participants for subsequent interviews was included in the form signed at timepoint 1. For subsequent interviews, participants were contacted via email or phone messaging to arrange interview dates and were asked to confirm willingness to participate before arranging subsequent interviews. At the commencement of each interview, consent was also sought verbally before starting the interview and participants were reminded of their right to withdraw.

5.3.9.2 Anonymity and confidentiality

All data were handled in accordance with the principles of confidentiality from the outset of the research. Only the research supervisor and researcher had access to personal information and data collected from participants. The data comprised of demographic information, consent forms, audio-recordings, and transcripts. All audio recordings and transcripts were encrypted and stored on a secure PC and consent forms were stored in locked cabinets with limited access on campus. All audio recordings were collected on a mobile device which was protected with a strong password and were deleted from the mobile device once transcription was completed. All data collected were anonymised to ensure privacy and confidentiality by use of pseudonyms. Each pseudonym was assigned a participant code to allow linkage of transcripts across time. Participant codes linking pseudonym to participants were destroyed once all transcription and analysis were completed.

5.3.10 Data analysis

LQR analysis is complex and multidimensional but provides unique analytical opportunities due to the potential for flexibility and innovation (Calman, et al., 2013). LQR analysis moves beyond the traditional cross-sectional analysis to longitudinal analysis and an articulation of both. In order to capture and compare differences at different timepoints, a synchronic and diachronic analysis approach is required (Grossoehme & Lipstein, 2016). According to Holland et al. (2006) there are three main components of LQR analysis:

1. Cross sectional analysis at each time point
2. Across time analysis across cases

3. Across time analysis within cases

This multidimensional analysis approach ensures that the wealth of longitudinal data is used and captures the three critical elements of LQR: time, process, and change (Lewis, 2007). Analysis should capture what is happening at each timepoint for each participant and across participants, as well as capturing processes and change across the participants, and specific to each participant (Grossoehme & Lipstein, 2016; Vogl et al., 2018). Cross sectional analysis and longitudinal analysis across and within cases ensures depth and breadth and temporal understanding thus providing an in-depth representation of findings over time. The current study adopted this approach.

Calman et al. (2013) argued that there are a variety of LQR analytical approaches that can be adopted to ensure a multi-dimensional analysis approach, and each provides its own unique strength to LQR analysis. For example, RTA (Braun & Clarke, 2006) provides an opportunity to capture in-depth cross-sectional experiences at each timepoint whilst trajectory analysis (Grossoehme & Lipstein, 2016) focuses on change overtime and the use of Saldaña's analytical questions (Saldaña, 2003) guides longitudinal analysis. RTA (Braun & Clarke, 2006), trajectory analysis (Grossoehme & Lipstein, 2016) and Saldaña's longitudinal analytical questions (Saldaña, 2003) were used for the current study to facilitate cross-sectional and longitudinal analysis. These were deemed to be the most suitable to elicit the experiences of self-medicating overtime, what changes happens, how it happens, why it happens and associated processes. The compatibility of different analytical approaches based on epistemological congruence in LQR was discussed in Chapter 3.

5.3.10.1 Longitudinal analysis

Cross sectional analysis was initially used to analyse each timepoint to inform the longitudinal analysis. While time-consuming in consideration of the amount of data, cross-sectional analysis provided the building blocks of longitudinal analysis and provided a snapshot of what was happening at each time point. This informed longitudinal analysis which was specifically examining changes and continuities in the experiences of participants with specific focus on influencers of self-medicating habits overtime. Braun et al's. (2006) step by step guideline to conducting RTA was used in the cross-sectional analysis of all timepoints interviews. Each was analysed separately using the steps described below:

Step 1: Familiarisation with data

Familiarisation with data was key to analysis in consideration of the longitudinal analytic roadmap adopted for this phase of the study. Developing interview guides and conducting all interviews allowed me to immerse in the data from the outset. Transcribing all interviews provided me an opportunity to interact with the data for prolonged times listening to each interview and rewinding recordings where necessary to capture all data. Even though transcribing of interviews was time-consuming, it offered me an opportunity to immerse myself in the data and to start making connections within the data. After transcription, I engaged with reading, and rereading of transcripts to further engage with the data. Due to the iterative nature of LQR, development of interview guides for timepoints 2, 3 and 4 required me to understand the issues discussed in the previous interviews in order follow up, further explore, and highlight them in subsequent interviews. Familiarising myself with interview data also marked the first stage of developing interview guides for the next phase of data collection. During this process I noted my initial thoughts and connections on the participants' experiences of living with chronic pain in relation to self-medicating, self-management, and relationships with pharmacy professionals. I also listened to audio recordings generated after interviews to reacquaint myself with summaries and immediate thoughts and connections that I had made during the data collection phase. This proved to be useful in identifying and developing connections whist familiarising myself with the data.

Step 2: Generation of codes

MAXQDA Pro 2021 was used in the organisation and coding of data (see Appendix LQR8). I adopted an inductive approach, and coded data both at a semantic level and latent level (Braun & Clarke, 2020). The experience I had gained of coding data at both levels during phase 1 of the study proved useful during the coding process. For timepoint 1 interviews this involved systematically coding each transcript by going through line by line and highlighting anything that was meaningful to interpreting experiences of living with and self-medicating for chronic pain. For the 3 remaining timepoints, to ensure consistency, an accumulative approach was adopted in the coding of each timepoint. The coding framework developed for timepoint 1 provided the starting point for timepoint 2 to ensure there was no repetition of codes and that new codes were clearly identified. This process was repeated for timepoint 3 with the previous coding framework built upon up until the analysis of timepoint 4. This was a time-consuming and iterative process that involved going through line by line noting any similar meanings with previous timepoints codes and matching them or identifying new codes. Of note was the different meanings that the same participants ascribed to the same experiences across different timepoints overtime. This is consistent with the type of change that can be identified in LQR discussed in section 5.3.2. I noted all instances of change in narratives and reinterpretations by participants which proved useful for the longitudinal analysis. During the coding of timepoint 1 interviews, I began to identify patterns and as I coded subsequent interviews these patterns diversified as different contexts and nuances were discussed as I developed a rapport with participants. For example, meanings ascribed to self-medicating with codeine-based analgesics evolved overtime from being a self-management strategy participant were wary of to an enabling strategy that they embraced and felt should not be stigmatised for in chronic pain management. The use of MAXQDA enabled me to manage the volume of data and iteratively code transcripts until codes were brief but still offered sufficient detail to inform patterns identified in the experiences of chronic pain management. It allowed me to use a cumulative approach in coding which facilitated the initial identification of continuity or change throughout the timepoints (see Appendix LQR8).

Step 3: Generating themes

MAXQDA provided me with an opportunity to generate themes through visual tools. I created MAXmaps for each timepoint data which allowed me to have a workspace where I could organise, combine, and group codes iteratively using visual tools to export data. This process facilitated the generation of subthemes and themes as I readjusted the MAXmaps. In addition, this proved useful as it highlighted codes that at a semantic level did not relate to others but once considered at a latent level were related to other codes. Through the iterative adjusting of codes for timepoint 1 interviews, I identified central meanings of grouped codes. For example, challenges in accessing adequate care which further linked with grouped codes ascribed to cost of care, delays in care and unsatisfactory care. Building on these links, I generated themes based on central meaning of grouped codes and subthemes based on patterns within that central meaning. For timepoint 2, 3 and 4 most of the central meanings of codes remained similar however with different perspectives and experiences. For example, within the provisional theme challenges in accessing adequate care, patterns of disengaging with care and feeling abandoned were identified especially in relation to how care was provided during the Covid-19 pandemic. During this process, central meanings/themes ascribed to self-medicating with codeine-based analgesics were also identified with different patterns of fluctuations across timepoints for participants depending on pain experiences. Identifying these fluctuations was useful at this stage as this later informed change in longitudinal analysis a key tenet of LQR. Even though RTA was used for cross-sectional analysis of each timepoint, during this stage I started identifying the building blocks of continuities or change in the data which subsequently informed longitudinal analysis.

Step 4: Reviewing themes

For timepoint 1 data, I reviewed provisional themes in two ways. Firstly, I reviewed the coherence between data excerpts and codes that had informed subthemes and themes. I returned to the dataset to ensure that the data and associated codes were a representation of sub-themes and themes. Secondly, I reviewed the themes for coherence with the data set and the extent to which they were capturing the influencers of self-medicating habits, and choice of medication in chronic pain management. This involved an iterative process of combining some themes, discarding, or adjusting accordingly until all relevant experiences and meanings represented by the codes were captured and represented in the themes and subthemes. For timepoint 2, 3 and 4, due to the continuity of most themes overtime albeit with additional subthemes, I also reviewed the coherence between data excerpts and codes that had informed existing and new subthemes and themes.

Step 5: Defining and naming themes

This involved refining and defining themes and subthemes identified in the data. I identified continuity of experiences across all timepoints which led to the extension of 3 themes across all timepoints. These themes evolved reflecting different individual contexts, but the essence remained the same throughout the 4 timepoints. One theme 'deterioration' was identified at timepoint 2 and extended across the remaining timepoints. Continuities of themes provided an indication of continuity and stability of experiences albeit within different contexts for each participant. Extracts that were used as part of the report were also identified at this stage based on their capability to elaborate on associated sub-themes and themes.

Step 6: Writing of findings

The purpose of conducting RTA for each timepoint of the study was to; 1. capture a snapshot of what was happening at each time point; 2. allow for identification of differences between timepoints; and 3. highlighting of broad changes overtime therefore forming the building blocks for longitudinal analysis. An overview of the cross-sectional themes and subthemes at each timepoint was created to inform the longitudinal analysis (see Table 5 and Appendix LQR9).

It is important to note that the cross-sectional analysis described was not a linear process that moved from one timepoint to the next. It was iterative and recursive requiring moving back and forwards between timepoints to interpret the experiences of participants. Through this process, my interpretation of participants' experiences changed as I learnt more about participants' perspectives while retelling their stories overtime (Carduff et al., 2015).

The process allowed me to interpret the experiences of participants using an in-depth understanding of participants’ beliefs, attitudes, perspectives, and individual contexts which otherwise would not have been possible from once off interviews. Following on from cross-sectional analysis of all timepoints, across case analysis and within case analysis were conducted to ensure depth and breadth and temporal understanding of the lived experiences of individuals living with chronic pain overtime.

Table 5

Overview of themes and subthemes from cross-sectional analysis

Timepoint 1	Timepoint 2	Timepoint 3	Timepoint 4
Theme 1: Challenges in accessing health services • Delays in accessing care • Inadequate care • Cost as a barrier	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own
Theme 2: No one understands • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and families	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority
Theme 3: Codeine provides options • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option. • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality

5.3.10.2 Across cases longitudinal analysis

Whilst the recurrent cross-sectional analysis at each timepoint discussed above captured differences between time points and broad changes overtime for the whole group of participants, it was not designed to capture the process of change (how it happened) and interrelated factors resulting in change at an individual level. The aim of across case longitudinal analysis was to explore the lived experiences overtime of individuals living with chronic pain with specific focus on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain focusing on change or stability overtime and the causes and consequences of change. A trajectory approach to longitudinal analysis and Saldana's 16 analytical questions in longitudinal qualitative research were used for across cases longitudinal analysis.

A trajectory approach to longitudinal analysis was adopted to capture the process of change in self-medicating for chronic pain and the influencers that bring on this change. Trajectory analysis focuses on change overtime, and this involved the use of matrices to highlight experiences and self-medicating habits at each timepoint and therefore capture key changes and process of change (Grossoehme & Lipstein, 2016). In addition, Saldaña's questions were used to guide the longitudinal analysis. Saldaña (2003) proposed 16 analytical questions to help with organisation of data and identify what change occurred or the absence of change, influencers of change, turning points and processes at play that interact to bring about change. The questions are divided into three categories: framing questions, descriptive questions, and analytic and interpretive questions as illustrated in Table 6. A step-by-step guide to how the across cases longitudinal analysis was conducted is described below:

Step 1: Creation of conceptually clustered matrix

This captured key themes from all the timepoints and the different experiences for each participant within these themes. A matrix was developed with participants on the Y axis and key themes from the cross-sectional analysis were placed on the X axis *(*see Appendix LQR10*)*. A summary of each participant's experience was also included. This provided a clear summary and overview of each participant's experience at a glance (Grossoehme & Lipstein, 2016).

Step 2: Creation of time ordered sequential matrix

A time ordered sequential matrix *(*see Appendix LQR11*)* for each of the participants was created with a summary of the participants experiences at each time point and an overall summary. Participants were placed on the Y-axis and the time point on the X- axis and explanations for experiences relating to self-medicating change or continuity were recorded. A summary for each participant's experiences and the resulting self-medicating habits was also included in the matrix. Codeine use within recommended doses was highlighted in green, whilst increases in self-medicating were highlighted in yellow. Elevated codeine use was highlighted in red.

Step 3: Capturing change/continuity

To capture change or continuity between all timepoints instances of change were identified by comparing the summary included in the time ordered sequential matrix between all timepoints; Saldaña's (2003) framing and descriptive questions (see Table 6) for longitudinal analysis were used at this stage.

Descriptive questions generate descriptive information that informs framing questions and analytic and interpretative questions that follow. They focus on types of change, stability or what is missing through time. Framing questions focus on identifying change and the factors at play whilst taking into consideration contextual influences for the participant (Saldaña, 2003). Descriptive and framing questions were used in this step to identify and gain an understanding of what change happens, how it happens and how participants experience and cope with change over-time with specific focus on self-medicating with OTC codeine in the management of pain. Emblematic themes can be defined as broad representations linking thematic and process analysis in capturing patterns or relationships within a data set (Neale, 2021). Three emblematic themes were identified which captured the trajectories of change or continuity influencing self-medicating with codeine-based analgesics. The emblematic themes were identified by building and extending upon the themes identified through RTA with change embedded in processes that shaped participants' experiences overtime.

Step 4: Creation of overall summary matrix

This involved creating a summary of emblematic themes matrix *(*Appendix LQR12*)* that captured change or continuity across all timepoints. Participants were placed on the Y-axis and emblematic themes on the X-axis. This ensured identification of participants with similar trajectories of change or continuity within each theme and was key in writing the findings.

Step 5: Application of Saldaña's analytic and interpretive questions

The final step involved using Saldaña's analytic and interpretative questions to further progress longitudinal analysis. Analytic and interpretive questions are iterative and integrate descriptive information to guide towards interpretation and theory generation. They focus on identifying common threads which tie changes together overtime. In addition, analytic and interpretative questions focus on identifying the through-line of the study. A through-line is described as a word or phrase which captures change, continuity, and processes at play through time. It is a way of analysing, and/or interpreting and capturing what is consistent through time and is of significance to the underlying meaning of changes observed in the research (Saldana, 2003). It can be strikingly evident within the data set or can be a culmination of the researcher’s interpretative construction of the longitudinal phenomena. It provides an interpretation of what connects change through time. It can take the form of a core theme which connects, and illuminates participant change continuity and associated process through time; the meaning of changes observed; a conceptualisation of a core category overtime or a recurring word with summative power for other categories (Neale, 2021; Saldana, 2003). The through-line was central in the lived experiences of participants and how overtime self-medicating choices and habits were developed and maintained in the self-management of chronic pain.

Table 6:

Questions to guide the analysis of LQR data. Adapted from Saldana (2003)

Framing Questions	1. What is different from one pool* of data to the next? 2. When do changes occur through time? 3. What contextual or intervening conditions appear to influence and affect participant changes through time? 4. What are the dynamics of participant change? 5. What preliminary assertions about participant changes can be made as data analysis progresses?
Descriptive Questions	1. What increases or emerges through time? 2. What is cumulative through time? 3. What kinds of surges or epiphanies occur through time? 4. What decreases or ceases through time? 5. What remains constant or consistent through time? 6. What is idiosyncratic through time? 7. What is missing through time?
Analytic and Interpretive Questions	1. Which changes interrelate through time? 2. Which changes oppose or harmonise with natural human development or constructed social processes? 3. What are the participant or conceptual rhythms through time? 4. What is the through-line of the study?

**Pool refers to each timepoint.*

5.3.10.3 Within cases longitudinal analysis

Case histories were used for case analysis of individual participants. These case histories provide a detailed illustration of emblematic themes identified. Though descriptive, they illuminate how participants individually experienced change or continuity, the process and causes of change, influences of change and resulting consequences to self-medicating with codeine-based analgesics. Case analysis involves chronologically condensing, reconstructing, and synthesising of individual cases. It facilitates diachronic through-time understanding of trajectories of individual experiences (Neale, 2021). Two emblematic case histories were selected based on the richness of data they provided and their capability to offer greater insights to the emblematic themes identified. They represented two contrasting approaches to chronic pain management and the resulting self-medicating habits despite both living with CWP. Their trajectories illustrated changes and continuity linked to their individual experiences. They illustrated the different influencers that can lead to transitioning from appropriate codeine use to misuse in chronic pain management (Neale, 2021).

The two emblematic case histories complement the longitudinal analysis by capturing and highlighting distinctive aspects of participants' experiences that could not be captured with across cases analyses. They provide an in-depth understanding of what change happens, how it happens and how the participants experience and cope with change over-time in the management of chronic pain. Case histories involve a condensation of data using a structured approach (Neale 2021). They aim to combine cross-sectional and longitudinal analysis. Whilst the analytical longitudinal approach used across cases was efficient in capturing change or continuity at a group level, using the same approach for case histories would not be as efficient. For example, Saldaña's longitudinal analytical questions are ideal in eliciting changes or continuity overtime across a group but have limited applicability in eliciting the same at individual level (Saldaña, 2003, Calman. 2013).

Neale (2021) proposed processual questions to help structure case histories (Table 7). These questions were used to ensure there was a coherent narrative of each case history. The first step began by inductively analysing each interview separately to create a case profile. Case profiles were created for each timepoint providing a summary of the participant's experiences and their influence on self-medicating with codeine-based analgesics. Changes and continuities were then identified by comparing the case profiles for each participant for all timepoints. The information from the time ordered matrices (Appendix LQR 11) for the across case longitudinal analysis proved useful in identifying change or continuity at each timepoint. In addition, it enabled the case histories to be structured through emblematic themes identified during the across case analysis phase. As such the case histories are presented in the form of the identified emblematic themes and compliment the themes in a more in-depth narrative.

Table 7

Questions to guide the analysis of Case Histories. Taken from Neale (2021)

1. What happened (events, practices, processes)?
2. When and where did it happen/over what space of time (setting, timeframes)?
3. Who was involved (agents)?
4. How was it done/how did things evolve (agency)?
5. Why was it done (purpose, motives, aspirations)?
6. What triggered and propelled the process (multiple influences, impetus)?
7. What meaning did it hold for those involved (lived experience)?
8. Did these meanings and perceptions shift over time (recursive understandings)?
9. Was the path straightforward, or were there detours along the way (pathway)?
10. What (if any) were the effects or impacts at different points in time (effects)?

5.3.11 Reflexivity in qualitative research

At the time I started my PhD studies, I was working in a community pharmacy and involved in the supply of OTC codeine. However, at the time of timepoint 1 interviews, I was now working as a health promotion professional within the disability sector but felt it necessary to divulge my background to participants during the recruitment process.

Initially participants perceived my role within the research process as a previous gatekeeper of OTC codeine-based analgesics in community pharmacies. This influenced the initial narratives of the first interviews especially around the issue of self-medicating with codeine-based analgesics and use of different pharmacies in acquiring OTC medication. Although I took the opportunity to explain my role as a researcher and reassure participants of the confidentiality involved in the research process, some participants were hesitant to divulge their self-medicating habits initially. I do suppose this had an influence on the experiences participants wished to share and those they withheld particularly as there is stigma attached to misuse of codeine in Ireland (Mcdonell, 2019). However, as the research progressed and rapport developed, participants divulged more experiences as they began to perceive me as a researcher rather than someone who was going to be judgemental about their self-medicating habits.

In addition, the longitudinal nature of the study meant that overtime my previous professional identity became less visible and my personal identity more visible in my interactions with participants. On reflection in subsequent interviews, I was sensitive in my probing to ensure that self-medicating habits were discussed within the natural flow of conversation which made participants relax and divulge more than in initial interviews. Furthermore, I made efforts in building a rapport with participants. This rapport further developed as timepoint 2, 3 and 4 interviews took place during a pandemic as previously discussed and inevitably led to discussions around my personal life, background and how I was also coping with the demands brought on by the pandemic. Due to the restrictions brought on by social distancing restrictions, participants welcomed the opportunity to have someone to talk to who listened as they felt the focus among their own social and family circles was mainly on the pandemic. This raised some ethical questions relating to the research process. However as argued by Swartz (2011), if nurtured the researcher-participant relationship can encourage more in-depth private accounts to be shared and provide a potentially therapeutic outcome for participants. I felt this was the case as I interacted with participants.

The final interviews were sometimes emotional as participants, and I felt that we had been through a journey together that was suddenly coming to an end. Some participants mentioned that the study had provided an opportunity to offload each six months in a safe space. In addition, there had been ongoing hope each time interviews occurred that the pandemic would be over by the time we got to final interviews, and these could be conducted face to face. However, at the time of timepoint four interviews, restrictions brought on by the pandemic were yet to be all lifted.

5.3.11.1 Different selves

Since commencing this study, I wrestled with my identity as a pharmacy technician and my identity as a researcher. As a pharmacy technician, I started the research with assumptions of why individuals misused OTC codeine-based analgesics coming from a place of frustration having been involved in the implementation of codeine regulations. My pre-study representations of what the results may be from a pharmacy technician perspective were that individuals misusing OTC codeine were driven by 1. the pleasurable effects of codeine implicated in its misuse, 2. withdrawal effects and, 3. physiological and psychological dependence to codeine. As a researcher, I knew there was more to the issue of codeine misuse that went further than my understanding from a community pharmacy perspective. In the early days, I had no realisation of how deep my assumptions were and as the research progressed this became visible to me as participants shared their experiences of self-managing pain. This required a lot of reflection on my part as I interacted with participants and data. The iterative nature of LQR analysis was key in ensuring that as I continuously interacted, my interpretation of participants experiences, perspectives and behaviour changed (Lewis, 2007). In addition, I specifically used bracketing as a way of mitigating the influence of preconceptions (Tufford & Newman, 2012). These took the form of strategically timed meetings with my supervisor conducted prior to, during, and following data collection, analysis, and writing. My research supervisor served as an interface between myself and the research data and as such through continuous interactions, I identified that my pre-study representations of what results may be could have hindered my ability to interpret the data and issues that required further exploration in my analytical approach. Bracketing ensured that I set aside my prior representations during interviews and analysis of data. In addition, due to the nature of LQR as a relatively new emerging methodology in qualitative research, I engaged with experienced researchers at conferences to seek views, comments, and opinions regarding my approach in conducting LQR research.

Furthermore, during this phase of the research, I had recently moved from community pharmacy to a health promotion role within the disability sector which helped to facilitate the shift of my assumptions. Professionally, I was now more aware of the challenges and gaps within the healthcare system in chronic illness management. These different roles eventually created a position of strength, particularly as I could bring in an in-depth theoretical and practical knowledge of codeine use, an understanding of the challenges participants experienced in navigating though the health system and my experience of research. In addition, this position was further strengthened as towards the end of the PhD, I moved on to a health promotion role involving looking at the wider determinants of health. This further enhanced the interpretative lens I used towards the end of the analysis.

5.3.11.2 Reflexive data collection and interpretation

Consent as a process is a critical ethical element of LQR (Calman et al., 2013; Tuthill et al., 2020). Throughout the research I was cognisant of the need to negotiate consent as an ongoing process. I sought written consent prior to timepoint 1 interviews and verbally prior to subsequent interviews. Due to the sensitive nature of the research focus, I was actively conscious of instances during the interviews where participants got upset and verbally checked for consent to continue. There were two instances during timepoint 4 interviews where participants became very emotional after reflecting on their chronic pain experiences and self-medicating patterns over the duration of the study and how they envisioned their future. I felt I had to seek consent to continue because; 1. it was not feasible to offer a meaningful comfort break in a remote interview; and 2. to acknowledge that I understood that these were sensitive topics and there was no obligation on their part to continue if it was upsetting.

During the interviews, despite posing questions from a holistic exploration perspective of living with chronic pain and associated experiences, participants mainly shaped their stories based on their interactions with healthcare providers. Participants discussed their experiences from a care-seeking lens, and this was reiterated throughout the research. There was a lot of frustration with their experiences in seeking care within health settings and as such they felt the research provided an opportunity to highlight how these experiences had shaped self-management strategies. Even though the interview questions explored the social issues associated with managing chronic pain, these were briefly discussed at timepoint 1. However, in subsequent interviews participants were not as forthcoming to discussing these. I suppose this was due to social issues mainly being constant throughout the lived experiences of participants and as such there was a sense that these were issues that could not be changed and therefore did not warrant further exploration. Instead, participants felt that sharing their experiences within healthcare settings had the potential to inform health service delivery changes and as such their focus on sharing their experiences were centred on these. The findings of the study reflect this focus on healthcare experiences and as such exploring these experiences overtime gave the participants a stronger voice a key strength of LQR (Saldaña, 2003).

The findings provide a representation of what participants considered most important to highlight in their experiences and this was central to how data was interpreted. This is consistent with the constructivist epistemology which emphasizes the importance of capturing what is meaningful as ascribed by participants in experiential interpretation (Braun & Clarke, 2019; Byrne, 2022). In addition, despite the limited willingness from participants to explore social issues relating to living with chronic pain, it was also crucial that these experiences were represented in the findings as they were instrumental in shaping self-management strategies within a socio-cultural context. The findings representing social issues associated with living with chronic pain were therefore limited in information in comparison with other themes.

The purpose of reflexive practice is to ensure transparency, trustworthiness, and accountability in the research process and therefore researchers need to be clear in their motivations to ensure an accurate representation of research findings (Doucet, 2008; Morse 2015). Throughout the research process, I continuously engaged with my research supervisor to seek views, comments, and opinions at all stages to ensure that the process of reflexivity was enhanced (Patton, 2014). In addition, where deemed necessary I recorded voice notes at the end of interviews that captured my immediate occurring thoughts about the interview and information that stood out that needed further reflection and exploration in subsequent interviews. In terms of my own stance, I had to be clear about my background of having been involved in the implementation of codeine regulations and the challenges this had brought in my role as a pharmacy technician. On the other hand, through my work as a health promotion professional, I was aware of the challenges participants faced in seeking interventions in chronic pain management. It is from this position that I conducted, analysed, and interpreted this research.

5.4 Summary of findings from longitudinal analysis across cases

5.4.1 Through-line: “Just managing”

Consistent and prominent throughout the longitudinal findings on the experiences of participants living with chronic pain was the through-line: “Just managing”. Chronic pain was experienced within complex interacting individual, environmental and social contexts that exacerbated and perpetuated the impact of chronic pain to daily living. Even though experiences differed based on individual contexts, the physiological and psychological distress resulting from living with and managing chronic pain was associated with; worry, frustration, helplessness, financial struggles, isolation, and misuse of OTC codeine-based analgesics. Individual knowledge, beliefs, and health status influenced how chronic pain was perceived and managed within environments that lacked support, empathy and understanding. Throughout the course of the longitudinal study, the experiences of participants were centred around finding ways of “just managing” chronic pain within environments characterised by insufficient support.

Within health systems, participants were not afforded the basic human right of access to pain management (Brennan et al., 2019). Health inequities led to different opportunities and access to care. In addition, the care offered within the health system was characterised by long waiting lists, fragmented care, biomedical approaches, risk mitigation approaches in analgesic prescribing and lack of trust. Establishment and continuity of care within this context was problematic and participants were “just managing” chronic pain to the best of their ability within the parameters of available resources and support. Furthermore, within familial, social, and other professional circles, participants felt like no one understood the burden and impact of living with chronic pain. Issues around lack of clear diagnosis, legitimacy, and pain invisibility impacted how participants’ experiences were perceived within these contexts. Throughout the study, participants strived to maintain some sense of normality and continuity. More often self-medicating with codeine-based analgesics was an enabler that provided a feasible option to “just manage” chronic pain within the challenging individual, environmental and social contexts participants were living and managing pain in. These experiences are represented in three emblematic themes: 1) Feeling disregarded; 2) Feelings of being misunderstood and 3) OTC codeine is my enabler.

The emblematic themes represent the experiences of participants over the duration of the study and demonstrated processes that influence change or continuity in self-medicating with codeine-based analgesics. Within this context, processes are defined as “*temporal constructs that convey a sense of flux and change and illuminate how lives unfold. They comprise a rich tapestry of events, actions and interactions that are linked together in a meaningful way through time*” (Neale 2021, p381). Environmental, individual, and social factors were all influential to the processes of change or continuity and on the positioning of participants on the continuum of OTC codeine use.

5.4.2 Theme 1: Feeling disregarded

This emblematic theme captures lived experiences of participants managing chronic pain within environments where they felt disregarded. These feelings stemmed from the way care was provided in health settings, how the health system was characterised by long waiting lists and how the care offered was fragmented and inadequate despite participants having to deal with the burden of chronic pain daily. Participants felt the healthcare system disregarded the need for equality in accessing services, timely interventions, and multi-disciplinary approaches to effectively manage chronic pain. Their experiences were characterised by lack of empathy, being dismissed, neglected, and undervalued in their efforts to seek care leading to participants adopting self-led care with limited or no support or interventions required in chronic pain management. These experiences necessitated self-led self-management approaches to deal with the physical, psychological, and social consequences of living with chronic pain. Self- medicating with codeine-based analgesics provided an option of "just managing" the debilitating effects of living with chronic pain.

For some participants (Helen, Katie, and Darren), the initial and ongoing decisions to seek medical intervention to manage chronic pain were not always based on need. Due to financial barriers, their experiences of managing chronic pain and seeking health interventions were shaped by their ability to afford medical care.

"I kept putting it off thinking 'the pain will go away if I kept taking the painkillers. It costs €60 like to see a doctor and you kind of want to pay that for serious stuff but the pain never went away". (Darren)

"I do get bad migraines at least once a week, but I haven't been to my doctor for 5 years, but I definitely need to see a specialist definitely, but I have to pay so much for a visit and then pay some more for medication and painkillers or whatever and right now I just I can't afford it. It is quite a lot of money even the GP visit itself never mind the specialist and the medication. It's kind of like unfair that I mean you're managing pain as well then you have all these huge bills in front of you like to actually manage the pain". (Helen)

As well as living with the burden of chronic pain, Helen, Katie, and Darren's experiences were characterised by the added worry of not being able to pay for timely health care interventions. This left them vulnerable and helpless with no meaningful care and throughout the study period they were "just managing" chronic pain in the best way possible for them. They felt disregarded within the healthcare system as the fact that they were living with the burden of chronic pain was not put into consideration in health provision policies.

These experiences expose the social injustice inherent in the Irish healthcare system that cause health disparities for individuals living with chronic pain. This social injustice meant that for participants like Helen, Katie, and Darren, they had limited initial and ongoing access to medical interventions. In addition, it was detrimental to the development of adaptive coping strategies leading to "just managing" chronic pain without adequate support. Within this context, codeine-based analgesics provided the feasible pharmacological option to "just manage" chronic pain despite participants knowing the associated adverse effects. The immediacy associated with symptomatic relief overrode the distal nature of adverse symptoms associated with codeine.

"I know that they just advise you that if it doesn't go away in 3 days you need to get medical help or whatever but sometimes you just need a good strong painkiller that is affordable and what they do not consider is medical help is €55 to go to a GP. They just think you should stop using the medication that is helping you, I don't get it to be honest". (Katie)

"I just take the painkillers, that is what I have to do". (Helen)

As highlighted by Helen and Katie, their experiences of managing chronic pain were embedded within a healthcare system characterised by disparities which led to disparate outcomes in self-medicating habits. This social injustice left them vulnerable to the development and maintenance of self-management strategies that were detrimental to their long-term well-being. In addition, this created a barrier to accessing other services as GPs are effectively the main gatekeepers to other primary care services and most secondary care services. However, notwithstanding the financial barriers to accessing medical care, for participants with the means to pay or who qualified for a medical card, engaging with health services in the management of chronic pain did not always translate to receiving adequate care and support. A common experience among participants was that interactions with medical professionals had not yielded expected results during the early stages of chronic pain and in ongoing care resulting in disengagement or lack of confidence overtime. Consultations with GPs were characterized by lack of empathy in addition to the disregard already experienced within health system approaches and policies. Lack of empathy in these early encounters by GPs was problematic at multiple levels. It impeded opportunities for participants to be referred to other health professionals or secondary care, the care and support provided was inadequate to manage chronic pain and this subsequently led to participants adopting prolonged acute pain management approaches. Of note, these experiences occurred at the backdrop of limited self-management experience as this was during the early stages of chronic pain. Lack of experience in managing chronic pain together with the lack of adequate medical intervention left participants feeling helpless.

"I have had a lot of bad experiences with my doctors, they were dismissive at first and would go like there is nothing wrong with you". (Jack)

"They just don't realise, if all doctors could get fibromyalgia for a week and see how it feels, they would definitely change their tune". (Amy)

The helplessness experienced by participants due to lack of empathy and dismissal left them feeling neglected, undervalued, vulnerable and misunderstood. Within this context, the availability of codeine-based analgesics without the need of a prescription, provided a viable option to alleviate the debilitating effects of pain. Jack's experience highlights how, the burden of pain and lack of understanding of the impact by his GP led to elevated self-medicating with the most effective medication that he had access to.

"My doctor was like, just watch it and keep an eye on it, and then eventually what actually happened was the pain was in my back one day and it had kind of, it was moving down into my legs and it was going on for a few days. I was nearly crying with the pain it was

really, really bad. So, I would use a lot more codeine painkillers than I use now at the very start. It would have been a few times a week and nearly every day at one point which I was against, but I was in so much pain and because it was quite an adjustment and thinking yeah, I didn't know what else to do". (Jack)

Jack's experiences capture the helplessness experienced by participants as they transitioned from acute pain to chronic pain. The occurrence of these experiences over a prolonged period of time were detrimental to the development of adaptive coping strategies as participants were focused on symptomatic relief with no adequate support. For participants there was a need to exert control over the situation but with limited feasible options. Elevated self-medicating was the only perceived viable pharmacological option during this phase.

On another level, lack of empathy due to not acknowledging the debilitating impact of chronic pain compromised the doctor-patient relationship which is crucial in the ongoing provision of care through primary care services and the co-ordination of secondary care services where required. Peter and Joanne's accounts highlight their experiences and the resulting compromised relationship between participants and GPs following interactions in chronic pain management.

"I mean yeah just some good doctors would help. I think doctors who take an interest or who are just sympathetic or that care for you like. You kind of want to be looked at as just a human being and not just another patient kind of like, they are not stocking the shelves in a supermarket like, It would be good if you're dealt with by someone who is gonna care and take a minute to help you. There's quite a lack of that unfortunately I feel like there is not really much point in having a service at all if you're not really gonna actually help the people who are coming through that system, I just use (OTC) codeine, that's just yeah what I have to do". (Peter)

"My own GPs are just horrendous like you know they are no help at all. I don't like them, and they don't like me". (Joanne)

Trust and confidence are important to the doctor-patient relationship and crucial to the provision of continuous care. Only Jack reported continuous engagement with his GP for pain management. For some participants these experiences had led to disengaging from GPs. Helen, Peter, Darren, and Katie had disengaged from their GPs whilst Amy, Louise, Joanne and Edel solely relied on themselves and secondary care in managing chronic pain.

"To be honest I don't really go to my GP for pain anymore, like what is the point? I have just learnt to deal with things myself". (Peter)

"I don't really go to my GP for my fibromyalgia and arthritis, I don't think there is anything he can do for me, don't get me wrong like I still go for minor things like chest infections and all that but for my pain I just go to the consultants even though I only see them twice a year". (Amy)

Participants' experiences suggest an uncaring attitude and lack of empathy in pain management leading to lack of trust and confidence in doctor-patient relationships. GPs tended to adopt a risk mitigation approach in their interactions due to the issues surrounding opioid addiction (McDonnell, 2021). Where opioid misuse was identified or suspected, GPs typically refused to prescribe or prescribed minimal amounts of opioid-based analgesics. Typically, therapies like physical treatments and behavioural treatments should be recommended first and prescription opioid-based analgesics are the next step in prescribing guidelines once OTC analgesics are ineffective (Dowell et al., 2022). Based on participants' accounts, physical and behavioural treatments were not provided as alternative options of managing chronic pain in their interactions. GPs tended to minimise opioid prescribing without providing alternatives or the recommended support.

"They will not just prescribe any prescription medication for pain for me, so I just do what I have to, use OTC codeine". (Katy)

Minimal prescribing and refusal to prescribe opioid-based analgesics without providing viable alternatives suggests a limitation within the medical system in providing adequate care that does not leave individuals living with chronic pain with limited options to effectively manage pain. The approach adopted by GPs occur at the backdrop of lack of alternative supports in effectively managing chronic pain and opioid misuse. Despite some participants being suspected of opioid misuse by GPs and refused opioid prescriptions, during the interviews none reported being referred to addiction services for opioid withdrawal. The system in which GPs operate whereby minimal or refusal to prescribe approaches are adopted when misuse is suspected, left participants helpless and vulnerable to the burden of chronic pain and in some cases opioid withdrawal symptoms if OTC codeine was ceased. Self-medicating with OTC codeine-based analgesics provided a viable option within this context.

"I have just been dealing with it, the doctor won't give me anything for using all the time he's like I will give you painkillers to use for a week if it comes back take paracetamol and come back if it gets worse". (Darren)

"If I go to the doctor, I don't know if there is anything they can do, so I kind of just manage it myself with over-the-counter codeine. Sometimes they may give you some medication, the last time I went the doctor gave me paracetamol and ibuprofen which is just like taking Smarties". (Peter)

As well as interactions with medical professionals not yielding expected results, timely access to services was problematic due to long waiting lists for interventions.

“There are always waiting lists for everything, even if you go in with your health insurance, I have been on a list for an operation for more than a year and I still haven’t heard from them”. (Louise)

“The problem is you are in pain, and you have to wait like nearly 2 years to see a specialist, then you go there, and they want to do a procedure but there is no theatre space so he couldn't do it and on and on it goes, the operation was eventually done closer to 3 years from the time I was referred”. (Edel)

“Because the waiting list to see a consultant is up to a year. The appointment I had got originally was for more than a year, but I got so debilitated during the summer”. (Amy)

The delay of specific interventions to alleviate pain has the potential to influence maladaptive coping strategies as during this time the burden of pain remains present but with limited resources to manage it effectively. All participants reported that GPs were reluctant to prescribe strong painkillers for long-term use leaving participants with OTC codeine-based analgesics as the only option other than paracetamol, ibuprofen, and aspirin. Whilst waiting for interventions, reduction of pain employing OTC analgesics was the only viable pharmacological option that participants believed could alleviate pain. Consequently, they developed self-management strategies that later shaped continuous self-medicating habits. These early self-management strategies were typically based on acute pain management approaches that are maladaptive to coping with chronic pain and harmful in the longer term. The unpredictability of the pain experienced and the ambiguity concerning the cause of the pain did not inspire adaptative coping strategies when there was no diagnosis. Self-medicating with codeine provided the best pharmacological option to exert some control over the situation within this context.

"OK yeah it was just codeine painkillers at that time and then just more and more pain over the years going back and forth with the doctor, getting hospital appointments trying to figure out what was wrong. So, I then I finally got diagnosed with fibromyalgia when I was 18". (Peter)

"So, I would use a lot more codeine painkillers than I do now at the very start. It would have been a few times a week and nearly every day at one point which I was against, but I was in so much pain". (Jack)

As highlighted by Peter and Jack's experiences, experiencing delays in health interventions are risk factors for misusing OTC codeine. Adverse effects of prolonged use of codeine were known but the need to alleviate pain had more precedence. The immediacy of relieving pain overrode the need to avoid misusing codeine which at this stage was providing the only option to alleviate symptoms. Prolonged persistence of pain without a diagnosis and the necessary interventions mediated this outcome.

In addition to delays in accessing medical interventions, multidisciplinary services in managing chronic pain were unavailable. Amy, Louise, Joanne and Edel were under the care of specialists but there were no multi-disciplinary approaches in the way care was delivered. This meant that despite affording private healthcare, their experiences in health services were characterised by gaps and lack of alternative therapies resulting in missed opportunities to receive comprehensive care.

"I am going to see the specialist orthopaedic surgeon in another hospital now. I have the neurologist, urologist and the orthopaedic surgeon. I see the neurologist in xxxx hospital, urologist in another, I am all over the place". (Joanne)

"I suppose the consultants are quick in prescribing meds. I suppose they don't mention alternatives. I think it would be great if they work in unison with some of the holistic

places and the alternatives. It's all chemicals and chemicals. It would be good having a dietician within a clinic to talk to as weight would affect the pain you are managing. I did raise this issue with the consultant about my weight and what the consultant told me was your weight would not have much significance to your condition seeing as rheumatoid arthritis is an auto immune disease. So, when I actually lost the four stone of weight off me, I actually found that my pain improved". (Louise)

"'It's not that there aren't people to help you, if you go for a specific thing for example, I can see the OT if I say I need a splint for my hand for swimming which is something I asked for in the beginning. I suppose I could ask to get a referral to a pain management clinic or pain management specialist so it's something that should run alongside rheumatoid arthritis treatment as well because I think when you function, they don't realise how much pain you live with". (Amy)

Within the healthcare system, the patient must assume the role of central worker in the coordination of health services required for their care. There is need for strong advocacy skills to ensure patients receive comprehensive care. Their level of health literacy and the ability to ask for specific services are determinants of the level of service and support a patient receives. Amy, Louise, Joanne and Edel reported limited involvement with GPs once they were under specialist care meaning coordination of care was mainly left to them if they required access to other services. None of the participants reported consistent involvement of other allied health professionals in the management of pain. This suggests a limitation within the health system in providing adequate support that met the needs of participants.

Despite the differences in how participants accessed healthcare services, their experiences highlight how they all had feelings of being disregarded albeit at different levels and from different perspectives. For Helen, Katie, and Darren, financial barriers in accessing care shaped their experiences and had no access to meaningful care leaving them feeling disregarded. For Amy, Louise, Peter, Joanne, Jack and Edel, despite being able to access medical interventions through private health insurance or on the public system, they also felt disregarded due to lack of empathy in interactions with healthcare providers, inadequate support, untimely interventions, and unavailability of multidisciplinary approaches in their treatment within health service provision. The lack of meaningful services due to financial barriers, limited availability of adequate services, and unsuccessful treatment efforts necessitated the development of self-management strategies to deal with the burden of chronic pain for all participants. Overall, self-medicating with OTC codeine-based analgesics provided an attainable opportunity to "just manage" chronic pain for all participants. However, each participant had distinctive self-management approaches in how they dealt with the symptoms, treatment, physical, psychological, and social consequences of living with chronic pain. These distinctive self-management approaches and their influence on self-medicating habits are highlighted in two case histories in the within cases findings presented in Section 3 of this chapter.

Similar experiences of feeling disregarded were also reported in the interactions between participants and community pharmacies. In the management of pain, pharmacists have a crucial role in advising on self-medicating, provision of OTC analgesics and advising on non-pharmacological alternatives (Cooper, 2013). However, as highlighted by Peter, there was lack of care, empathy, and consideration in interactions with pharmacies.

"Imagine if a pharmacist kind of cared more than a GP, it would be nice yeah, any caring from anywhere would be nice. It's just that there is there's such a stigma around it now like with pain medication and I hate that because I feel like I'm just doing what I need to do sometimes to survive and like just live my life and try and enjoy it, but it's kind of when you go in you are made to feel like this is like such a bad thing that you shouldn't do and it's

horrible to kind of feel like maybe guilt or shame sometimes like when you're already suffering in that way I don't know ". (Peter)

Ideally, relationships between pharmacists and patients should be characterised by care, trust and understanding. However, issues around codeine sales shape the interactions between pharmacies and patients in chronic pain management. The occurrence of this lack of expected care from pharmacy professionals as well as receiving similar treatment by GPs highlight how participants felt disregarded in their chronic pain journey within different aspects of care provision. Being disregarded by both GPs and pharmacy professionals who constitute primary care services and should provide first contact, accessible, comprehensive, continuous, and co-ordinated person-focused care demonstrates how participants were alone in their efforts to manage chronic pain. The introduction and implementation of codeine regulations had led to the unintended consequence that pharmacies had now also adopted a risk mitigation approach similar to GPs sometimes instead of a caring, understanding and trustworthy approach.

"They literally make you feel like a junkie, excuse my language, but it is really upsetting like it really gets me down because the thing that gets to me about the codeine thing in the chemist like there is 8mg of codeine and you are there thinking do you have any idea if they saw my MRI they will be going like you should be on morphine or something and its difficult". (Joanne)

"It's like the Spanish inquisition when you go in there. When you go and ask for them, they ask you questions and questions but if it's for paracetamol they don't even ask me who they are for but for codeine they do it all the time". (Helen)

"Sometimes I feel that it is an inexperienced person or young one who works behind the counter who probably don't know much about codeine and is just repeating what she thinks she has to say, and I think I could probably write an essay on pain relief". (Amy)

These experiences demonstrate the conflicting priorities between pharmacies and participants. Codeine regulations implementation in pharmacies was central to these conflicting priorities. Being subjected to questioning each time participants went to buy codeine-based analgesics was frustrating, upsetting and demeaning for participants. Participants felt like pharmacy professionals diminished their suffering and overlooked the experience and knowledge participants had of managing chronic pain. They felt judged and mistrusted and this created an environment that did not depict care and was not conducive to meaningful interactions. From the participant's perspective, symptomatic relief was the sought-after outcome with codeine-based analgesics which are the strongest available analgesics that pharmacies can provide without a prescription. From the pharmacy's perspective, interactions were informed by the need to implement codeine regulations, mitigate risk, and fulfil their role as gatekeepers. Consequently, effective provision of care in chronic pain management was difficult to achieve within this context due to guidelines that seem to be too rigid to allow meaningful interactions. Therefore, communication between pharmacies and participants did not develop naturally, and this limited deep exploration of other issues associated with chronic pain management.

"If advice was offered like not forced or anything like oh you must sit down, you must answer these questions before I sell it to you kind of thing maybe if it was offered like I would be open to it". (Peter)

"You just stand there in front of everyone like a schoolboy, trying to justify yourself and its normally to a young one, that is not right". (Darren)

Within this context, participants felt there was no need for prolonged interactions and went prepared to steer discourse in a manner that was satisfactory and convincing to the pharmacy staff. The main goal was to get a supply of codeine-based analgesics without getting involved in prolonged explanations.

"They would ask who it is for, then I would explain. What it is for then they would explain and say its fine and you know they tell you about the addictive nature of codeine, it's up to 3 days and if you are still in pain go to your doctor. I mean once you tell them what they want to hear and there are so many pharmacies if you really want it you know yourself you can go to a different pharmacy every time". (Louise)

"Well, you tell them what they want to hear, and I move around a lot with my job so I just buy them where I am working at the time". (Darren)

The differing goals between pharmacy professionals and participants are evident in the accounts of participants. The sought-after outcome for each party during these interactions is somewhat achieved despite the different approaches. Within this context, participants felt justified to circumvent the regulations through adjusting their narratives and pharmacy hopping in order to purchase codeine-based analgesics. In essence, the regulations do not achieve the intended purpose of curtailing misuse but have indeed fostered tension-filled and untrustworthy relationships between pharmacies and patients in chronic pain management.

"I know that pharmacists say that but like you can go to different places it depends on the pharmacist as well you know like one pharmacist might think this is your first box of codeine whereas you might have been using them for 6-months". (Amy)

Disengagement with Irish pharmacies in chronic pain management was reported by Amy and Peter. In consideration of the feelings of frustration and upset evoked by interactions in Irish pharmacies and being judged, mistrusted, dismissed, and diminished, participants actively sought easier alternatives in buying codeine-based analgesics. These were problem-solving approaches to reduce interactions with Irish pharmacies.

"I do buy in Spain, but I think they are copping onto that because I know some people have now been refused. In the past I have gone to the States I have bought a tub of whatever you know their kind of standard painkiller and the last time I went to England I bought some codeine which is even stronger than what we have here". (Amy)

"I now use much stronger codeine tablets than what you find here. So, I go up North and I buy it up there because it's so much stronger and cheaper it's like a tenth of the price of what it costs here so I just buy it up there and come back it's much easier that way there is no hassle up there". (Peter)

Contrarily, participants perceived pharmacies as reliable sources of information and advice in non-codeine related interactions. In the absence of pharmacy staff needing to exert the gatekeeping role that is required in the implementation of codeine regulations, participants demonstrated willingness to engage with pharmacy staff.

"I do trust my pharmacist and they can be quite helpful. Like say if I go in with a cough, they are quite helpful actually in explaining how to manage and what to watch out for so yes once you are not asking for the codeine its fine". (Jack)

"One of the pharmacists there has really taken an interest in my condition and has read and compiled quite a lot of information. When I go in, he ensures I don't take anything that can interact with my medication and always checks up on how I am doing". (Edel)

Contrary, to over-the-counter codeine interactions, a sense of trust can be evidenced once the conflict of purchasing codeine-based analgesics is removed. Without the barrier of codeine regulations, interactions were characterised by care, understanding and trust. These experiences indicate the effectiveness of pharmacies within primary care in providing health advice to patients to manage diseases. However, in the case of chronic pain management, this is not the case. This dichotomy originates from the fact that participants felt that they were disregarded and therefore there was no caring on the part of the pharmacies. In addition, participants had become experts in managing chronic pain albeit with some maladaptive coping strategies and were aware of what is available in pharmacy. They typically went in to purchase rather than to seek advice. The existence of codeine regulation protocols enforced unwanted interactions and participants resented these resulting in tensions with pharmacy staff. Past experiences with interactions over codeine-based analgesics did not encourage further exploration of other alternatives in chronic pain management. Past experiences in managing pain, the burden of pain and the associated demands contributed to shaping behaviour in self-medicating habits.

Being disregarded by both GPs and pharmacy professionals who constitute primary care services and should provide first contact, accessible, comprehensive, continuous, and co-ordinated person-focused care demonstrates how participants were alone in their efforts to manage chronic pain. Throughout the study, participants felt disregarded at different levels and perspectives depending on environmental, social, and individual factors. The next section presents the trajectories that capture change/continuity in participants feeling disregarded. They represent events, actions and interactions that were linked together to the process of change or continuity in feeling disregarded and how that impacted the positioning of participants on the continuum of codeine use.

5.4.2.1. Trajectory 1: Continuity in feeling disregarded

Overtime, continuity in feeling disregarded within healthcare systems was evident for all participants but experienced differently. This continuity can be attributed to the interaction between environmental, social, and individual factors such as lack of access to quality healthcare, socio-economic status and differences in the underlying conditions resulting in chronic pain. For Amy, Louise, Jack, Joanne, Peter and Edel, despite having access to GPs and specialist care, their experiences within health service provision remained constant. There were still no multi-disciplinary and holistic approaches to health service delivery within the health systems throughout the study. Affordability was a determinant of access to other alternatives in pain management and efforts to engage with other services were mainly self-led.

"I did look into getting physio but because my consultant doesn't offer it, I was trying to get it on my own and it is so expensive. I would need to go often and paying €60 per session there is no way I could keep up with it. I must say though it worked then when I did a few sessions." (Amy – Timepoint 2)

Amy's experience in trying to enhance her care highlight how participants were continuously failed by the lack of multi-disciplinary services. Despite having private health insurance, health literacy on how to effectively manage chronic pain, co-ordinating her own care and strong advocacy skills, her experiences still demonstrate lack of adequate support highlighting the disregard felt by participants.

Continuity in feeling disregarded can also be attributed to prescribing protocols and lack of non-opioid therapies in the case of GPs and in the case of pharmacies lack of change in codeine supply regulations. For example, despite Joanne's efforts to engage with GPs to get support and therefore changing her GP, the outcome was the same.

"My GP is now refusing to give me more prescription codeine and this is the new GP I changed to after the previous one did the same". (Joanne: Timepoint 4)

Refusal to prescribe without offering the necessary support to manage pain was an experience that consistently left participants feeling they had no option but to rely on OTC codeine-based analgesics. Interactions with pharmacies did not yield any more support beyond attempts to curtail the misuse of OTC codeine. Codeine regulation implementation remained central to interactions with pharmacies throughout the study regardless of the extra burden brought on by COVID-19 restrictions.

"You would think that with Covid and all it will be easier but no no no, you still have to go through the questions but sure what's new?". (Darren Timepoint 3)

"I have been cocooning since this whole thing started and I ring the chemist over the phone to order what I need, and they send it in a taxi. They will still ask you as if you are there which to be honest, I don't see the point". (Amy Timepoint 2)

For Darren, Helen and Katie, the struggle to afford medical interventions continued throughout the research period. Efforts to access health services through the public system were not always successful despite the evident need for medical interventions.

"I am not seeing anyone at the moment, but both the knee and the migraines are getting worse. I can't get a medical card now as I am assessed together with my parents since I still live at home. The painkillers are only working to an extent but looking into the future I need to do something. As I always say, the first thing I'm gonna spend my money on once I start working is go to a doctor so I can have many options of how I can go on". (Helen: Timepoint 4)

For Helen, due to the continuity of being refused the basic human right to pain management, there was a sad acceptance of the situation and she had lost hope that health service approaches to care provision would change. She was resigned to the fact that she was alone in her chronic pain journey and found hope in envisaging how she could resolve the issue on her own in the future. The reduced efficacy of codeine-based analgesics further compounded the problem and brought further worry and uncertainty to what the future held. Similarly, reduced efficacy of OTC codeine-based analgesics was problematic for Darren and had brought uncertainty to his future.

"I really haven't been to the doctor no, I find the codeine takes the edge off but the pain has been constant, and it's getting worse up to a point where I think I might have to stop working but I am self-employed you see and I have always been working so because of that I cannot get a medical card and because I kept on working during Covid I can't apply for the card whereas if I had stopped they would have given it to me but you can't live like that". (Darren – Timepoint 3)

Darren's account highlights the complexity of the challenges associated with barriers to adequate care and maintaining daily activities whist living with the burden of chronic pain. He faced the dilemma of either choosing to forgo his profession in order to have free access to care. Within this context, OTC codeine-based analgesics enabled him to continue in his profession albeit at the detriment of his health without having to make these life-changing decisions. The reduced efficacy of OTC codeine-based analgesics further compounded the challenges leaving him helpless, vulnerable, and fighting to maintain his professional identity despite now experiencing the adverse effects of codeine.

"I know I shouldn't be doing it; I know my stomach is in bits because of them but sure what else can I do?" (Darren Timepoint 2)

"I do try not to take many you know, like there was a time when I did overdo it and I was getting these migraines if I didn't take them, and I knew myself that this was not good". (Helen – Timepoint 3)

The impact of this social injustice inherent within the healthcare system is such that the entry point to care is a considerable barrier due to associated financial costs. This inadvertently led to helplessness and within this context elevated self-medicating with codeine-based analgesics allowed participants to “just manage” by bridging the gap but left participants vulnerable to adverse effects.

Within this trajectory of continuity in feeling disregarded, the positioning of participants on the continuum of codeine use was influenced by interactions between environmental, social, and individual factors. Health disparities and compromised quality of care, the existence and implementation of analgesic prescribing protocols and codeine supply regulations without adequate alternative physical and behavioural treatments represented environmental factors whilst affordability based on socio-economic status represented social factors and frequency and persistence of pain specific to each participant represented individual factors. These three factors were linked and interacted together overtime to represent the process that influenced continuity in self-medicating with codeine-based analgesics within this trajectory.

5.4.2.2. Trajectory 2: Increases in feeling disregarded

Increases in feeling disregarded within healthcare systems was evident overtime for participants who had ongoing access to care; Amy, Louise, Joanne, Jack and Edel. Despite the ongoing challenges already evident in receiving timely access to care at timepoint 1, over the remaining duration of the study this worsened to the point of having no access to medical interventions or receiving unsatisfactory alternative modes of service delivery where possible. This change was influenced by complex environmental factors brought on by the COVID-19 pandemic. The restrictions associated with the pandemic and the facilitation of social distancing guidelines caused significant issues in health service delivery. Non-urgent appointments were cancelled or postponed, and COVID-19 related illnesses and urgent care were prioritised. The postponement or cancelation of appointments was further exacerbated by the impact of COVID-19 to healthcare staffing levels (McAuliffe et al., 2022). As a result, the care participants received throughout the pandemic was at best limited and in some cases postponed.

"So, my next appointment was supposed to be in August to get a guided injection, that was changed to November and then they could not see me still. I have rung to see if I can get another guided injection, but I don't know when that will happen, and my knee is not great at the moment". (Amy – Timepoint 3)

"Some parts have gotten worse like my left hand is really bad, like one of my fingers is slipping in and out of joint so it's quite painful. The consultants have been ringing me and sending prescriptions if I need them, but it is not the same and they don't give you the strong painkillers for use all the time. So, I have to rely on over the counter. I know I am way overdue for an operation for my foot but what else can you do? At least I am still alive". (Louise – Timepoint 3)

"So, it's now two years since I last saw my consultant". (Edel – Timepoint 4)

Despite the unintentionality of this further disregard, the burden of chronic pain remained throughout the pandemic and complex interactions between social and psychological issues such as isolation, internalisation of the negative COVID-19 societal narratives and perceptions further exacerbated the general wellbeing of participants. Coping with chronic pain within this context was challenging as highlighted by Amy and Joanne.

"I got in the habit of listening to all the figures of the people who had it, those who died, and I would be doing this at the end of the day. I was just so afraid that if I got it that

would be the end of me. I just watched too much stuff around COVID-19, and I would have had a little bit of anxiety and that was affecting my sleep and with Fibromyalgia if you don't rest well it's just difficult to go through the day". (Amy -Timepoint 3)

"I haven't been doing well with the pandemic and all and worrying about my mum, not being able to get anything done at the hospital. I have just been taking codeine all the time and I don't know what is worse now the pain or the side effects". (Joanne – Timepoint 4)

Due to the longevity of the pandemic and associated restrictions, reduced care, the persistent nature of chronic pain and the psychological impact, participants struggled to cope, and this influenced self-medicating for some participants. For example, Edel who up to Timepoint 3 had always managed to self-medicate within recommended levels of codeine despite constantly experiencing persistent pain reported elevated consumption of codeine.

"I have not been to my consultant for years now. I am not one for taking pain medication especially with the risk of addiction, but it has been so difficult, and I have no choice but to keep taking the codeine. It has been so difficult for me knowing the side effects of codeine and having worked in addiction services to comprehend that I have had to take codeine daily". (Edel -Timepoint 4)

Edel's account captures the helplessness experienced due to limited medical interventions and the resulting change to self-medicating habits. Within this trajectory of being further disregarded by healthcare systems, the positioning of participants on the continuum of codeine use was influenced by an interaction of the following environmental, social, and individual factors. The restrictions associated with COVID-19 and associated restrictions and compromised quality of care represented environmental factors whilst limited social interactions due to COVID-19 restrictions represented social factors and frequency and persistence of pain specific to each participant and psychological states due to the impact of

COVID-19 represented individual factors. These specific factors were linked and interacted together overtime to represent the process that influenced self-medicating with codeine-based analgesics within this trajectory.

5.4.3 Theme 2: Feelings of being misunderstood

This emblematic theme captures lived experiences of participants within their social, familial, and other settings. Throughout the study, all participants felt that the suffering they went through was misunderstood except by those with lived experience of chronic pain. This subsequently impacted the support provided within these settings. Lived experiences of participants were characterised by not being listened to, lack of empathy and unrealistic expectations. Participants lived and managed chronic pain within these settings and had to deal with the physiological, psychological, and social impacts within these environments. Even though brief, this emblematic theme provides contextual insights into the environment in which self-management approaches in managing pain had developed and were maintained overtime.

Feelings of being misunderstood were a common experience identified in participants' experiences with friends and family. Participants felt like their suffering was minimised due to lack of understanding. Within social and family circles participants' accounts highlighted limited understandings of the impacts of living with chronic pain and how this was reflected in ongoing interactions.

"I think they don't get it. I think it's difficult for them, I don't know. There is just something about it like, they don't know how it feels and when its closer to home it's harder to accept, you know?". (Peter)

"My family are all quite good and most of them don't really like they don't talk about this because they don't really know". (Jack)

Lack of understanding within familial circles left participants with limited emotional support to manage the psychological impact of pain. Participants' accounts demonstrate how they went through the chronic pain journey alone especially in consideration of the lack of formal emotional support within health service provision. Combined with the lack of understanding within formal and informal systems around participants resulted in participants "just managing" and coping on their own.

"I think an acknowledgement from other people would make a difference". (Amy)

"Like to be honest I don't complain that much because if I did, I just would be complaining all the time and that's exhausting for me and for everybody else so yeah just kind of get on with this really yeah". (Peter)

Despite the lack of understanding, there were no efforts made to inform and educate peers and family of what they were going through.

"I suppose I could talk to my family, but they have their own problems as well who doesn't? I think with friends you don't want to be known as the one who is always moaning, people get fed up listening to you". (Louise)

"You have to be careful with friends as well you don't want to become the friend that they don't want to meet because you're always whingeing about your pain or going on about yourself. You don't need to talk about it you know, we talk about lots of other things". (Amy)

Concerns around being a burden were instrumental to not discussing their experiences with friends and family. Only acute episodes warranted seeking for help and sharing some of their experiences. From this perspective, families and friends provided functional support, but once acute phases passed this ceased as well and participants would not highlight their ongoing suffering. Of note is these experiences occurred at the backdrop of reduced social interactions due to chronic pain-related reduction in activity.

"I would often have to cancel things and sometimes at the last minute and sometimes making people mad and then really trying to get people to understand because you look fine and then you suddenly say I can't do this". (Amy)

"The thing is you look fine and even if like friends at work organize a walk and I really want to do it and it's 2K and so often I go like well I'm just going to go through it and usually in the end something goes wrong. It's just frustrating that stuff that I want to do and I can't. Like a cousin of mine had show tickets and I thought great I get to go to that and it was in summer and I thought OK we're going to have to travel on the Luas and then we have to walk and we're going to be standing and I just thought I can't do this and I just had to say I'm really sorry I can't go so I kind of have to know in advance even more mundane stuff like shopping". (Edel)

Efforts to engage in activities were problematic within this context. The incongruency between physical limitations and appearance was also problematic and left participants in difficult situations in their efforts to maintain social roles. Chronic pain invisibility was central to friends and families not understanding the impact of living with chronic pain and associated withdrawal from activities.

"I think they will understand but it's not something I try and talk about a little bit not too much. I tell people so that they know but they probably can see any way if I'm using my stick. I just let them know what I have". (Amy)

"I met my aunt when I had my walking stick and since then she now does ask how I am whenever we meet". (Jack)

An external signifier of the pain experienced lends credibility in social and familial circles. Through different experiences, participants were made to feel as if they had to provide proof that they were in constant pain. The experiences of participants highlight the challenges within the environments in which they lived in and managed chronic pain. In addition to the suffering, participants felt they had to justify the credibility of their experiences to others. They had to deal with the negative emotional reactions from friends and family evoked by their inability to participate due to the physiological limitations associated with chronic pain. Participants had to manage unrealistic expectations within the environments they lived in and the reality of living with chronic pain had far more reaching consequences for some participants.

"Sometimes I feel like my husband just thinks I am lazy". (Edel)

"It definitely contributed to the breakdown of my marriage because for a long time he did everything for me and at some stage I was even in a wheelchair. We couldn't do normal things as a family; we couldn't go for outings you know even when my daughter was young". (Louise)

"It costed me my marriage, with all these issues happening things just didn't work out". (Joanne).

This overview captures insights into the environment in which self-management approaches in managing pain had developed and were maintained overtime. The experiences of participants signify how the suffering went beyond living with constant pain. Participants had to contend with the resulting further consequences of living with chronic pain in all other aspects of their life. In addition to chronic pain being a disrupter to valued activities, it was also a disruptor to life trajectories and transitions. Maintaining normality and continuity within these environments that lacked understanding subsequently resulted in limited support and was influential to self-medicating. The next section presents one trajectory that captures the continuity of these experiences within familial and social settings.

5.4.3.1 Trajectory 1: Continuity in feelings of being misunderstood

Throughout the study, experiences of being misunderstood were consistent for all participants within familial and social circles. The absence of change within these settings depicted ongoing difficult experiences that participants had to contend with as well as live with the physical burden of chronic pain. At all timepoints, this is something participants did not delve into much in their accounts as there was an acceptance of knowing they could not change this. There was an unease acceptance of the situation and participants forged relationships and were careful not to become a burden. Emotional support was therefore limited and combined with the lack of multidisciplinary services that include formal emotional support, coping with the psychological impact of living with chronic pain was a constant challenge.

“Especially now with Covid and all that, people have their own concerns but what they do not realise is as well as the pandemic, I still have to live with pain every day. You just have to get on with it really”. (Louise: Timepoint 3)

“You know they probably can’t remember a time when I had no pain so of course they don’t even ask about that aspect of my life. Don’t get me wrong it’s not like they don’t care but I think they sometimes forget that for me this is a day-to-day thing”. (Peter: Timepoint 2)

Within this trajectory, social factors interacted with individual factors in developing and maintaining self-medicating habits within settings that were characterised with lack of understanding. Social factors include limited understanding in familial and social circles resulting in limited support. Whilst individual factors include the underlying condition causing chronic pain, frequency and intensity of pain and the amount of support required. Interactions between the two factors represent the process that occurred to maintain continuous and, in some cases, elevated self-medicating with OTC codeine-based analgesics.

5.4.4 Theme 3: OTC codeine is my enabler

This emblematic theme captures lived experiences of how OTC codeine is an enabler for participants to maintain some sense of normality and continuity despite living with the burden of chronic pain, being disregarded within healthcare systems, and feeling like no one understood their suffering within familial, social, and professional settings. OTC codeine-based analgesics enabled participants to participate in valued activities and maintain role identities. Within this theme, self-medicating represented a self-management approach of "just managing" pain which enabled participants to deal with the physical, psychological, and social consequences of living with chronic pain.

The challenges highlighted in accessing health services and managing chronic pain left participants vulnerable as they had to deal with the burden of pain without adequate supports. Participants actively engaged with problem solving to mitigate the burden of chronic pain. However, day to day decision making differed depending on different responses to environmental, social, and individual factors. Participants' experiences of living with chronic pain demonstrated the disruptive nature of pain to daily living and participation in valued activities as highlighted by Amy and Peter.

"Pain is exhausting you know, makes you feel tired, makes you feel miserable, makes you feel a bit down sometimes, it is irritating because it keeps you awake and disturbs your sleep like I go to sleep on one shoulder an hour later I wake up because my shoulder is

hurting and sometimes I wake up fully and it takes me time to go back to sleep. It has impacted my ability to travel. Fibromyalgia pain is kind of like a sleep pain cycle, so you don't go into that nice deep sleep and then it affects your pain level so the less you sleep the more pain you are in, so it impacts me every day". (Amy)

"It's excruciating, it's hard to be in this much pain, like when you think about it it's like a torture technique or something". (Peter)

The debilitating impact of chronic pain to daily living is evident in Peter and Amy's accounts. It had a negative physiological, psychological, and social impact leaving participants with limitations in all aspects of daily living. Participants actively engaged with problem solving approaches to mitigate the burden of chronic pain. Within this context, participants had to consistently make daily decisions to somewhat achieve symptomatic relief so they could take part in day-to-day activities.

"*I have to go here, I have to work, I have to get to work so I need to take something, but if you are at home, you don't necessarily have to take something. But between commuting and actually working it has just taken so much out of me I seem to think I spend a lot of my weekend recovering, feeling very tired. Some days when I am in a bad way by the time I get to work I am pretty much done in energy wise". (Amy)*

"I don't like to take time off sick at work. If I have to drag myself in I would do it. I rather take leave rather than sick leave. So, unless if it is something that is really out of my control that I have to be at the hospital or whatever other than that I don't take time off sick just because I'm feeling crap and I cannot work from home. I'm like I'm better off just going in, take painkillers if I have to and go. Sometimes I'm foggy headed in work and I'm probably useless and I know I'm not as productive as I should be but at least I am there". (Edel)

Within these experiences, chronic pain conflicts with competing goals of pursuing valued activities for participants. To counteract this conflict, self-medicating with OTC codeine-based analgesics enabled participants to somewhat achieve their goals albeit with compromised capacity to fulfil these goals. Prioritisation of continuing to work despite experiencing pain daily, motivated participants to engage in problem solving that enabled them to achieve this goal. In addition, as well as conflicting with personal goals, chronic pain threatened to disrupt participants' professional identities and as such the maintenance of these identities was enabled and achieved through self-medicating. The need to meet these goals and maintain role identities informed frequency of use as highlighted by Joanne's account.

"Like I literally do everything, their bags are packed, washing ironed, lunches and dinner made that is my job. I don't mean it like that but when I can't I mean my daughter really helps but again it's not her job but at the same time if my mum is sick I would do it for her. I mean like they are well looked after but it is frustrating for them. On school mornings, I have to get up an hour earlier to make sure I can function before the kids wake up. I have my cup of tea, 3 codeine tablets, a few cigarettes I know I am very bold, but I do it so that I can function". (Joanne)

The value brought on by self-medicating was that it enabled participants to achieve goals and to maintain role identities and as such the distal nature of adverse effects associated with continuous use or overdosing were superseded by the instant enablement and meaning it gave to achieving daily functioning. As demonstrated by participants' accounts, maintaining an identity as a mum or a healthcare professional in the case of Amy and achieving associated activities was important and prioritised. Within this perspective, self-medicating provided an effective and enabling solution in maintaining valued activities and role identities. This enablement brought on by self-medicating with OTC-codeine based analgesics was of great value to participants as it occurred at the backdrop of previous unsuccessful experiences in efforts to seek for more effective ongoing pharmacological treatments.

"I have just been dealing with it, the doctor won't give me anything for using all the time he's like I will give you strong painkillers to use for a week if it comes back take paracetamol and come back if it gets worse". (Joanne)

"I just use OTC codeine, that's just yeah what do I have to do, I can't get a prescription for them or anything and because they won't give that out you know. It's like I'm afraid to ask at this point. I don't ask for anything anymore from doctors I just kind of deal with things myself". (Peter)

"I don't always have prescription medication. I will have to ask my doctor and talk to him about specific pain. They don't generally give you an ongoing prescription for opioids or something I suppose unless if you really need it". (Amy)

Limited access to prescription medication left participants vulnerable to experiencing more elevated pain with limited opportunities and options to achieve symptomatic control. Past experiences around the reduced efficacy of other OTC analgesics informed the choice of medication in self-medicating decisions. Access to codeine-based analgesics afforded participants to achieve a meaningful life despite the burden of chronic pain. For participants, cessation or reduced self-medicating with the strongest analgesic available to them would mean having to contend with the disruption to life trajectories, role identities and functioning associated with chronic pain.

"I did use paracetamol in the beginning, but it just stopped working so codeine-based medication really is the only thing I can take". (Joanne)

"I don't find anything like that helpful like paracetamol or ibuprofen it's kinda just like taking smarties or tik tacs". (Peter)

Despite participants’ experiences indicating OTC codeine-based analgesics as an enabler they reported reduced efficacy in achieving symptomatic control overtime. However, participants felt they had no other options and were “just managing” chronic pain in the best way possible. All participants demonstrated an awareness of the adverse effects associated with elevated self-medicating. However, the debilitating effects of chronic pain, the need to exert control over pain, lack of viable options and counteracting the disruptiveness of chronic pain led to self-medicating with OTC codeine-based analgesics. The risks associated with prolonged codeine consumption were considered a worthwhile risk than living in pain. Altering this belief enabled participants to consciously make decisions to misuse codeine-based analgesics without feelings of regret, anxiety, or fear. Participants felt the burden associated with chronic pain and improved quality of life achieved by misusing codeine justified their decisions.

“*Obviously I don't want to be addicted to anything, but it is quite tough, and I wouldn't like any damage to my body, but I think because it's a lifelong pain and the pain can be quite bad with fibromyalgia, I think I'd rather have that addiction than to be in constant pain because it is quite tough. I can tolerate some small amount of pain rather than addiction but I think it depends on the pain levels so if it's quite bad if my pain is really bad as it is some days and some days I think I don't want to take this codeine, I don't want to take this medication but I think I would rather take it and rather have a small percent of damage to the liver than to live in pain. I saw something a few months ago it I don't know if it shortens lifespan or something like that or some kind of damage and I was thinking that's really bad but then I thought would I rather live longer for a year with pain or live a year less of my life and no pain or less pain and I was like you know what I would take the year and be happy. I'm not happy if it causes damage but I will take a bit more of a risk if it means I am in less pain* *because some days the pain is unbearable. Sometimes I can't even do anything so I do think it can be worth taking things to make yourself better". (Jack)*

"You think would I rather live longer with pain or live less with no pain and I'm like you know, I don't mind living less as long as I am happy within that time. I am not happy that I may end up with liver damage, but I will take the risk if it means I am in less pain". (Darren)

These accounts highlight the considerations involved in the decision-making process to continuously self-medicate for symptomatic relief. Participants' deliberations highlighted the dilemma they faced in their efforts to minimise pain interference with everyday life. The lack of adequate support and effective relationships with health-care providers, alternative cognitive and behavioural and therapies to manage pain meant that self-medicating constituted most of their self-management approaches. Within this context, the benefit of symptomatic relief outweighed the risks associated with elevated or continuous codeine consumption. In-order to minimise the risks, participants endeavoured to establish a balance between developing adverse effects and maintaining a meaningful life. The lack of adequate support in health provision meant there was limited shared decision-making with medical professionals and participants embraced the possible consequences associated with their decisions to self-medicate. They felt they were looking after their own interests and striving to make the best out of the situation they found themselves in.

"I feel I don't know I feel quite strongly about it for me anyway, I feel like it's up to me, it is like my life and it's my choice if they won't give them out because of the health risks and stuff I feel like I think I'd rather you know be addicted and have like some kind of quality of life". (Peter)

Minimisation of risks whilst continuously self-medicating with codeine was also evidenced by how participants considered and compared the strength between OTC and prescription codeine. From a comparative and risk minimisation point of view, OTC codeine was considered a safer option demonstrating that participants in their own way were making efforts to mitigate the risks associated with codeine consumption whilst enabling themselves to lead a meaningful life.

"So, if you take two prescription codeine it will be the same as taking 8 over-the-counter codeine, so in terms of sleepiness and everything so I would rarely take prescription codeine. Obviously after my knee replacement I did but if I was feeling rough, my first one of choice would be over-the-counter codeine". (Amy)

"I can honestly say now I don't really want to go down the road of like prescription codeine-based painkillers. I took them before, but I was totally like (clicks fingers) I literally go into a sweat. Prescription codeine is not much good for me but that is the thing that gets to me about the OTC codeine in the chemist like there is only 8mg of codeine and they don't want to sell it to you". (Joanne)

This theme captures how OTC codeine-based analgesics were an enabler in lived chronic pain experiences. It highlights contextual issues embedded in self-medicating decisions and what are the foundational underlying issues in elevated codeine consumption for chronic pain management. The extent to which codeine was required as an enabler to daily living differed depending on environmental, social, and individual factors for each participant. The next section presents the trajectories that capture change/continuity to the extent that participants relied on OTC codeine as an enabler. The trajectories capture and present events, actions and interactions that were linked together overtime to influence the positioning of participants on the continuum of codeine use.

5.4.4.1 Trajectory 1 – Increases in use of codeine as an enabler

For Joanne, Edel and Darren, there was an increase in self-medicating with OTC codeine overtime. This increase can be attributed to the interaction between environmental, social, and individual factors such as inadequate care within the health system, financial barriers, pain intensity and frequency and individual psychological processes. The deterioration of underlying conditions associated with chronic pain overtime was associated with increased pain frequency and intensity resulting in increases in use of codeine as an enabler.

"Since the last time we met things have not really been going well. The pain I have been feeling is excruciating, I feel like this is the most pain I have ever felt, and I am definitely deteriorating, and I presume as time goes on it will only get worse". (Edel -Timepoint 4)

"The arthritis in my hands is worrying me and being a plasterer and all is probably not the best thing I could be doing now but what else can I do"? (Darren – Timepoint 3)

This deterioration and increased pain intensity occurred at the backdrop of reduced access to health services and cancelled medical interventions due to the COVID-19 pandemic. Between the burden of pain, minimal medical interventions, a reluctance from GPs to prescribe opioid-based analgesics for long periods, elevated self-medicating with OTC codeine-based analgesics enabled participants to manage the debilitating effects of pain.

"I was supposed to have an operation to server some of the nerves in my back but that has not happened because of COVID, and I am in absolute agony all the time. I have just been taking codeine and they are now saying I may need on operation because my stomach is destroyed, my legs are swollen due to the salt in the soluble tablets". (Joanne – Timepoint 4)

"I am not one for taking pain medication especially with the risk of addiction, but it has been so difficult, and I have no choice but to keep taking the codeine. It has been so difficult for me knowing the side effects of codeine and having worked in addiction services to comprehend that I have had to take codeine daily". (Edel -Timepoint 4)

"Between the MS and the back pain, I don't even know which is which. It has been getting worse and worse. I don't know but they can do whatever and I am happy to pay anything to get rid of it. It feels like all my nerves are squashed and mangled up and it is unbearable, I just want it gone and gone for good". (Joanne - Timepoint 4)

Within this trajectory, the change identified overtime in self-medicating habits was influenced by an interaction between increased frequency and intensity of pain, minimal or ceased medical interventions due to Covid 19 restrictions and a reluctance from GPs to prescribe opioid-based analgesics for long periods or alternative therapies. These issues were linked and interacted overtime to represent the process that influenced increases in use of codeine as an enabler.

5.4.4.2 Trajectory 2 – Decreases in use of codeine as an enabler

For Jack, there was a gradual decrease in self-medicating with OTC codeine overtime. This decrease can be attributed to the interaction between environmental, individual, psychological, and social factors such as changes brought on by COVID-19, non-pharmacological interventions, lifestyle changes and psychological processes resulting in decreased frequency and intensity of pain overtime.

“It's actually it's improved so I know last time we were talking about the codeine, so I don't really take it much anymore, but the pain has improved a lot now I don't know there's a lot of different things so I'm not sure which one it was yeah”. (Timepoint 2)

Due to environmental changes brought on by COVID-19, Jack’s routine had drastically changed from timepoint 1 as compared to all other timepoints. Prior to the changes brought on by COVID-19, Jack had been struggling coping with daily activities associated with working and attending college. This subsequently was associated with increased pain intensity and frequency as well as fatigue. Within this context, OTC codeine-based analgesics were an enabler for daily activities.

“The commute because it's two hours each way or so. So, it does take up a lot of energy and then even with the tutorials because I could just do them online and I find they take up a lot of energy I am finding I have a lot more energy and then obviously that means then from that I have less pain” (Jack – Timepoint 2)

For Jack, the reduced daily demands due to COVID-19 restrictions and the guidelines surrounding self-isolation had a positive impact on his experiences of living with chronic pain. The changes brought on by the restrictions provided an opportunity for a different lifestyle resulting in different approaches to coping with chronic pain. As well as the more relaxed routine, consistent exercising was associated with less pain frequency and intensity, and this subsequently led to decreased self-medicating with OTC codeine-based analgesics.

“I just, you know, realised that I haven't had like bad pain in a while now I still get it the odd time. With COVID and being at home and all I started to exercise a bit more. I really do like exercising now and I used to not exercise as much because I thought you know that would make my pain worse now, I know that that's not always the case”. (Jack - Timepoint 2)

Reduced pain frequency and intensity were central to Jack decreasing self-medicating with OTC codeine-based analgesics. This desired outcome motivated Jack to incorporate exercising as part of his ongoing pain coping strategy and increased his self-efficacy. This further motivated Jack to explore other self-management strategies in managing chronic pain. As a result, this provided Jack with different options to achieve symptomatic relief.

"I have had the pain this long and because I know it's not going to go away and at the start I thought if I take painkillers, I could get rid of it. I didn't know how else to manage it and also not being busy and as active with college and stuff like that has helped and the further I am in this I am like there is other ways to do this and I have tried the painkillers, I have tried all those things and it hasn't helped so maybe I will finally use exercise and these other things and yeah I am not sure I think genuinely I have had it a bit longer and I have had time to think about it". (Jack - Timepoint 3)

The change that Jack experienced led to chronic pain reinterpretation as his self-management strategies broadened. This reinterpretation was associated with acceptance of the enduring nature of chronic pain and the need to incorporate adaptive coping strategies.

"Now I am like I will see how I get on before I take painkillers I suppose the main way I manage pain now is exercise, heat pads, resting as well and with the pandemic one good thing is because I can work from home is I don't have to commute, standing up or walking around for long so I am not as drained as much and I found that used to flare up my pain". (Jack - Timepoint 4)

Within this trajectory, the decrease in self-medicating was influenced by an interaction between lifestyle changes, active coping resulting in decreased frequency and intensity of pain. Jack also experienced a shift in his psychological perception of chronic pain. For Jack, these factors interacted overtime and represent the process that influenced decreased self-medicating with codeine-based analgesics.

5.4.4.3 Trajectory 3 - Decreases and increases in use of codeine as an enabler

For Amy, Peter, Helen, Louise and Katie, self-medicating decreased and increased overtime. These changes were due to interactions between environmental, individual, and social factors. Some changes were abrupt whilst some were gradual. Changes brought on by COVID-19 measures, had abrupt different effects for each participant. For Amy, Louise and Katie, COVID-19 guidelines facilitated a more relaxed daily routine whereby participants could pace themselves to meet daily demands and rest when required. There were no conflicts between chronic pain and completing daily goals. Self-management strategies reflected the relaxed routine as daily demands were minimised. Within this context, the frequency and intensity of pain did not automatically lead to self-medicating, but participants had opportunities to incorporate alternative behavioural and cognitive coping strategies without the burden of daily demands. Subsequently, this had an impact on self-medicating resulting in a decrease in self-medicating with OTC codeine-based analgesics.

"The one thing I will say though that is because I am at home I can rest when I need to rest, I can stop when I need to stop, I don't have to be hiking around a rucksack, I don't have to be commuting, I don't have to be traveling back and forth from work so I am probably managing differently but yes I have had I don't know maybe I have listened to my body a little bit more". (Amy- Timepoint 2).

"I am now running my business from home, and it is much easier now. Of course, there is more paperwork and all and a lot of Zoom meetings, but the good thing is I am not on my feet. I can sit on the couch, relax in bed and all that". (Louise – Timepoint 2)

However, for Peter and Helen, the restrictions brought on by the pandemic were associated with an increase in self-medicating due to lack of daily structure and different ways of working. For Peter, the lack of structure in daily routines impacted his ability to cope with pain due to fatigue whilst for Helen the change in ways of working further exacerbated chronic pain resulting in elevated self-medicating. OTC codeine-based analgesics enabled daily functioning at a time when participants had limited options due to the restrictions imposed by the pandemic.

"I am way more tired not really sleeping, the pandemic hasn't helped with that I'm trying to get into a routine of getting to sleep early and getting up early to kind of get back into it but it's tough so that's not helping with the pain either. So, I'm just exhausted like a permanent state of exhaustion pretty much". (Peter -Timepoint 2)

"Because of the restrictions a lot of my work is now on my laptop, and I have been getting worse migraines and more often as a result of that, but I just have so much stuff to do on my laptop so I'm on it constantly on the screen till late hours so that's worsening, and I can't change that". (Helen – Timepoint 3)

"I can't seem to stop watching things on my phone or laptop. Once I finish my work I kind of continue and it is not helping" (Helen - Timepoint - 4)

In addition, deterioration as well as flare ups accounted for some of the periods when self-medicating increased for all participants. Of note, these occurred at the backdrop of delays or cessation of medical interventions due to the COVID-19 pandemic.

"I had an acute episode of very bad back pain probably in the middle of August or September like I was in absolute agony". (Amy – Timepoint 3)

"Some parts have gotten worse like my left hand is really bad, like one of my fingers is slipping in and out of joint so it's quite painful. The consultants have been ringing me and

sending prescriptions if I need them, but it is not the same and they don't give you the strong painkillers for use all the time. So, I have to rely on over the counter. I know I am way overdue for an operation for my foot but what else can you do? At least I am still alive". (Louise – Timepoint 3)

Furthermore, in addition to changing routines, deterioration and limited medical interventions causing fluctuations in self-medicating, weather had an impact on pain frequency and intensity as well. Depending on the underlying cause of chronic pain, warm weather tended to ease pain for Amy, Peter and Louise whist cold weather increased pain intensity and frequency. Self-medicating during the different seasons ebbed and flowed mimicking the level of pain intensity and frequency.

"We're in winter now so it always gets worse around then yeah definitely just really badly affected by the cold weather". (Peter – Timepoint 4)

"Now with the weather being nice that's the other thing that really helps me is getting some sun so when the weather is nice, I take my hour in the afternoon. I lie out in the sun, and I find it absolutely great, the sun in my joints is just like, it just helps, it really helps with my pain", (Amy – Timepoint 2)

Decreases and increases in self-medicating within this trajectory can be attributed to responses to environmental factors such as lifestyle changes due to COVID-19 restrictions, limited medical interventions and weather fluctuations. This was associated with increases and decreases depending on their impact on pain frequency and intensity. In addition, individual factors related to biological and psychological factors influenced self-medicating mainly due to the demands inflicted by type of underlying condition and other pain coping strategies employed.

5.4.5 Summary of Section 2

This section brought together findings of the longitudinal analysis across cases. The prominent and consistent flow that influenced self-medicating habits throughout participants' experiences was the through-line: “just managing”. Three emblematic themes: feeling disregarded; feelings of being misunderstood and OTC codeine is my enabler captured lived experiences of participants and the resulting trajectories linked to self-medicating. The next section presents the findings of the longitudinal analysis within cases.

5.5 Findings from longitudinal analysis within cases

5.5.1 Introduction

The findings from the longitudinal analysis across cases presented in the previous section were useful in understanding the experiences of the group of participants and factors that influence self-medicating and choice of medication. This section presents findings from longitudinal analysis within cases that complement the previous findings by capturing and highlighting distinctive experiences in participants' experiences that could not be captured with across cases analysis. The longitudinal analysis within cases provides significant insights of what change happens, how it happens and captures the complexity and nuances in each participant's chronic pain management journey and how they experience, respond and cope with change overtime.

Two case histories were selected based on the richness of the data they provided and their capability to offer greater insights to the emblematic themes identified. Case histories involve a condensation of data using a structured approach that combines cross-sectional and longitudinal analysis (Thomson, 2007; Neale, 2021). The two case histories represent two contrasting approaches to chronic pain management and the resulting self-medicating habits despite both living with CWP. Their trajectories illustrate individual experiences as environmental, social, and individual factors interacted to bring on change or continuity that influenced self-medicating habits. The case histories illustrate the different influencers that can maintain appropriate codeine use or lead to transitioning from appropriate codeine use to misuse in chronic pain management. The approach adopted in selecting the two case histories is similar to other previous LQR studies (Carduff, 2013; Thomson, 2007).

The two case histories are presented below: one depicting Peter's chronic pain journey, a male participant living with fibromyalgia and the second one Amy, a female participant living with fibromyalgia and rheumatoid arthritis. Each case history is structured around the three emblematic themes: 1. Feeling disregarded; 2. Feelings of being misunderstood and 3. OTC codeine is my enabler. They demonstrate the central role of the through-line “just managing” in the experiences of individuals living with chronic pain overtime.

5.5.2 Case History 1: Peter’s chronic pain journey

Peter was aged between 25 and 30 years during the time of the study and lived alone. He was interviewed at three timepoints over the duration of 18 months as he had been so unwell during timepoint 3 interviews. Peter was a mature undergraduate student and volunteered when he could. At the time of the study, he had been living with fibromyalgia for 15 years. Peter had started experiencing pain at the age of 12 and had received a diagnosis after 6 years. He experienced pain and fatigue daily which impacted day to day functioning and was a huge cause of anxiety and anger. Despite living with the debilitating effects of chronic pain for almost 15 years, Peter struggled to make sense of what was happening to him. Living with pain was a daily physical and emotional struggle and it was difficult to maintain a meaningful social life. Peter accessed health services as a public patient and had no private health insurance. At the time of the study, he was not under the care of his GP or any specialists to manage pain. Through an online support group Peter had found a doctor willing to prescribe Low Dose Naltrexone (LDN), an orally active opioid receptor unlicensed medication sometimes used in chronic pain conditions despite the minimum evidence base on its efficacy. Peter managed pain with OTC codeine-based analgesics and efforts to incorporate non-pharmacological approaches to manage pain were inconsistent. OTC codeine-based analgesics were Peter’s preferred choice of OTC analgesics and overtime efficacy had reduced but he had no other viable alternatives to manage chronic pain. Based on past experiences, paracetamol, ibuprofen, and aspirin were not effective in managing pain. Peter valued OTC codeine-based analgesics as an enabler to daily functioning and strongly felt codeine addiction was preferable to the debilitating effects of chronic pain. He felt that he had been failed within the health system and had no other option but to continuously self-medicate with OTC codeine-based analgesics. Peter's chronic pain journey is one of persistent pain, fatigue, anxiety, and helplessness demonstrating the struggle to live with the debilitating effects of chronic pain.

The purpose of this case history is to explore Peter's experiences of living with chronic pain across the three emblematic themes; 1. Feeling disregarded; 2. Feelings of being misunderstood and 3. OTC codeine is my enabler. The importance of the through-line "just managing" in chronic pain management and resulting self-medicating habits will be highlighted throughout.

5.5.2.1 Theme 1: Feeling disregarded

Peter experienced challenges in accessing health services and felt disregarded within the health system and throughout his chronic experience he was "just managing" in the best way he could. Peter's experiences in using health services in chronic pain management had not yielded the support expected resulting in unmet physical and psychological health needs. Initially it had taken 6 years for Peter to receive a diagnosis and at some point, he had been misdiagnosed. Peter had started taking OTC codeine-based analgesics during his childhood years for symptomatic relief without really knowing or understanding the reason he felt so much pain. During this time the main aim would have been to completely eradicate pain, and this shaped his self-medicating habits. The unpredictability of the pain experienced and the ambiguity concerning the cause of the pain had not inspired adaptative coping strategies when there was no diagnosis and appropriate medical intervention for the underlying condition.

"OK yeah it was just codeine painkillers at that time and then just more and more pain over the years going back and forth with the doctor, getting hospital appointments trying to figure out what was wrong. So, I then I finally got diagnosed with fibromyalgia when I was 18". (Peter- Timepoint 1)

Despite finally get a diagnosis, Peter's experiences in seeking medical interventions were overshadowed by the risk mitigation approach on curtailing codeine use adopted by his then GP. During the time leading to a diagnosis Peter had at times been prescribed prescription codeine-based analgesics and his GP overtime became reluctant to keep on prescribing to the point of refusing to prescribe.

"I can't get them on prescription anymore. I just did not get along with my old GP, he wouldn't do anything for me so I don't know but to be honest like I'm afraid to ask at this point. I don't ask for anything anymore from doctors I just kind of deal with things myself because the experience is not great in like yeah with doctors". (Timepoint 1)

These experiences with his GP shaped the relationships Peter had with healthcare professionals. Instead of fostering interactions characterised by shared decision-making, Peter's care experiences left him feeling alone with no confidence in the value of engaging with healthcare professionals in chronic pain management. Refusal to prescribe without providing alternative ways of managing pain was problematic for Peter. Peter's GP had adopted a risk mitigation approach to codeine prescribing in his pain management interactions. This disregard was consistent throughout the study and was influential to Peter's self-medicating habits. Peter had inadequate support and had to rely on himself to "just manage" chronic pain. Despite the refusal to prescribe due to suspected codeine misuse, Peter had not been offered treatment options for codeine dependency or other alternative therapies to manage chronic pain. Peter had previously been prescribed anti-depressants to treat the psychological symptoms he was experiencing without being offered treatments guided by cognitive behavioral principles. The approach adopted was narrow in its focus and therefore was not effective.

“With fibromyalgia you are kind of you're on high alert all the time, your body is in fight or flight mode. I guess it’s the way to describe it so I don't know, anyone who suffers from anxiety would kind of understand like, if you've ever had a panic attack it's like that, but all of the time and my memory is not great either. The worst part of it is the anxiety that comes with it just kind of I don't know it feels it feels ridiculous but sometimes it does just make you so anxious, but I don't know to a point where you are like what is wrong with me you know what's wrong but at the same time you don't it's really hard to wrap your head around sometimes. My GP prescribed an antidepressant for it, I tried a few of those I hated all of them they made everything worse, and I felt like a zombie, so I just you know I just refused that a lot of times. I felt like it was kind of forced upon me a lot of the time like why don’t you just take them”. (Timepoint 1)

The helplessness experienced by Peter due to not being listened to, dismissed, and neglected is clearly evident here leading to Peter “just managing” the debilitating effects of chronic pain and associated psychological impact. This disregard stemmed for the lack of holistic approaches in the interventions Peter was offered. The lack of options and alternative ways of managing the psychological impact of living with chronic pain led to unmet needs for Peter and highlights the contextual issues and the backdrop on which Peter was managing pain from. Peter strongly felt that within the healthcare system there was a disregard of the debilitating effects of living in constant pain. Peter had experiences of not being listened to, ignored, and left on his own to manage chronic pain despite trying to engage with his GP.

Due to this disregard, Peter had and eventually disengaged from his GP and moved to another GP. However, he was afraid of asking for prescription codeine-based analgesics, he only went to the new GP for other minor aliments or infections. This was consistent throughout the study and his feelings of being disregarded within the health system did not change.

"I just don't feel like cared for you know. You go in and they're kind of just like yeah yeah yeah like they're not interested like. I need somebody to take a massive interest in me, in my life like you go there you know looking for answers or solutions and you kind of just feel like they want you in and they want you out again. There is no compassion, you don't really feel like there is help offered. They don't want to listen and kind of anything you say is like brushed off like. I find it just all like condescending and they look at you like you don't know what you're talking about or even if they say Oh yeah, I understand. It's like no you don't, you really don't and you're not trying to understand, you don't understand! I live with this, you don't. The least you can do is take 5 minutes to listen to like how I feel or why I want strong painkillers and kind of even think about what I'm saying like take it on board like you know". (Timepoint 1)

"It's incredibly frustrating because I understand it to an extent why they don't want to prescribe but like prescription codeine is there for a reason and it's for people that are in pain. I am a person in pain therefore you know I need it. I understand you know they're worried about addiction, liver damage but you know at the end of the day it's up to me to look after myself. I'm aware of these things, I decide like when I take it or when I don't take it and I'm a responsible person. Why do they get to decide like no you don't deserve this like who does then you know? I feel it's fine if they're like oh well you know like we want to prolong your life and like great you want to prolong my life so can I have like I want quality of life so yeah like for me I feel like there's no point in having a long life if you are kind of like miserable all the time like being in pain all the time". (Timepoint 1)

Peter's accounts capture the dismissiveness experienced in interactions with health professionals. These experiences left Peter feeling helpless, frustrated, neglected, undervalued, and vulnerable. In addition, Peter felt undermined that he had no voice in the decision-making of his care. The lack of shared decision-making approaches in the interactions with GPs left Peter with no other feasible pharmacological alternatives to manage chronic pain. Peter lived and managed chronic pain within these experiences where the debilitating impact of living with chronic pain was disregarded therefore limiting the support offered. This disregarded emanated from mandatory opioid restrictions in prescribing resulting in GPs positioning themselves as opioid gatekeepers instead of providing care and support in chronic pain management. By taking on the role of opioid gatekeepers, GPs inadvertently avoided treating chronic pain altogether. The lack of alternative therapies further compounded this as they could not refer to other services in a timely manner.

Similarly, Peter's experiences in community pharmacies reflected the same disregard and gatekeeping approaches in pain interactions. Pain management interactions were informed by the need to implement codeine regulations by pharmacists.

"Imagine if a pharmacist kind of cared more than a GP, it would be nice yeah, any caring from anywhere would be nice. It's just that there is there's such a stigma around it now like with pain medication and I hate that because I feel like I'm just doing what I need to do sometimes to survive and like just live my life and try and enjoy it, but it's kind of when you go in you are made to feel like this is like such a bad thing that you shouldn't do and it's horrible to kind of feel like maybe guilt or shame sometimes like when you're already suffering in that way I don't know ". (Timepoint 1)

"It's like the Spanish inquisition there. You know I can't just deal with that anymore. I just go up North as I said before. 1. it's much cheaper, 2. there is not much hassle there and 3. It's even much stronger than the stuff you get here". (Timepoint 4)

The disregard from both GPs and pharmacists was influential to the way Peter disengaged from both services. He was no longer under the care of his GP for chronic pain management and had decided to go to other jurisdictions for OTC codeine-based analgesics supplies. This left Peter with no support in primary care therefore removing first contact point of care and continuous focal point of care within the community. Peter's experiences in his efforts to seek healthcare services were detrimental to adaptive coping strategies and led him to "just managing" pain with the limited resources available to him. The continuity in being disregarded and subsequently no support within primary care and the debilitating effects of living with persistent pain were linked and interacted overtime to present the process that contributed to elevated self-medicating with OTC codeine-based analgesics for Peter.

5.5.2.2 Theme 2: Feelings of being misunderstood

Within professional and familial settings Peter felt misunderstood and his experiences were characterised by unrealistic expectations and lack of acknowledgement of his suffering. Despite these experiences, Peter had to find ways of "just managing" chronic pain and maintain normality in the best possible way he could. Peter's experiences within professional settings indicated unrealistic expectations when he required services. The level of proof required in accessing services was unrealistic and there was no consideration of the challenges involved in seeking that proof. Pain invisibility and lack of external signifiers meant that Peter felt that within his university he was not believed and there was no trust. For Peter, refusal of GP letters as proof of his disability was unrealistic and signified a lack of understanding in consideration of the lack of access to specialist services.

"I'm actually trying to get disability support and I've gotten some of them, they've given me a studies support tutor. But I am having a big problem trying to get approved for funding and I've given them two doctors' letters, but they won't accept, and they want a consultant's letter. I've contacted nearly every hospital I've ever been to, and they have told me that the consultants have retired, or they've never heard of the consultant, or they have my name but no record of me ever attending that department". (Timepoint 2)

"So, it turns out hospitals only keep your medical records for like 7 years or something and my diagnosis is like years ago, so they don't have a record. So, I don't know what's going on and now with all the hacking and everything now that's happening like no one can do anything for me in the hospital. I don't know how I will get funding for my studies". (Timepoint 4)

Peter's experiences highlight the complexity of living with chronic pain within settings that are rigid and do not consider contextual issues in the expectations they have when interacting with individuals with chronic illness. His experiences highlight the reality within the environments Peter lived and managed chronic pain in. Instead of receiving support, additional demands were put on him due to living with chronic pain and Peter felt misunderstood. Similarly, Peter felt that his family did not quite understand his suffering, and this was reflected in the support they provided.

"I think it's difficult for them I don't know there's just something about it like well I don't really know how to explain it like when it's close to home it's like harder to accept. They definitely don't understand the pain I go through, definitely not and like to be honest I don't complain that much that's exhausting for me and for everybody". *(Timepoint 1)*

“*I don't see them as much but when I had the first vaccine mum looked after me which was really nice. Even though we don’t talk about the pain, just to be around people that like you love and care about and which I don't know just make me happy makes it all worth it and not that the pain doesn't matter but it's I don't know less of I don't know just being happier is somewhat of a pain reliever if that makes sense yeah”. (Timepoint 4)*

Despite the lack of direct acknowledgement of the suffering, Peter drew the support of family and focused on the positives of familial relationships in the best way he could. However, this left him coping with the day-to-day realities of managing chronic pain on his own. Of note is for Peter these experiences occurred at the backdrop of reduced access to health services in chronic pain management due to disengaging and reduced social interactions due to social anxiety, pain related reduction in activity and restrictions brought on by the COVID 19 pandemic. Within this context Peter was “just managing” chronic pain on his own and this lack of acknowledgement and support around him was influential to self-medicating. These experiences remained constant throughout the study period and shaped Peter’s experiences of living with and managing chronic pain.

5.5.2.3 Theme 3: OTC codeine is my enabler

Despite the challenges of being disregarded in the health system and being misunderstood within professional and familial settings, Peter actively engaged with problem solving efforts to mitigate the burden of chronic pain. Due to accessing health services publicly and subsequently disengaging with GP and specialist services, Peter had limited formal opportunities and resources in chronic pain management. He was “just managing” on his own and focused on self-medicating to achieve symptomatic relief. Codeine was an enabler for Peter to achieve daily functioning even if it was not completely eradicating pain. This was consistent throughout the study.

"It was not really a tough decision to decide to just look after myself. Like no one was willing to do that, it's all about trying to stop you taking codeine like. I can't get a prescription for them or anything and because they won't they don't like to give that out you kind of get it in a way but at the same time like what am I supposed to do". (Timepoint 2)

I don't ask for anything anymore from doctors I just kind of deal with things myself because experience is not great in like yeah with doctors". (Timepoint 1)

Peter's accounts revealed helplessness to deal with chronic pain after being disregarded within healthcare systems when he tried seeking help. To enable himself to function and bridge the gap left by refusal to prescribe analgesic and lack of interdisciplinary care, Peter relied on self-medicating with OTC codeine-based analgesics. They represented an enabler in a situation where Peter had limited options to manage pain. Peter's efforts were centred on finding ways to eradicate pain and this focus influenced elevated self-medicating behaviours with OTC codeine-based analgesics without consistently engaging with other alternative coping behaviours. The lack of support in both primary and secondary care left Peter vulnerable and to exert control to the situation he sought alternative pharmacological alternatives in the hope of eradicating pain.

"I also just take the LDN yeah, I don't actually get that from my GP. I don't know if it is doing more harm than good like but this doctor is like the only person who prescribes it for this like off label use, he just has an interest in the area so I go to him and he's charging like next to nothing for it, just for the visit because he has to, but he genuinely just cares and he wants to help people and it kind of gives you hope. I suppose he really like talks and treats

you like a human being and sympathizes with you, it's nice for a change I wish more people were like that". (Timepoint 4)

Despite not being sure of how helpful the unlicenced medication was, it had become part of his efforts to exert control over the situation. The doctor who prescribed it had been different in interactions from previous experiences with other healthcare professionals and Peter valued this. He felt listened to, cared for and this gave him a sense of hope. However, in the interviews Peter was reluctant to explore his use of LDN, he felt this is something he just had to do in consideration of his circumstances.

Peter demonstrated an awareness of adaptive coping strategies to help alleviate pain and had positive experiences from engaging with some. However, despite this, these were not prioritised. The perceived difficulty associated with exercising superseded the benefits and he struggled with self-belief, self-ability, and motivation to continue exercising with no adequate external support.

"The great thing about the physiotherapy course I went to is that it gets you going but once you're done you have to keep it up yourself yeah which is hard, you have all these notions like yeah I'm just going to keep going with this and but you know life happens yeah so yeah I have the knowledge of it now so at least I know that at least if I wanted to pick it up again I could do it out myself yeah". (Timepoint 1)

"A friend of mine used to take me swimming and that was good actually like but I haven't gone back to that and actually I bought this bike with good intentions yeah but other than cycle it to bring it home I haven't been on it like. Even cycling it to bring it home was so difficult and painful because I hadn't done it like in years like". (Timepoint 4)

Physical exercising whilst living with fibromyalgia is associated with some level of discomfort. To exercise effectively, Peter needed had to have some level of pain acceptance and self-efficacy in-order to become consistent. Peter described keeping up with exercising as “hard” and highlighted how despite his good intentions he could not consistently exercise. He believed that there was need for him to find medication that would be helpful as this would remove the need to engage with physical activities to manage the condition. Within this context self-medicating was an easier more attainable option that enabled him to “just manage” the debilitating effects of chronic pain.

Inconsistence in engaging with physical exercise was also similar with other coping alternatives. He utilised heat therapy seasonally in the cold winter months. Peter demonstrated an awareness of the benefit of taking supplements however, there was a lack of consistence in his approach in using these supplements.

“When I remember I try to take like magnesium and stuff like that and it's kind of just helps overall. I have a lot of kind of twitches and things like that which is really annoying, so I read the magnesium can help with that but it’s just that I never remember to take it”. (Timepoint 4)

The inconsistence in incorporating non-pharmacological self-management strategies and reduced utilisation of available resources in managing chronic pain contributed to elevated self-medicating habits. For Peter, consumption of OTC codeine-based analgesics was the main and at most times, the only self-management strategy he employed. Peter felt he had no other option but to continuously consume the strongest analgesics available to him which enabled him to problem solve and exert control to relieve the burden of chronic pain.

5.5.3. Summary of Peter's case history

This case history captured Peter's experiences of living with chronic pain across the three emblematic themes; 1. Feeling disregarded; 2. Feelings of being misunderstood and 3. OTC codeine is my enabler. The through-line "just managing" is central to how Peter managed chronic pain and the resulting self-medicating habits. Peter's self-medicating with OTC codeine-based analgesics was elevated overtime in response to environmental, social, and individual factors. He had periods when he would attempt to decrease self-medicating due to adverse side effects and reduced efficacy. Within the period of the study there were changes and continuities that influenced Peter's self-medicating habits. Continuity in 1. refusal to prescribe analgesics, 2. not being offered cognitive-behavioural based alternative therapies and treatments to manage chronic pain, and 3. maladaptive coping strategies contributed to elevated self-medicating habits. Change in pain frequency and intensity due to deterioration of condition overtime also contributed to elevated self-medicating habits with OTC codeine-based analgesics. Overall, the positioning of Peter on the continuum of codeine use was a complex interaction of these continuities and changes in environmental, social, and individual factors.

5.5.4 Case History 2: Amy’s chronic pain journey

Amy was aged between 50 and 55 years during the time of the study, was employed full-time as an addiction nurse and lived alone. She was interviewed at four timepoints over the duration of 18 months. At the time of the study, she had been living with rheumatoid arthritis and fibromyalgia for approximately 20 years. Amy had undergone knee replacement surgery 2 years prior to the research and occasionally used a walking stick when required. Amy experienced pain daily and daily functioning was impacted. She struggled to go to work, exercise or maintain a meaningful social life. However, through research and her medical background, Amy had an in-depth understanding of rheumatoid arthritis and fibromyalgia. She understood the trajectory, longevity of the conditions and associated chronic pain. This knowledge and understanding influenced Amy’s self-management strategies in symptomatic control. Amy had private health insurance and accessed health services as a private patient. She was under the care of a rheumatoid consultant to manage pain and engaged with her GP for other ailments. Amy was on prescription medication to manage the conditions which included disease-modifying drugs and anti-inflammatories but had no ongoing prescribed analgesics. Amy consistently incorporated non-pharmacological approaches in the day-to-day management of pain that included exercising, heat and cold therapy, rest, supplements, and mindfulness. Amy’s knowledge and understanding of the conditions and associated chronic pain were influential to self-medicating habits. OTC codeine-based analgesics were Amy’s preferred choice of OTC analgesics. Based on past experiences, paracetamol was not effective in managing pain. She could not self-medicate with ibuprofen or aspirin as they were contraindicated with her prescribed medication. Amy was wary of taking prescribed codeine-based analgesics for prolonged periods due to the higher codeine content. Amy preferred to take OTC codeine-based analgesics even when she had prescription analgesics. Amy’s chronic pain journey is one of resilience, hardiness, tenacity and demonstrates her determination to keep on going despite the debilitating effects of living with CWP.

The purpose of this case history is to explore Amy's experience of living with chronic pain across the three emblematic themes; 1. Feeling disregarded; 2. Feelings of being misunderstood 3. OTC codeine is my enabler. The importance of the through-line "just managing" in chronic pain management and resulting self-medicating habits will be highlighted throughout.

5.5.4.1 Theme 1: Feeling disregarded

Amy experienced ongoing challenges in accessing health services and felt disregarded within the health system. Despite Amy having private health insurance, there was lack of multidisciplinary approaches in health service delivery. This meant Amy experienced significant gaps in the care received and as she deteriorated overtime, these gaps widened. The lack of multidisciplinary approaches in health service delivery remained constant for Amy throughout the study.

"There is no team, it's ok they're all there waiting to see you when you get an appointment you could ask. I find the nurses they have stuff they have to do so there isn't a lot of room in that to be chatting to you so I kind of don't know them despite going there for a few years, but I don't ask them much. There is a helpline that you could ring but it's not really an advice line it's for ringing to get a prescription so yeah, I just get the support when I see my consultant which is only twice a year". (Timepoint 1)

Despite accessing health services privately, Amy's care was fragmented and therefore inadequate. Amy's accounts capture how despite having access to specialist services, the care she received was narrow in its focus leaving her with insufficient support. The onus was on

Amy to request specific interventions. The continuity in lack of multi-disciplinary approaches in health service delivery overtime was associated with Amy having unmet physical and psychological health needs throughout the study. This led to an overreliance on Amy to “just manage” and seek her own care despite being under specialist care. Amy had to be the central worker in co-ordinating her care and ensure she had access to other complimentary health interventions required to effectively manage chronic pain. She had to rely on her own knowledge and her ability to afford complimentary care required to effectively manage chronic pain.

“I have gone to see a counsellor, so I did go to see somebody that I paid for myself in the beginning I have gone to one through the HSE a little, so I had to try and arrange to continue seeing one and it was all too expensive, and I stopped then”. (Timepoint 1)

“You know over the years I have tried physio and it works at the time, but I can’t just afford to go all the time so I kind of wait when the stiffness becomes unbearable then I go for a few sessions then”. (Timepoint 4)

Despite their effectiveness, efforts to incorporate complimentary care were not sustainable overtime due to the financial burden associated with paying for extra services. Within this context, engaging with ongoing meaningful complementary care was problematic for Amy. In addition to contending with the debilitating effects of chronic pain, Amy had to contend with financial struggles due to the disregard within health services by providing inadequate support in chronic pain management. The periods that Amy could afford physiotherapy sessions were associated with less pain frequency and intensity. Engagement and continuity with effective non-pharmacological interventions was an influencer of appropriate OTC codeine use whilst lack of and cessation of such interventions posed a risk factor for inappropriate OTC codeine use.

"The physio definitely helps you know, afterwards I am not in as much pain especially at night. The stiffness is better, I sleep better and its just easier to cope with the pain then". (Timepoint 4)

The continuity in lack of multi-disciplinary approaches overtime was a factor that influenced Amy's positioning on the continuum of codeine use resulting in increases and decreases in self-medicating habits. Increases in self-medicating with OTC codeine-based analgesics were associated with increased pain intensity and periods when she could not afford complimentary care to chronic pain management and was only relying on bio-medical interventions included on her private insurance. Decreases in self-medicating were associated with decreased pain intensity and periods when she could afford to incorporate complimentary care. Overtime, the level of complimentary care incorporated in chronic pain management and associated pain frequency and intensity were linked and interacted overtime to represent the process that influenced level of self-medicating with OTC codeine-based analgesics for Amy.

In addition to lack of multi-disciplinary approaches in healthcare delivery, ongoing frequency of access to specialist services was problematic and it was minimal at best. Amy was typically seen twice yearly in a very rushed manner due to the demands within the healthcare system. In her accounts, Amy expressed a reluctant acceptance of the minimal interactions with her consultant and how they adopted bio-medical approaches in the interactions. That meant that during the long duration between appointments, there was an overreliance on Amy to "just manage" the day-to-day effects of chronic pain as she had no support in managing chronic pain from her GP. At best these interactions served the purpose of achieving functionality without taking a holistic approach in managing chronic pain.

"I would never complain about my consultant he is excellent, but I only get to see him twice a year, he's a busy man, maybe if I shouted louder and you ask for more things to be done but you only get two appointments a year. They are quite medically focused you know they are looking at your inflammation factors, your joint deterioration, if you need your knee injected". (Timepoint 1)

"I used to see him only twice a year before Covid you know for a very short time as well and I wouldn't waste that precious time talking about other things other than what I need to help me function". (Timepoint 3)

Due to the introduction of COVID-19 regulations, Amy experienced disruption to the already minimal access to health services resulting in change to the frequency and mode of access Amy had to care. This change led to lack of timely access to interventions and treatment as she deteriorated overtime. Of note is, these experiences were occurring at the background of reluctancy on Amy's part to attend the Accident and Emergency services due to concerns around the risk of getting infected with COVID-19 in hospitals.

"My rheumatology appointment there was changed to a phone consultation as well. The pain in my knee was ok in the beginning when I had the injection in my knee and that helped, now the effect has worn off and it has been excruciating". (Timepoint 3)

"Because you couldn't get an appointment with a consultant, and I wouldn't go near a hospital. I had to take medication during the acute episode I mean it was horrendous like, I have never had pain like that before not even when I got my knee replaced. I had spasms and all and this is new pain. I have never had pain like that in my back before". (Timepoint 3)

Within professional and health settings, Amy felt there was a lack of understanding of the debilitating effects of living with chronic pain resulting in not being listened to, lack of empathy and consideration. These experiences were consistent throughout the study and did not change. Within health settings, this lack of understanding was reflected through the inadequate services Amy was offered which she felt were not proportionate with the level of suffering she went through living with rheumatoid arthritis and fibromyalgia.

“They just don’t realise, if all doctors could get fibromyalgia for a week and see how it feels, they would definitely change their tune”. (Amy – Timepoint 1)

“You know XXXXX is providing physio at the moment online I mean what the hell is online physio! I need deep tissue massage you can’t do that online”. (Timepoint 3)

Amy felt this inconsideration and disregard was consistent within the health system and as well as other government agencies as this was reflected in the way decision-making was made during the development of COVID-19 restriction guidelines. Postponement and cancellation of non-urgent care in hospitals resulted in Amy not accessing services she had received prior to the restrictions, and this subsequently impacted her wellbeing. The restriction guidelines did not consider the impact caused by the longevity of not providing non-urgent care to individuals like Amy who over time her conditions deteriorated without the necessary support and interventions required. This left Amy with inadequate support, and she had to rely on herself to “just manage” the debilitating effects of chronic pain during this time.

“I know my mobility has really decreased and I probably now need my second knee replaced but it’s been more than a year now since I last saw my consultant. I haven’t got a guided injection now since this whole thing started and my mobility has certainly decreased”. (Timepoint 4)

In addition to postponing non-urgent care there was no consideration of how individuals living with chronic pain required specific facilities to manage chronic pain during lockdowns. The lack of necessary environmental facilities required in effective management of conditions like fibromyalgia further impacted Amy’s wellbeing throughout the lockdown periods. The longevity of these lockdowns further compounded the problem as Amy still tried to exercise to relieve pain despite the lack of support and facilities.

“I just think that there was no joint up thinking. I still think that they could have done individual assessments with people, they could have allowed people with disabilities you know access to a swimming in a pool. Even the one in XXXX hospital they use for aqua physio could have been opened for that. There should have been some thought given to people who need to exercise in a different way. I see why exercise classes had to stop but I don’t see why pools had to close for individuals swimming for exercise because for people like me you can’t really exercise out of water because its weight bearing”. (Timepoint 2)

“So, the kind of exercise I started doing in the first lockdown like I started walking and doing exercise videos, in other ways that has created more difficulties because my knee is really bad now you know”. (Timepoint 3)

The change in the already minimal access to health services was a factor that influenced Amy’s positioning on the continuum of codeine use resulting in increases in self-medicating habits. Increases in self-medicating with OTC codeine-based analgesics were due to elevated pain, lack of timely interventions, limited self-management opportunities due to environmental changes and deterioration of condition. Reduced access to health services due to COVID-19 restrictions, reduced physical activity self-management efforts, and increase in pain intensity and frequency were linked and interacted overtime to represent the process that contributed to increased self-medicating with OTC codeine-based analgesics for Amy.

5.5.4.2 Theme 2: Feelings of being misunderstood

Within professional, familial, and social settings Amy felt misunderstood and her experiences were characterised by unrealistic expectations and lack of acknowledgement of her suffering. Despite these experiences, Amy had to maintain normality and continuity professionally and at a personal level and found ways of "just managing". Amy's experiences in her workplace during the COVID-19 pandemic reflected a lack of empathy and consideration due to lack of understanding of her conditions. There were expectations for her to go back to work following the first lockdown during the pandemic despite being immuno-compromised. From timepoint 2 to timepoint 4, this was a huge concern for Amy as she felt it was risky for her to be at work due to difficulties in maintaining social distancing guidelines whilst interacting with patients.

"*Because I am cocooning, I am being very careful. I am getting a bit anxious that I'm going to be pressurised into going back when I am not ready. They asked me to get a letter from my consultant which I am still trying to get. They wouldn't accept one from my GP you know. They just don't get it that it will not be safe for me even with all the measures put in place because I am immuno-compromised. This just doesn't help thinking about that on top of everything else". (Timepoint 3)*

The need to provide proof of her conditions and associated risk was unrealistic and there was no consideration of the challenges involved in seeking that proof without access to specialist services because of the pandemic. Despite Amy having external signifiers of chronic pain, there was no trust and acknowledgement and understanding of how vulnerable Amy was to infections. This lack of understanding was further compounded by the fact that Amy worked among healthcare professionals who she would have expected to understand her circumstances without seeking proof. Similarly, within daily living Amy so often found that she had to provide proof of living with chronic pain before getting any considerations within society.

"The main reason for using that stick is to give people an indication that there's something wrong so that I can sit in public transport because I find it very hard to stand you know. If I don't have the stick, it is very hard to get someone to give up their seat whereas when you have it people generally people are good". (Timepoint 1)

Similarly, Amy felt that her friends and family did not quite understand her suffering, despite providing the support they could. In as much as functional support was provided by friends Amy's accounts signify the need for both emotional as well as practical support. However, there was an acceptance that friends were doing the best they could within their own interpretation and understanding of the effects of living with chronic pain.

"I have had times when people have really gone mad at me especially if you plan to go and they want to go or I've promised I want to do something and I can't go. I have really good friends while I might not sit and talk to them about the pain they are brilliant at say I have one friend at the moment that helps me do the stuff that I need to do in the house to move the things you know decluttering when I had my knee done my friends were incredible because I basically came straight from the hospital I didn't have to go into rehab". (Timepoint 1)

However, COVID-19 restrictions impacted the functional support Amy received from family and friends and this led to isolation. This was further compounded by the fact that Amy herself was cocooning resulting in minimal face to face interactions with anyone.

"I don't like being by myself. Usually because normally during the day I am busy socialising with work colleagues it doesn't bother me but now. In terms of my friends, it's been hit or miss others are busy because they have kids, so they are home schooling, trying to

cook, trying to organise stuff so maybe they haven't got much time, I think. They were great or better in the beginning every now and then I get absolutely desperate for company". (Timepoint 3)

The continuity in lack of adequate support due to minimal understanding from professional, familial, and social settings left Amy to deal with the associated day-to-day impact of chronic pain on her own. Of note, this occurred at the backdrop of minimal or ceased health services, exercising opportunities, and reduced social interactions due to COVID-19 restrictions. For most of the study period this is the environment that Amy was living and managing chronic pain in. These environmental and social factors interacted over time with the debilitating effects of chronic pain and were contextual to how Amy responded to chronic pain from a self-medicating context.

5.5.4.3 Theme 3: OTC codeine is my enabler

In response to the challenges of being disregarded in the health system and being misunderstood in other settings, Amy actively engaged with problem solving to mitigate the burden of chronic pain. Despite incorporating various strategies to manage chronic pain, codeine was Amy's enabler for periods when she struggled to function due to increased pain frequency and intensity. However, the need for codeine as an enabler was not continuous but increased and decreased as she went through changes in her circumstances. Amy actively made efforts to avoid elevated self-medicating even though this was not always possible during flare-ups and periods of dealing with new pain.

Due to accessing health services privately, Amy had more resources and choices in chronic pain management. Amy demonstrated an in-depth understanding of fibromyalgia and rheumatoid arthritis. She understood the illness trajectory, the importance of incorporating appropriate non-pharmacological self-management strategies and the impact to chronic pain symptoms. Amy utilised all available resources at her disposal in managing chronic pain and understood the interconnectedness between physical health, mental health, and coping strategies.

"I pretty much have pain and stiffness nearly all the time it's just your normal becomes different to somebody else. I definitely think as time goes on you get more challenges you know definitely because even though the medication modifies the disease it doesn't stop it so the disease progresses". (Timepoint 1)

The only thing that helps it is about 40 minutes of exercise a day and even if I had no fibromyalgia I would still exercise because it just helps my mood particularly if I do it during the day. "It just helps with my mood; it makes me more productive afterwards and I just find I can cope with the pain better". (Timepoint 2)

These understandings were central to how Amy lived with and managed chronic pain and subsequently the frequency of when she required codeine as an enabler. Amy actively engaged in exercise as part of her self-management approaches. She was committed to exercising consistently to minimise the burden of chronic pain resulting in minimal self-medicating with OTC codeine-based analgesics. Amy's preferred choice of exercises demonstrated a mindset in which she considered her ability to perform the exercise effectively considering the ever-present pain. Where possible, she engaged in exercises like swimming and aqua aerobics which are not weight bearing and enabled her to exercise effectively. Despite the limited resources to exercise brought on by COVID-19 restrictions, Amy had still found ways to keep on exercising. Perceived benefits of exercising and self-efficacy influenced continuity despite the physical challenges encountered in maintaining consistent exercising. Amy continuously engaged with physical activity considered beneficial to coping with chronic pain whilst pain was present without attempting to avoid activities.

"What helps fibromyalgia is exercise but sometimes you don't feel like exercising when you're exhausted. I am probably not disciplined in many things in my life, but I'm definitely disciplined in exercise because I know it helps so I exercise five or six days a week, so I swim, and I do aqua aerobics and a gentle workout in the gym and that helps". (Timepoint 1)

"Even though they closed the gyms, that doesn't stop me exercising. I am cocooning so I avoid going out, but I have found these exercise classes, mind you I can't do the floor exercises and all but I just go along at my own pace". (Timepoint 2)

Amy demonstrated an acceptance of pain which facilitated adaptive coping strategies enabling her to adjust to living with chronic pain. She had accepted the new normal of living with pain and her focus was not on getting rid of pain but on learning to co-exist with pain. Amy demonstrated pain willingness and acceptance and was willing to experience pain without continuously self-medicating to avoid pain. This enabled her to consistently engage with adaptive coping behaviours in chronic pain management.

"I'm quite a determined person so I generally get on with it but I have had periods of time when things have been worse. For example, I had my knee replaced so the period leading up to that from the time my knee went that was horrible my mobility decreased, I was in agony most of the time and I could barely walk. I still tried to exercise, I just hoped on my good leg and swam but I had to pretty much pull back at the gym because there was only little that I could do so I did. I really didn't stop unless I couldn't physically drive myself there". (Timepoint 1)

In addition, Amy engaged with other non-pharmacological strategies of managing pain: heat or cold therapy, resting and supplements. Despite over-the-counter codeine-based analgesics being her first choice of painkillers, they formed part but not her main self-management strategy.

"I would often use heat there and it works but if you have inflammation pain, heat is not the best, I know I should use frozen, but you have to put it over something because you can't put ice on your skin, elevating works, change of position helps maybe some meditation helps I do a bit of that. I would do a bit of mindfulness as well especially say for trying to go to sleep and I can't, I do a bit of mindfulness especially when I can't go to sleep because I'm in so much pain and I don't necessarily want to take something. It's breathing into the pain and just accepting it and say yes, I have pain in my knee. I'm not analysing or thinking about it but just acknowledging it is there and just breathing into it. It doesn't make it go away it just makes you calm around it you know. If you just kind of say yeah, my knee is killing me or my back is hurting me, or my shoulder is sore and yes I have pain but that is ok". (Timepoint 1)

Understanding of rheumatoid arthritis and fibromyalgia and associated trajectories, pain willingness and acceptance were central to how Amy managed chronic pain. Within this context, Amy understood that she could never be able to completely eradicate pain and even though self-medicating with OTC codeine-based analgesics was her preferred choice of pharmacological intervention and were an enabler when required, she understood the associated risks with long term use. She demonstrated vast knowledge of opioid addiction and related consequences, and this helped inform her day-to-day self-medicating habits.

"So, pain control is really complex, if I was to take the kind of painkillers that I would need to take to get rid of the pain I will probably need to be taking some kind of codeine so if I

do that all the time, I would still have the worry of addiction and worry of the side effects". (Timepoint 1)

"So I was taking a lot of codeine with my knees and I was quite concerned about it and I was trying weaning them off quite quickly because I'm aware of the side effects and addiction issues maybe that's also a bad thing and this is obviously from my profession see because I am an addiction nurse that's where I work so I think it's just knowing about addiction and that codeine is a risk but it doesn't stop me taking it at all but it makes me careful". (Timepoint 2)

In addition, underpinning these understandings and steps taken to exert control over pain was high health literacy informed by her own medical background and other information seeking behaviours. Amy's level of health literacy gave her the ability to ask for specific interventions as evidenced by her account.

"Nothing they gave me worked. I had to keep adjusting the medication till it was right. So, it was a rough time, and I couldn't get the spasms under control but because of my job I have worked before with MS patients, and I was aware of XXXXX medicine, so I suggested that to him and that is what eventually worked. If I hadn't known that I just don't know". (Timepoint 3)

Throughout the study Amy's approach to managing chronic pain was consistent. She continuously incorporated non-pharmacological and physical activity in her self-management strategies. The continuity of these strategies contributed to Amy's positioning on the continuum of OTC codeine-based analgesic use. However, despite being consistent with self-management strategies, the burden of elevated pain would sometimes result in Amy self-medicating with OTC codeine-based analgesics for longer than the recommended 3 days at a time. Amy understood the transient nature of flare ups and how to mitigate pain during these times. Within this context, increased use of codeine enabled her to manage flare ups and achieve symptomatic control. Between this understanding and the experience of pain management, flare ups did not warrant trying first-line analgesics first prior to using codeine. Learned histories and experience provided a strong rationale to not try first-line treatments prior to using codeine-based analgesics as well as seeking prescription medication after 3 days as recommended by the codeine guidelines. Instead, Amy self-medicated with codeine with an awareness of the addictive potential and was careful to avoid continuous use. However, in some cases depending on the frequency and intensity of pain, this necessitated her to self-medicate beyond the recommended timelines. Within this context, the definition of misuse evoked by the guidelines is unrealistic and rigid when brought under the lens of the lived experiences of codeine use.

5.5.5 Summary of Amy's case history

This case history captured Amy's experiences of living with chronic pain across the three emblematic themes; 1. Feeling disregarded; 2. Feelings of being misunderstood and 3. OTC codeine is my enabler. The through-line "just managing" is central to how Amy managed chronic pain and the resulting self-medicating habits. Amy's self-medicating with OTC codeine-based analgesics fluctuated overtime in response to different environmental, social, and individual factors. Within the period of the study, there were changes and continuities that influenced Amy's self-medicating habits. Continuity in receiving pharmacological treatment targeting the underlying causes and pathophysiology of chronic pain and continuity in engaging with adaptive self-management strategies were influencers of appropriate self-medicating with codeine. This continuity depicted stability and contributed to minimal self-medicating with OTC codeine-based analgesics. However, continuity in lack of multi-disciplinary approaches overtime and in lack of adequate support due to being misunderstood in healthcare and professional settings depicted a failure of progress within support structures. This contributed to increases in self-medicating with OTC codeine-based analgesics. The change brought on by the COVID-19 restrictions resulted in reduced care and this contributed to increased self-medicating. In addition, the change brought on by deterioration of conditions overtime contributed to increased self-medicating. Overall, the positioning of Amy on the continuum of codeine use was a complex interaction of all the continuities and changes in environmental, social, and individual factors.

5.5.6 Concluding remarks

The two case histories presented captured and highlighted distinctive experiences and significant insights of what change happens, how it happens and the impact of that change to self-medicating. They captured the complexities and nuances in each participant’s chronic pain management journey and how they experience, cope, and respond to change/continuity over-time in the management of chronic pain. The contrasting habits in self-medicating presented in these case studies demonstrate individual differences in self-management approaches in chronic pain management. They represent the personal lived experiences of how Peter and Amy navigated within structures that lacked adequate support and over relied on the sufferer to find ways of “just managing” chronic pain. Whilst the case histories focus on two individuals, similar experiences, and responses to change/continuity among the wider sample were reflected within the two case histories. The next section presents the discussion of phase two of the study.

5.6 Longitudinal Qualitative Research Discussion

5.6.1 Introduction

The aim of phase two of the study was to qualitatively explore the lived experiences of individuals living with chronic pain with specific focus on influencers of self-medicating habits, and choice of medication in the self-management of chronic pain overtime. It is the first study to longitudinally explore and capture the experiences of a cohort of participants living with chronic pain to better understand their experiences and how this influences habits in self-medicating within an Irish context. The study provides novel findings on the complex interaction of continuities and changes in environmental, social, and individual factors that influence choice of medication and positioning on the continuum of OTC codeine use in the self-management of chronic pain overtime. It provides an in-depth elaboration of the experiences of participants in self-managing chronic pain; what change happens, how it happens and how participants experience and cope with change over-time in self-medicating habits.

This section outlines the discussion of the key findings from phase two of the study. It incorporates the findings from both longitudinal analysis across cases and longitudinal analysis within cases. Firstly, an overview followed by key findings are discussed and the section is structured around the environmental, social, and individual factors that interact to influence choice of medication and self-medicating habits in the self-management of chronic pain. A summary of the findings is outlined to conclude the chapter.

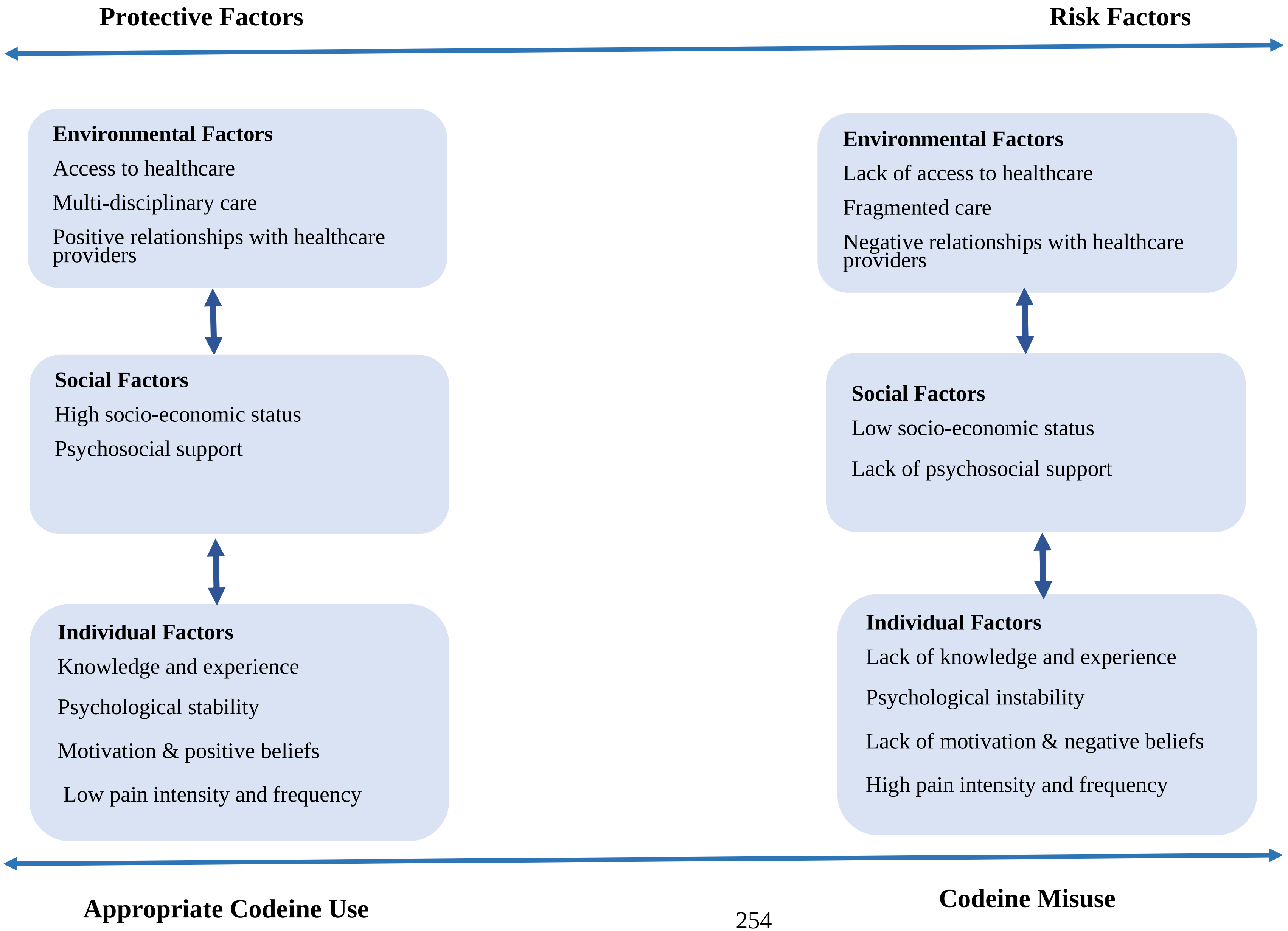
5.6.2. Overview of key findings

The current findings highlight how individuals living with chronic pain were “just managing” pain by self-medicating with OTC codeine-based analgesics considering the inadequate support in health systems, familial, social, and other professional settings. It identified three emblematic themes that captured the lived experiences of individuals managing chronic pain; 1) Feeling disregarded; 2) Feelings of being misunderstood; and 3) OTC codeine is my enabler. Within these emblematic themes, environmental, social, and individual factors were linked and interacted overtime to influence choice of medication and the positioning of participants on the continuum of OTC codeine use overtime. Figure 1 below drawn from SFMF provides a visual presentation of how these factors can influence self-medicating overtime in chronic pain management.

Environmental factors included access to healthcare, the type of care participants had access to and the types of relationships with healthcare providers. Social factors included socio-economic status and psychosocial support. Individual factors included level of knowledge of health condition and associated management strategies, psychological states, motivation levels, individual beliefs, and level of pain intensity and frequency. These three factors represent the events, actions and interactions that were linked together in a meaningful way overtime. Their interaction overtime represents the processes that influenced change or continuity in self-medicating with OTC codeine-based analgesics.

Figure 1:

Factors Influencing Self-Medicating with OTC Codeine-based Analgesics in Chronic Pain Management: Drawn from the SFMF (Grey et al., 2015).



5.6.3 Environmental factors influencing self-medicating habits

Whilst previous studies in Ireland have explored, codeine purchasing trends (Wells et al., 2019), characteristics of codeine dependence (Van Hout et al., 2018), codeine misusers' profiles (Van Hout et al., 2017), comparative studies of codeine misuse (Carney et al., 2018) and best practices in the management of opioid abuse (Norman et al., 2016), there is little known about the key factors that influence the positioning of individuals self-managing chronic pain on the continuum of codeine use within the general population. One of the key findings from the interviews with individuals living with chronic pain was the influence of environmental factors to self-medicating habits with OTC codeine-based analgesics. Lack of adequate access to health services led participants to "just managing" in the best way they could with resources available to them.

Throughout the study, the diagnosis story was prevalent at all timepoints with regards to initial experiences of accessing health services and subsequent care received. From participants' experiences, there was a clear connection to what occurred during the initial stages of chronic pain in accessing health services and how this had shaped self-medicating habits. The unpredictability of the pain experienced and the ambiguity concerning the cause of the pain had not inspired adaptative coping strategies when there was no diagnosis and appropriate medical intervention at the time. Lack of diagnosis, delayed diagnosis and lack of appropriate medical intervention were found to be associated with elevated self-medicating habits with codeine-based analgesics. This finding further supports the relevance of diagnostic uncertainty, a perception that healthcare providers are unable to provide accurate explanations of health problems resulting in efforts to exert control with actions, perceived as helpful (McKoane & Sherman, 2022). In the current study, elevated self-medicating with OTC codeine-based analgesics at the initial stages of chronic pain was influenced by diagnostic uncertainty and self-medicating represented efforts to exert control with actions perceived as helpful. This finding supports research by Serbic and Pincus (2013) who identified an association between diagnosis uncertainty and self-led efforts to seek alternative treatments in a study with individuals living with chronic low back pain without a clear diagnosis.

In addition, to diagnostic uncertainty, the complexity of not finding effective treatment and the unpredictability of the pain experienced was also influential to self-medicating. These experiences further support the relevance of the uncertainty in illness theory which posits that the ambiguity concerning illness, complexity of treatment in health services, lack of information about diagnosis and the unpredictability of illness trajectory is associated with maladaptive coping behaviours (Mishel & Braden, 1988; Wright et al., 2009). The current study identified an association between participants who expressed continuity in diagnosis uncertainty and uncertainty in illness with elevated self-medicating with OTC codeine-based analgesics. However, for participants who expressed an understanding of the underlying causes, trajectory, and complexity of treating chronic pain, efforts to self-medicate within recommended guidelines were highlighted albeit with periods where this was not always possible due to pain interference brought on by the progressive and debilitating nature of chronic pain.

Central to this continuous or periodical elevated self-medicating with OTC codeine-based analgesics was the access participants had to care and the quality of care provided within health services. Despite chronic pain being mostly managed outside of care settings (Nicholas & Blyth, 2016), ongoing access to interdisciplinary care is critical in facilitating educating and maintenance of evidence-based self-management strategies in the management of chronic pain as highlighted by the CCM (Bodenheimer et al., 2002; Gatchel et al., 2014). A key finding in the current study was how the organisation of care was problematic in developing other effective self-management strategies besides self-medicating. In cases where participants had no access to health services due to the 2-tier system of service delivery, establishment and maintenance of other effective self-management strategies was problematic and OTC codeine-based analgesics provided a feasible option for symptomatic relief. The current finding is consistent with previous studies where lack of access to adequate health services was associated with minimal self-management strategies (Fu, et al., 2016a; Fu, et al., 2016b). However, for participants with access to health services, the lack of interdisciplinary care led to biomedical approaches that did not achieve optimum outcomes in the treatment of chronic pain due to lack of multidimensional approaches in addressing chronic pain factors. This lack of effectiveness is consistent with the biopsychosocial approach which posits that effective treatment of chronic pain requires treatments that combine biological, psychological, and social factors as well as their interplay in treating chronic pain (Gatchel, 2013; Hadi et al., 2017; Kamper et al., 2015). Based on the current findings, the use of treatment approaches that do not include multidimensional approaches to integrate all factors relating to chronic pain is a risk factor for elevated self-medicating with OTC codeine-based analgesics.

The ineffectiveness of biomedically-focused care was problematic at multiple levels. Biomedically focused care could not facilitate establishment and maintenance of self-management strategies leading to an overreliance on pharmacological interventions. It did not incorporate shared problem solving and decision making to achieve agreed goals between health professionals and participants in self-management. Therefore, participants sought more pharmacological interventions overtime which conflicted with the gatekeeping role GPs adopted in opioid supply leading to negative relationships perceived by participants as lack of empathy, interest and understanding due to refusal to prescribe. This led to some participants disengaging from health services and resorted to “just managing” with OTC codeine-based analgesics. This finding is consistent with previous research that identified an association between disengagement from health services and self-led efforts to manage chronic pain with negative outcomes (Hadi et al., 2017; Kenny, 2004).

Despite the ineffectiveness of biomedical approaches, a benefit of care was identified in how participants who continuously engaged with care were "just managing" pain. Despite receiving biomedical care only, participants coped better as they had access to other pharmacological options, felt cared for to an extent and had the reassurance of being listened to. Continuous care albeit limited was associated with more efforts to adhere to recommended levels of self-medicating with OTC codeine-based analgesics despite the debilitating effects of chronic pain. However, long durations between appointments with health service providers or cessation of care influenced elevated self-medicating with OTC codeine-based analgesics. Participants still had to deal with flare ups and new pain due to deterioration overtime without support. Infrequent access to health services led to unmet physical and psychological health needs (Lynch et al., 2008), resulting in participants relying on available pharmacological resources (OTC codeine-based analgesics) to "just manage" chronic pain.

Another key finding under environmental factors influencing self-medicating habits was the quality of care provided in pharmacies in chronic pain management interactions. Interactions were characterised by what participants perceived as lack of, care, empathy, and consideration. This finding is not consistent with previous findings in other studies that depict pharmacists as being on the front line of pain care (Hahn, 2009; Strand et al., 2016), important contributors to healthcare systems (Van Eikenhorst et al., 2017) and ideally placed to provide guidance in self-medicating for pain (Perrot et al., 2019). More specifically, this is inconsistent with the role theory which posits that pharmacists have role dimensions which includes information sharing, responsible behaviour, creating a patient-centred relationship and interpersonal communication in interactions with patients (Guirguis et al., 2005; Worley et al., 2007; Worley-Louis et al., 2003). Experiences characterised by what participants perceived as lack of; care, empathy, and consideration are not typical in pharmacist-patient interactions. This can be explained by the fact that pharmacist approaches in the current study were guided by risk mitigation approaches as codeine gatekeepers in the supply of codeine. Implementation of codeine regulations formed a barrier to consultations with participants and fostered tension filled relationships resulting in a hindrance to pharmacists fulfilling their role as healthcare providers within primary care. The gatekeeping role adopted by pharmacists is a hindrance to use of pharmacies as health services in the front line of pain care. It is a missed opportunity for chronic pain management support in primary care and contributes to self-led decision making in self-medicating. This disconnect results in participants "just managing" based on self-medicating approaches perceived as helpful in achieving symptomatic control. However, a literature review on implications for patient-pharmacist interactions highlighted the role of lived experience within pharmacist/patient interactions leading to patients knowing what is effective to manage specific conditions and therefore not requiring the input of pharmacists within interactions (Guirguis et al., 2005). Within this context, participants went to pharmacies knowing what was available and effective to manage chronic pain and did not require the input of pharmacists to make self-medicating decisions and choices.

In addition, based on the cognitive developmental model of substance abuse by Liese and Franz (1996), continuous use of codeine is enabled by its availability as a legitimate analgesic for pain management (Van Hout et al., 2017). Despite the regulatory protocols associated with codeine supply, its availability in community pharmacies without a prescription enables misuse and abuse. The liminal space that OTC codeine-based analgesics currently occupies in the community pharmacy where its neither a typical OTC product nor a prescription product was influential to participants' approaches to getting supplies. The classification was unusual for participants, and they perceived it as an OTC product that must be sold when requested.

The final key finding under environmental factors influencing self-medicating habits was the impact of seasonal differences. Weather had an impact on levels of self-medicating throughout the study period. Depending on the underlying cause of chronic pain, warm weather was associated with reduced self-medicating whilst cold weather was associated with elevated self-medicating due to fluctuating pain intensity and frequency. Previous studies have reported an association between cold weather and reported pain in individuals with chronic pain (Edefonti et al., 2012; Macfarlane et al., 2010; Yimer et al., 2022). In the current study, the association between cold weather and reported pain was a factor that contributed to elevated self-medicating. During cold months, participants were “just managing” to alleviate increased pain. However, there are several potential factors that could have mediated between weather and levels of self-medicating. Participants tended to engage in more physical activity in summer months which is associated with reduced pain (Geneen et al., 2017).

5.6.4. Social factors influencing self-medicating habits

In previous studies of codeine use within an Irish context, little is known on the impact of social factors overtime to self-medicating with OTC codeine-based analgesics (Foley et al., 2017; McDonnell, 2019; Van Hout et al., 2018; Van Hout & Norman, 2016). One of the key findings from the interviews with individuals living with chronic pain was the influence of social factors in self-medicating habits with OTC codeine-based analgesics. Social factors were significantly influential to individuals living with chronic pain having inadequate support resulting in overreliance on themselves to “just managing” pain. Socio-economic status (SES) was identified as influential to self-medicating decisions and choices in chronic pain management. High SES was associated with private health insurance affordability. Participants with private health insurance had more resources and choices in chronic pain management affording them specialist care and opportunities to have streamlined biomedical interventions specific to the underlying conditions they had. Underlying causes and pathophysiology of chronic pain were targeted for treatment, intervention, and corrective surgeries to mitigate the impact of the conditions were carried out albeit in an untimely and inconsistent manner. Despite the lack of interdisciplinary care, ultimately, high SES was associated with more efforts to self-medicate within recommended use whilst low SES was associated with elevated self-medicating with OTC codeine-based analgesics. This inequality and social injustice resulted in health disparities and even though there was lack of interdisciplinary treatment that incorporated cognitive behavioural approaches in chronic pain treatment, it created different levels and experiences of “just managing” chronic pain. More choices and opportunities in care albeit biomedically focused was associated with periodic elevated use whilst less was associated with continuous elevated self-medicating. This finding is consistent with previous research on SES and health outcomes in chronic pain and in other chronic conditions (Fliesser et al., 2018; Tan et al., 2019). More specifically, Bonathan et al. (2013) found an association between low SES and elevated analgesic use. However, different predictors of SES have been found to have different impacts to different health outcomes. For example, low levels of education were associated with minimal self-management strategies (Bonathan et al., 2013). In the current study, income was central to health insurance affordability and afforded those who could afford it more choices and opportunities in chronic pain management and subsequently influenced self-medicating decision making. Of course, other SES factors could have been at play as well in consideration of the link between high SES and for example education (Geyer et al., 2006). In addition to supporting other findings on SES and health outcomes, this finding is consistent with SFMF which highlights the impact of financial resources to self-management (Schulman-Green et al., 2016).

Another key finding under social factors influencing self-medicating habits was the impact of living with chronic pain to social life. The physical and psychological limitations associated with chronic pain meant that participants struggled to maintain a meaningful social life. Participants had to lose valued social activities, for example social outings resulting in changes to their close relationships and wider social circle. Taking part in social outings could be challenging due to physical limitations associated with chronic pain and having to expend energy that is often lacking. Within this context, maintaining a meaningful social life was difficult due to lack of understanding from friends resulting in reduced social interactions and loss of social roles. This finding is consistent with previous studies on the impact of chronic pain that identified stigmatisation responses from friends and loss of social roles (Holloway et al., 2007; Snelgrove & Liossi, 2009).

In addition, the incongruence of how one appears and how one experienced pain was problematic for participants especially when they could not meet expected commitments within familial, social, or professional settings. Pain invisibility raised issues of legitimacy and hindered others truly understanding the experiences of participants in relationships. Most families, friends and work colleagues failed to adapt, and discussing chronic pain experiences was avoided resulting in participants feeling unsupported. Participants had learnt not to complain as this was perceived as being a burden to everyone. These findings mirror other chronic pain studies that have found pain invisibility, (Lempp et al., 2009; Slade et al., 2009) leading to families and friends not understanding the real experiences of living with chronic pain, and therefore leaving sufferers feeling unsupported and a burden (Smith & Osborn, 2007; Thomas & Johnson, 2000).

In the current study, participants were “just managing” to enable them to maintain social, familial and professionals roles. More often the decision to self-medicate with OTC codeine-based analgesics was influenced by attempts to maintain valued activities and normality around professional, social, and familial circles. Lack of understanding from work colleagues, friends, and family due to pain invisibility was key to participants ensuring that they were not a burden despite living with the debilitating effects of chronic pain.

5.6.5 Individual factors influencing self-medicating habits

In previous studies of codeine misuse within an Irish context, little is known about the impact of individual factors overtime to self-medicating with OTC codeine-based analgesics (Foley et al., 2017; McDonnell, 2019; Van Hout et al., 2018; Van Hout & Norman, 2016). One of the key findings from the interviews with individuals living with chronic pain was the influence of individual factors on self-medicating habits with OTC codeine-based analgesics. Elevated self-medicating with OTC codeine-based analgesics was identified during the early stages of chronic pain for all participants. During these early stages of the chronic pain experience, participants may not have realised that they were suffering from chronic pain. Responses to chronic pain would have been informed by past acute pain experiences of coping with pain. Within this context, self-medicating with the strongest analgesics available to alleviate the symptoms of pain made common sense. Responding to health threats in this case persistent pain based on coping experiences previously proven to be effective in the past further supports and is consistent with the CSM of illness self-regulation (Gillanders et al., 2013; Hagger & Orbell, 2022).

Based on the CSM of illness self-regulation (Leventhal, Meyer, & Nerenz, 1980), a health threat results in individuals relying on past cognitive and emotional representations to better understand and manage the threat. Through these illness representations, individuals develop coping strategies to manage the threat and associated negative impacts. In the current study, pain representations led to initial self-medicating with OTC codeine-based analgesics for symptomatic relief with the expectation of eradicating pain and associated negative effects. Advice received from pharmacists at the point of sale to stop consumption after 3 days was ineffective. Based on the CSM of illness self-regulation, illness representations and associated coping responses are based on lay beliefs that may be inconsistent with expert recommendations (Hagger & Orbell, 2022). Within this context, the delays in accessing health services, delayed diagnosis and interventions previously discussed were problematic for participants as this prolonged self-medicating due to the persistence of pain. OTC-codeine efficacy in comparison with first line treatments like paracetamol or ibuprofen further reinforces lay beliefs of illness representations and coping responses in the management of persistent pain. Due to the persistent nature of pain, pain representations and coping responses can be altered overtime based on appraisals that identify self-medicating with OTC codeine-based analgesics as effective to control pain. Ease of accessibility and cost of OTC codeine-based analgesics in comparison with other interventions that may not be easily accessible and costly further reinforces self-medicating to alleviate pain. Despite, participants knowing the associated effects of prolonged codeine use, the immediacy associated with coping with pain based on appraisals was more important than the distal nature of the risks associated with codeine misuse. Taking steps to mitigate pain that was present made more sense than to be concerned of effects which were not present, and they had no illness representations of. Based on the CSM of illness self-regulation, delayed health service use and medical interventions at the early stages of chronic pain are risk factors for continuous elevated self-medicating.

Further compounding the problem is the addictive potential of codeine. With prolonged use, physiological and psychological dependence can occur and once it occurs stopping consumption can cause adverse side effects (Frei et al., 2010; Labianca et al., 2012; Nielsen et al., 2018). This is consistent with reports of some participants who had experienced withdrawal side effects when they tried to decrease self-medicating levels. From a neurobehavioral approach, the overlap between the analgesic and reinforcement effects of codeine in the brain structures can influence continuous use. Within this context, the analgesic effect, relaxing effect, feelings of euphoria and altered consciousness associated with codeine can reinforce continuous use (Bechara et al., 2019). In addition, the lack of effective regulations and protocols in the supply of OTC codeine-based analgesics facilitates prolonged self-medicating. This is consistent with the cognitive developmental model depicting use, misuse and dependence of codeine containing medicines by Van Hout et al. (2017). Based on the model, the current findings depict how initial and ongoing use of codeine was influenced by physiological determinants such as pain, withdrawal symptoms and tolerance. Participants had then developed beliefs that focused on the efficacy and benefits of codeine and expectations associated with codeine use. These enabling beliefs reinforced continuous use for legitimate therapeutic reasons justifying codeine as an enabler within their individual contexts despite being aware of the adverse side effects. The availability of codeine albeit with regulations that could be circumvented enabled continuous use (Van Hout, et al., 2017). Within this context, the lack of interdisciplinary care compounded the problem due to lack of supported development and incorporation of other cognitive behavioural approaches to managing chronic pain. Codeine represented an enabling strategy allowing participants to “just manage” the debilitating effects of chronic pain.

Other individual factors were found to influence elevated levels of self-medicating with OTC codeine-based analgesics past the initial stages of the chronic pain experience.

Another key finding in the current study was adaptation to chronic pain post the initial stages was found to influence self-medicating habits. Participants who demonstrated an understanding of the trajectory and treatment of chronic pain in their narratives and accepted pain as enduring and a new norm typically engaged with cognitive-behavioural approaches to manage chronic pain. These adaptive strategies in managing pain were associated with decreased levels of self-medicating with OTC codeine-based analgesics. This finding is consistent with psychological flexibility - a process focused behavioural model that facilitates the capacity to change behaviour by focusing on the present moment, change or persist in behaviour to serve valued ends (Karayannis et al., 2023; McCracken & Morley, 2014; McCracken & Vowles, 2014). In the current study, the core dimensions of PF; awareness, acceptance and engagement were all influential to decreased levels of self-medicating. Participants who were fully aware, acknowledged and welcomed pain sensations and associated negative effects in their narratives managed chronic pain better and subsequently self-medicated less. This finding further supports findings in previous research between mindfulness and pain intensity (Namjoo et al., 2019). In addition, participants who demonstrated in their narratives willingness to experience pain and pain related stress: pain acceptance (McCracken & Vowles, 2008), reported less severe pain and less psychological distress and anxiety. This finding further supports previous studies that identified pain acceptance with better pain outcomes (Gillanders et al., 2013; Kratz et al., 2018; McCracken & Vowles, 2008). In the current study, participants with narratives associated with pain acceptance reported lower self-medicating with OTC codeine-based analgesics similar to previous studies that associated pain acceptance and lower prescription opioids use (Esteve et al., 2021; Lin et al., 2015). Furthermore, participants who engaged in valued activities like goal directed physical activities to manage chronic pain and committed to these activities managed chronic pain better and subsequently reported self-medicating less. This further supports the findings of a Cochrane review on the positive impact of physical activity and exercise in chronic pain management for adults (Geneen et al., 2017). Overall, participants with narratives related to PF reported low self-medicating with OTC codeine-based analgesics in chronic pain management. However, despite the influence of PF, experiences of participants indicated episodes when levels of self-medicating would increase due to inadequate pain control, pain induced insomnia and demanding daily demands. This can be explained by the concept of pain interference: the extent to which pain can adversely affect engagement with cognitive-behavioural approaches and behavioural activities (Karayannis et al., 2023; Karayannis et al., 2017). Due to pain interference, participants could disengage with cognitive behavioural approaches resulting in limited coping strategies and therefore increased pain intensity and frequency. Within this context, elevated self-medicating with OTC codeine-based analgesics served the purpose of alleviating pain during these episodes.

Within PF, self-efficacy and health literacy were identified as influential to pain acceptance and engagement dimensions. Engaging in valued activities like goal directed physical activities to manage chronic pain and committing to these activities was influenced by self-efficacy. Findings indicate that the choices of physical activities participants chose were in line with their ability to perform them with the ever-present pain. This is consistent with self-efficacy, a construct that refers to an individual’s perception to execute behaviours required and judgements of their capacity to execute those behaviours (Cheng et al., 2020; Turner et al., 2005). More specifically, participants who demonstrated functional self-efficacy - a construct that refers to an individual’s confidence and ability to execute specific physical activities had narratives associated with acceptance and engagement on the dimensions of PF. Functional self-efficacy enabled individuals to consistently engage with physical activity resulting in reduced pain intensity and subsequently decreased self-medicating. This finding also adds specificity to the SFMF on the influence of motivation and self-efficacy to self-management efforts (Cheng et al., 2020; Jackson et al., 2014; Schulman-Green et al., 2016).

In addition to functional self-efficacy, health literacy (Nutbeam, 2000), was found influential to informing the type of physical exercises helpful to specific conditions to alleviate pain within the engagement dimension of PF. Participants whose narratives indicated personal and social skills indicating their ability to gain access, to understand and use this information to maintain and promote good health were able to identify appropriate physical activities that were consistently incorporated to manage chronic pain. As a result, this was linked to reduced pain intensity and decreased self-medicating. This finding further supports previous research which identified that health literacy was associated with reduced prescription opioid use and better pain outcomes (Rogers et al., 2020). In addition, health literacy facilitated information seeking behaviours that identified effective non-pharmacological interventions and execution of these interventions to manage chronic pain in the current study. Overall, participants whose narratives indicated PF, self-efficacy and health literacy reported minimal self-medicating with OTC codeine-based analgesics in chronic pain management except for periods where pain interference necessitated increased self-medicating.

Another key finding on individual factors that contributed to self-medicating was lack of adaptation to chronic pain post the initial stages. Participants who interpreted and described pain as extremely threatening, had heightened anxiety over the pain experience, avoided activities assumed to increase pain, demonstrated pain hypervigilance, and had a diagnosis of clinical depression reported high pain frequency and intensity requiring elevated self-medicating to manage chronic pain. This finding further supports the FA model which posits that individuals develop and maintain chronic pain due to catastrophising, fear of pain, avoidance of activity and hypervigilance all contributing to subjective pain intensity and emotional distress (Leeuw et al., 2007; Norton & Asmundson, 2003). In the current finding, participants whose narratives were associated with catastrophising, anxiety over pain and depression reported elevated self-medicating. This is consistent with previous research which identified heightened opioid misuse with catastrophising, anxiety over pain ,(Jacobsen & Butler, 1996; Valdes et al., 2015; Vlaeyen et al., 2004), and depression (Fischer et al., 2012; Gatchel, 2009). Overall participants whose narratives indicated catastrophising and anxiety over pain and had a clinical depression diagnosis reported elevated self-medicating with OTC codeine-based analgesics.

5.6.6 Conclusion

Overall, the LQR study presents various novel and unique insights on the experiences of individuals living with chronic pain and influencers of self-medicating habits. It is the first study to longitudinally explore and capture the experiences of a cohort of participants living with chronic pain to better understand their experiences and how this influences self-medicating habits within an Irish context. It identified the through-line "Just managing" as the driver of OTC codeine use in chronic pain management. Three emblematic themes that captured the lived experiences of individuals managing chronic pain; 1) Feeling disregarded; 2) Feelings of being misunderstood; and 3) OTC codeine is my enabler. Through these emblematic themes, the study highlights how individuals living with chronic pain were "just managing" despite the lack of care and support in health systems, familial, social, and professional settings. These experiences were the driver of choosing OTC codeine-based analgesics and self-medicating habits in the self-management of chronic pain.

Chapter 6: Synthesis Chapter

6.1 Introduction

This chapter presents the synthesised findings from phase one and two to achieve the overall aim of the current study that is to explore the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. Synthesising the findings from both phases of the study provided an opportunity to present a comprehensive, holistic, and higher-level interpretation of the factors influencing self-medicating both from the perspective of community pharmacy professionals and individuals self-medicating for chronic pain. First the chapter discusses the methodological approach adopted in synthesising phase one and two of the study followed by the synthesised findings. The overall aim of the study is then addressed and synthesised findings on the factors that influence the positioning and transitioning on the continuum of OTC codeine use in pain management are presented. Limitations of the study are discussed followed by the original contributions, implications of the study and concluding remarks to conclude the chapter.

6.2 Triangulation

Various methods of synthesising qualitative research have been established overtime with the most common including thematic synthesis, meta-ethnography, and triangulation (Barnett-Page & Thomas, 2009). Thematic synthesis refers to the identification of recurrent themes within different qualitative data sets (Thomas & Harden, 2008). Meta-ethnography refers to the selection, comparison, and analysis of qualitative studies to create new concepts or interpretations (Barnett-Page & Thomas, 2009). Thematic synthesis has particular strength in capturing similarities within different qualitative data sets, but it is less suited to analysis where the aim is eliciting recurrent themes that would represent different data sets. Similarly, meta-ethnography is useful for synthesising findings interpretively but is limited in terms of the ability to provide the structure to capture not only similarities but divergences, disparities, and interrelations within the findings. In addition, both approaches do not enhance the validity, credibility, and dependability to the same extent as for example triangulation (Golafshani, 2015).

Triangulation refers to the use of either multiple data sources, methods, theories, or observers to develop an enriched comprehensive understanding of phenomena (Johnson et al., 2017; Noble & Heale, 2019; Patton, 1999.). It helps explore and explain complex phenomena through the use of multiple data sources and approaches to analysis. This enhances the possibility of offering a more balanced explanation and interpretation (Carter et al., 2014; Guion et al.,2011). The primary goal of triangulation is to explore convergence, complementarity, silences, and dissonance to achieve the overall goal of enhancing validity, credibility, and dependability of conclusions (Farmer et al., 2006). Convergence refers to the consistency or agreement of findings leading to the same conclusion whilst complementarity refers to different perspectives on the same phenomena which can relate in building a more comprehensive understanding from individual findings. Silence refers to the absence of a theme in other findings whilst present in one finding. Dissonance refers to when two or more sources of data addressing the same phenomena produces unexplainable divergent explanations which can be equally important in bringing a more nuanced understanding of a phenomenon or provide a point of departure for different theory development (Farmer et al., 2006; Heale & Forbes, 2013). By using information from different sources and methods to interpret the same phenomena, in addition to exposing convergence, triangulation can expose multi-dimensions of the same phenomena through the complementarity of multiple data sources. In addition, it can expose unexplainable divergences through dissonance in findings (Carter et al., 2014; Golafshani, 2015).

Triangulation was adopted in the current study as it offered a more comprehensive understanding and interpretation of both phases of the research and enhanced validity, credibility, and dependability of the research. Within qualitative research methodologies that involves naturalistic inquiry, triangulation offers the opportunity to explore and validate themes across studies. It establishes a valid interpretation of the phenomena being explored through the convergence and complementarity of themes derived from different qualitative methods exploring the same phenomena (Jonsen & Jehn, 2009). Indeed, triangulation has been adopted in thematic analysis (Johnson et al., 2017; Jonsen & Jehn, 2009) and in LQR studies (Johnston et al., 2016; Nevedal et al., 2019) to enhance validity credibility and dependability. Within the current study, triangulation of RTA and LQR facilitated cross-validation of the themes on the factors influencing positioning and transitioning on the continuum of OTC codeine use in pain management.

Triangulation has an established role in healthcare research and can facilitate a better understanding of health-related phenomena (Noble & Heale, 2019). For example, Johnson et al. (2017) employed triangulation to explore decision-making in pre-hospital care. Sources of information for triangulation included information from interviews with ambulance service staff, review observations of paramedic shifts, focus groups of paramedics and focus groups of service users. The findings revealed the complexities and realities of pre-hospital care from the different perspectives of service providers and service users. In addition, the use of different qualitative data collection methods enhanced the exploration of the realities of pre-hospital care. Triangulation allowed each method used to expose aspects of reality and cross validation between paramedics and service users (Johnson et al., 2017). Similarly, Heale et al. (2018) employed triangulation to explore the quality of care provided for patients with diabetes in a nurse practitioner led clinic. Data from interviews with nurse practitioners, chart audits and data from literature was used in triangulation to further support conclusions. Triangulation can ensure that conclusions in healthcare research can capture insightful aspects from multiple dimensions to offer more comprehensive understandings of health-related phenomena (Heale et al., 2016).

6.2.1 Triangulation protocol in current study

The current study adopted a multi-method and multiple data source triangulation approach to integrate the cross-sectional findings from pharmacy professional interviews, LQR findings of within case analysis and across case analysis (case histories). Synthesising findings that included different qualitative methodological approaches and data sources offered a more multidimensional and thorough examination of the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management that could not be gained by a single qualitative method (Johnson et al., 2017). The multi-method and multiple data source triangulation approach ensured that RTA exposed themes that captured the views and experiences of pharmacy professionals in OTC codeine related interactions whilst LQR exposed emblematic themes that incorporated temporality in the experiences of individuals self-medicating with OTC codeine. Each method exposed insightful aspects of reality from both the perspectives of pharmacy professionals and from individuals self-medicating for chronic pain. It allowed cross checking of findings therefore enhancing validity, credibility and dependability of the identified issues that influence self-medicating in pain management (Noble & Heale, 2019).

6.2.2 Weighting of phases

Carter et al. (2014) highlighted the challenges associated with data triangulation using multiple qualitative methods and data sources. Challenges include how to find robust approaches to analyse multiple qualitative data together and how data is weighted against each other in findings. Weighting of data refers to the priority afforded to the different data being used in triangulation. For example, within current study whether pharmacy professional findings or lived experience findings were to be given priority in synthesising the findings to address the overarching aim of the study. To address these challenges, Morse (2009) suggests analysing qualitative data separately before synthesising to address the research question. For the current study, cross-sectional pharmacy professional interviews and LQR interviews were analysed separately before synthesising findings through triangulation therefore removing the need to prioritise any findings. This approach enabled both findings to be weighted equally as they each addressed important aspects of the factors that influence choice of medication in the self-management of chronic pain from different perspectives. Triangulation ensured that insightful aspects of multi-dimensional reality captured by both professional and lived experience findings were synthesised to present a holistic, comprehensive, and higher-level interpretation of the factors influencing the positioning and transitioning on the continuum of OTC codeine use in pain management (Heale & Forbes, 2013; Morse, 2015).

6.2.3 Analysis

The multi-method and multi-data source triangulation protocol taken in the current study, was informed by Farmer et al. (2006). It involved the examination of the data for convergence, complementarity, silence, and dissonance. The following steps were taken to analyse findings:

Step 1: Sorting the data

This involved sorting out of findings from cross-sectional pharmacy professional interviews, LQR across cases and within cases findings. Data sets were reviewed to identify the key themes identified across all findings to create a unified list of themes. Themes from both phases were combined under environmental, social, and individual factors. This marked the first step into determining convergence, complementarity, and dissonance on the findings from pharmacy professionals and individuals self-medicating with OTC codeine-based analgesics.

Step 2: Convergence coding

This involved comparing all 3 data sets of findings in relation to meaning, interpretation and prominence of themes. Convergence coding was conducted using Microsoft word to manage data sets. To code for convergence, themes that had similar meanings were all initially highlighted in one colour across all 3 data sets. For example, themes; systemic failures and feeling disregarded were highlighted within data sets as they all elaborated on the influence of inadequate health services to self-medicating. Once all data sets were coded with all similar themes highlighted to a specific colour, the process of characterising the degree and type of convergence was completed using the following criteria:

1. Agreement

   Within similar themes data was coded to identify full agreement on meaning, prominence and specific examples provided within each theme. For example, within themes; systemic failures and feeling disregarded, lack of timely access to healthcare services was highlighted prominently in all findings as influential to self-medicating. There was full agreement from all data sets on the meaning of lack of access and examples provided all elaborated on the impact of delayed healthcare access to pain symptoms and how this influenced self-medicating habits. Such data was coded as instances of agreement.

2. Partial agreement

   Once all data with full agreement was coded, data was then coded to identify partial agreements on either meaning or prominence to identify partial agreements within similar themes. For example, within the unintended consequences of codeine regulations and feeling disregarded themes, all data sets agreed on the resulting negative relationships due to the introduction of codeine regulations. However, pharmacy professionals felt that their role was undermined by codeine consumers whilst findings from the lived experiences of managing pain highlighted pharmacy professionals as unsupportive, uncaring and risk-mitigation focused. Such data was coded as instances of partial agreement.

3. Silences

The following step involved coding all data sets for silences. The initial coding of similar themes using a colour coding approach was useful for identifying silences within the data. Themes that were not included in other findings were not colour coded. For example, themes related to the complex environments pharmacy professionals implemented codeine regulations in were specific only to phase 1 of the study and therefore were not colour coded. Similarly, experiences within social, familial, and other professional settings which were specific only to phase 2 were not colour coded. Such data was coded as instances of silences.

4. Dissonance

The final stage of convergence coding involved identifying disagreements on meaning and prominence across all findings. For example, pharmacy professionals highlighted social influences such as lifestyle choices as influential to self-medicating. However, participants in phase 2 highlighted the debilitating effects of pain as influential to self-medicating. Such data was coded as instances of dissonances.

Step 3: Convergence assessment

Following the triangulation protocol was not a linear process but involved going back to convergence coding to compare meaning and prominence of themes until all data sets were synthesised. This stage involved assessing all identified compared segments to ensure a full assessment of the level of convergence. This process involved going back and forth to double check the level of convergence identified with the examples provided across all data sets.

Step 4: Completeness assessment

The final stage involved going back to all data sets to ensure a comparison of the nature of unique topic areas from the perspective of pharmacy professionals and lived experiences of managing pain to identify key differences in perspectives. In addition, this process ensured the completeness of synthesising findings by identifying any insights that may have been initially missed in convergent coding. Based on the convergence assessment, it was evident that all data sets agreed, confirmed, and complemented core factors that influence positioning and transitioning on the continuum of codeine use. Although there were instances of silences and dissonances identified, this can be attributed to the different participants samples and focus in the 2 phases of the study. Findings of the triangulation are elaborated in section 2 of this chapter.

6.3 Reflexivity in qualitative research

Despite following the triangulation protocol by Farmer et al. (2006), triangulation was a complex process that involved a lot of reflection on my part. Despite the epistemological congruence between LQR and RTA, I found that data sets where shaped by different focuses of experiences. Pharmacy professionals' focus was on self-medicating from a broader perspective that included acute and chronic pain self-medicating whilst individuals living with chronic pain focused on self-medicating for chronic pain. This proved challenging when I coded data for convergences as the different focuses had shaped data for each phase of the study. However, through rigour in convergent coding where there was no complete convergence identified, the different perspectives brought on complementarities between data sets that contributed to a more complete interpretation of the factors influencing positioning and transitioning on the continuum of codeine use in pain management.

Despite the large volume of LQR data, I had to ensure that both phases were weighted equally in triangulation as they addressed important aspects of the factors that influence self-medicating for pain from different perspectives. Following the triangulation protocol by Farmer et al. (2006) enabled me prioritise data equally through data sorting, convergence coding and assessment as well as completeness assessment. In consideration of the large data sets generated by qualitative research, triangulation allowed me to demonstrate validity of the interpretations from all data sets. It allowed me to bring together perspectives from pharmacy professionals and individuals living with chronic pain who were self-medicating with OTC codeine-based analgesics. Bringing together themes from RTA and emblematic themes from LQR facilitated the identification of core factors influencing positioning and transitioning on the continuum of codeine use.

6.4 Synthesised findings

6.4.1 Convergence

There were notable agreements and consistencies across the findings of phase one and phase two of the study. Firstly, the influence of inadequate health services to self-medicating with codeine-based analgesics was highlighted across both phases in the themes systemic failures and feeling disregarded by both pharmacy professionals and individuals self-medicating for chronic pain respectively. Financial barriers, untimely access to health services and lack of multi-disciplinary approaches in the provision of health services were highlighted as influential to self-medicating in pain management. Financial barriers were implicated in delays in seeking medical interventions both at the initial point of access and ongoing care for participants who paid privately for care. Both pharmacy professionals and individuals self-medicating to manage chronic pain corroborated on how use of health services was delayed and, in some cases, avoided especially when codeine-based analgesics could alleviate pain. Pharmacy professionals highlighted the difficulties in codeine consumers stopping self-medicating after three days to seek medical intervention due to associated costs. Individuals living with chronic pain corroborated and expounded on how self-medicating with codeine-based analgesics provided a cost-effective alternative to managing pain and how the longevity associated with chronic pain could subsequently lead to elevated self-medicating overtime. The findings from both phases corroborated the impact of the social injustice inherent in the Irish health system which caused disparities and left participants “just managing” pain in the best way they could based on the care opportunities their socio-economic status afforded them.

In addition, pharmacy professionals highlighted how lack of timely access to healthcare services influenced self-medicating as individuals living with pain were left without adequate care whilst waiting for secondary services. Delays in accessing care were implicated as influential to frequency of self-medicating whilst waiting for services despite pharmacy professionals referring codeine consumers to seek pain management care. Individuals self-medicating for chronic pain highlighted this in their experiences and elaborated on the complexities of having no access to effective interventions whilst having to contend with the debilitating effects of chronic pain. Elevated self-medicating bridged the gap between untimely and lack of access to health services and the burden associated with living with chronic pain. Furthermore, pharmacy professionals highlighted the lack of multi-disciplinary approaches in chronic pain management resulting in fragmented care as influential to self-medicating habits. The lived experiences of individuals living with chronic pain attested to this and further highlighted the influence of fragmented care to self-medicating. The lack of comprehensive care meant that participants were left with unmet physiological and psychological needs in chronic pain management and self-medicating with codeine-based analgesics provided an alternative feasible way to manage pain albeit insufficient. These convergences across both phases further accentuated the through-line of phase two of the study of how individuals living with chronic pain were “just managing” in the best way they could be due to lack of adequate support within the health system.

Secondly, they were notable agreements on the ineffectiveness and deficiency of the codeine regulations in curtailing the purchase of codeine-based analgesics to deter misuse from both phase one and phase two of the study. Adjustment of discourse to meet the protocols of codeine regulations and pharmacy hopping were highlighted in both phases as influential to elevated self-medicating despite the existence of codeine regulations. Pharmacy professionals explained how codeine consumers were now well versed with the regulations and adjusted their narratives to suit the protocols therefore rendering the regulations redundant. Similarly, participants in phase two corroborated this with their main goal highlighted as being able to get a supply of codeine-based analgesics without getting involved in prolonged explanations when they went to pharmacies. In addition, pharmacy hopping was highlighted as influential to the ineffectiveness and deficiency of codeine regulations. Pharmacy professionals elaborated on how this further compounded the ineffectiveness of codeine regulations due to differences in the implementation of regulations in different pharmacies sending conflicting messages to consumers. They further elaborated on the lack of an efficient mechanism to identify elevated purchasing as influential to misuse. Of note was also the agreement across phase one and phase two findings on how unrealistic it was to expect individuals self-medicating to stop after the recommended three days of codeine consumption. Both findings implicated the inadequacy of the health system in meeting the needs of individuals managing pain as influential to self-medicating and within this context it was unrealistic to stop an effective coping mechanism after three days without a feasible alternative. Findings from phase two further elaborated on how experience in chronic pain management was influential to choice of analgesics and elevated self-medicating habits more that recommendations from codeine regulations. Learned histories on the efficacy of OTC analgesics and experience provided a strong rationale not to try first-line treatments prior to using OTC codeine-based analgesics as well as seeking prescription medication after three days as recommended by the codeine guidelines.

Thirdly, there was agreement from both the perspective of pharmacy professionals and individuals self-medicating for chronic pain on the limitation on choices for OTC second line analgesics. Whilst participants in phase two reported the lack of efficacy of alternative analgesics, pharmacy professionals further elaborated the need to broaden options on OTC pain medication with analgesics that are not liable to abuse and with no addictive potential.

6.4.2 Complementarity

There were also notable instances of complementarity where the findings from one phase agreed with the other phase but from different perspectives. Through complementarity across phase one and two, multiple dimensions were exposed where one phase built upon and extended a complimentary understanding of the same issue but coming from different perspectives (Farmer et al., 2006).

Firstly, there was agreement and consistency from both phases on the dichotomy of patient/pharmacy relationships in codeine interactions and non-codeine interactions. Tension-filled relationships in codeine related interactions and conducive relationships in non-codeine interactions were highlighted in both phases of the study. However, the perspectives of pharmacy professionals and individuals self-medicating for chronic pain on the causes of this dichotomy were different. Both findings agreed on how the introduction of codeine regulations had resulted in oppositional goals in codeine-related interactions resulting in relationships characterised by conflict, divisions, and lack of trust. Pharmacy professionals felt codeine consumers did not embrace their role in pain management but instead viewed them as a hindrance to getting codeine-based analgesics. However, participants in phase two felt interactions were hindered by the way pharmacy professionals were only interested in implementing codeine regulations and therefore adopting a gatekeeping role instead of a supportive, caring, empathetic and information provision role. Interestingly, findings from pharmacy professionals corroborated this as they reported the implementation of codeine regulations as central to pain interactions instead of information provision and providing support. They described scepticism as influential to the way they responded to codeine-based analgesics requests and asked codeine protocol questions. Pharmacy professionals reported a general reluctance to supply codeine-based analgesics and had adopted approaches focused on controlling the supply of OTC codeine rather than ensuring it was consumed safely.

Findings of both phases of the study highlighted how the introduction of codeine regulations had brought on the unintended consequence of tension filled interactions that were not conducive to meaningful interactions characterised with information-seeking behaviours and provision of support in interactions. This was confirmed by both findings which depicted non-codeine interactions as characterised by trust, care, and meaningful consultations conducive to shared decision making in the management of other ailments. Pharmacy professionals elaborated on how these tension-filled interactions were influential to elevated self-medicating due to lack of opportunities to engage with individuals managing pain and provide other pharmacological and non-pharmacological interventions. However, participants who were self-medicating for chronic pain felt they knew what was effective in achieving symptomatic relief and enduring negative relationships with pharmacy professionals was another burden they had to contend with in their efforts to self-manage chronic pain.

6.4.3 Silences

There were various notable silences across the phases of the study. This can be attributed to findings from both phases highlighting and exploring issues that were specific to each cohort and directly linked to their experiences. However, these silences are key to presenting a comprehensive, multidimensional holistic interpretation of the factors influencing self-medicating both from the perspective of pharmacy professionals and individuals self-medicating for chronic pain (Farmer et al., 2006).

In phase one, pharmacy professionals reported the complexity of implementing codeine regulations within environments characterised by competing demands and limited resources to devote to pain consultations. They elaborated on the ethical dilemmas they faced due to conflicts of interest at a professional, regulatory, business, and personal level around effectively implementing codeine regulations. Pharmacy professionals reported the resulting hostile working environments and the psychological distress evoked by the conflicts resulting from the implementation of codeine regulations. They further highlighted the limitations surrounding the provision of proper pain consultations. The lack of remuneration for time spent during pain consultations limited the involvement of pharmacists as reimbursed services were prioritised more. In addition to the lack of remuneration, pharmacy professionals felt they had been given the sole responsibility of addressing the OTC codeine epidemic without effective mechanisms to address the problem, adequate support from regulatory agencies and other health professions. They felt the misuse of OTC codeine was a significant national problem that warranted more collaborative efforts at a national level to effectively address it.

In phase two, even though individuals self-medicating for chronic pain agreed with pharmacy professionals on the influence of inadequate health services to self-medicating habits, they expounded on experiences that were specific to interactions with healthcare professionals. These interactions were characterised with what was perceived as disregard of their suffering, risk mitigation approaches to prescribing and lack of understanding, support, empathy, and trust. Findings in phase two further elaborated on how self-management strategies had developed within this context were there was limited healthcare support and, in some cases, no support due to participants disengaging from health services. Mostly participants had to co-ordinate their own care and assume control and decision-making on their own due to the inadequacy of the health system and negative experiences reported in their interactions with healthcare professionals. In addition, findings from phase two revealed the lived experiences of individuals self-medicating for pain in other settings influential to the development and maintenance of self-management strategies other than healthcare settings.

Feelings of being misunderstood were inherent in the experiences of participants in familial, social, and professional settings and this influenced how they managed chronic pain. Furthermore, the findings elaborate on how OTC codeine-based analgesics were an enabler of valued activities and role identities considering the debilitating effects of living with chronic pain and negative experiences in healthcare, familial, social, and other professional settings. Due to the longitudinal and iterative nature of LQR, findings also revealed the complex interactions between all the environmental, individual, and social factors that brought on change overtime and how this influenced self-medicating.

6.4.4 Dissonance

There were various notable dissonances across the phases of the study. Within the context of self-medicating, these divergencies between pharmacy professionals and individuals self-medicating for chronic pain are key in understanding the assumptions of each cohort. They provide a more nuanced understanding of the issues at the interface between community pharmacies and individuals managing chronic pain and how this influences self-medicating. In addition, they serve as a point of departure for further research to explore these divergencies (Farmer et al., 2006).

In phase one, pharmacy professionals highlighted social influences such as lifestyle choices, social norms, and evolving information sources as influential to self-medicating with OTC codeine-based analgesics. However, in phase two, individuals self-medicating for chronic pain highlighted the debilitating effects and burden of chronic pain, being disregarded within health services, and being misunderstood within other settings as the drivers of self-medicating with OTC codeine-based analgesics instead of social influences.

Self-medicating provided symptomatic relief for the ever-present pain and enabled them to participate in valued activities and maintain role identities.

In addition, pharmacy professionals highlighted how codeine consumers had no clear understanding of the aetiology of pain and the need for treatment approaches that targeted the pathophysiology of pain. Furthermore, they highlighted how first line analgesics like paracetamol, ibuprofen, and aspirin were effective in the continuous management of pain, but individuals managing pain preferred codeine-based analgesics as first line treatments instead. This preference of codeine-based analgesics was partly attributed to the storage of OTC codeine analgesics in the dispensary being associated with much stronger prescription only analgesics. However, findings from phase two revealed that despite participants being generally aware of the aetiology of chronic pain and the need for targeted treatments, lack of access to timely care and multi-disciplinary holistic approaches in chronic pain care and the debilitating effects of chronic pain led them to focusing on alleviating pain with the strongest analgesics they could access. In addition, the decision to choose codeine-based analgesics was not partly influenced by where they were stored but by past experiences on the limited efficacy of first-line treatments and the availability of codeine-based analgesics without the need for a prescription. Participants were “just managing” chronic pain in the best way they could with the resources they had access to. Furthermore, findings in phase two revealed that despite the addictive potential and associated adverse effects of OTC codeine, participants considered it safer in comparison with prescription codeine or other prescription only opioid analgesics. Within this context, participants considered self-medicating with OTC codeine as a more balanced attainable option between achieving symptomatic relief and reducing the risk of dependence, addiction, and other adverse effects associated with opioids.

In as much as these dissonances highlight underlying issues and the differences in perspectives at the interface between community pharmacies and individuals self-medicating for chronic pain, they can also be attributed to differences in focus and perspectives in the two phases of the study. Pharmacy professionals’ views and experiences were based on a much broader perspective of interacting with individuals self-medicating for both acute and chronic pain in addition to pain driven by lifestyle choices. On the contrary, findings from phase two were based on the specific experiences of living with and managing chronic pain associated with an underlying disease.

6.5 Discussion of key findings in the current study

The purpose of this section is to address the overall aim of the study and provide a comprehensive, multi-dimensional holistic explanation from the synthesis of phase one and phase two on the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. The discussions from the findings of the views and experiences of pharmacy professionals and the lived experiences of individuals living with chronic pain were presented in Chapter 4 and 5 respectively. Firstly, this section outlines the factors identified in phase one and two that influence positioning and transitioning on the continuum of OTC codeine use in pain management. Secondly, the synthesised findings on the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management are outlined before critically examining each factor in relation to literature and policies.

6.5.1. Phase one and two findings

Findings in phase one identified three themes: unintended consequences of codeine regulations, systemic failures, and social influences as influential to self-medicating choices and habits in pain management. Within these themes, negative relationships fostered by codeine regulations implementation hindered opportunities to provide support, conflicts of interest, systemic failures within the health system and in the classification of OTC analgesics and evolving information-seeking behaviours and social norms were implicated in influencing self-medicating with OTC codeine-based analgesics. Findings in phase two identified the through-line “just managing” and three emblematic themes: feeling disregarded, feelings of being misunderstood and OTC codeine is my enabler. Within these emblematic themes, environmental, social, and individual factors were linked and interacted overtime to influence choice of medication and the positioning of participants on the continuum of OTC codeine use overtime. Environmental factors included access to healthcare, quality of care participants had access to and relationships with healthcare providers. Social factors included socio-economic status and psychosocial support. Individual factors included level of knowledge of health condition and associated management strategies, psychological states, motivation levels, individual beliefs, and level of pain intensity and frequency (see Figure 1 on Page 257).

6.5.2. Synthesised findings

Synthesis of findings of phase one and phase two allowed a higher level, comprehensive and multi-dimensional synthesis of the environmental and social factors influencing self-medicating with OTC codeine-based analgesics. On environmental factors, there was convergence on the influence of access to healthcare, quality of care and classification of OTC analgesics. There was complementarity concerning the negative relationships between pharmacy professionals and individuals self-medicating for chronic pain fostered by codeine regulations implementation across both phases. In addition, phase one findings further broadened environmental factors by adding the complexity of implementing codeine regulations within the community pharmacy environment. Furthermore, phase two expounded on relationships with healthcare providers in chronic pain management. Together both phases built a holistic picture of the environmental factors that influence the positioning and transitioning of individuals on the continuum of OTC codeine use in pain management.

On social factors, there was convergence on the influence of SES to managing pain and self-medicating. Phase one further broadened social factors by adding the social influences that drive OTC codeine use. The synthesised findings on the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management are presented in Table 8 as drawn from the Self and Family Management Framework (Grey et al., 2015).

Table 8

Factors Influencing Positioning and Transitioning on the Continuum of OTC Codeine Use in Pain Management - *Drawn from the Self and Family Management Framework (Grey et al., 2015).

Environmental Factors
Access to healthcare
Quality of healthcare
Classification of OTC analgesics
Relationships with healthcare providers (GPs, pharmacy professionals, secondary care)
Social Factors
Socio-economic status
Psychosocial support
Social influences
Individual Factors
Health status
Knowledge and experience
Psychological stability
Motivation & beliefs

These environmental, social, and individual factors were linked and interacted overtime to influence self-medicating with codeine-based analgesics. Within these interactions, all factors were of equal importance, and all posed as risks or protective factors to self-medicating with codeine-based analgesics within recommended guidelines. They all represented the events, actions and interactions that were linked together meaningfully through time to influence self-medicating choices and habits in pain management. The identified environmental, social, and individual factors represent the processes influential to positioning and transitioning on the continuum of codeine use in pain management.

6.6 Environmental factors

6.6.1 Access to healthcare

Findings in the current study indicate an association between the level of access to healthcare an individual has with their positioning on the continuum of codeine use. Limited health access was associated with elevated self-medicating whilst increased access was associated with recommended self-medicating. Based on the CCM, access to health systems is instrumental to effective self-management through provision of information, activation of strategies and motivation (Bodenheimer, 2016). Moreover, early intervention is key to promoting effective self-management in chronic pain management (Gordon et al., 2017; Mills et al., 2016; Schulman-Green et al., 2016). The current study is consistent with literature, safe self-medicating requires early and ongoing access to healthcare services to promote effective self-management strategies that do not mainly rely of self-medicating for symptomatic relief. According to the WHO guidelines, access to pain management is a fundamental basic human right (WHO, 2020). IASP guidelines recommend timely and appropriate treatment for effective management of chronic pain (International Association for the Study of Pain, 2011). The experiences of participants in the current study reflect the lack of access to primary and secondary care in chronic pain management.

6.6.2 Quality of healthcare

Findings in the current study indicate an association between healthcare quality and positioning on the continuum of codeine use. According to the biopsychosocial approach, effective treatment of chronic pain requires treatments that combine biological, psychological, and social factors as well as their interplay in treating chronic pain (Gatchel, 2013; Hadi et al., 2017; Kamper et al., 2015). For optimum outcomes, interdisciplinary care must be provided within the same settings that includes physicians, psychologists, physiotherapists, occupational therapists, and nurses (Adler, 2009; Alonso, 2004; Bevers et al., 2016; Gatchel et al., 2014). Previous research in Ireland has identified and called for a national model of care for chronic pain management (Purcell et al., 2022; Fullen et al., 2006). However, to date there is none. IASP provides guidelines in standards of care in chronic pain management. It recommends multi-disciplinary care with clinicians from different specialities who deliver care in a co-ordinated, patient centred and evidence-based approach (IASP, 2009). The experiences of participants in the current study reflect the lack of access pathways for chronic pain treatment highlighting the need for a national model of care for chronic pain management in Ireland that includes timely, accessible co-ordinated and evidence-based interdisciplinary care.

6.6.3 Classification of OTC analgesics

Findings in the current study highlighted the ineffectiveness of the codeine regulations to curtail frequent supply in community pharmacies and subsequent elevated use of OTC codeine-based analgesics despite pharmacies highlighting the associated risks at the point of sale. International research show that Ireland has the second-highest sales per person (30 dosage units per person) for OTC codeine-based analgesics across 31 countries in Europe, Africa, Asia, America, and South America despite regulations being in effect since 2010 (Richards et al., 2022). In consideration of literature, theory, empirical evidence, rates of OTC codeine sales in Ireland and the findings of the current study, upscheduling of codeine from OTC to prescription only in Ireland would significantly reduce codeine consumption.

However, it is important to note the limitations in OTC analgesic classifications highlighted in the current findings by both pharmacy professionals and individuals self-medicating for chronic pain. Currently, Ireland only has paracetamol, ibuprofen, aspirin, and codeine as oral analgesics available OTC (Health Products Regulatory Authority, 2023). Apart from codeine, these are sold on their own or in combination. Codeine is only available in combination with other analgesics. In comparison with other countries, Ireland has a limited option of OTC oral analgesics. For example, oral NSAIDs like naproxen and diclofenac are available without a prescription in Australia in low doses (Healthdirect, 2023). Of note also is, Australia has an established model of care for chronic pain management (Model of Care for Chronic Pain Management in South Australia, 2016). Furthermore, a review on care delivery models for chronic pain in Australia reported consistent access to multi-disciplinary teams and multimodal treatments that included medication, interventional procedures, and psychologically informed PMPs (Agency for Clinical Innovation, 2021). Therefore, up scheduling codeine from OTC to prescription only should be considered in tandem with developing and implementing a model of care in chronic pain management and down scheduling of appropriate NSAIDs from prescription only to OTC.

6.6.4 Relationships with healthcare providers

Findings in the current study identified negative relationships with healthcare providers including pharmacy professionals as influential to self-medicating with OTC codeine-based analgesics. The findings implicate risk mitigation approaches both from GPs and pharmacy professionals around codeine consumption as central to the development of negative relationships. In the case of GPs, risk mitigation approaches in prescribing opioid-based analgesics typically left participants with limited pharmacological alternatives. In addition, the lack of adequate cognitive behavioural based alternative interventions in chronic pain management further compounded the negative relationships as participants felt neglected, dismissed, and disregarded by their GPs. However, provision of adequate accessible care for chronic pain management through primary and secondary care and development and implementation of a national model of care would address the issues central to the negative relationships between GPs and patients in chronic pain management. Likewise, the upscheduling of codeine from OTC to prescription only and down scheduling of appropriate NSAIDs from prescription only to OTC has potential to foster more positive relationships between pharmacy professionals and individuals self-medicating for pain as already evidenced in non-codeine interactions. The removal of codeine regulations has potential to promote use of community pharmacies as information sources through more natural and conducive interactions in pain management.

6.7 Social factors

6.7.1 Socio-economic status

Findings in the current study indicate an association between SES and positioning on the continuum of codeine use. The social injustice inherent within the Irish healthcare system is such that access to care is determined by affordability to pay. The current finding is consistent with previous research which found an association between low SES with reduced healthcare utilisation (Beyera et al., 2019) and elevated analgesic use (Bonathan et al., 2013) in chronic pain management. Socioeconomic disparities create health inequalities that influence self-management approaches and subsequently health outcomes in chronic pain management. The experiences of participants in the current study reflect the social injustice inherent within the Irish healthcare system highlighting the need for health service delivery approaches that offer individuals living with chronic pain care based on need instead of affordability.

6.7.2 Psychosocial support

In the current study participants in phase two described how they felt misunderstood in familial, social, and professional settings and the resulting lack of psychosocial support. Pain invisibility raised issues of legitimacy and participants avoided discussing their experiences therefore reducing opportunities for support. The development and implementation of a national model of care for chronic pain management in Ireland that includes timely, accessible co-ordinated, evidence-based interdisciplinary care would provide formal psychosocial support required in chronic pain management. Interdisciplinary care in chronic pain management requires a multi-disciplinary team that includes psychologists and counsellors that can provide psychological support and guidance on how to cope within social circles (Gatchel et al., 2014; Mills et al., 2016; Model of Care for Chronic Pain Management in South Australia, 2016).

6.7.3 Social influences

In the current study, pharmacy professionals highlighted social influences such as lifestyle choices, social norms, and evolving information sources as influential to self-medicating with OTC codeine-based analgesics. Upscheduling of codeine from OTC to prescription only in Ireland would negate the impact of social influences in codeine consumption. As discussed in section 6.5.3, upscheduling of codeine has potential to increase first-line analgesic use as an alternative to codeine-based analgesics once supply is only acquired with a medical prescription (McCoy et al., 2022; Schaffer et al., 2020). Social influence will have no role once the option to self-medicate with OTC codeine-based analgesics is removed.

6.8 Individual factors

The current study found an association between health status, knowledge, and experience of managing chronic pain, psychological stability, motivation to adopt effective self-management strategies and beliefs on perceived control over chronic pain and positioning on the continuum of codeine use. The main interventions that target individual factors in chronic pain management are CBT, ACT, self-management, and education interventions. There is meta-analytic evidence on the efficacy of CBT, ACT (Eccleston et al., 2009; Williams et al., 2020), and self-management (Du et al., 2017), which underpins a widespread adoption of psychological treatments for chronic pain. The provision of PMPs which incorporate psychological treatments guided by cognitive behavioural principles delivered by a team of interdisciplinary health professionals is crucial to achieve optimum chronic pain management (Gatchel et al., 2014; Williams et al., 2020). Pain education and active self-management strategies that focus on individual factors are usually substantial components of PMPs, where participants are taught exercise, attention diversion, activity pacing, goal setting, self-monitoring, deliberate exposure to pain, adherence to treatment plans, meditation, sleep management, thought management and communication skills (Du et al., 2017; Nicholas & Blyth, 2016). The efficacy of PMPs in improving health status, knowledge, and experience of managing chronic pain, psychological stability, motivation to adopt effective self-management strategies and beliefs on perceived control over chronic pain is well established (Hoffman et al., 2007; Williams et al., 2020). PMPs are cost effective, reduce unnecessary healthcare utilisation, and enable more appropriate healthcare use (British Pain Society., 2013; Turk, 2002). To date, there are only 5 (31,25%) public hospital departments in Ireland offering PMPs. Geographical distribution of PMPs is limited and access to this much needed service is problematic (Purcell et al., 2022). In the current study, only 2 participants reported attending a PMP at some stage in their chronic pain care highlighting the need for PMP services with an adequate geographical distribution across the country in chronic pain management.

6.9 Study limitations

Although the findings of this study have contributed new knowledge to the understanding of factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management, the study has some limitations. In phase one, the sample of pharmacy professionals consisted of 15 female and 10 male participants and to some extent may represent more of the experiences of female pharmacy professionals than male pharmacy professionals. However, this may be a representation of the reality of gender distribution within pharmacy professionals as data in Ireland indicate a higher proportion of pharmacists and pharmacy assistants identifying as females than males (Pharmaceutical Society of Ireland, 2023). In addition, of the 25 pharmacy professionals who took part, 18 worked in urban community pharmacies whilst the remaining 7 worked in both urban and rural pharmacies. It can be argued that the findings reflect more of the issues at the interface between urban community pharmacies and codeine consumers than those in rural community pharmacies in Ireland.

In phase two, the participant sample comprised of participants aged between 21 – 55 years. The age range of the sample meant that the experiences of older individuals were not captured within this study especially in consideration of the higher prevalence of chronic pain in older individuals (Fayaz et al., 2016; Pitcher et al., 2019; Raftery et al., 2011). In addition, the sample of the LQR included a higher number of females than males, so to some extent may represent more of the experiences of females than males. However, most population-based studies have found higher prevalence of chronic pain in women than in men (Fillingim et al., 2009; Ruau et al., 2012). Furthermore, it must also be acknowledged that most of the research was conducted during a pandemic and as such to an extend experiences in chronic pain management were linked to this. However, it added another dimension to the study as chronic pain management is lived and experienced within different contexts.

Overall, even though the design of the study adopted triangulation to synthesise and cross validate findings, it must be noted that sources of research (RTA and LQR) used were conducted by the same researcher. Synthesising additional research by other researchers with current findings will have further strengthened the study. However, this approach could not be adopted as to there was no identified research with the same focus within Ireland at the time of analysis.

6.10 Original contributions of the study

The current study has various contributions to knowledge. Firstly, the qualitative cross-sectional research with pharmacy professionals collated key insights on 1. The complexity inherent in decision-making at the point of sale during interactions between pharmacy professionals and codeine consumers within the general population, 2. The deficiency of the regulations adopted to mitigate misuse and abuse of codeine; 3. The barriers that impair the ability for pharmacy professionals to effectively deter elevated use of codeine-based analgesics in pain management; and 4. The impact of evolving information-seeking behaviours and social norms in self-medicating with OTC codeine-based analgesics. The current study brings an understanding of the perspective of pharmacy professionals who have been tasked as gatekeepers to implement codeine supply regulations and therefore can inform appropriate intervention strategies in codeine supply within an Irish context. It provides an understanding of the impact of codeine regulations 8 years after initial implementation contributing to codeine supply and use knowledge in Ireland.

Secondly, another key contribution is, the LQR study is the first study to explore and capture the experiences of a cohort of participants living with chronic pain to better understand their experiences and how this influences self-medicating habits within an Irish context. The findings led to the identification of factors that influence self-medicating with OTC codeine in chronic pain management. Environmental, social, and individual protective and risk factors were identified that influence choice of medication in the self-management of chronic pain and how they can interact overtime to influence positioning and transitioning on the use of codeine in chronic pain management. Another key contribution is, it is the first study to identify a driving force (through line - the common thread which captures change, continuity, and processes at play through time) “just managing”, in continuous self-medicating with OTC codeine-based analgesics. The novel LQR design adopted in the study uncovered processes of continuity/change overtime that influence positioning of individuals living with chronic pain on the continuum of codeine use. The combination of both longitudinal analysis across cases and within cases ensured a depth and breadth understanding of the experiences of managing chronic pain. It captured what change happens in the chronic pain experience, how the change happens and how participants experience and cope with change over-time in self-medicating habits. Within an Irish context, it is the first study to capture and elaborate on the influence of environmental, social, and individual factors overtime to self-medicating with codeine-based analgesics. It collated key insights on, 1. the impact of the healthcare structures and approaches adopted within healthcare systems and how these influences self-management of chronic pain overtime, 2. the impact of SES to the chronic pain management experience and how it shapes self-management of chronic pain overtime, 3. the impact of familial, social, and professional interactions in self-management of pain and how this influences self-medicating, 4. individual psychological processes that influences self-medicating with OTC codeine-based analgesics overtime. This has important implications for health policy and medicines supply regulations as changes can promote safe self-medicating in the self-management of chronic pain.

Thirdly, the synthesis of both phases is another key contribution of the study. It offered a multidimensional, and higher-level interpretation of the factors influencing self-medicating both from the perspective of community pharmacy professionals and individuals self-medicating for chronic pain (Farmer et al., 2006; Heale & Forbes, 2013). By using information from 1. experts by profession and experts by lived experience and 2. qualitative cross-sectional research and LQR to explore the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management the study exposed key insights that otherwise could not have been exposed by use of one cohort or method

(Golafshani, 2015; Patton, 1999). Another key contribution is, it is the first study to adopt a triangulation design in understanding the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management within an Irish context. Triangulation exposed key convergences and complementarities enhancing validity, credibility, and dependability of the research.

6.11. Implications of current study

The current study provides an explanation of how environmental, social, and individual factors interact overtime to influence positioning and transitioning on the continuum of codeine use in chronic pain management. With approximately 1 in 3 adults living with chronic pain (Raftery et al., 2011), and the Irish population purchasing 30 dosage units per person - second highest across 31 countries (Richards et al., 2022), the findings of the current study have significant implications for OTC codeine provision, health policies and research.

6.11.1 Codeine provision implications

The findings from the current study can help inform safe provision of codeine in pain management. Within the EU, countries like Germany, Italy, France, Finland, Greece, and Portugal require a prescription to supply any strength of codeine (Foley et al., 2015; Hockenhull et al., 2022). Research in Australia following the upscheduling of codeine to prescription only in 2018 after experiencing challenges similar to what Ireland is going through now show positive changes (McCoy, 2022, Schafer 2020, Bruno & Nielsen, 2018). Findings from current study show the need to change current provision approaches of codeine in Ireland. Based on these findings, upscheduling of codeine from OTC to prescription only would address the codeine epidemic in Ireland. In addition, down scheduling of appropriate

NSAIDs from prescription only to OTC will extend the options available for OTC analgesics. Furthermore, the extent of codeine use in Ireland can at best be estimated due to the lack of robust mechanisms to collect sales data (Richards et al., 2022). Revision in medication legislation on the supply of codeine in Ireland could improve access to codeine consumption data if pharmacies are required to supply codeine on prescription only.

6.11.2 Policy implications

The findings from the current study also have significant implications for health policies. Firstly, the findings shed light on how the lack of a national model of care (Purcell et al., 2022), for chronic pain management is problematic for individuals living with chronic pain as evidenced by the fragmented limited care provided. Effective interdisciplinary care in chronic pain management requires clear guidelines to inform service delivery (Agency for Clinical Innovation, 2021). In addition to previous calls made (Purcell et al., 2022; Hurley et al., 2006) the current findings highlight the immediacy and extends the call for the development and implementation of a national model of care for chronic pain management in Ireland.

Secondly, the Sláintecare Implementation Strategy and Action Plan 2021 - 2023 under Reform Programme 1 states the need to focus and prioritise improving safe, timely access to care and promoting health and wellbeing in Ireland (Government of Ireland, 2018). Sláintecare is a high-level policy roadmap in Ireland that sets out to deliver a whole systems reform in health and social care services. Through implementation strategies, it proposes to establish a universal single-tier health service and integrated patient focused high quality care in primary and community services (Burke et al., 2018). The current findings provide explicit evidence of the immediate need to provide adequate accessible care for chronic pain management through primary and secondary care informed by a national model of care through this reform.

Thirdly, the Sláintecare Implementation Strategy and Action Plan 2021 - 2023 under Reform Programme 2 states the need to achieve a universal single-tier health and social care system, where everyone has equitable access to services based on need, and not ability to pay in Ireland (Government of Ireland, 2018). The current findings expose the level and consequences of the social injustices in the current health system for people living with chronic pain. There is immediate need for implementation of a universal single tier health service that offers individuals living with chronic pain health services based on need instead of affordability. Lastly, the findings of the current study could inform future international policies as well, for example, the 1961 Single Convention on Narcotic Drugs and the WHO Expert Committee on Drug Dependence on the risks associated with the provision of codeine as an OTC analgesic (WHO, 2023).

6.11.3. Research implications

The current findings highlight various issues relevant for future research. The findings highlight the issues at the interface between community pharmacies and codeine consumers under the existing codeine regulations and can be used as an evidence base to track change or lack of progress in future studies as codeine legislation approaches evolve overtime. The findings from the LQR study identified factors influencing self-medicating with OTC codeine-based analgesics in chronic pain management. The identified environmental, social and individual factors are an application of the SFMF in self-medicating with OTC codeine-based analgesics in chronic pain management within an Irish context. The findings provide a foundation and opportunities for future research to explore self-medicating with OTC codeine-based analgesics using the SFMF within other contexts and jurisdictions. The environmental factors identified: 1. access to care, 2. quality of care and 3. relationships with healthcare providers provides an evidence base for further research in clinical settings to explore how adopting different approaches to these factors can impact self-medicating in chronic pain management.

In addition, on the social factors identified as influential to self-medicating with codeine-based analgesics, there was dissonance on social influences (lifestyle choices, social norms, and evolving information choices) between the two phases of the research. Pharmacy professionals highlighted the impact of social influences whilst findings from the lived experiences highlighted the impact of socio-economic status and psychosocial support in managing chronic pain and self-medicating. Farmer et al. (2006) highlighted how dissonances in findings can serve as a point of departure for further research to explore divergencies. Following on from current findings, further research could explore the impact of lifestyle choices, social norms, and evolving information choices from a lived experience perspective to build on and add clarity to the current findings.

Furthermore, the current findings highlighted how individual physiological and psychological factors are influential to self-medicating with codeine-based analgesics. Future research could build from the current findings by focusing on the impact of individual factors to self-medicating with codeine-based analgesics. For example, longitudinal quantitative research using experience sampling to pattern the effect of health status, psychological states, and daily activities to self-medicating. This has potential to provide a more in-depth understanding of the direct association between biopsychosocial factors, choice of medication and self-medicating habits in the self-management of chronic pain.

6.12 Concluding remarks

This thesis presented a multidimensional exploration of the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management. The qualitative cross-sectional research with pharmacy professionals provided insights from the perspective of OTC codeine gatekeepers who have been tasked with implementing regulations to deter misuse. Their views and experiences highlighted the unintended consequences of codeine regulations, systemic failures and the social influences that are central to how codeine is supplied and consumed in pain management. The LQR with individuals self-medicating for chronic pain provided lived experience insights on how they felt disregarded within the health system, felt misunderstood within social, familial, and professional settings and how OTC codeine-based analgesics were an enabler. The through-line "just managing" encapsulates the driver of self-medicating within these contexts. The following factors underpinning the lived experience of chronic pain management interact overtime to present the processes that influence the positioning and transitioning on the continuum of OTC codeine use; 1. environmental factors (access to healthcare, quality of healthcare, classification of OTC analgesics and relationships with healthcare providers), 2. social factors (socio-economic status, psychosocial support, and social influences) and 3. individual factors (health status, knowledge and experience, psychological stability and motivation and beliefs). The factors influencing self-medicating with OTC codeine-based analgesics are key to understanding how they are linked and interact overtime to influence how individuals respond to pain from a self-medicating perspective. Collectively, both the qualitative cross-sectional research and LQR presented a comprehensive, multidimensional, synthesised explanation of the factors that influence positioning and transitioning on the continuum of OTC codeine use in pain management therefore fulfilling the aim of the study.

The study has contributed to and filled significant gaps on our understanding of OTC codeine misuse in pain management. The findings have significant implications for codeine provision, healthcare policies and further research going forward.

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Appendices

Appendix C1: Research Participation Invitation

Research Participation Invitation

Researcher: **Talent Nyamakope (BSc), Postgraduate Student in the Department of Psychology at Maynooth University**

Phone number: **01 708 6479**

Email: talent.nyamakope.2018@mumail.ie

Supervisor: **Dr Deirdre Desmond (PhD), Senior Lecturer**

Phone number: **01 708 6479**

Email: deirdre.desmond@mu.ie

Project title: Pain management with over-the-counter medication in Irish community pharmacies.

Dear,

I am writing you to let you know about a research study that I am conducting on *Pain management with over-the-counter medication in Irish community pharmacies*. I am hoping that you will grant permission for me to invite some of your staff to take part in the study. I am interested in interviewing pharmacy staff who work as pharmacists, OTC advisors and pharmacy technicians in Irish community pharmacies.

About me

I am a full-time postgraduate student with Maynooth University currently working part-time as a pharmacy technician. I have more than 15 years' experience working as a pharmacy technician; and hold a BSc (Hons) in Psychology (First Class Honors).

About my research

The aim of the research study is to explore the views and experiences of community pharmacy staff on their interactions and relationships with patients/consumers in the management of pain with over the counter (OTC) medication. The study has been approved by the Ethics Committee in Maynooth University. The objectives of the study are:

5. To explore the healthcare advice provided in community pharmacies on pain management.
6. To explore the influence of the community pharmacy structure to the service provided on pain management.
7. To explore the relationship between pharmacy workers and patients/consumers in pain management.
8. To explore the issues surrounding the sale of over-the-counter (OTC) medication for pain management with specific focus on codeine based pain medication.

What does taking part involve?

Participation is voluntary and will involve one-to-one interviews lasting approximately 60-90 minutes. Interviews will be conducted at a venue that is convenient to the participant. During the interview, I will ask questions about the participant's role and experiences on their interactions with patients managing pain with OTC pain medication. There are no right or wrong answers, I am interested in learning more about community pharmacy staff views and experiences. With permission from participant, the interview will be recorded using a mobile device (the device is encrypted and protected with a strong password). The information generated will be transformed into text (i.e., transcribed) and any identifying information will be removed to protect participants' confidentiality. Anonymity will be maintained throughout the study by use of pseudonyms on transcripts. No individual participant or pharmacy will be identified in the final report.

What will happen to the information gathered?

Participants will have an opportunity to review and amend the transcript if they wish to do so. Any personal details collected to facilitate interview venue arrangements and checking of transcripts will be confidentially destroyed after transcript checking is finished. Data will be held on a secure desktop PC at Maynooth University. Data generated from this study will be analysed and findings will be published in academic journals, presented to the Pharmaceutical Society of Ireland as well as at appropriate conferences.

I am hoping to complete 25-30 interviews within the next eight weeks with pharmacists, OTC advisors and pharmacy technicians from both independent and chain pharmacies. Your approval to approach prospective participants in their respective pharmacies will help to facilitate this research study. If you are interested in learning more about the study and what it involves, I would be happy to meet, at a time and place convenient to you, to review the study in more detail. Thank you for taking the time to read about the study.

Yours Sincerely,

Talent Nyamakope.

Appendix C2: Participant Information Sheet

Researcher: **Talent Nyamakope (BSc)**

Phone number: **01 708 4765**

Email: **talent.nyamakope.2018@mumail.ie**

Project title: Pain management with over-the-counter medication in Irish community pharmacies.

Project details

The purpose of this study is to explore the views and experiences of community pharmacy staff on their interactions and relationships with patients/consumers in the management of pain with over-the-counter medication.

- As a prospective participant you are requested to take part in an audio-recorded interview sharing your views and experiences on your interactions with patients/consumers managing pain with over-the-counter medication.
- Interviews will be recorded using a mobile device that is encrypted and protected with a strong password. All data will be removed to a secure desktop PC at Maynooth University as soon as it is practicable.
- The data generated from the interview will be transcribed and you will be requested to check the transcript.
- Anonymity will be maintained throughout the study by use of pseudonyms on transcripts.
- All anonymised data will be held securely in rooms with limited access and electronic data will be saved on a secure server at Maynooth University.
- Data generated from this project will be analysed and findings will be published in academic journals, presented at appropriate conferences, and presented to the Irish Pharmaceutical Society.
- Data will be retained for ten years after which paper-based data will be confidentially shredded and electronic data will be securely deleted.
- All personal details collected to facilitate interview venue arrangements and checking of transcripts will be stored separately to the data with access restricted to the

postgraduate researcher. Details will be confidentially destroyed after transcript checking is finished.

- It must be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or during investigation by a lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.
- Should you experience any stress following participation, please contact your General Practitioner or alternatively the HSE National Counselling Service which can be accessed free of charge on 1850 24 1850.

Appendix C3: Interview Guide (Healthcare Assistants and Pharmacy Technicians)

Interview Guide (Healthcare Assistants and Pharmacy Technicians)

Scene Setting Questions

1. How long have you been working as an OTC assistant/pharmacy technician?
2. In general, how busy is the pharmacy you work in?
3. How big is the retail space in comparison with the healthcare/pharmacy space?
4. In general, which area in the pharmacy is the busiest, retail or pharmacy?
5. Do you have large prescription volumes?
6. In your dispensing, can you estimate the proportion of private prescriptions in comparison with medical card prescriptions?
7. How far is the nearest GP, hospital or medical centre where you most likely get prescriptions?

Interview Questions

1. **Can you tell me about your role in OTC pain management in the pharmacy?**

   Prompts

   - *How does that go in your interactions with patients with pain?*
   - *Do you feel that the patients you interact with in pain management understand your role?*

2. **Can you tell me about your role in assisting and selling of retail products in the pharmacy?**

   Prompts

   - *How does that impact your healthcare role in pain management?*

3. **Can you tell me about the sale of over-the -counter pain medication to patients managing pain?**

   Prompts

   - *How do you feel about the protocols involved in selling codeine-based medication?*
   - *How do your interactions go on the sale of codeine-based pain medication?*
   - *How do you identify dependence or abuse potential?*

- *Where codeine dependence or abuse is suspected, how do you manage these interactions?*
- *Do you ever refuse sales?*

4. **Each codeine sale is referred to the pharmacist. How do you feel about that?**

   Prompts

   - *How do your interactions with the pharmacist go in these referrals?*
   - *Do you feel that patients realise the significance of your role in the sale of codeine-based pain medication?*

5. **How do you feel about recommending codeine-based pain medication?**

   Prompts

   - *Do you recommend codeine-based medication often?*

6. **Do you have anything else you would like to share of your interactions with patients looking for codeine-based pain medication?**

Appendix C4: Interview Guide (Pharmacists)

Interview Guide (Pharmacists)

Scene Setting Questions

1. How long have you been working as a community pharmacist?
2. In general, how busy is the pharmacy you work in?
3. How big is the retail space in comparison with the healthcare/pharmacy space?
4. In general, which area in the pharmacy is the busiest, retail or pharmacy?
5. Do you have large prescription volumes?
6. In your dispensing, can you estimate the proportion of private prescriptions in comparison with medical card prescriptions?
7. How far is the nearest GP, hospital, or medical centre where you most likely get prescriptions?

Interview Questions

1. **Can you tell me about your role in OTC pain management in the pharmacy?**

   Prompts

   - *How does that go in your interactions with patients with pain?*
   - *Do you feel that the patients you interact with in pain management understand your role?*
2. **Can you tell me about your role in assisting and selling of retail products in the pharmacy?**

   Prompts

   - *How does that impact your healthcare role in pain management?*
3. **Can you tell me about the sale of over-the -counter pain medication to patients managing pain?**

   Prompts

   - *How do you feel about the protocols involved in selling codeine-based medication?*
   - *How do your interactions go on the sale of codeine-based pain medication?*
   - *How do you identify dependence or abuse potential?*

- *Where codeine dependence or abuse is suspected, how do you manage these interactions?*
- *Do you ever refuse sales?*

4. **Each codeine sale is referred to you. How do you feel about that?**

   Prompts

   - *How do your interactions with OTC advisors/technicians go in these referrals?*
   - *Do you feel that patients realise the significance of your role in the sale of codeine-based pain medication?*

5. **How do you feel about recommending codeine-based pain medication?**

   Prompts
   - *Do you recommend codeine-based medication often?*

6. **Do you have anything else you would like to share of your interactions with patients looking for codeine-based pain medication?**

Appendix C5: Ethical Approval

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

21 March 2018

Talent Nyamakope
Department of Psychology
Maynooth University

Re: Application for Ethical Approval for a project entitled: Pain management with over-the-counter medication in Irish community pharmacies.

Dear Talent,

The above project has been evaluated under Tier 2 process, Expedited review and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 31 March 2019.

Kind Regards,

Dr Carol
Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Dr Deirdre Desmond, Department of Psychology, Maynooth University.

Reference Number
SRESC-2018-031

Appendix C6: Participant Consent Form

Research study Title: Pain management with over-the-counter medication in Irish community pharmacies.

Principal Investigator:	**Talent Nyamakope (BSc)**
Address:	**Maynooth University, Maynooth, Co. Kildare**
Telephone number:	**01 708 4765**
Email Address:	**talent.nyamakope.2018@mumail.ie**

Supervisor's Name:	**Dr Deirdre Desmond (PhD)**
Address:	**Maynooth University, Maynooth, Co. Kildare**
Telephone Number:	**01 708 6479**
Email Address:	**deirdre.desmond@mu.ie**

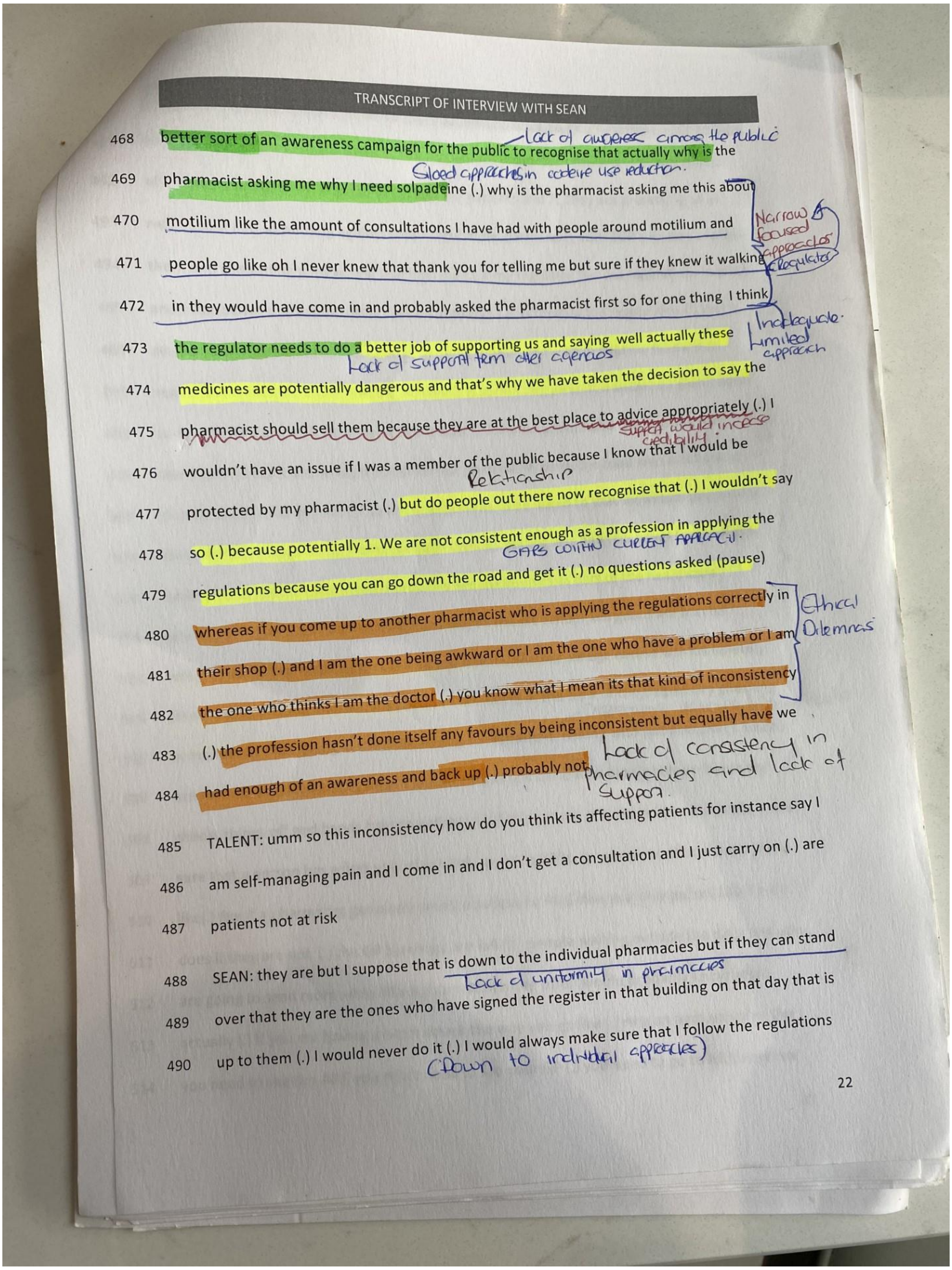
	Please Tick
I have been provided with an information sheet detailing the research project.	
I understand the research project and the nature of my participation in the research project.	
I understand that I am voluntarily taking part in the research project.	
I consent to taking part in an audio-recorded interview.	
I understand that all data collected will be anonymised and will be stored securely for a period of ten years after which it will be securely destroyed.	
I am aware that all collected data will be kept confidential, and I understand the limitations of the confidentiality.	

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at

research.ethics@mu.ie* or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Signature ……………………………………………………………………….
Date…………………………………………………….

Appendix C7: Coded transcript



TRANSCRIPT OF INTERVIEW WITH SEAN

better sort of an awareness campaign for the public to recognise that actually why is the pharmacist asking me why I need solpadeine (.) why is the pharmacist asking me this about motilium like the amount of consultations I have had with people around motilium and people go like oh I never knew that thank you for telling me but sure if they knew it walking in they would have come in and probably asked the pharmacist first so for one thing I think the regulator needs to do a better job of supporting us and saying well actually these medicines are potentially dangerous and that's why we have taken the decision to say the pharmacist should sell them because they are at the best place to advice appropriately (.) I wouldn't have an issue if I was a member of the public because I know that I would be protected by my pharmacist (.) but do people out there now recognise that (.) I wouldn't say so (.) because potentially 1. We are not consistent enough as a profession in applying the regulations because you can go down the road and get it (.) no questions asked (pause) whereas if you come up to another pharmacist who is applying the regulations correctly in their shop (.) and I am the one being awkward or I am the one who have a problem or I am the one who thinks I am the doctor (.) you know what I mean its that kind of inconsistency (.) the profession hasn't done itself any favours by being inconsistent but equally have we had enough of an awareness and back up (.) probably not

Lack of awareness among the public

Siloed approaches in codeine use reduction.

Narrow & focused approaches (Regulator)

Inadequate. Limited approach

Lack of support from other agencies

Support would increase credibility.

Relationship

GAPS WITHIN CURRENT APPROACH.

Ethical Dilemmas

Lack of consistency in pharmacies and lack of support.

TALENT: umm so this inconsistency how do you think its affecting patients for instance say I am self-managing pain and I come in and I don't get a consultation and I just carry on (.) are patients not at risk

SEAN: they are but I suppose that is down to the individual pharmacies but if they can stand over that they are the ones who have signed the register in that building on that day that is up to them (.) I would never do it (.) I would always make sure that I follow the regulations

Lack of uniformity in pharmacies

(Down to individual approaches)

22

Appendix LQR1: Research Participation Invitation

Research Participation Invitation

Researcher: **Talent Nyamakope (BSc), Postgraduate Student in the Department of Psychology at Maynooth University**

Phone number: **01 708 4765**

Email: talent.nyamakope.2018@mumail.ie

Supervisor: **Dr Deirdre Desmond (PhD), Senior Lecturer**

Phone number: **01 708 6479**

Email: deirdre.desmond@mu.ie

Project title: The Lived Experiences of Self-Care in Pain Management and Self-Medicating.

Dear

I am writing you to let you know about a research study that I am conducting on *Lived Experiences of Self-Care in Pain Management and Self-Medicating.* I am seeking approval to advertise for participant recruitment among your members via your website, social media links and centres. I am interested in interviewing adults with chronic pain, self-medicating with over-the-counter analgesics including codeine-based analgesics.

About me

I am a full-time postgraduate student with Maynooth University. I have more than 15 years' experience working as a community pharmacy technician; and hold a BSc (Hons) in Psychology (First Class Honours).

About my research

The aim of this research is to explore the lived experiences of individuals managing pain and how these experiences influence choice and use of over the counter (OTC) pain medications in self-medicating.

The objectives of this research are:

- To explore the lived experiences of individuals managing pain overtime and the strategies they employ to achieve good pain control.
- To explore self-medicating habits in the self-management of pain with specific emphasis on over-the counter codeine-based analgesic use.
- To explore the psychosocial factors that influence choice and use of medication for pain experience, focusing on change or stability overtime and the causes and consequences of change.
- To explore the relationships between participants and pharmacies in the self-management of pain.

What does taking part involve?

Participation is voluntary and will involve one-to-one interviews lasting approximately 60-90 minutes. Interviews will be conducted at a venue that is convenient to the participant at four time points (initial interview, 6 months, 12 months and at 18 months). During the interview, I will ask their experiences of managing pain, strategies they use to control pain, over-the-counter analgesic use and their interactions with pharmacies. There are no right or wrong answers, I am interested in learning more about their experiences. With permission from the participant, the interviews will be audio-recorded. The information generated will be transformed into text (i.e., transcribed) and any identifying information will be removed to protect participants confidentiality. Anonymity will be maintained throughout the study by use of pseudonyms on transcripts.

What will happen to the information gathered?

Participants will have an opportunity to review and amend interview transcripts if they wish to do so. Any personal details collected to facilitate interview venue arrangements and checking of transcripts will be confidentially destroyed after transcript checking is finished. Data will be held on a secure desktop PC at Maynooth University. Data generated from this study will be analysed and findings will be published in academic journals, presented to pain management organisations as well as at appropriate conferences.

I am hoping to recruit 15 participants and your approval to advertise for participant recruitment will help to facilitate this research study. Prospective participants will have the opportunity to opt-in to the research if they wish to do so, participation is entirely voluntary. If you are interested to learn more about the study and what it involves, I would be happy to meet, at a time and place convenient to you, to review the study in more detail. Thank you for taking the time to read about the study.

Yours Sincerely,

Nyamakope

Talent Nyamakope.

Appendix LQR2: Research Participation Leaflet

Maynooth University
National University of Ireland Maynooth

Researcher: Talent Nyamakope BSc
Contact Details: 086 173 4625
talent.nyamakope.2018@mumail.ie

Are you managing chronic pain with pain medication including solpadeine or nurofen plus?

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY

What does participation involve?

As a participant you are requested to take part in audio-recorded interviews at four time points (initial interview, 6 months, 12 months and at 18 months) sharing your experiences of managing pain and how these experiences influence choice and use of over-the-counter (OTC) pain medications in self-medicating.

If you are interested in participating or to learn more about the research and what it involves, please do not hesitate to contact me.

Appendix LQR3: Research Participation Sheet

Maynooth University
National University of Ireland Maynooth

Research Participation Information Sheet

Researcher: **Talent Nyamakope (BSc), Postgraduate Student in the Department of Psychology at Maynooth University**

Phone number: **086 708 4765**

Email: talent.nyamakope.2018@mumail.ie

Supervisor: **Dr Deirdre Desmond (PhD), Senior Lecturer**

Phone number: **01 708 6479**

Email: deirdre.desmond@mu.ie

Project title: The Lived Experiences of Self-Care in Pain Management and Self-Medicating.

Project details: The purpose of this study is to explore the lived experiences of individuals managing pain and how these experiences influence choice and use of over the counter

(OTC) pain medications in self-medicating. I am interested in interviewing individuals with chronic pain for more than 3 months and are managing pain with over-the-counter medication including Solpadeine or Nurofen plus. You are invited to take part in 4 one-to-one interviews sharing your experiences on how you are managing pain. The interviews will be carried out once every six months (initial, 6-months, 12-months and 18-months). Please read the information below and take some time to consider if you would like to take part. If you would like to know more or are interested in participating, please contact me directly using the contact details provided above. I am hoping to interview 15 participants.

- If you agree to take part, for each of the 4 interviews, I will arrange a time and venue at your convenience to complete the interview. During the interview, which will last approximately 60 – 90 minutes, I will ask questions about your experiences in managing pain, strategies you use to control pain and how over-the-counter pain medication helps. There are no right or wrong answers, I am interested in learning more about your own experiences. If you agree I will record the interview using a mobile device (the device is encrypted and protected with a strong password). The information generated will be transformed into text (i.e., transcribed) and any identifying information will be removed to protect your confidentiality. The audio recording will be destroyed as soon as is practicable. You will have an opportunity to review and amend the transcript if you wish to do so.
- Any personal details collected to facilitate interview venue arrangements and checking of transcripts will be stored separately to the data with access restricted to the postgraduate researcher. Details will be confidentially destroyed after transcript checking is finished.
- All data will be held on a secure desktop PC at Maynooth University.
- Anonymity will be maintained throughout the study by use of pseudonyms on transcripts.
- All anonymised data will be held securely in rooms with limited access and electronic data will be saved on a secure server at Maynooth University.
- Data generated from this project will be analysed and findings will be published in academic journals, presented at appropriate conferences and presented to the Irish Pharmaceutical Society.
- Data will be retained for ten years after which paper-based data will be confidentially shredded and electronic data will be securely deleted.
- It must be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or during investigation by a lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.
- Participation in the research does not constitute or substitute for medical advice, if you are concerned about any of the issues raised in the research, please discuss the issues with your GP or health services.
- We do not anticipate that you will experience any distress from participation in this research study. Should require support in managing pain, please contact your General

Practitioner or alternatively the HSE National Counselling Service which can be accessed free of charge on 1850 24 1850.

- The protocol for this study has been approved by (SREC) at MU. If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Thank you for taking the time to read about the study and for considering taking part. Please do not hesitate to contact me or my research supervisor if you would like further information.

Appendix LQR4: T1 Interview Guide

Interview Guide

1. **Can you tell me about your pain experience?**
   Prompts
   - *How has your life changed due to living with pain?*
   - *How do you manage day to day activities?*
   - *How has living with pain impacted your family/social/work life?*
   - *How does living with pain make you feel?*

2. **Can you tell me how you manage pain?**
   Prompts
   - *How do you manage to achieve good pain control?*
   - *How did you learn to achieve good pain control?*
   - *Are there any pain control strategies you have used that did not work?*
   - *Do you have sources that you seek advice on how to effectively manage pain?*
   - *Do you feel you have enough information/resources to self-manage pain?*
   - *Is there any support you feel would assist you in self-managing pain?*

3. **Do you have family/friends who support you in managing pain?**
   Prompts
   - *How do they support you?*
   - *Do you feel your family/friends understand the pain you experience?*
   - *Are there things they do that you find unhelpful?*
   - *Is there anything you feel your family/friends could do to support you in managing pain?*

4. **Can you tell me how you use over-the-counter medication in controlling pain?**

   Prompts
   - *Do you use any prescription pain medication?*
   - *Which over-the-counter pain medication do you mainly use?*
   - *How often do you use over-the-counter pain medication?*
   - *Which over-the-counter pain medication is your first choice for managing pain?*
   - *How effective is paracetamol/ibuprofen/aspirin in controlling the pain?*
   - *How effective is Solpadeine/Nurofen Plus in controlling the pain?*

5. **Can you tell me of your experiences when you go to pharmacies/chemists looking for pain medications?**

   Prompts

   - *Do you normally buy over-the-counter pain medication in one pharmacy?*
   - *Do you feel that pharmacists and pharmacy assistants have a role in assisting you in managing your pain.*
   - *Do you trust the advice pharmacists/pharmacy assistants give when you are buying over-the-counter medication?*
   - *Can you tell me of your experience the last time you went to buy Solpadeine or Nurofen plus?*
   - *Is that typical of your experiences when you buy Solpadeine or Nurofen plus?*
   - *Is there anything that you would suggest that pharmacies could do to improve self-management of pain?*

6. **Is there anything else you would like to share that you feel I should know?**

7. **Questions on markers of socioeconomic status**
   - *Do you have health insurance, General Medical Services Card or you pay privately for your medical costs?*
   - *Are you employed?*
   - *What level of education do you have?*
   - *How far is your GP from where you live?*

Appendix LQR5: Subsequent Interview Guide Example

1. **Can you tell me how you have been since the last time we met?**

Prompts

- *How has been the pain experience?*
- *How are you managing day to day activities?*
- *How is your family/social/work life at the moment?*
- *How does managing pain continuously make you feel?*

2. **Have you been to your GP or Specialist in the last 6 months?**

Prompts

- *How did the visit go?*
- *Has your prescription medication changed in the last 6 months?*
- *Have you had any procedures or surgeries done in the last 6 months?*
- *Has there been an improvement since your last interaction with your GP/Specialist?*

3. **Can you tell me how you are currently managing pain?**

Prompts

- *Can you talk me through how you would typically manage pain when you are having a flare up?*
- *Do you manage to achieve good pain control?*
- *Are there any pain therapy activities you are currently engaging with?*
- *Are you currently taking any prescription pain medication?*
- *Which over-the-counter pain medication are you currently using?*
- *How often do you use over-the-counter pain medication?*
- *Which over-the-counter pain medication is your first choice for managing pain?*
- *How effective is over the counter medication in controlling the pain?*

4. **Can you tell me of your interactions with pharmacies in managing pain?**

Prompts

- *Do you normally buy over-the-counter pain medication in one pharmacy?*

- *Have you sought advice on pain management from a Pharmacist in the last 6 months?*
- *Can you tell me of your experience the last time you went to buy over the counter medication?*
- *Is that typical of your experience when you buy over the counter medication including Solpadeine or Nurofen plus?*
- *Is there anything that you would suggest that pharmacies could do to improve self-management of pain?*

5. **Are you receiving support from family and friends**
    - *How do they support you?*
    - *Is there anything you feel your family/friends could do to support you in managing pain*

6. **Expanding on identified themes from previous interviews. This section was informed by previous interviews for each participant.**
    - For example: In our last interview we discussed how weather was impacting the way you manage pain. Can you tell me about your recent experiences with that?

7. **Reflection questions (final interview only)**

    - Looking back to 18 months ago, how has been the whole chronic pain experience?
    - How are your self-medicating habits now?
    - How do you envision your future in terms of living with chronic pain?
    - How do you envision your future in terms of self-managing pain

8. **Is there anything else you would like to share that you feel I should know?**

Appendix LQR6: Ethical Approval

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

21 March 2019

Talent Nyamakope
Department of Psychology
Maynooth University

RE: Application for Ethical Approval for a project entitled: Lived Experiences of Self-Care in Pain Management and Self-Medicating

Dear Talent,

The Ethics Committee evaluated the above project and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 31 August 2021.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Dr Deirdre Desmond, Department of Psychology Maynooth University

Reference Number
SRESC-2019-018

Appendix LQR7: Consent Forms

Research study Title: The Lived Experiences of Self-Care in Pain Management and Self-Medicating.

Principal Investigator: **Talent Nyamakope (BSc)**

Address: **Maynooth University, Maynooth, Co. Kildare**

Telephone number: **01 708 4765**

Email Address: **talent.nyamakope.2018@mumail.ie**

Supervisor's Name: **Dr Deirdre Desmond (PhD)**

Address: **Maynooth University, Maynooth, Co. Kildare**

Telephone Number: **01 708 6479**

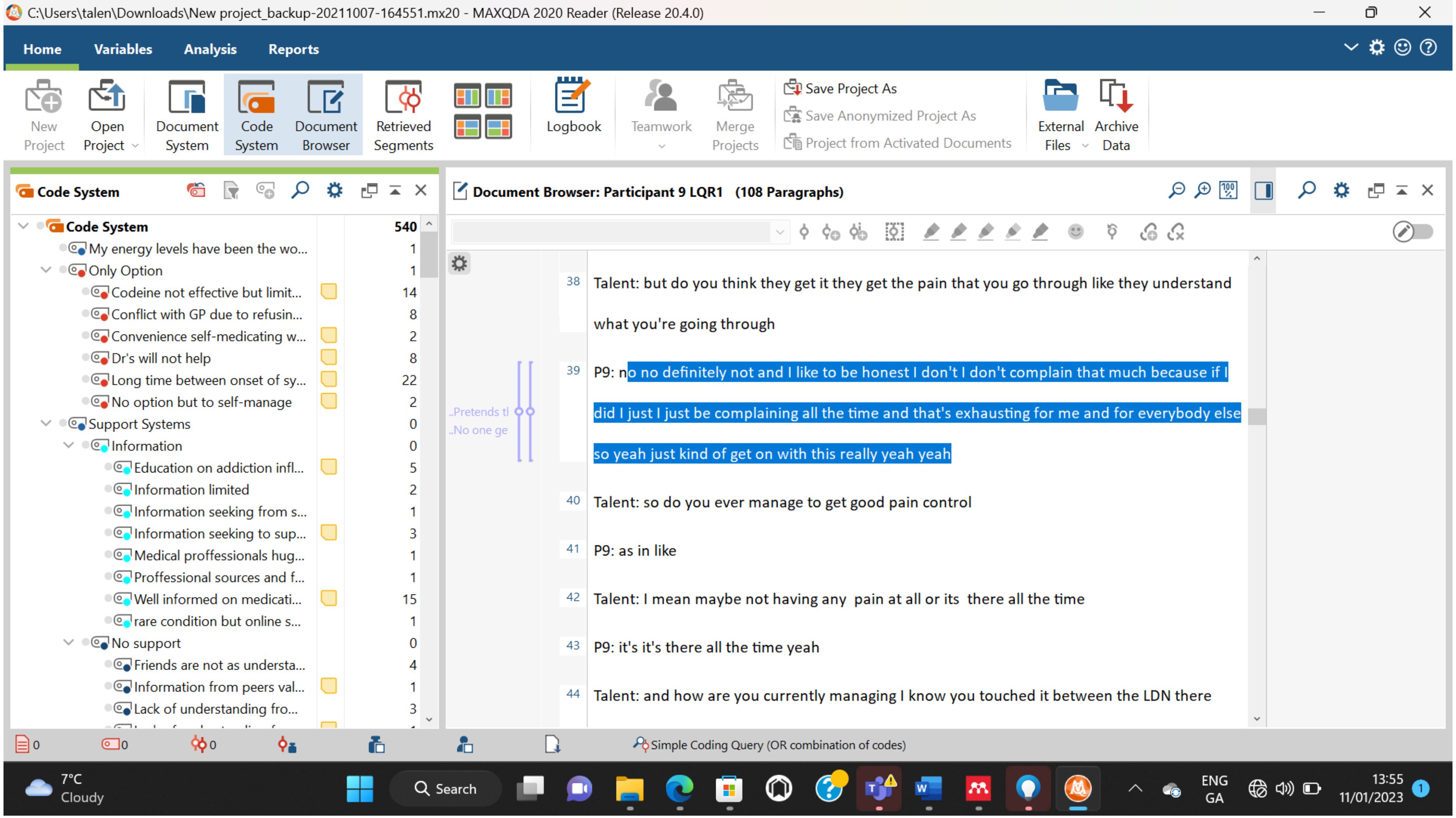
Email Address: **deirdre.desmond@mu.ie**

	Please Tick
I have been provided with an information sheet detailing the research project.	
I understand that I will be invited to take part in up to 4 interviews.	
I understand that I am voluntarily taking part in the research project, and I have the right to withdraw and the right to decline participation at any stage.	
I consent to taking part in an audio-recorded interview and to be contacted again to consider taking part in a subsequent interview.	
I understand that all data collected will be anonymised and will be stored securely for a period of ten years after which it will be securely destroyed.	
I am aware that all collected data will be kept confidential, and I understand the limitations of the confidentiality.	

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at *research.ethics@mu.ie* ***or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.***

Signature ……………………………………………………………………….
Date…………………………………………………

Appendix LQR8: Sample of Coded Transcript



Code System

Code System	540
My energy levels have been the wo...	1
Only Option	1
Codeine not effective but limit...	14
Conflict with GP due to refusin...	8
Convenience self-medicating w...	2
Dr's will not help	8
Long time between onset of sy...	22
No option but to self-manage	2
Support Systems	0
Information	0
Education on addiction infl...	5
Information limited	2
Information seeking from s...	1
Information seeking to sup...	3
Medical proffessionals hug...	1
Proffessional sources and f...	1
Well informed on medicati...	15
rare condition but online s...	1
No support	0
Friends are not as understa...	4
Information from peers val...	1
Lack of understanding fro...	3

Document Browser: Participant 9 LQR1 (108 Paragraphs)

38 Talent: but do you think they get it they get the pain that you go through like they understand what you're going through

39 P9: no no definitely not and I like to be honest I don't I don't complain that much because if I did I just I just be complaining all the time and that's exhausting for me and for everybody else so yeah just kind of get on with this really yeah yeah

40 Talent: so do you ever manage to get good pain control

41 P9: as in like

42 Talent: I mean maybe not having any pain at all or its there all the time

43 P9: it's it's there all the time yeah

44 Talent: and how are you currently managing I know you touched it between the LDN there

Appendix LQR9

Overview of themes and subthemes from cross-sectional analysis

Timepoint 1	Timepoint 2	Timepoint 3	Timepoint 4
Theme 1: Challenges in accessing health services • Delays in accessing care • Inadequate care • Cost as a barrier	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own	**Theme 1: Challenges in accessing health services** • Delays in accessing care • Inadequate care • Cost as a barrier • Cessation of care • You are on your own
Theme 2: No one understands • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and families	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority	**Theme 2: No one understands** • Minimising of suffering in healthcare services • Risk mitigation approaches • Disengagement • Minimal understanding from friends and family • Not a priority
Theme 3: Codeine provides options • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option. • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality	**Theme 3: Codeine provides options** • Codeine is the only option • Codeine is the preferable option • Codeine is the safer option • Exerting control • Striving for normality
	• **Theme 4: Deterioration** • Getting worse with time • It’s up and down	**Theme 4: Deterioration** • Getting worse with time • It’s up and down	**Theme 4: Deterioration** • Getting worse with time • It’s up and down

Appendix LQR10:

Conceptually Clustered Matrix

	Challenges in accessing health services	**No one understands**	**Codeine provides options**	**Deterioration**	**Summary**
Amy	Rheumatologist led care. Daily prescribed medication to manage conditions but no ongoing pain medication. No access to multi-disciplinary care. Had no access to services during Covid. On waiting list for over 2 years for surgical procedures at Timepoint 4	No-co-ordinated care despite having access to specialist services through private insurance. Friends did not understand when she had to cancel and was wary of overburdening friends from complaining.	Preferred OTC codeine as compared to prescription due to reduced side effects. Self-medicated only as a last resort as she incorporated physical exercise and non-pharmacological alternatives	Condition was progressive over the duration of the study and therefore overtime pain intensity and frequency had increased	Very high health literacy. Is very knowledgeable and confident to ask Dr's to prescribe specific medication from own experience working in the medical field. Coordinates own care.
Louise	Specialist led care but no multidisciplinary approach in care. Access to ongoing prescription medication to manage conditions. Received minimal remote care during Covid. On waiting list for over 2 years for surgical procedures at Timepoint 4	No-co-ordinated care despite having access to specialist services through private healthcare insurance. Felt her condition was not prioritised and should have continued to receive care during Covid. Louise had gone through a divorce and felt living with chronic pain had attributed to this outcome due to lack of understanding. Did not discuss pain experience with friends as she didn’t want them to look at her differently and felt they would not understand it anywhere	Despite having access to prescription codeine. Louise had minimal amounts each month and supplemented with OTC codeine-based analgesics for persistent and breakthrough pain and flare ups	Conditions were progressive and the lack of surgical interventions during COVID contributed to further deterioration	Very resilient and had a positive outlook. Valued the bio-medical approach in pain management. Incorporated physical exercising and dieting when she could to manage pain.

Helen	No continuous access to GP care due to financial barriers	Initially found GP to be dismissive without offering support and then disengaged	Codeine provided the only pharmacological option to manage pain since disengaging with GP	Due to lifestyle changes pain frequency and intensity had increased over the duration of the study	Socio-economic status was a determinant of the interventions she currently received. Hoped this would change once she started working or got approved for a medical card
Joanne	Received care from different specialists in different hospitals without communication between specialists. Had prescribed medications daily to manage conditions. Negative relationships with GPs due to conflict around codeine misuse and refusal to prescribe. Had no access to services during Covid. On waiting list for over 2 years for surgical procedures at T4	Lack of empathy from GP. Changed GP and still had similar experiences. Lack of empathy from pharmacies and employed pharmacy hopping to obtain OTC codeine supplies	Elevated self-medicating daily with codeine as well as overdosing to alleviate pain and meet daily demands. Was concerned about adverse side effects but felt she had no other option, and they were safer in comparison to prescription codeine-based analgesics	Conditions were progressive and the lack of surgical interventions during COVID contributed to further deterioration	The narratives Joanne employed to describe her pain experience contradicted the level of functionality expressed in her day-to-day living suggesting catastrophising. Fear of pain evident in narrative. Joanne also had a clinical diagnosis of depression and anxiety and was taking prescribed medication
Edel	Access to specialist care. However, was wary of taking ongoing medication to manage condition due to previously experienced side effects. Preferred to use OTC analgesics for symptomatic relief	Medical professionals were generally not aware of her condition and dismissed some of her concerns. Was once asked if she was experiencing domestic abuse and hiding it due to the number of dislocations on her record. Struggled to make family understand she could not perform	Due to being wary of prescription medication, OTC codeine-based analgesics were participant's preferred option to manage pain. However, she was very resilient and self-medicated only when pain became unbearable	Condition was progressive and deteriorated over the course of the study and participant was starting to struggle with day-to-day tasks, had to get an automatic car and weight bearing exercise was a challenge	Very resilient, high health literacy, pain acceptance and pain willingness, awareness and engagement. Very informed due to information-seeking behaviours as most professionals do not understand her condition. Fighting to remain mobile for as long as possible. Feels

		basic tasks. Perceives family thought she is lazy.			giving in will result in disability and wheelchair use.
Katie	No continuous access to GP care due to financial barriers	Had been dismissed by GP during initial attempts to seek medical intervention. Had been advised to use paracetamol for pain and based on experience it had limited efficacy	OTC Codeine-based analgesics were the only pharmacological option to manage pain since disengaging with GP	Migraine frequency was up and down and could not identify any triggers for them	Despite the longevity of the time and the consistency of migraines participant had no other strategies of managing and sorely relied on self-medicating
Jack	GP led care and on medication specific to condition. Had a good ongoing relationship with GP. Initially GP was prescribing OTC codeine as participant was on a medical card, but this was later on changed to ibuprofen at the participant's request.	Initial attempts to seek medical interventions with GP had not yielded expected results and had to go to A&E to finally get a diagnosis and prescribed medication. Family knew of his condition but did not acknowledge or discuss it. Felt using a cane was the only way people understood but he was not comfortable being seen with a cane	Initially OTC-codeine-based analgesics provided the only option to self-manage pain, but as self-management strategies improved this ceased to be the case. Incorporating alternative management strategies reduced pain frequency and intensity.	Condition was progressive overtime. However, incorporating alternative management strategies provided symptomatic relief	Overtime participant developed effective self-management coping strategies that decreased the need to self-medicate with OTC codeine-based analgesics and was using ibuprofen instead
Peter	No continuous access to GP care due to conflict around misuse of codeine resulting in self-led management. Sourcing unlicensed medication from another doctor	Felt GPs and Pharmacy staff were not supportive, and interactions were characterised by judgemental attitudes. Felt his family did not want to acknowledge his struggle and did not understand the burden of chronic pain	OTC codeine-based analgesics were the only pharmacological option to self-manage pain since disengaging with GP and having no specialist care	Condition deteriorated over the duration of the study	Peter felt strongly that the effects of codeine side effects were more manageable than living with chronic widespread pain. Self-medicating enabled him to function. Post diagnosis Peter had been prescribed anti-depressants but had

					ceased taking them due to adverse side effects
Darren	No continuous access to GP care due to financial barriers. Initial attempts to engage did not build confidence with GP. Saw no need to pay for a service that did not meet his expectations around prescribing options.	GP was dismissive and participant felt not listened to. No alternative support was provided resulting in disengaging. Participant felt family were not understanding how he was struggling to keep on working and were not supportive of him to consider stopping work	OTC Codeine-based analgesics provided the only pharmacological option to manage pain in the absence of GP support	Overtime and due to the type of work participant did, arthritis worsened over the duration of the study	Maintaining his work and not seeing value in engaging with GP was central to continuous self-medicating with OTC codeine-based analgesics

Appendix LQR11

Example of Time Ordered Sequential Matrix

Codeine use within recommended doses highlighted in green,

Increases in self-medicating highlighted in yellow.

Elevated codeine use highlighted red.

Participant	Timepoint 1	Timepoint 2	Timepoint 3	Timepoint 4	Summary
Amy	Does not engage with GP regarding chronic pain. Sees consultant rheumatologist only twice a year but would prefer to be seen more often. No holistic and multi-disciplinary approach within the service. Participant is left to deal with pain with no support. No referrals to pain specialists, OT Physio, dietician, psychologist. Once had to pay for a counsellor so she could offload. Currently taking codeine periodically when pain is unbearable. Prefers to take before bed as they help with sleeping. Pharmacy hopping due to difference in pricing. Always ensures she has some handy	Rheumatologist recently retired and new one is not as thorough. Received a guided injection in the left knee in March which has eased the pain and helps with walking. Currently working from home (WFH) and there is no need to self-medicate to meet daily demands. Codeine intake has drastically reduced. Has taken them twice in the last couple of months.	Experiencing new back pain and condition is deteriorating. Not seen Rheumatologist since and injection has worn off resulting in more pain in knee. Phone consultation offered and prescription codeine prescribed for a week. She requested a back scan but is still waiting. Attended physio privately but could only afford a couple of sessions Codeine intake increase due to acute episode but had concerns around staying on prescription codeine and therefore preferred OTC codeine	Had another phone consultation with rheumatologist. It will be almost 2 years before the next appointment which she is hoping it will be face to face. Phone consultations are not ideal, but participant is quite knowledgeable and is able to ask for specific procedures and medications. However still no investigation and tests for the back pain. Codeine intake has decreased, only self-medicating for elevated and persistent pain	Psychological flexibility: Pain acceptance and willingness, awareness, hardiness, engagement, very high health literacy evidenced in narratives. Is very knowledgeable and confident to ask Dr's to prescribe specific medication. Coordinates own care. On Celebrex, Neurontin and Methotrexate, to manage condition but no ongoing analgesics. WFH is helping with pacing. Understanding of chronic pain influential to intake of codeine. OTC codeine is preferable to RX. **Decreases and increases in self-medicating with OTC codeine**

Louise	Specialist led care but no access to multidisciplinary care. Access to ongoing prescription medication to manage conditions. Has ongoing prescription for opioid analgesics which she takes once a day. Self-medicates for breakthrough pain	Minimal care during Covid. Normally receives guided injections to manage pain but has only been getting phone consultations, Pain is worsening. On waiting list for surgical intervention. Increased intake of opioid prescription analgesics and self-medicating for breakthrough pain	Minimal remote care during Covid. Currently having a flare up as well as experiencing tooth pain. On waiting list for surgical intervention. Prescription analgesics are not controlling pain much Self-medicating has increased due to increased pain intensity	Received minimal remote care during Covid. On waiting list for over 2 years for surgical procedures. Condition has deteriorated and is now taking prescription opioid analgesics morning and evening then self-medicates for breakthrough pain	Very resilient and has a positive outlook. Values the bio-medical approach in pain management. Incorporates physical exercising and dieting when she can to manage pain. Psychological flexibility **Decreases and increases in self-medicating with OTC codeine**
Helen	No engagement with GP due to financial barriers. Only self-managing with OTC analgesics. OTC codeine-based analgesics are the first choice of painkillers when in pain especially for the migraines as there is nothing much that she can do to alleviate pain. Self-medicates for a few days every week	Frequency and intensity of migraines have increased due to a different routine. Self-managing due to financial barriers. Currently managing migraines with codeine. Aware of the risk of constantly taking medication but the need to control pain takes precedence. Codeine takes edge off but is not completely effective. Tries to take twice a day but does go up to four times a day if pain is intense.	Frequency and intensity of migraines have reduced due to different routine. Finding time to exercise and therefore knee is much better. Self-managing due to financial barriers. self-medicating with codeine for migraines. Not sure if they are even effective but the psychological effect of taking something is helpful. **Self-medicating every week has reduced since pain intensity and frequency is less**.	Self-managing due to financial barriers. Painkillers are not as effective but has no other options until she can access medical intervention. Taking codeine for both knee pain and migraines. Very aware of dependency and addiction issues but tries to moderate to control this. Self-medicating more due to the increased intensity of pain.	Codeine analgesics are the only option since disengaging with GP. Wary of constantly taking medication but has no other option if in extreme pain. Has had periods of overdosing before due to elevated pain, felt she had developed resistance Struggling with side effects. Efforts to exert control over pain and mainly bio-medically focused. **Decreases and increases in self-medicating with OTC codeine**

Appendix LQR12

Summary of Emblematic Themes Matrix

Participant	Feeling disregarded	Feelings of being misunderstood	OTC codeine is my enabler.
Amy	**Continuity in feeling disregarded and further disregarded**: No multi-disciplinary and holistic approaches to effectively manage conditions. Cessation of medical appointments during the pandemic Cancelation of surgical interventions	**Continuity in feelings of being misunderstood** Risk mitigation approaches in pharmacies without providing adequate alternatives Lack of acknowledgement and limited understanding from friends and family Lack of understanding from work	**Decreases and increases in self-medicating** Deterioration of condition, flare ups and delayed surgical interventions resulting in increased self-medicating Effective medical interventions and incorporation of self-management strategies resulting in reduced self-medicating Weather fluctuations resulting in self-medicating based on the different fluctuations of pain frequency and intensity OTC codeine enables valued activities when in heightened pain, new pain and in-between procedures
Louise	**Continuity in feeling disregarded and further disregarded** No multi-disciplinary and holistic approaches to effectively manage conditions. Phone consultations throughout the pandemic Cancelation of surgical interventions	**Continuity in feelings of being misunderstood** Risk mitigation approaches in pharmacies without providing adequate alternatives Lack of acknowledgement and understanding from friends Attributed divorce to ex-husband not understanding	**Decreases and increases in self-medicating** Deterioration of condition, flare ups and delayed surgical interventions resulting in increased self-medicating Decreased self-medicating after flare ups and medical interventions OTC codeine enables valued activities when in heightened pain, new pain and in-between procedures
Helen	**Continuity in feeling disregarded** Social injustice due to health delivery policies that did not afford the human right to pain management Health disparity	**Continuity in feelings of being misunderstood** Risk mitigation approaches in pharmacies without providing adequate alternatives	**Decreases and increases in self-medicating** Pain frequency and intensity increase and decrease without adequate care OTC codeine-based analgesics are an enabler of valued activity and the only

		Lack of acknowledgement and understanding from friends	pharmacological intervention available to Helen due to disparity
Joanne	**Continuity in feeling disregarded and further disregarded** No multi-disciplinary and holistic approaches to effectively manage conditions Cessation of medical appointments during the pandemic Cancelation of surgical interventions	**Continuity in feelings of being misunderstood** Refusal to give continuous opioid analgesic prescription by GPs without providing viable alternatives to manage chronic pain Risk mitigation approaches in pharmacies without providing adequate alternatives. Engages in pharmacy hopping to acquire codeine supplies Lack of acknowledgement and understanding from friends Attributed divorce to ex-husband not understanding	**Increases in self-medicating with codeine** Deterioration of condition without adequate care Delayed medical interventions OTC codeine-based analgesics are an enabler of valued activity
Edel	**Continuity in feeling disregarded and further disregarded** No multi-disciplinary and holistic approaches to effectively manage conditions Cessation of medical appointments during the pandemic	**Continuity in feelings of being misunderstood** Risk mitigation approaches in pharmacies without providing adequate alternatives Lack of acknowledgement and understanding from family	**Increases in self-medicating with codeine** Deterioration of condition without adequate care OTC codeine-based analgesics are an enabler of valued activity
Katie	**Continuity in feeling disregarded** Social injustice due to health delivery policies that did not afford the human right to pain management. Health disparity	**Continuity in feelings of being misunderstood** Risk mitigation approaches in pharmacies without providing adequate alternatives	**Decreases and increases in self-medicating** Pain frequency and intensity increase and decrease without adequate care OTC codeine-based analgesics are an enabler of valued activity
Jack	**Continuity in feeling disregarded and further disregarded** No multi-disciplinary and holistic approaches to effectively manage conditions.	**Continuity in feelings of being misunderstood** Lack of acknowledgement and understanding from friends and family	**Decreases in self-medicating with codeine** Adaptive self-management strategies which help alleviate pain symptoms Lifestyle changes Psychological flexibility

Peter	**Continuity in feeling disregarded** Disengagement due to refusal of GPs to prescribe without viable alternative options Medical records when requested could not be found	**Continuity in feelings of being misunderstood** Refusal to give continuous analgesic prescription without providing viable alternatives to manage chronic pain Risk mitigation approaches in pharmacies without providing adequate alternatives Engages in pharmacy hopping to obtain codeine supplies. Goes to different jurisdictions with less strict codeine supply regulations Lack of acknowledgement and understanding from friends and family	**Decreases and increases in self-medicating** Reduced efficacy of codeine-based analgesics resulting in decreased self-medicating Adverse effects of codeine resulting in decreased self-medicating Weather fluctuations affecting pain resulting in self-medicating based on the different fluctuations of pain frequency and intensity
Darren	**Continuity in feeling disregarded** Social injustice due to health delivery policies that did not afford the human right to pain management Health disparity	**Continuity in feelings of being misunderstood** Refusal to give continuous analgesic prescription without providing viable alternatives to manage chronic pain Risk mitigation approaches in pharmacies without providing adequate alternatives Lack of acknowledgement and understanding from family	**Increases in self-medicating with codeine** Deterioration of condition without adequate care OTC codeine-based analgesics are an enabler of valued activity. Enabled Peter to continue in work

Presentations arising from this thesis

Nyamakope, T., & Desmond, D. (2018) *Pain management with over-the-counter medication in Irish community pharmacies*. 15th Annual Psychology, Health and Medicine conference, 6th June, Ulster University, Coleraine, United Kingdom

Nyamakope, T., & Desmond, D. (2019) COPE: *A study of COdeine relationships in Pain management through sElf-medicating*. Psychology@20 Departmental Research Day, 30th January, Maynooth University, Maynooth, Co. Kildare, Ireland.

Nyamakope, T., & Desmond, D. (2019) *Pain management with over-the-counter medication in Irish community pharmacies*. 16th Annual Psychology, Health and Medicine conference, 22nd March, Maynooth University, Maynooth, Co. Kildare, Ireland.