# Exploring Factors Associated with Regret Following Cancer Treatment

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# Declaration

I have read and understood the Departmental policy on plagiarism.

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education.

Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

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# Abstract

Following a diagnosis of cancer, patients are often faced with important medical decisions regarding their treatment. This decision-making process can be difficult as patients may not receive sufficient information about their options or may struggle to interpret the information they do receive. An unsatisfactory decision may lead to later decisional regret, which has been linked to a lower quality of life in survivors. While some research has begun to explore the factors that influence decisional regret, few studies have comprehensively examined the role that psychological and social factors may play in this process. The aim of the current project was to analyse and compare the factors associated with the emergence of decisional regret in cancer survivors internationally and in Ireland.

Two studies were conducted. Study 1, a systematic review, analysed international literature aimed at exploring factors associated with decisional regret in 27,982 cancer patients and survivors. Study 2, a survey, explored factors associated with regret in 92 cancer survivors in Ireland (the majority who were breast and prostate cancer survivors). In this study, sociodemographic, health, psychological and social support information was analysed in its ability to predict regret as measured by the Decision Regret Scale. Public and patient involvement was used to aid the interpretation of the findings.

In Study 1, regret in cancer patients/survivors was associated with various socio-demographic factors, poorer physical health, a number of treatment types, an unsatisfactory decision-making process, poorer mental health and lack of social support. More generally, these factors were grouped into those which were modifiable and less modifiable from the patient’s perspective. These results were mirrored in Study 2, with better physical and psychological well-being, higher levels of shared-decision making and resilience being the 3 factors which most strongly predicted regret.

While regret was low amongst survivors, results highlight the many factors which may have an effect on the emergence of regret in oncology populations. As regret can be an obstacle to full-recovery from cancer, researchers and health-care professionals should continue to work towards better methods of identifying patients most at risk of experiencing regret as well as methods of mitigating the emergence of this negative phenomenon.

# Chapter 1

# General Introduction

## 1.1 Introduction

Cancer is a disease known by all and experienced by many. While the search for a cure continues, there are a number of treatment options that patients may avail of, including surgery, radiation therapy, chemotherapy and hormone therapy. In many cases, more than one treatment type is available, leaving the patient with a difficult decision to make. As discussed below, this decision can lead to decisional-regret which in turn may lead to lower quality of life, long after treatment has ceased. Unfortunately, the long-term well-being of cancer survivors is often overlooked as they may be left with little valuable support after receiving the ‘all-clear’ (Owen, Goldstein, Lee, Breen & Rowland, 2007; Shroevers, Helgeson, Sanderman, & Ranchor, 2010).

This thesis aims to explore the experience of treatment-related regret and decision making in cancer survivors in more detail. Understanding the factors which can lead to this experience is merited so that health care professionals may be in a position to reduce the likelihood of regret as survivors navigate the disease trajectory. In this chapter, the concepts of treatment decision making and regret are introduced prior to presenting a more detailed overview of the aims and objectives of the current project

## 1.2 Cancer Survivorship

The most recent report published by the National Cancer Registry (2018) shows that cancer cases in Ireland are on the rise and that they may double by 2045. It was estimated that over 200,000 people were living with or beyond cancer in 2019 in Ireland alone, with 40,000 people receiving a diagnosis each year (O’Connor, O’Donovan, Drummond, & Donnelly, 2019). Worldwide, there were 17 million new cases of cancer in 2018, with the most commonly diagnosed cancers being lung, female breast, bowel and prostate cancer (Cancer Research UK, 2019). Advances in cancer detection and a wider range of treatment options have also resulted in an increasing numbers of cancer survivors, with breast and prostate cancer survivors making up most of survivors living in Ireland (O'Connor et al., 2019).

With more survivors comes the need for a general understanding of the supports that would be of most benefit for patients not only during the illness and treatment, but also after. Physical and psychological side effects of cancer and/or treatment may affect survivors long after treatment has been completed (Brydøy et al., 2009; Mao et al., 2013; Monje & Dietrich, 2012; O'Connor et al., 2019). Furthermore, psychosocial side effects are common as cancer survivors may report decreases in their quality of life which can occur as a result of changes associated with their ability to take part in previously normal activities such as self-care, work, hobbies, or family life (Carelle et al., 2002). A need for greater access to support services, sexuality related needs, as well as information, have also been reported by Irish cancer survivors (O'Connor et al., 2019). This suggests that efforts are needed to be made to provide continued support for survivors. One area in which patients may benefit from support is in the area of treatment decision making, discussed in more detail below.

## 1.3 Treatment Decision Making

### 1.3.1 Types of Treatment Decision Making

The choice of cancer treatment can have considerable consequences for patients whose future well-being, often extending to that in later survivorship, depends on this decision. While not all cancer treatments are preference sensitive, in many cases there may be different options available for patients and clinicians. For example, prostate cancer treatment may involve surgery (prostatectomy), radiation therapy, brachytherapy or hormonotherapy (Pearlstein, Basak, & Chen, 2019). While these treatments may be similar in terms of their clinical efficacy, the outcomes can result in different side effects for patients and they may need to be considered as part of the decision-making process.

Decision making in health care settings can take many different forms depending on the role that the patient and health care professional (HCP) play in this process. This can include shared decision making (SDM) which is currently a popular approach (Cahill, Zilidis, & Grundy, 2018; Driever, Stiggelbout, & Brand, 2020), as well as autonomous decision making (also referred to as patient-centred), which contrast with the more traditional paternalistic approach (Lepping, Palmstierna, & Raveesh, 2016).

The paternalistic approach refers to acts of authority by the physician in directing care and in the distribution of resources to patients (Sandman & Munthe, 2010). The patient's wishes and choices are not respected in this type of decision making. It has been described as acting for the good of the patient, without the patient's will (Groll, 2014a), and has been less favoured in recent years as it disregards patient autonomy. The paternalistic approach does not treat patients as knowledgeable enough about their condition and typically ignores the patients' opinions, thoughts and feelings (Sandman & Munthe, 2010). However, an argument can be made for some use of paternalism when patient autonomy is not possible, and when the principle of benefiting the patient is prioritised in the HCP's decision-making process (Groll, 2014b; Roeland et al., 2014).

In contrast, the patient-centred approach respects patient autonomy, which is the ability of a person to make their own decision without the health care provider influencing them (Lepping, & Raveesh, 2014). Patient autonomy allows for the physician to educate the patient but not to decide for the patient. The growth in popularity of this approach has pushed clinicians towards the assessment of decision making preferences of their patients and the facilitation of independent decision making with appropriate information provision (Ahmed et al., 2018; Rodriguez-Osorio & Domingue-Cherit, 2008). While this approach may be more preferable than the paternalistic approach, studies show that many patients prefer to give up complete autonomy in decision making in favour of the SDM approach (Deber, Kraetschmer, Urowitz, & Sharpe, 2007).

In SDM, both the patient and physician contribute to the medical decision-making process (Fried, 2016; Hargraves, LeBlanc, Shah, & Montori, 2016). Typically, the physician shares the relevant risks and benefits of all treatment alternatives with the patient, while the patient shares relevant personal information that might make one treatment or side effect more or less tolerable than others with the physician. Both parties use the shared information to come to a mutual medical decision. This decision making approach has become the topic of research interest in recent years due to the belief that it allows patients to receive care which is right for them, therefore reducing medical errors and improving post-treatment satisfaction (Brodney, Fiwler, Wexler, & Bowen, 2016; Vercellini et al., 2018).

More recently, decision making in health care settings has been changed by advances in medicine and technology (Salvador et al., 2017; Sun, 2017; Voena & Chiarle, 2016). Notably, clinical advances have resulted in more treatment options available, which may put pressure on the patient’s decision making process, especially if they feel uninformed or are lacking the required health literacy (Erlen, 2004). However, advances have also led to positive developments. For example, decision aids have transformed decision making in health care by allowing patients to better understand the number of treatment options available, their risks, benefits, and costs (Leighl et al., 2011). Many studies find that the use of a decision aid results in more post-treatment satisfaction and less post-treatment regret in patients (Brooks et al., 2019; Søndergaard et al., 2019). Decision aids are now widely used to facilitate the SDM approach (Spatz, Krumholtz, & Moulton, 2017).

### 1.3.2 Theoretical Approaches to Understanding Decision Making Preferences

Studies show that people’s preferences around decision making strategies vary substantially and that while SDM is a popular choice it is not favoured universally (Deber et al., 2007; Deucher et al., 2016; Rodriguez-Osorio & Dominguez-Cherit, 2008). Some suggest that more research into the SDM strategy is needed (King & Moulton, 2006), especially since there is a lack of guidance about how to achieve it (Elwyn et al., 2012; Légaré et al., 2010). Other studies show that many patients prefer to leave the decision completely up to their physician, i.e., paternalistic decision making (Arora & McHorney, 2000).

Traditional theories of decision making may explain people’s preferences of involvement. For example, Ritov and Baron (1995; 2004) describe how the phenomenon of omission bias can influence decision making. According to the researchers, this bias comes from people’s preference to choose no action rather than action (Brewer, DeFranklin, & Gilkey, 2016). For example, Ritov and Baron (1995) found that subjects were reluctant to vaccinate their children if they were told that there was a possibility of death resulting from the vaccination, even if this occurrence is much less likely than death caused by the disease prevented by the vaccination. This may explain why some patients decide to leave the decision up to the physician, as transferring the action onto someone else releases the patient of responsibility for consequences.

Patient avoidance of action may also be explained by the involvement of emotion in decision making. Our everyday life experiences leave no doubt that emotion impacts our decision making (cancer diagnosis is undoubtedly an emotional experience) (Lakomski & Evers, 2010; Lerner, Li, Valdesolo, Kassam, 2015; Morrice, 2013), and that the consequences emerging from our decisions can influence our emotions (Schwarz, 2000). There is an influence of emotion on avoidance of action and the key emotions involved in this process are anticipated regret and fear (Anderson 2003). The experience of regret is elaborated on in section 1.4.

Of course, while some patients may prefer not be involved in decision making, other studies find that many patients do want to be informed and involved where possible (Brom et al., 2014; Chewning et al., 2012; Guadangoli & Ward, 1998). However, patient involvement may not always lead to a satisfactory treatment choice, partly as humans can find it difficult to make fully rational decisions.

An early theory of decision making which assumed that people are rational as they choose between uncertain options by examining the utility of each option and logically considering the probability of that option occurring (Mongin, 1997; Schoemaker, 1982), has been disproved (Dhami & al-Nowaihi, 2006). Instead of basing decisions on a rational calculation, our decisions are instead formed by our risk-aversive nature in respect to gains, and risk-acceptant nature in respect to losses (Breen, van de Werfhorst, & Jæger, 2014). When deciding, we prefer not to lose rather than to gain. For example, it has been shown that participants incorrectly predict their level of happiness to decrease significantly after a loss than to rise after a gain (Kermer, Driver-Linn, Wilson, & Gilbert, 2006).

When presenting treatment-related information, physicians tend to present the risk and benefits side-by-side, giving patients a fair opportunity to see both the possible benefits and side-effects of each choice (Oussedik, Anderson, & Feldman, 2017). The patients’ risk aversive nature however may lead towards the risk being weighed more heavily than the benefit, resulting to poor and irrational treatment choices (Oussedik et al., 2017). In order to avoid this, physicians may present the risk of choosing a treatment against the risk of not choosing it (Oussedik et al., 2017). This is the guiding principle behind decision aids – to present risk and benefits of choosing (or not choosing) various treatments.

Several other studies find that patients want to be asked their opinion but wish to leave the final decision to the medical experts (Levinson, Kao, Kuby, & Thisted, 2005; Schoenfeld et al., 2018). These results have encouraged research on matching patient participation level preferences with the decision making process as this results in more satisfaction and less regret post-treatment (Brom et al., 2014; Brown et al., 2012; Kiesler & Auerbach, 2006; Robinson & Thompson, 2001).

As detailed above, traditional theories of decision making can aid understanding of this process in a healthcare setting and show why patients may or may not want to be involved. Recent studies show the vast number of factors that may affect decision making, including an individual's socio-demographic characteristics, their psychological appraisals and the amount of support they receive during the decision-making process (Dias-Ferreira, 2009). For instance, an individual's age, gender, level of education, marital status and socio-economic status may affect decision making styles (Hubbard, Kidd, & Donaghy, 2008; Schneider et al., 2006). This implies that decision making is a complex process and the outcomes may be guided by a multitude of complex factors.

It is important to note that most studies on decision making practices and patient preferences have been conducted outside of Ireland, aside from some studies conducted, for example, in collaboration with the National Cancer Registry of Ireland (NCRI) (Sharp et al., 2013). Also, these studies have tended to focus on one cancer type in isolation (e.g. prostate or breast cancer), rather than cancer types more generally. The current project aims to address this gap as well as more specifically focusing on one particular consequence of decision making, that is regret (discussed in more detail below).

## 1.4 Regret

### 1.4.1 Definitions of Decisional Regret

Most decisions have consequences, and cancer treatment decisions have consequences which can affect the well-being and quality of life of patients long post-treatment. One negative consequence which very often appears in studies of cancer treatment is the experience of regret (Albkri et al., 2018; Flitcroft, Brennan, & Spillane, 2018; Walczak & Velanovich, 2018).

The feeling of regret is a common experience in many contexts, and multiple theories and approaches have attempted to explain this emotion more broadly. There is, however, some disagreement as to how this process arises. Philosophical theories have attempted to explain regret according to the internal state with which it is accompanied and by the circumstances in which it occurs. An attempt has also been made to distinguish regret from other similar emotions like disappointment, guilt, remorse or sadness (Gilovich & Medvec, 1995, Kedia & Hilton, 2011). A definitional issue was found by the philosophical approach to regret: specifically, can a person say that they regret something if they would hypothetically do it again? (Gilovich & Medvec, 1995). According to Hampshire (1960), such a feeling could be described as anxiety, guilt or a wish to have been placed in different circumstances, but it cannot be said to be regret. According to Gilovich and Medvec (1995) however, this view of regret has been disagreed with by many scholars as it is possible to think of examples of actions which people have regretted but were forced to repeat it in order to reach a goal.

The economic approach to understanding regret proposes that people will sacrifice monetary gain in order to avoid subsequent regret (Gilovich & Medvec, 1995; Martinez & Zeelenberg, 2015). This suggests that people are subconsciously aware of the negative effects that regret may have on them. Several studies show that anticipated regret affects our choices

(Hetts, Boninger, Armor, Gleicher, & Nathanson, 2000; McCormack & Feeney, 2015; Wright & Ayton, 2005). However, Gilovich and Medvec (1995) find that economical theorists' definition of regret is too narrow as it includes the difference between the value of the chosen option versus other alternatives, but it does not consider the path by which an option was decided (this too can affect regret).

Research on counterfactual thinking has also added to our understanding of regret and why it occurs. Counterfactual thinking involves thoughts about alternatives to past events. These thoughts can regulate behaviour and our emotional response to past events (Epstude & Roese, 2008; Medvec, Madey, & Gilovich, 1995). Engaging in counterfactual thinking has been found to evoke negative emotions like dissatisfaction, envy, distress and most notably regret (Baron, 2000; Broomhall, Phillips, Hine, & Loi, 2017; Zeelenberg et al., 1998). Research on counterfactual thinking has addressed the problems found with the economic approach. This approach is concerned with people's imagined alternatives to their choice, and unlike in the economic approach regret is not seen to be tied to known outcomes only (Coricelli & Rustichini, 2010). The counterfactual thinking approach also sees the path by which a decision was made as an important part of the emergence of regret. Different paths may lead to the same outcome and their counterfactual consideration may lead to different levels of regret (Epstude & Jonas, 2015). Unlike in the economic approach, this research does not consider regret to be tied to the outcome of the decision in isolation to other factors.

The Decision Justification Theory (Connolly & Zeelenber, 2002) suggests that decision related regret has two main components, which can occur in isolation or simultaneously: the outcome of the decision and the self-blame for the choice made. When regret occurs due to the combination of both, a person regrets the 'incorrect' decision made and blames themselves for doing so (Connoly & Zeelenber, 2002). However, a person may be happy with the outcome of their decision, and still feel self-blame, Connolly and

Zeelenber (2002) provide an example of a drunk driver arriving home safely – the driver accepts that their decision had a good outcome but feel self-blame as they imagine what could have happened. A well thought-out decision which results in bad consequences may result in regret due to unwanted outcomes, but self-blame may not be present as a person understands they did everything they could to make an informed choice, e.g., a parent whose child's well-researched vaccination against a deadly disease results in unwanted side effects (Connolly & Zeelenber, 2002). The theory provides an interesting explanation as to why regret may occur in those both those who take responsibility for a decision and those who do not, as well as those who are satisfied with the outcome of their decision and those who are not.

Theoretical approaches to understanding regret can provide some insight into what gives rise to this experience. A drawback of much empirical research in this area however is that it tends to focus on hypothetical scenarios rather than real-world decision-making. The study of regret in health-related contexts can give a more in-depth understanding of regret in practice.

### 1.4.2 Regret in Cancer Survivors

Regret is reported by those who feel they made an inappropriate choice, or by those who failed to do something they feel should have been done for a better outcome. The healthcare setting is filled with situations which put both health care professionals and their patients under pressure to make decisions, especially decisions about treatments. For this reason, regret is commonly studied in relation to treatment decision making across various patient groups (Advani et al., 2019; Holmes et al., 2017; Tanno & Bito, 2019). Regret can be described as occurring in three contexts here: outcome regret – regret which comes from the outcome of a decision, option regret – regret stemming from the alternative chosen, and process regret – regret linked to the way in which the decision was made (Connolly & Reb, 2005). All three types of regret may be experienced at once, individually or in different combinations. For example, a patient may regret the treatment decision-making process but not the actual treatment chosen or its outcomes (Connolly & Reb, 2005).

Cancer patients are the most widely researched population by researchers of regret post treatment (Cuypers et al., 2019; Peterson et al., 2019; Windon et al., 2019). This is likely due to the vast amount of treatment options available to cancer patients and, as mentioned above, the more treatment options available, the bigger the possibility for regret (Chernev, Böckenholt, & Goodman, 2015). Recent research however suggests that the prevalence of regret in cancer patients is surprisingly low considering the amount of treatment choices often available (Lee & Knobf, 2015; Martinez et al., 2015; Shakespeare et al., 2017). Despite this, regret in cancer patients and survivors remains an important topic for researchers, especially given its known relationship with lower QoL post-treatment and throughout survivorship (Albkri et al., 2018; Clark, Ray, Ashton, 2001; Diefenbach, Mohamed, Horwitz, & Pollack, 2008; Hu et al., 2008). Understanding how best to mitigate later regret in individuals with cancer is an important aspect of the quest to fulfil the needs of both cancer patients and survivors.

Regret post-cancer treatment may occur for many reasons and has commonly been found in patients who experienced: lower sexual functioning post-treatment (Davidson, So, & Goldenberg, 2007; Diefenbach & Mohamed, 2007; Rattcliff, Cohen, Pettaway, & Parker, 2013; Christie, Sharpley, & Bitsika, 2015), a decrease in role and social functioning (Davidson et al., 2007), increased pain (Davidson et al., 2007), disease-specific side effects (e.g., urinary dysfunction) (Diefenbach & Mohamed, 2007; Christie et al., 2015), high expectations of treatment which were not reached (Schroeck et al., 2008), low satisfaction with preparatory information (Sheehan, Sherman, Lam, & Boyages, 2007), or a longer time since treatment (Christie et al., 2015; Hu et al., 2008), amongst others. In addition, a range of socioeconomic factors may be associated with regret, for example financial difficulty (Davidson et al., 2007; Lee & Knobf, 2015). It is important to note that most studies mentioned have focused on prostate cancer patients, with less known about influences of regret in other cancer types. More research on the factors which are linked to regret post-treatment in different types of cancers is needed.

As discussed above, regret may be described in three contexts and it is not always associated with the treatment chosen. It has been shown that the path to the decision also influences the emergence of regret. Unsatisfactory levels of involvement in the decision-making by the patient, or a low level of understanding of the medical information at the time of the decision have been linked with the emergence of decisional regret (Davidson et al., 2007; Hack, Degner, & Watson, 2006; Mancini et al., 2012). Insufficient time may also play a role in a rushed decision making process and a later emergence of regret (Shepherd, Tattersall, & Butow, 2008). As discussed above, people experience more regret from negative outcomes stemming from action, rather than the same negative outcomes coming from inaction (Gilovich & Medvec, 1995; Chapman & Coup, 2006). An unsatisfactory level of involvement does not necessarily mean that the patient wanted to be more involved than they were. Sometimes, due to negative consequences of the treatment, the patient may feel like they should have stepped aside and let the physician make the decision instead. This, however, is rare. Even though we often feel like action produces more regret than inaction (Kahneman & Tversky, 1982) and regrettable actions are troubling, it seems that regrettable failure to act causes more regret in real-life situations (Gilovich & Medvec, 1995).

There have been attempts made to mitigate decisional regret in various patient populations with the use of decision aids, some being very successful (Knops, Legemate, Goossens, Bossuyt, & Ubbink, 2013). Many of these aids concentrate on increasing patient participation in the decision making and ensuring a greater understanding of the medical information (Gaston & Mitchell, 2005; Kennedy et al., 2012; O’Connor et al., 1999). However, greater involvement in decision making does not always lead to less regret post-treatment. Furthermore, decisional regret does not always occur simply due to an inappropriate level of patient involvement or understanding. There are a number of other factors that may need to be considered.

### 1.5 Limitations of Current Research

Emerging research is adding to a greater understanding of the importance of decision making aids in the mitigation of decisional regret in patients. However, most of the studies conducted concern themselves with cancer patients only, and rarely with long-term cancer survivors. This limits our knowledge of the emergence of decision regret at different time points. More specifically, the vast amount of these studies are concerned with prostate cancer (Chien, Chuang, Liu, Li, & Liu, 2014; Davidson & Goldenberg, 2003; Diefenbach & Mohamed, 2007) and breast cancer patients (Andersen, Bowen, Morea, Stein, & Baker, 2009; Hack et al., 2006; Sawka et al., 1998; Sheehan et al., 2007). There is a lack of work conducted with other cancer patients, or with the general cancer patient population to establish whether there are any trends in the experience or regret. This problem is worthy of investigation, as other forms of cancer can also be treated by different means (e.g., head and neck cancer, liver cancer, skin cancer, etc.), and a decision on the type of treatment is required. In other words, other cancer patients may also experience regret and it is worth exploring experiences across various groups. In addition, while a good deal of work has explored how aspects of the decision making process may impact regret, less research has explored how a range of sociodemographic, psychological and social factors may influence this experience and relatively little research has been conducted on this topic in an Irish context. Detailed considerations of such issues may be helpful in informing the development of interventions aimed to reduce the likelihood of later regret.

## 1.6 The Current Study

### 1.6.1 Aims and Objectives of the Current Research

The current research aims to explore the factors which have been found to be associated with the emergence of decisional regret in cancer patients and survivors. This will be achieved by two studies. Study 1 is a systematic review of existing literature in the area, while Study 2 involves an exploration of the decision making experiences and prevalence of regret in a sample of cancer survivors living in Ireland.

In the following chapters, these studies and their findings will be described in more detail. Chapter 2 describes study 1, which reviews research on different cancer survivors in order to achieve a better understanding of those who are most prone to experience regret post-treatment. The methodology for study 2, which aims to explore the factors associated with the emergence of decisional regret in Irish cancer survivors, is described in Chapter 3, with results described in Chapter 4. In discussing the results of this study (Chapter 5), findings will be compared to those from study 1, the systematic review, in order to investigate the similarities and/or differences associated with the emergence of regret between Irish cancer patients and the international literature. Finally, using public and patient involvement (PPI) Chapter 6 describes how the results of both studies may inform interventions concerned with the wellbeing of cancer survivors, and particularly those living in Ireland.

### 1.6.2 Chapter Summary

This chapter has reviewed theoretical approaches to understanding treatment decision making and regret. Research points to an association between certain aspects of cancer treatment decision making and the emergence of decisional regret. More specifically, the research described here discusses the association between regret and the level of patient involvement in the treatment decision making process. While literature suggests that this is a common reason for the emergence of regret in cancer patients/survivors, it is not the only one. Alternative studies of various cancer patients may uncover more specific factors linked to the emergence of regret and suggest that it is not enough to simply attribute the treatment type chosen for regretful feelings to occur. A detailed analysis of the different factors found by studies conducted world-wide with various cancer patients will be discussed in the systematic review in Chapter 2.

# Chapter 2

# A Systematic Review of the Factors Associated with Regret Post-cancer Treatment

## 2.1 Overview

The literature reviewed in the previous chapter highlighted that there are many possible reasons for the emergence of decisional regret in cancer patients and survivors. Factors associated with regret may include survivor psychological, socio-demographic and health-related characteristics. In order to gain more insight into the emergence of decisional regret in those with cancer diagnoses, this chapter describes a systematic review investigating the factors associated with the experience of regret in a range of cancer survivors

## 2.2 Background and rationale

A diagnosis of cancer is understood to not only affect individuals during the illness or treatment period, but also during survivorship. The feeling of regret has been found to impact cancer patients and survivors negatively (Davidson, So, & Goldberg, 2007; Diefenbach & Mohamed, 2007). As outlined in chapter 1, regret has been defined as a negative feeling or emotion, which is associated with thinking about a past event or choice (Connolly & Reb, 2005). With many studies now focusing on this phenomenon (Benedict; Thom, & Kelvin, 2015; Christie, Sharpley, & Bitsika, 2015; Fernandes-Taylor & Bloom, 2011), we are beginning to understand exactly what individuals regret about their treatment, but also about other aspects of their experience while ill. In healthcare settings regret can occur in three main contexts: outcome regret – regret which comes from the outcome of a decision, option regret – regret stemming from the alternative chosen, and process regret – regret linked to the way in which the decision was made (Connolly & Reb, 2005). All three types of regret may be experienced at once, individually or in different combinations (Connolly & Reb, 2005). For example, a patient may regret the treatment decision-making process but not the actual treatment chosen or its outcomes Quite often, it is found that the specific treatment type chosen is the cause of regret in cancer patients (Ratcliff, Cohen, Pettaway, & Parker, 2013).

For example, cancer treatment generates most reports of regret in medicine, more than clinical trials and prophylactic breast surgery (Sawka et al., 2012, as cited in Christie et al., 2015).

The literature reviewed in the previous chapter showed that regret may be linked to the level of patient involvement in the decision making process. However, studies have found many other factors which may be associated with regret. It is important to note that this association does not imply causation. Nevertheless, studies of this nature allow for a clearer understanding of the environment in which decisional regret may occur in cancer patients/survivors. An individual's ethnicity, age, psychological well-being, education-level, or income-level are all factors, amongst many others, which have been found to be associated with this phenomenon. However, more research is needed to fully understand this complex process.

A number of systematic reviews analysing studies of regret in cancer patients have been conducted (Christie, et al., 2015; Flitcroft, Brennan, & Spillane, 2018; Wilson, Ronnekleiv-Kelly, & Pawlik, 2017). The findings of these reviews suggest a broad spectrum of factors associated with regret, e.g., sexual and urinary function, age or longer time since treatment (Christie et al., 2015), unclear nature of information provided to patients, depression, distress or negative body image (Flitcroft et al., 2018), type of surgery, disease-specific quality of life or shared decision making (Wilson et al., 2017). However, these reviews often have very narrow inclusion criteria, allowing for studies concentrating on one cancer type or one treatment type only. This systematic review aims to analyse studies of cancer regret in patients and survivors of all cancer types in order to create a broader overview of the challenges faced by cancer patients before, during and after various treatment types. It is important to understand the common experiences of survivors to enable the provision of supports for this group, and to identify those most at risk of experiencing regret.

## 2.3 Objective

The objective of this review is to provide a synthesis of evidence on the correlates of regret in general oncology populations across various study designs, with the intention of identifying potentially modifiable factors that may inform interventions tailored towards supporting survivors.

## 2.4 Method

### 2.4.1 Search Strategy for Identification of Studies

The study was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Appendix A). Studies in English up to April 2019 with no restrictions on time period were searched using: Web of Science, PubMed, PsycINFO and EMBASE. To ensure the maximum reach, the databases were searched using the following free text search terms and Boolean operators: “cancer survivors” OR “cancer patients” AND “decision” AND “regret” OR “decisional regret”. These terms were selected following an investigatory search of available literature (Aning, Wassersug, & Goldenberg, 2012; Chien, Chuang, Liu, Li, & Liu, 2014; Goepfert et al., 2017) and based on their occurrence as well as their relevance to the research question. The terms were piloted in all of the databases used in different combinations in order to ensure the literature search was not limited. The reference lists of relevant articles were also checked for additional suitable studies.

### 2.4.2 Criteria for Inclusion

Studies included in the review were required to satisfy specific inclusion criteria, agreed on by two reviewers. The criteria for inclusion can be found in Table 1 below. Only studies in which the participants were adults were included in the review. At the time of the study, the participants must have been patients or survivors of any type of cancer. Data collected from carers of cancer patients/survivors, relatives of cancer patients/survivors, or doctors was not included. The review included studies which only collected primary data directly from participants who had been diagnosed with cancer and which used a measure of decisional regret. Studies which mentioned measuring treatment regret in cancer patients/survivors but did not clearly state the measure used were not included. This was to ensure that any regret reported in association with other factors could be assessed. However, any study which captured a measure of regret was considered for inclusion, including self-reported assessment, quantitative close-ended questions, open-ended questions and qualitative questions. Most of the studies analysed used validated measures of regret (e.g. Decision Regret Scale) but unvalidated measures were also considered to meet this inclusion criterion. Studies measuring regret about fertility preservation were not included. At least one factor associated with the emergence of decisional regret must have been studied for the article to be included in the review. This review included studies published in English. Studies from peer-reviewed journals were included in the review. Poster/conference abstracts were not included. Studies of any design type (qualitative, quantitative, mixed etc.) were considered for inclusion.

**Table 1**

*Systematic review inclusion and exclusion criteria*

| Criteria | Inclusion | Exclusion |
|---|---|---|
| **Types of participants** | • Adults<br>• Cancer patients/survivors<br>• Primary data | • Minors<br>• Carers of cancer patients/survivors<br>• Relatives of cancer patients/survivors<br>• Health-care professionals |
| **Measurement of regret** | • Validated measure of regret used in quantitative studies<br>• A discussion of regret in qualitative studies | • Non-validated measure of regret used<br>• Measure of regret used not clearly stated |
| **Regret measured in association with at least one other factor** | • Studies which measured the association between the emergence of regret and at least one other factor | • Studies which measured regret but did not study the association between its emergence and other factors |
| **English language** | • Studies published in English | • Studies not published in English |
| **Publication type** | • Peer-reviewed journal | • Conference/ poster abstract |
| **Study Design** | • Any | • / |

### 2.4.3 Screening Procedure

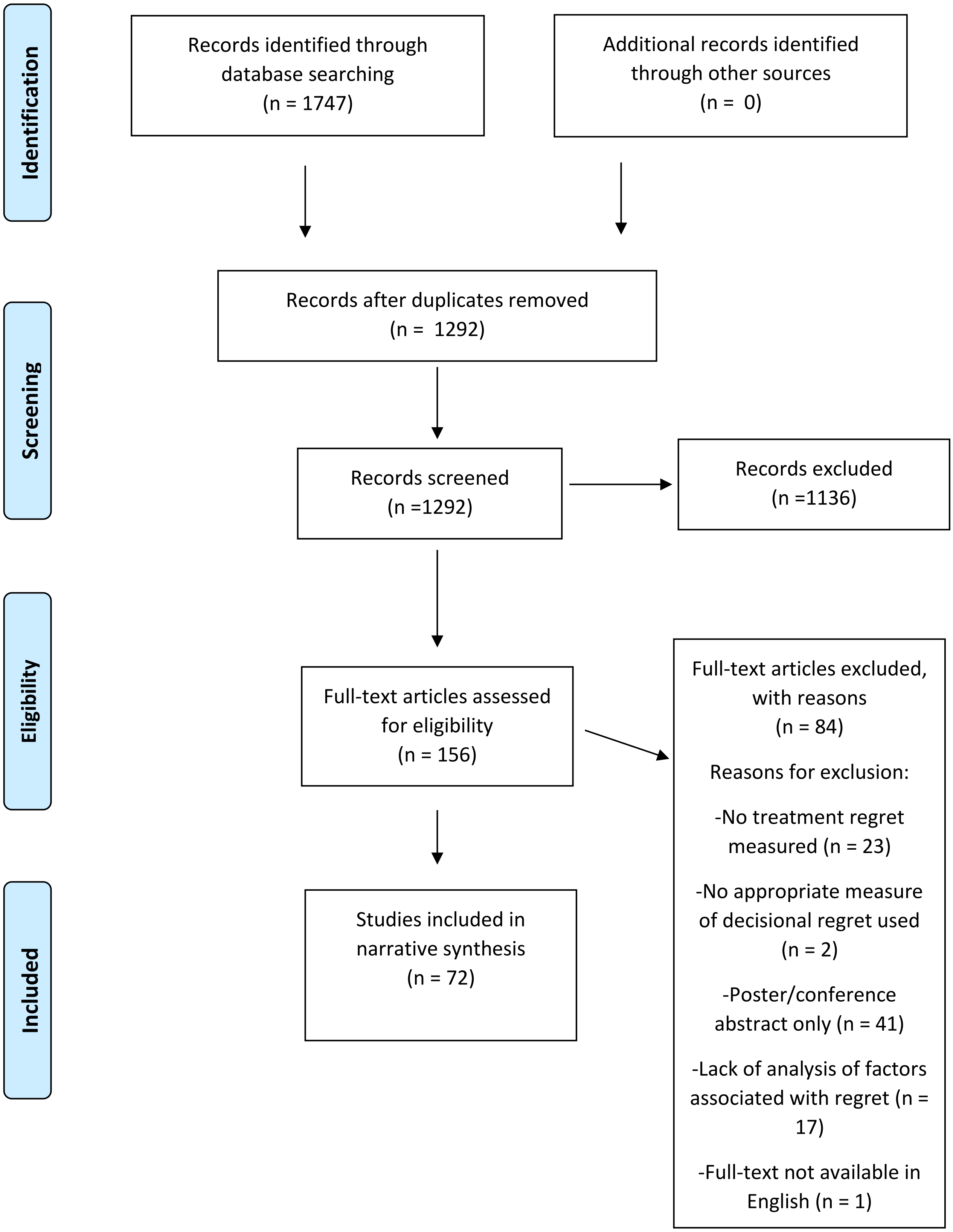
Results from the database searches were transferred into Rayyan (Ouzzani, Hammady, Federowich, & Elmagarmid, 2016) an open-source web application created for systematic reviews. This application allowed both reviewers to have access to the articles at the same time, to read abstracts, mark articles as included/excluded/maybe, organise them into categories, leave notes and to see the decisions of the fellow researcher.

Titles and abstracts of articles found in the database search were first independently screened by both reviewers to establish whether they met the inclusion criteria. Where conflicts occurred, these were discussed until agreement was reached. Full texts were sourced for articles, which appeared to be suitable after the initial screening. This was done using the Maynooth University library database and Google Scholar. In some instances, the authors of articles were contacted with a request for a copy of the full text. Full texts were then read to ensure they met the inclusion criteria. A number of articles did not have full texts as the abstracts came from posters and conferences, thus did not meet the inclusion criteria. The reference lists of included studies were also screened for relevant articles but none were included in the final review.

The database search returned 1747 articles, 455 of which were initially removed, as they were duplicates, leaving 1292 articles for the screening process. After the screening of the remaining titles and abstracts by the two reviewers, full texts were obtained for 156 studies. Based on the inclusion criteria, a further 84 articles were excluded. This was mostly due to the lack of an appropriate measure of regret and/or no factors linked to the emergence of regret. The process described is further illustrated in Figure 1 below (based on the flow diagram of The PRISMA Group, 2019).

**Figure 1**

*PRISMA flow diagram for various phases of the systematic review*



### 2.4.4 Quality Appraisal

Methodological quality was assessed using the Mixed Methods Appraisal Tool (MMAT) Version 2018 (Hong et al., 2018; Pace et al., 2012; Souto et al., 2015). Two reviewers conducted the appraisal. Each reviewer independently assessed the quality of each study using a checklist (Appendix B). The individual assessments were then compared and any discrepancies were discussed. As per the MMAT user guide, the studies were not awarded points or scores. Instead, the user guide advised "to provide a more detailed presentation of the ratings of each criterion to better inform the quality of the included studies" (Hong et al., 2018, p.1). Studies of low methodological quality were not found. However, if studies of low quality were found, they would not have been excluded as the user guide discouraged this.

Each study was categorised and assessed using seven questions: two screening questions and five questions relevant to the category of the study. There were three possible answers to each question: 'Yes'. 'No' and 'Can't tell'. A comment section beside each question allowed for a justification of each answer chosen. The two screening questions ('Are there clear research questions?' and 'Do the collected data allow to address the research questions?'), required a 'Yes' answer, which all studies in the review satisfied. Otherwise, it was assumed that the paper is not an empirical study and cannot be assessed using the MMAT. One of two 'Yes' answers indicated low quality, three 'Yes' answers indicated moderate quality, four or five 'Yes' answers indicated strong quality. All of the studies were found to be strong or moderate quality.  Studies of low methodological quality were not found suggesting a low risk of bias.

### 2.4.5 Data Extraction and Analysis

The following information was extracted from included studies by one researcher: design, setting, participants, cancer type, treatment, measure of regret, prevalence of regret, and factors associated with regret. This information was then discussed and agreed with the second researcher. Results were analysed using the process of narrative synthesis, which is a commonly-explored approach followed by other researchers (Ngwenya et al., 2017; Scalia et al., 2018).

## 2.5 Results

### 2.5.1 Description of Studies

After all exclusions, 72 articles were found to be of relevance to the review. Table 2 provides details of these studies. The studies in the review involved various designs: 3 qualitative, 12 quantitative randomized controlled trials, 53 quantitative descriptive and 4 used mixed methods (as per MMAT categorisation).

The studies were conducted in a range of countries: 39 in the USA, 8 in Canada, 5 in Australia, 3 each in Taiwan and The Netherlands, 2 each in England, Scotland, Turkey and China and 1 each in France, Ireland, Germany, Spain, Italy and Iran. The sample sizes ranged from 28 to 2,030 participants, with a total of 27,982 participants taking part in all of the studies combined. Most of the studies were concerned with prostate cancer (n = 42, 58.33%) and breast cancer (n = 20, 27.78%). However, a number of studies focused on less prevalent cancer types: thyroid cancer (n = 2, 2.78%), oropharyngeal carcinoma (n = 1, 1.39%), head and neck cancer (n = 1), colon cancer (n = 1), uveal melanoma (n = 1), colorectal cancer (n = 1), laryngeal (n = 1) acute myeloid leukaemia (n = 1). One study involved patients suffering from more than one cancer type – specifically cancer patients with a tumour who underwent adjuvant chemotherapy.

Treatment types undertaken by the participants in the studies included: surgery, radiotherapy, hormone therapy, brachytherapy, active surveillance, endocrine therapy, adjuvant radioactive iodine treatment, stem cell transplant, orchiectomy, chemical castration and watchful waiting. Many of the studies were inclusive of a range of treatments (Cuypers et al., 2019), while others only allowed the inclusion of specific treatment types (Kinsella et al.,2012). Many studies did not provide details of the treatment type undertaken by the participant or provided limited information about this (Diefenbach, & Mohamed, 2007; Goepfert et al., 2017).

As per the inclusion criteria, the studies in this review were required to measure regret. The most common tool used was the five-item Decision Regret Scale (O'Connor, 2003; n = 39, 54.17%) followed by the two-item regret questionnaire by Clark et al (2001; n = 9, 12.5%). Many of the studies used adapted versions of those scales or other validated Likert scales (Schroeck et al., 2008). Other studies assessed regret using a single item question (Christie, Sharpley, Bitsika, & Christie, 2017) or, in the case of qualitative studies, asked participants to discuss their experience of regret, e.g., 'Looking back, is there anything about your treatment that you would do differently?' (Fernandes-Taylor, & Bloom, 2011). Description of all methods used can be found in Table 2. References of all studies included in the review can be found in Appendix C.

Overall, the level of regret experienced by participants was low. Of the 22 studies reporting the percentage of regret experienced, results ranged from 0%-56% (M = 21%). Four additional studies reported percentages of participants experiencing low (M = 26.3%), moderate (M = 37.9%) or high (M = 10.5%) regret, while a single study reported percentages of regret experienced by participants at three time points (baseline post-treatment = 10%, 3 months post-treatment = 17.3%, 12 months post-treatment = 10%). Ten studies reported regret obtained from the DRS with scores ranging from 4.9 to 22.1 (M = 14.4). A number of studies however did not provide information on regret prevalence and simply discussed correlates of this.

**Table 2**

*Summary table of studies included*

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 1. | Albkri et al. (2018). | France | 226 | Male | Prostate | Surgery, radiotherapy, hormone therapy | Single item | Quantitative descriptive | 27.8% undecided or regretted choice of treatment; 69.4% did not regret it. |
| 2. | Berry et al. (2012). | USA | 794 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 3. | Chien et al. (2014) | Taiwan | 40 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Mean scores of decisional regret at T1 and T2 were low and did not change over time ($\beta = 0·6$, $p > 0·05$). |
| 4. | Christie et al. (2017) | Australia | 40 | Male | Prostate cancer | Radical prostatectomy | The single DRS item 'The choice did me a lot of harm' | Quantitative descriptive | Not provided |
| 5. | Clark et al. (1997) | USA | 201 | Male | Prostate cancer | Medical or surgical castration | Three items tapping misgivings about the choice that was made and a wish to reverse that decision | Mixed methods | Not provided |
| 6. | Collingwood et al. (2014) | USA | 556 | Male | Prostate cancer | Robotic-assisted laparoscopic prostatectomy | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 7. | Cuypers et al. (2019) | The Netherlands | 382 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | After 12 months, 15% of participants regretted their treatment choice. |
| 8. | Davison et al. (2007) | Canada | 130 | Male | Prostate cancer | Radical prostatectomy, 30% of sample received neoadjuvant hormone therapy also | The 5-item Decisional Regret Scale | Quantitative descriptive | Men had no regrets over their decision to have surgery |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 9. | Diefenbach & Mohamed (2007) | USA | 793 | Male | Prostate cancer | 3-dimensional conformal radiation therapy, brachytherapy, prostatectomy | Two items from the Decision Regret Scale | Quantitative descriptive | Not provided |
| 10. | Fernandes-Taylor & Bloom (2011) | USA | 449 | Female | Breast cancer | Not mentioned | 'Looking back, is there anything about your treatment that you would do differently?' | Mixed methods | 43% of women regretted their breast cancer treatment. |
| 11. | Goepfert et al. (2017) | USA | 1729 | Male and female | Oropharyngeal carcinoma | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | 38.6% of patients reported no regret (ie, proportional regret score of zero), 45.8% of patient had “mild” regret, and 15.5% of patients reported “moderate to strong” regret. |
| 12. | Hoffman et al. (2017) | USA | 934 | Male | Prostate cancer | Not mentioned | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | Overall, 14.6% expressed treatment decision regret. |
| 13. | Holmes et al. (2017) | USA | 804 | Male | Prostate cancer | Not mentioned | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | Overall, 13% of participants reported regret concerning their treatment decision. |
| 14. | Hu et al. (2008) | USA | 195 | Male | Prostate cancer | Not mentioned | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | 18% were regretful of their treatment choice. |
| 15. | Hurwitz et al. (2017) | USA | 652 | Male | Prostate cancer | Radical prostatectomy, external beam radiation therapy, brachytherapy, or active surveillance | The 5-item Decisional Regret Scale | Quantitative descriptive | At 36 months, 13%, 18%, 9%, and 7% of patients reported low regret, and 5%, 7%, 0%, and 2% of patients reported high regret in the RP, EBRT, BR, and AS groups respectively. |
| 16. | Karuturi et al. (2019) | USA | 480 | Female | Breast cancer | Endocrine therapy and chemotherapy | The 5-item Decisional Regret Scale | Quantitative descriptive | The decision-regret score was 17.2 for endocrine therapy and 17.7 for chemotherapy. |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 17. | Kinsella et al. (2012) | England | 82 | Male | Prostate cancer | Radical prostatectomy | 2-item regret questionnaire by Clark et al. | Quantitative randomized controlled trials | Not provided |
| 18. | Lantz et al. (2005) | USA | 1633 | Female | Breast cancer | Not mentioned | “If I had it to do over, I would make a different decision about what type of surgery to have” | Quantitative descriptive | Not provided |
| 19. | Ratcliff et al. (2013) | USA | 95 | Male | Prostate cancer | Radical prostatectomy | Participants responded to seven items related to the frequency with which they had thoughts about how their current situation could have turned out more positively had they made a different treatment decision | Quantitative randomized controlled trials | Not provided |
| 20. | Schroeck et al. (2008) | USA | 400 | Male | Prostate cancer | Retropubic radical prostatectomy or robot-assisted laparoscopic radical prostatectomy | Regret was measured by a previously validated five-level Likert scale addressing whether patients wished they could have changed the kind of treatment they received. | Quantitative descriptive | 19% of men reported regret. |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 21. | Shakespeare et al. (2017) | Australia | 82 | Male | Prostate cancer | Surgery and post-prostatectomy radiotherapy | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | 16.9% were regretful of their overall treatment experience. |
| 22. | Taha et al. (2011) | Canada | 260 | Female | Breast cancer | Not mentioned | Women with a breast cancer experience were asked to indicate on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree) how much she concurred with five statements regarding regret pertaining to her breast cancer treatment decisions (i.e., “I regret the choice that was made”) | Quantitative descriptive | Not provided |
| 23. | van Tol-Geerdink et al. (2016) | The Netherlands | 240 | Male | Prostate cancer | Not mentioned | 18 regret statements were developed, in part derived from previous studies. | Quantitative randomized controlled trials | Not provided |
| 24. | Wang et al. (2018) | Taiwan | 154 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | The mean score on the DRS for the study sample was 8.10. Overall, the sample reported low rates of decisional regret. |
| 25. | Windon et al. (2019) | USA | 150 | Male and Female | Head and neck cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Participants expressed low levels of regret (median score, 5; IQR, 0-25 on a scale of 100). |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 26. | Lin (2011) | Taiwan | 100 | Male | Prostate cancer | Radical prostatectomy | The original regret scale was developed by Clark et al and includes 3 items: the patient's wish that he could change his mind about the type of treatment he received, his belief that his QOL would be better if he had chosen a different treatment option, and whether he was bothered by the fact that other men had received very different prostate cancer treatments. In this study, we added 1 item to this scale: whether the man regretted that he had received an RP. | Quantitative descriptive | 31% of the participants reported experiencing regret. |
| 27. | Maguire et al. (2017) | Ireland and Northern Ireland | 1229 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | The mean Decisional Regret score of 18.02 suggests that levels of regret amongst were reasonably low, yet there was considerable variation here (SD = 19.52). 14.5% of survivors experienced high levels of regret (a score above 50). |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 28. | Mahal et al. (2015) | USA | 484 | Male | Prostate cancer | Surgery or radiation | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | Not provided |
| 29. | Martinez et al. (2013) | USA | 1536 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale – altered for the purpose of this study to reflect elements specific to breast cancer surgery | Quantitative descriptive | Mean regret in the overall sample was 4.9 at time 1 and 5.4 at time 2. |
| 30. | Mollica et al. (2017) | USA | 1093 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 31. | Morris et al. (2015) | USA | 794 | Male | Prostate cancer | Not mentioned | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | 12% experienced treatment decisional regret. |
| 32. | Nicolai et al. (2016) | Germany | 160 | Male and female | Breast or colon cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 33. | Calderon et al. (2019) | Spain | 403 | Male and female | Not specified | Chemotherapy or radiotherapy or both | The 5-item Decisional Regret Scale | Quantitative descriptive | The mean DRS score was 10.6. Most participants (51.9%, n = 209) experienced no decision regret. |
| 34. | Chambers et al. (2018) | Australia | 28 | Male | Prostate cancer | Not mentioned | No specific measure of regret. However, men in the study mentioned feeling regret in the interview. | Qualitative | Not provided |
| 35. | Davison et al. (2014) | Canada | 151 | Male | Prostate cancer | Robotic-assisted laparoscopic radical prostatectomy or open radical prostatectomy | The 5-item Decisional Regret Scale | Quantitative descriptive | The mean total decision regret score of patients in the RARP was 19.34 (SD = 20) and the ORP group 21.32 (SD = 24.6). |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 36. | Hacking et al. (2013) | Scotland | 123 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 37. | Hawley et al. (2008) | USA | 2030 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | About 39% had a lot of decision regret, 30% a moderate amount of regret and another 31% reported very little regret. |
| 38. | Lee et al. (2015) | USA | 123 | Female | Breast cancer | Mastectomy alone (50.4%) | The 5-item Decisional Regret Scale | Quantitative descriptive | Women reported a low to moderate level of regret with their decision (M = 29.1, SD = 19.0). |
| 39. | Lam et al. (2013) | China | 276 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trails | Not provided |
| 40. | Lam et al. (2014) | China | 286 | Female | Breast cancer | Surgery | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 41. | Sawka et al. (2012) | Canada | 44 | Male and female | Thyroid cancer | Adjuvant radioactive iodine treatment | The 5-item Decisional Regret Scale | Quantitative descriptive | Decision regret was generally low (mean 22.1, standard deviation [SD] 13.0). |
| 42. | Schuermeyer et al. (2016) | USA | 96 | Male and female | Uveal melanoma | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | At the baseline, 10% (n=10) of patients had some or full decision regret. At 3 months, 17% (n=11) had some or full decision regret, while at 12 months, 10% (n=8) had some or full decision regret. |
| 43. | Sepucha et al. (2015) | USA | 97 | Male and female | Breast cancer | Surgery | One item assessed whether patients would choose the same type of surgery again. | Quantitative descriptive | A little more than half of respondents (60.8%) would definitely have the same type of surgery again, indicating no regret. |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 44. | Shepherd et al. (2019) | Scotland | 137 | Male and female | Colorectal cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 45. | Shuman et al. (2017) | USA | 57 | Male and female | Laryngeal cancer | 46% treated surgically, 54% nonsurgically | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 46. | Spittler (2012) | USA | 102 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Mixed methods | The majority of the women reported low decision regret (79%) and of these 44% had no decision regret. |
| 47. | Wagland et al. (2019) | England | 97 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Mixed methods | Not provided |
| 48. | Watts et al. (2014) | Australia | 138 | Male | Prostate cancer | Prostate specific antigen (PSA) testing (might need to exclude as not cancer treatment) | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 49. | Mishel et al. (2009) | USA | 256 | Male | Prostate cancer | Not mentioned | Decisional Regret Subscale, a 3-item subscale of the Quality of Life Scale | Quantitative randomized controlled trials | Not provided |
| 50. | Step et al. (2009) | USA | 216 | Female | Breast cancer | Adjuvant therapy | Decision regret likert scale | Quantitative descriptive | Not provided |
| 51. | Step et al. (2009) | USA | 179 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 52. | Parker et al. (2018) | USA | 288 | Female | Breast cancer | Contralateral prophylactic mastectomy (CPM) | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 53. | Repetto et al. (2016) | Italy | 204 | Male | Prostate cancer | Active surveillance (AS), open radical prostatectomy, robotic radical prostatectomy, and brachytherapy | The 5-item Decisional Regret Scale | Quantitative descriptive | Most of the patients had a low or null degree of regret on the Treatment Regret Scale from 0 to 100 (78.1% obtained a score <30, and about 30% of the sample had a score equal to zero). Only 4.7% scored 60 or more, indicating some degree of regret. |
| 54. | Shahrzad & Seyedeh Narjes (2019) | Iran | 60 | Female | Breast cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 55. | van Stam et al. (2018) | The Netherland | 454 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 56. | Noyan et al. (2006) | Turkey | 125 | Female | Breast cancer | Mastectomy (and breast reconstruction) | Satisfaction/regret likert scale | Quantitative descriptive | Not provided |
| 57. | Advani et al. (2019) | USA | 421 | Female | Breast cancer | Lumpectomy plus whole-breast irradiation, brachytherapy, or endocrine therapy or mastectomy with or without radiation | The 5-item Decisional Regret Scale | Quantitative descriptive | 23.8% of respondents reported experiencing local therapy decisional regret |
| 58. | Hu et al. (2003) | USA | 96 | Male | Prostate cancer | Not mentioned | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | 16% of participants reported regret. |
| 59. | Steer et al. (2013) | Australia | 220 | Male | Prostate cancer | Image-guided intensity modulated radiation therapy and 3-dimensional conformal radiation therapy. | 2-item regret questionnaire by Clark et al. | Quantitative descriptive | 3.8% of patients expressed decision regret for their choice of treatment. |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 60. | Lavery et al. (2012) | USA | 703 | Male | Prostate cancer | Robot-assisted laparoscopic prostatectomy | The 5-item Decisional Regret Scale | Quantitative descriptive | Of the patients 88% did not regret the decision to undergo robot-assisted laparoscopic prostatectomy. |
| 61. | Clark et al. (2003) | USA | 747 | Male | Prostate cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 62. | Clark et al. (2001) | USA | 201 | Male | Prostate cancer | Orchiectomy (29%) or chemical castration (71%) | Two items asking if a patient wished he could change his mind and the belief that he would have been better off with the treatment not chosen. | Quantitative descriptive | 23% of participants reported regret. |
| 63. | Drevdahl & Dorcy (2012) | USA | 45 | Male and female | Hematologic malignancies | Stem cell transplant | Interview questions about regret | Qualitative | Noting that they had “no other choice,” participants expressed no regret posttransplant. |
| 64. | Shaverdian et al. (2017) | USA | 276 | Male | Prostate cancer | Stereotactic body radiation therapy, intensity modulated radiation therapy, or high-dose-rate brachytherapy. | “A validated tool” | Quantitative descriptive | 13% expressed regret with their treatment. |
| 65. | Daum et al. (2017) | USA | 201 | Male | Prostate cancer | Not mentioned | The satisfaction with decision scale (Holmes-Rovner et al., 1996) | Quantitative descriptive | Not provided |
| 66. | Davison, B. J., & Goldenberg, S. L. (2003) | Canada | 67 | Male | Prostate cancer | Radical prostatectomy<br>External beam radiation,<br>Brachytherapy,<br>Watchful waiting. | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |

| Study no. | Reference | Country | N | Gender | Cancer | Treatment Type | Measure of regret | Study design | Prevalence of regret |
|---|---|---|---|---|---|---|---|---|---|
| 67. | Diefenbach et al. (2008) | USA | 391 | Male | Prostate cancer | External beam radiation | Three items from the 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |
| 68. | Doğan et al. (2017) | Turkey | 162 | Male | Prostate cancer | Not mentioned | Interview question: Do you regret having undergone this surgery? | Qualitative | 16% regretted having undergone surgery, while another 1.7% had indecisive thoughts on regret. |
| 69. | Mohamedali et al. (2010) | Canada | 35 | Male and female | Acute myeloid leukaemia | Chemotherapy | The 5-item Decisional Regret Scale | Quantitative descriptive | Decisional regret scores were low among respondents, with a mean score of 8.67 out of 25. |
| 70. | Reamer et al. (2017) | USA | 160 | Male | Prostate cancer | Surgery, radiation, active surveillance (AS)/watchful waiting (WW). | "Existing scales modified for study" | Quantitative descriptive | Men in the sample had little regret (median score: 1.0 on a 5-point scale, SD: 0.8) with their treatment decision-making process. |
| 71. | Sawka et al. (2015) | Canada | 70 | Male and female | Thyroid cancer | Not mentioned | The 5-item Decisional Regret Scale | Quantitative randomized controlled trials | Not provided |
| 72. | Swanick et al. (2018) | Canada | 1650 | Female | Breast cancer | Lumpectomy plus whole-breast irradiation, lumpectomy plus brachytherapy, lumpectomy alone, mastectomy without radiation therapy, and mastectomy plus radiation therapy | The 5-item Decisional Regret Scale | Quantitative descriptive | Not provided |

### 2.5.2 Narrative Synthesis

The assessment of each full-text revealed different types of factors associated with the emergence of regret in cancer patients/survivors. These factors were noted and later split into categories, according to their nature, e.g., a study which found ethnicity to have an association with regret was put into the 'socio-demographic factors' category. Most studies examined factors which fit into more than one category. Those categories were then further grouped into two broad sections: "less modifiable factors" and "modifiable factors" associated with regret (see Table 3). During the analysis, a clear distinction between the two was noted. Specifically, modifiable factors were considered to be those that may be changed from the patient's perspective, e.g., a patient feeling distressed post-treatment may reach for professional help in order to mitigate this feeling. There are also factors which the patient has no control over, e.g., socio-demographic factors like age. Less modifiable factors were those which the patient had little or no control over.

**Table 3**

*The categories of factors found to be associated with regret*

| **Less modifiable factors associated with regret** | **Modifiable factors associated with regret** |
|---|---|
| Socio-demographic factors | Decision making process, the consultation, level of understanding of information received or searched for/ counselling, etc. |
| Clinical factors, health status and physical side effects | Psychological and social factors |
| Treatment type | |

### 2.5.3 Theme 1: Less modifiable factors associated with regret

In the analysis of less modifiable factors, the factors were further organised into three categories: socio-demographic factors, clinical factors (or factors associated with the patient's health status including side effects experienced) and factors associated with the treatment type received. It is important to note that while some patients in the studies did have control over the treatment chosen, the nature of the treatment itself was considered a less modifiable factor here as the patient has no control over the effects of treatment. In contrast, treatment decision-making was considered as a modifiable factor in a category in Theme 2.

#### *1. Regret associated with socio-demographics*

Twenty-two (31%) of the studies (2, 3, 6, 8, 9, 12, 14-16, 18, 20, 28-31, 37, 50, 51, 56-58, 60) in the analysis reported an association between regret in cancer patients/survivors and specific socio-demographic factors including: marital status (2, 14; regretful men were less likely to be in a relationship), education level (2, 3, 16, 18, 30, 50, 51, 56, 57, 58; higher education associated with less regret), race (6, 14, 15, 16, 18, 20, 28, 29, 30, 31, 37, 57; Caucasian patients in the USA tended to regret less than other racial groups), age (9, 12, 16, 31, 50, 51, 60; no clear pattern found, both younger and older patients were found to experience regret in different studies), income level (18, 56; higher income associated with less regret) and post-treatment financial difficulties (8; financial difficulties associated with higher regret).

Some interesting patterns may be observed here. All of the studies concerned with race in cancer patients found that Caucasian individuals often reported less regret than non-white patients. This was true for both males and females. However, it is important to note that all of those studies were conducted in the USA, where racial differences may be more apparent. Another pattern which appeared from the analysis of socio-demographic factors in the studies suggests that lower education levels may be associated with the emergence of regret in cancer patients/survivors. This was also found to be the case with lower-income levels. No clear pattern was found in the levels of regret in different age groups as various studies found more regret in younger and older patients. None of the studies analysed reported a comparison of the emergence of decisional regret between males and females. This is likely due to the focus on recruitment of patients with specific cancer types, which differentially affects males and females. The studies which conducted an analysis of socio-demographic factors and their relationship with regret can be found in Table 4 below.

### *2. Regret associated with clinical factors, health status and physical side effects*

Twenty-four (33%) of the studies (6, 8-12, 14, 15, 17, 19, 20, 24, 26, 29, 30, 31, 35, 45, 58, 60-64) found an association between the patient’s health status pre and/or post-treatment and the emergence of regret. This also included the experience of side effects from cancer or treatment.

Prostate cancer patients were the largest group of participants in this review. Therefore, the largest number of physical factors associated with regret were prostate cancer specific. Prostate cancer patients reported regret associated with: poorer physical health (14), lower health related quality of life (HRQoL) scores (35, 58, 60), lower scores on the functional and global QoL subscales (33, 67), poorer physical component summary scores (14), surgical complications (6), sexual dysfunction/ urinary dysfunction/ erectile dysfunction (6, 9, 12, 15, 17, 19, 26, 31, 35, 60, 61), pain (8), bowel function bother (12, 14, 26), poor hormonal function (15), nausea (62), lower Expanded Prostate Cancer Index scores (20), poorer perceived physical condition (26), higher Gleason score (30, 64), PSA level/concern (12, 61, 64) and T1c disease (64). In contrast, one study found that regretful men less frequently reported sexual dysfunction (62). Interestingly, one study found that non-obesity in African men was associated with greater regret levels (6).

Breast cancer patients similarly reported regret associated with a range of physical health problems. These included: premature menopause (10), later breast cancer stage (24) and a second diagnosis of breast cancer (29). Difficulty swallowing was a factor associated with regret in oropharyngeal carcinoma patients (11). Laryngeal cancer patients reported regret associated with lower voice-related QoL (45). A study of patients with hematologic malignancies (63) found that regret was associated with the patient's perceived decreased cognitive abilities. While all of the studies reported different health-related factors, it is clear that poorer physical health may be associated with the emergence of decisional regret. Studies which analysed the relationship between clinical factors, health status, physical side effects and regret can be found in Table 4 below.

### *3. Regret associated with the treatment type received*

Treatment type chosen/received was found to be associated with regret in twenty-six (36%) of the studies in this analysis (6, 9-11, 14, 17, 18, 20, 21, 24-26, 29, 31, 41, 52, 56-59, 60, 62, 64, 66, 69, 72,). The studies in this analysis included various cancer patients who underwent different treatments; therefore, no pattern of regret associated with specific treatment types was found. Some of the studies did not report on the specific type of treatment, while others provided this information in detail. Some of the treatments found to be associated with higher regret in prostate cancer individuals in the studies were: medical or surgical castration, robotic-assisted laparoscopic prostatectomy, brachytherapy, androgen-deprivation therapy and radical prostatectomy.

Breast cancer patients regretted radiation, chemotherapy, hormone therapy, surgery, mastectomy, lumpectomy, axillary nodal dissection and others. Oropharyngeal carcinoma patients regretted therapeutic combination treatment. Head and neck cancer patients regretted undergoing surgery or radiation therapy alone instead of a combination of treatments (25). One study (9) found an association between regret and treatment modality. One study (18) found regret in breast cancer patients who decided to not undergo breast reconstruction post-mastectomy. Three studies (14, 60, 69) found that a longer interval since treatment in cancer patients was associated with greater regret, while another (6) found that longer stay in hospital post-treatment resulted in higher reports of regret. The same study (6) found that African American men who received secondary therapy reported more decisional regret than white men, suggesting not only an association between regret and treatment type but also ethnicity. This shows just how difficult it may be to predict and to mitigate the emergence of regret, as more than one factor may be involved.

### 2.5.4 Theme 2: Modifiable factors associated with regret

Modifiable factors are those which either the doctor or patient may clearly have some control over. In the analysis, these factors were further split into two broad categories: regret associated with the decision-making process and regret associated with social/psychological factors.

#### *1. Regret associated with the decision making process (e.g., consultation/level of understanding of information received or searched for/ counselling)*

This category of the analysis was the one most commonly investigated in the studies reviewed. It included all factors associated with the decision making process, the consultation with health specialists, the level of understanding of the information provided by doctors or searched for by the patient. Thirty (42%) of the studies analysed (1, 2, 7, 10, 12, 13, 17, 18, 23, 24, 26, 30-32, 34, 36, 38-41, 43, 44, 46-49, 51, 55, 62, 68) explored the associations between these factors and the emergence of decisional regret in patients.

The patients in the studies analysed reported regret associated with the decision making process for many reasons. A number of studies (1, 2, 68) found that regretful patients believed to have received incomplete information regarding their diagnosis or treatment, or that their perceived preparation for decision-making was low. Decision uncertainty and decision conflict was found to be associated with regret in four studies (30, 38, 40, 46), while confidence level was found to be negatively correlated with decision regret in another (46). One of those studies (38) also found an inverse significant relationship between the level of comfort in using the English language and difficulty with communication with physicians and decisional regret. One study (43) found lower decision regret in patients who received treatment which matched their goal, suggesting the importance of goal setting prior to treatment decision making.

Four studies found that decisional regret was negatively associated with satisfaction understanding potential treatment side effects (10, 31, 47, 68). Another study (47) also found this to be the case and found that unchallenged treatment preferences and an absence of clinical recommendations resulted in higher levels of regret. One study (40) found regret to be significantly predicted by lower quality in establishing a shared decision-making framework, being offered multiple treatment options and greater duration of consultation. One qualitative study (10) notes that women regretted having chemotherapy for breast cancer as they were not aware that this may decrease their chance of having children in the future. The same study also found that many women expressed regret associated directly with the doctor in charge of their treatment, one noting that her doctor did not have enough time for her and another one stating that her doctor had no “bed-side manner”. Several women in this study also regretted not being more active in seeking information about their treatment and not knowing enough about its possible side effects. One study (34) reports of patients who described feeling regret about late diagnosis or treatment and this was commonly attributed to delays by clinicians.

Six studies (23, 36, 39, 44, 48, 49) found less regret in patients who were given a decision aid, than in those who were not. In contrast, one study (7) found that the receipt of a decision aid had no statistically significant association with lower odds of reporting regret. In another study (41), decision regret significantly differed according to who made the final decision: the patient (mean 19.0, SD 11.3), patient and doctor (mean 19.5, SD 7.4), and the doctor (mean 32.9, SD 20.37). Another study (17) found that preoperative counselling altered treatment choices in prostate cancer patients and those who received this counselling experienced far less treatment-related regret than those in the control group. Finally, one study (32) found more regret in patients who reported not feeling empathy from their physician.

Two patterns have been found in the studies analysed above. The first being that a number of studies (12, 13, 26, 62) found less regret in patients who reported being well-informed at the time of the treatment decision. The second being that less regret was found in patients who had as much involvement in the decision-making process as desired, i.e., patients who were not more involved than preferred, or less involved than preferred reported less regret across a number of the studies (18, 24, 32, 47, 51, 55, 68).

### *2. Regret associated with psychological and social factors*

Twenty-one (29%) studies (2-5, 7, 8, 10, 14, 15, 19, 22, 26, 27, 30, 33, 37, 40, 42, 63, 67, 68) in the analysis found an association between psychological or social factors and the decisional regret in cancer patients. A pattern suggesting that regret is associated with poorer mental health is evident in all of these studies, with two (15, 19) simply reporting an association between regret and poorer mental health scores. Four studies found regret to be associated with higher anxiety scores (2, 7, 40, 42), with another two (14, 27) finding an association between regret and fear of recurrence. Three studies found regret to be associated with higher depression scores (4, 7, 42). Two studies (5, 33) found that the more distress displayed by patients, the higher the levels of decisional regret, with an additional study (26) reporting more regret in patients displaying distress from treatment complications. One study (14) found that emotional domains differed between regretful and non-regretful people. This result was mirrored by another study (3) which found that patients with greater psychosocial adjustment experienced less regret. Another study (30) found that patients who displayed higher optimism and resilience also reported less regret. Another study (63) reports higher levels or regret to be associated with feelings of wanting to return to “normal”. Another study (22) found regret to be associated with blaming oneself for negative events associated with the illness.

Three studies (10, 37, 68) found an association between social support and decisional regret, with more support being associated with less regret. Perceived poorer self-care habits, for example in the form of not joining a support group, were also associated with higher levels of regret (10). One study (8) found a correlation between higher levels of regret and changes in QoL in men with decreases in role and social functioning. Lastly, two studies (14, 30) found higher levels of spirituality to be associated with lower levels of regret.

**Table 4** *Studies which investigated the relationships between regret and five types of factors*

| Category | Factor | Studies with sig. relationship | Studies with no sig. relationship | Studies with partial relationship |
|---|---|---|---|---|
| Socio-demographic variables | Marital status | 2, 14 | | |
| | Education level | 2, 3, 16, 18, 50, 51, 56, 57, 58 | 30, 37, 68 | |
| | Socioeconomic status | | 6 | |
| | Race/Ethnicity | 6, 14, 15, 16, 18, 28, 29, 30, 31, 37, 57 | 20 | |
| | Age | 9, 12, 16, 31, 50, 51, 60 | | |
| | Employment status | 9 | | |
| | Income level/ financial difficulties | 8, 18, 56 | | |
| Clinical factors, health status and physical side effects | General physical health condition/ HRQoL scores/ QoL scores | 14, 26, 33, 35, 58, 60, 67 | 53 | |
| | Non-obesity | 6 | | |
| | Cancer stage | 24, 64 | 20 | |
| | Gleason score | 30, 64 | 20 | |
| | Biochemical recurrence | | 20 | |
| | Lower EPIC domain scores | 20 | | |
| | Health utility | | 57 | |
| | Sexual dysfunction/erectile dysfunction | 6, 9, 12, 15, 17, 19, 26, 35, 60, 61 | 62, 68 | |
| | PSA level/ PSA concern | 12, 61, 64 | | |
| | Urinary dysfunction | 9, 19, 26, 31 | | 15, 35 |
| | Pain | 8 | | |
| | Bowel dysfunction | 12, 14, 26 | | |
| | Hormonal dysfunction | 15 | | |
| | Nausea | 62 | | |
| | Premature menopause | 10 | | |
| | Second diagnosis of cancer | 29 | | |
| | Difficulty swallowing | 11 | | |
| | Voice-related quality of life | 45 | | |
| | Perceived decreased cognitive abilities | 63 | | |
| Treatment factors | Surgical complications | 6 | | |
| | Prostate cancer treatment | 6, 9, 17, 20, 21, 26, 31, 58, 59, 62, 64 | 66 | |
| | Breast cancer treatment | 10, 11, 19, 24, 29, 56 | 52, 72 | 57 |
| | Head and neck cancer treatment | 25 | | |
| | Thyroid cancer treatment | | 41 | |

| | | | | |
|---|---|---|---|---|
| | Longer interval since treatment | 14, 60, 69 | | |
| | Longer stay in hospital post-treatment | 6 | | |
| | Treatment modality | 9 | | |
| Decision making process | Being well-informed | 1, 2, 10, 12, 13, 26, 62, 68 | | |
| | Decision uncertainty | 38 | | |
| | Confidence level | 46 | | |
| | Communication difficulty | 38 | | |
| | Matched goal | 43 | | |
| | Understanding potential side effects | 10, 31, 47, 68 | | |
| | Decisional conflict | 30, 40, 46 | | |
| | Little SDM | 40, 41 | | |
| | Being offered multiple treatment options | 40 | | |
| | Greater duration of consultation | 40 | | |
| | Blaming health-care professionals | 10, 32, 34 | | |
| | Use of decision aid | 23, 36, 39, 44, 48, 49 | 7, 54, 71 | |
| | Preoperative counselling | 17 | | |
| | Preferred level of involvement | 18, 24, 32, 47, 51, 55, 68 | | |
| | Unchallenged treatment preferences | 47 | | |
| | Lack of clinical recommendations | 47 | | |
| Psychological and social factors | Overall poor mental health scores | 15, 19 | | |
| | Anxiety | 2, 7, 40, 42 | | |
| | Depression | 7, 42 | | 4 |
| | Distress | 5, 26, 33 | | |
| | Emotional domains of QoL | 3, 14, 30 | | |
| | Wanting to return to “normal” | 63 | | |
| | Fear of cancer recurrence | 14, 27 | | |
| | Blaming oneself for negative events | 22 | | |
| | Social support | 10, 37, 68 | 70 | |
| | Poor self-care habits | 10 | | |
| | Changes in QoL with decreases in role and social functioning | 8 | | |

## 2.6 Discussion

The aim of this review was to understand the complexity of factors which may have an impact on the emergence of decisional regret in cancer patients. Results show that the level of regret found in patients in the studies analysed was quite low, which mirrors findings from previous systematic reviews (Hoffman et al., 2017; Spittler, 2012; Steer et al., 2013). A systematic review of 90 studies investigating whether regret in cancer patients is longitudinally-stable found that less than 20% of patients experienced any regret (Aarhus & Huang, 2020). However, the current review found that regret was often found in a significant minority of patient samples. The decrease in well-being in the presence of regret suggests that minimising the risk of this is an important consideration in supporting survivors achieve a better and healthier cancer survivorship.

Two broad types of factors emerged from the analysis – less modifiable factors associated with regret and modifiable factors associated with regret. The first are factors which a cancer patient/survivor has little or no control over. They may relate to life pre-diagnosis or be directly related to the illness and the experiences it brings. The second are factors which may be altered or controlled by the patient or their doctor. For some patients experiencing regret, it may be too late to alter some factors discussed below in order to mitigate their regret. For example, a patient reporting regret cannot go back in time to change the treatment decision-making process. However, this research may help inform the provision of supports for cancer survivors. It is hoped that the results of this analysis can be used in order to inform future interventions aimed at those concerned, thereby mitigating the emergence of regret in cancer patients and survivors. While many of the factors in this category are “fixed”, i.e., cannot be changed, these findings may be of use to clinicians who wish to identify patients prone to experiencing regret.

### 2.6.1 The role of sociodemographic and health-related factors in the experience of regret

The patterns found amongst socio-demographic factors linked to the emergence of regret show that less regret occurs in those who are: in a relationship, have a higher education and have a higher income (or less financial difficulty caused by cancer/treatment). In all of the studies concerned with ethnicity, white individuals were found to report less regret than non-white cancer patients/survivors (Collingwood et al., 2014; Kim et al., 2016). It is important to note however that all of those studies were conducted in the USA which limits the generalisability of results. No differences or patterns found in age, with various studies finding younger patients to report more regret, and older patients in others. It is also notable that no studies in the review performed an analysis of gender differences in decisional regret of cancer patients. However, most studies included focused on breast or prostate cancer only and therefore would not have been able to conduct this analysis. This is something which should receive more attention in the future in order to establish whether cancer supports should be tailored differently to men or women. While such socio-demographic factors cannot be altered, this review highlights various groups of patients which need to be looked out for during their illness, as they may be increasingly prone to experiencing decisional regret.

The results also indicate that overall poorer physical health and the experience of negative side effects is associated with greater levels of decisional regret in cancer patients (Berry, Wang, Halpenny, & Hong, 2012; van Stam et al., 2018). While one surprising study result suggests that non-obesity in African-American men can be associated with higher regret levels (Collingwood et al., 2014), overall, this analysis found a relationship between poorer health status and higher levels of regret. While in most cases, poorer physical health cannot be avoided, it may be possible to prepare patients for what is to come after cancer treatment. The finding that many patients reporting regret also report negative physical side effects suggests that providing information about what is to come after treatment is vital. The longevity of these symptoms also needs appropriate consideration, as it is important to understand that physical side effects can continue long into survivorship. This may be done with appropriate decision aids which have been found to improve satisfaction post-treatment (Kearing, Berg, & Lurie, 2016; Whelan et al. 2014). The review also highlights that patients tend to regret side-effects which they were not aware of while making their treatment decision, leaving them no time to prepare for the negative outcomes of their chosen treatment type. Healthcare professionals need to take this into account when preparing patients for the aftermath of the cancer treatment.

### 2.6.2 The role of the cancer treatment in the experience of regret

The review did not find any clear pattern between the emergence of decisional regret and specific treatment types. However, findings highlight the variety of cancer treatment types which may be associated with regret in cancer patients and survivors, suggesting that regardless of treatment, all survivors are at risk of experiencing regret (Fernandes-Taylor & Bloom, 2011; Lin et al., 2011; Ratcliff et al., 2013). This finding suggests the importance of choosing the “best” treatment option available for specific patients. Naturally, regret may occur despite the patient and/or doctor feeling like an appropriate treatment type was selected and this may occur for many reasons, including negative physical side effects experienced post-treatment, the treatment not working, or a long stay in hospital due to the treatment. Despite this, the review findings suggest that assisting cancer patients in their decision making may be of benefit.

### 2.6.3 The role of treatment decision-making in the experience of regret

The review finds that overall, the better informed patients are before making their treatment decision, the less regret they report post-treatment (Lam et al., 2013; van Tol-Geerdink et al., 2016). However, it is important to note that little regret is reported by cancer patients whose wishes regarding a desired level of involvement in the decision-making are met. This finding has also been found in a systematic review of cancer patient's involvement preferences (Hubbard, Kidd, & Donaghy, 2008). It is important to understand that patient involvement preferences vary (Marahrens et al., 2017; Sekimoto et al., 2004). The review finds that the best regret-related results are found in those who are as much involved in the decision-making as they wish. Some patients do not feel the need to be involved in the decision-making process and prefer to leave the decision up to their doctors. Honouring this decision leads to less regret in patients (Nicolai et al., 2016). Future interventions should aim to assess involvement preferences for patients. This would allow healthcare providers to establish an appropriate method of decision-making.

The review also found that doctors of cancer patients have an impact on the emergence of decisional regret. Individuals report more regret if they feel their doctors were not empathetic enough, had no bedside manner or were not understanding enough (Nicolai et al., 2016). Good communications skills, empathy and understanding are essential for the well-being of patients implying that more training could be provided to doctors in this area (Fallowfield, 2008; Kee, Khoo, Lim, & Koh, 2018). Effective doctor-patient communication is also essential for patient understanding (Janz et al., 2017), and as discussed above, this minimised the emergence of regret. These findings suggest that healthcare professionals should recognise the importance of appropriate care of not only the physical needs of the patient, but also the psychological needs.

Additionally, less regret was found in those who reported less decision uncertainty at the time of the treatment decision-making, those who felt like the treatment they selected matched their goal and those who used a decision aid. These findings suggest the importance of selecting an appropriate decision-making style, as this factor may strongly influence the emergence of decisional regret (Lam et al., 2014; Sawka et al., 2012; Wang et al., 2018). Not only is an appropriate decision-making style important as once again it is evident that well-informed patients report better outcomes (Heisig et al., 2015; Manne et al., 2010). This pattern has been evident through different aspects of this analysis implying that cancer patients should not be treated as individuals who know far less than the health-care professionals. Honouring their input, feelings and knowledge is important for their well-being.

### 2.6.4 The role of psychosocial factors in the experience of regret

The review found a relationship between higher levels of regret and poorer mental health scores (Chien et al., 2014; Hu et al., 2008; Wilson et al, 2017). This pattern is evident amongst all of the studies which measured the relationship between regret and psychological factors. Less regret was found in patients who displayed: less anxiety, less depression, less fear of cancer recurrence, and less distress. Some studies found that survivors with lower regret reported greater psychosocial adjustment, higher optimism, higher resilience, and higher spirituality. Other aspects of survivor appraisals emerged as associates of regret in some studies, including not blaming themselves for the negative events associated with their illness and not displaying a “need to go back to a normal life”. A cancer diagnosis brings a great psychological strain on its sufferers (Hewitt, & Rowland, 2002), and the link between poor mental health and high levels or regret is evident throughout this review. This finding highlights the need for doctors to be mindful of not only the physical well-being of their patients, but also the psychological impact that a cancer diagnosis and treatment may have on them (Zebrack, 2011). Healthcare professionals should inform individuals of available interventions which aid psychological well-being in cancer patients, e.g., music interventions (Bradt, Dileo, Magill, & Teague, 2016; Zhang et al., 2012), yoga (Lin, Hu, Chang, Lin, & Tsauo, 2011), meaning-centred group psychotherapy (Breitbart et al., 2015), mindfulness stress reduction training (Bränström, Kvillemo, Brandberg, & Moskowitz, 2010) or other psychological interventions (Casellas-Grau, Font, & Vives, 2014; Jassim, Whitford, Hickey, & Carter, 2015).

Social support (Mollica, Underwood, Homish, Homish, & Orom, 2017) was also found to be associated with less regret, although this factor was less frequently studied in the research review. While social support cannot be forced by the patient or healthcare professional, doctors should inform patients of the support services available on- and offline (Attai et al., 2015; Bender, Jimenez-Marroquin, & Jadad, 2011; van Uden Kraan et al., 2008). Spirituality also cannot be orchestrated. Once again, doctors may suggest religion-based support groups to cancer patients who may want it.

Surprisingly, caregiver and family influence on decision making and related regret was not a factor identified in the studies reviewed. Family members are often involved before, during and after the medical consultation and may stimulate discussion at home, away from the medical expert (Laidsaar-Powell et al., 2016). They may also stimulate patient autonomy as they help to breakdown difficult to understand or overwhelming information (Laidsaar-Powell et al., 2016). However, as with personal involvement in decision-making, patients hold preferences on the level of involvement of their caregivers and family members (Laidsaar-Powell et al., 2016). An unsatisfactory level of involvement in decision-making as seen by the patient may affect the emergence of decisional-regret.

No consistent pattern of factors associated with regret was found between different cancer types, suggesting that any type of cancer warrants the possibility for regret to occur due to different factors. This also suggests that while systematic reviews concerned with the well-being of cancer patients of one cancer type only can allow researchers to better understand regret in a specific cohort, this also may restrict the generalisability of results (Lin, Aaronson, Knight, Carroll, & Dudley, 2009; Zhong, Smith, Haghighi, & Mancuso, 2018). From this review it seems that regret in cancer patients can be treated as a general issue and not one that varies according to the type of illness.

It is important to note that not all of the relationships found between regret and a specific factor were significant. Furthermore, a significant relationship between decisional regret and another factor cannot be interpreted as a cause of the emergence of regret. The inconsistent findings suggest the complexity of factors which may affect the emergence of decisional regret and that it may not always be easy to predict those who are at risk of regret.

## 2.7 Limitations

It is possible that the search terms relating to decisional regret used in the database search did not uncover all studies investigating regret, due to different phrasing used to describe this phenomenon. However, it was the intention to focus on this experience specifically, and the search term was in line with other systematic reviews in the area. Another limitation may be the number of databases used. The use of additional databases could have ensured the inclusion of more relevant studies. Another limitation of the current study is that any measure which attempted to capture the experience of regret was considered for inclusion and while most of the studies included used validated measures, some studies did not. Similarly, the reliability of the studies was not considered and neither was the statistical power of the studies in relation to the magnitude of variables associated with regret.

The type of studies included in the review may also be considered as a limitation of the current research. The majority of the studies included used a cross-sectional design making it difficult to make assumptions of causality. Very few of the studies were prospective, and this limited the results to one time point only. Studies which captured regret with various means (self-reported measures, qualitative measures, open-ended questions, close-ended questions) were included in the review. However, the search terms may not have picked up various measures with single items measuring regret, for example patient-reported outcomes.

This review intended to be very inclusive and attempted to inspect the factors associated with decisional regret in patients suffering from various types of cancer, in comparison with other systematic reviews on the topic (Christie et al., 2015; Flitcroft et al., 2018; Wilson et al., 2017). However, most of the studies which met the inclusion criteria were concerned with either prostate cancer patients only (58.33%) or breast cancer patients only (27.78%). This result mirrors the prevalence of prostate and breast cancers worldwide, with breast cancer being the second most common cancer worldwide (2.09 million cases) and prostate cancer being the fourth (1.28 million cases) (World Health Organisation, 2018). Lung and colorectal cancers are also very prevalent, but not as much research is being conducted about the regret in survivors of these cancer types. This may be because lung and colorectal cancers are top of the list of cancers which cause most deaths, and a smaller number of survivors than breast and prostate cancers (World Health Organisation, 2018). Nevertheless, this review highlights the need for researchers of well-being in cancer survivors to be more inclusive, as sufferers of less prevalent cancers are currently being overlooked.

In some cases, it is unclear whether the physical side effects reported by the participants in the studies included occurred due to the cancer itself, or the treatment underwent. Therefore, this analysis undoubtedly contains side effects occurring for both reasons, so should be interpreted with caution. Regret in cancer patients/survivors in these studies was associated with a wide range of factors.

Lastly, USA is overly represented in the studies analysed. This may limit overall generalisability as healthcare contexts may differ in the USA compared to other countries.

## 2.8 Conclusion

It has been found that most systematic reviews of regret in cancer patients have concentrated on one cancer type only. This limits the generalisability of the results to other cancer populations. This review was conducted in order to create a broader overview of the reasons why survivors of different cancer types may report regret post-treatment. The results of the review present the complex nature of the many factors which may have an effect on the emergence of the negative feeling that is regret in cancer patients and cancer survivors. As regret can be an obstacle to full-recovery from cancer (Davidson et al., 2007), this review suggests that more research into mitigating its emergence is needed. The research available today highlights the complexity of factors associated with regret in cancer patients and survivors. However, more attention needs to be directed towards finding interventions of minimising it – interventions which will inform both the patient and doctor as well as interventions which will work to mitigate regret.

In summary, this chapter has illustrated the range of factors found to be associated with the emergence of decisional regret in cancer patients and survivors. Study 2 aims to explore this further by examining the relationships between factors associated with the emergence of regret in cancer survivors living in Ireland.

# Chapter 3

## Study 2 - An Analysis of the Factors Associated with Post-Treatment Regret in Cancer Survivors Living in Ireland - Method

## 3.1 Overview

The systematic review detailed in Chapter 2 uncovered the factors most commonly associated with regret, including sociodemographic variables, the treatment type undertaken, physical wellbeing and side effects, the decision making process, and psychosocial factors. Building on these findings, study 2 aimed to explore the experiences of cancer survivors living in Ireland. In this chapter, the methodology for this study is described in more detail.

## 3.2 Aim of the Study

The aim of this study was to explore the experiences of Irish cancer survivors in relation to their treatment decision-making, and to establish factors associated with decisional regret. More specifically, the study had three main objectives:

1. To describe the characteristics of a sample of Irish cancer survivors who have undergone treatment.
2. To understand the experiences of decision making in relation to cancer treatment.
3. To explore the associations between sociodemographic, health, decision making, and psychosocial factors and the experience of decisional regret.

## 3.3 Sample

The sample comprised of cancer survivors living in Ireland. Inclusion criteria were being at least one-year post diagnosis, over 18 years of age, having undergone cancer treatment and currently not being a cancer patient. Participants who were cancer free but at the time of the study still undergoing treatment (e.g. medication) were included. A further inclusion criterion included being fluent English speaking. Participants were recruited from both online and community cancer support groups between January 2019 and September 2019. More information on the recruitment process is provided in section 3.6.

## 3.4 Design

The study employed a cross-sectional survey design, with the main outcome variable being decisional regret. The study also used mixed methods to gain an in-depth insight into participant's experience of their illness: from the time of diagnosis, through to treatment decision making and current survivorship.

## 3.5 Measures

A questionnaire was designed based on previous literature investigating the well-being of cancer patients and/or cancer survivors, also informed by the findings of the systematic review. The survey included validated scales and sets of questions, most of which have featured in other studies concerned with the well-being of cancer patients and/or cancer survivors. Measures included were those hypothesised to associate with treatment decision making and in particular with the experience of decisional regret. Responses were obtained using Qualtrics, a web-based survey tool (Qualtrics, Provo, UT). All sections of the questionnaire underwent a thorough analysis which allowed for the inclusion of relevant questions only. The full questionnaire can be found in Appendix D.

### 3.5.1 Sociodemographic and Health Information

The first section of the survey obtained participants' socio-demographic and background information as well as information regarding their health and cancer diagnosis. Participants were asked to report their: age, gender identity (male, female, other), nationality (Irish, other), number of dependent children, marital status (married, never married, widowed, separated, divorced, living with partner/co-habiting, living in a civil partnership), highest education level obtained (primary, secondary or third level), employment status (working for an employer, looking after family/home, unable to work due to permanent sickness/disability, self-employer, retired, student, unemployed, other), including whether employment status had changed since diagnosis, and whether they had caring responsibilities for a family member (feeding, dressing, etc.). Participants were also asked about their ability to make ends meet. Specifically, participants were asked to rate their agreement with the question “Thinking of your total monthly income: are you able to make ends meet?” on a scale of 1 (very easily) to 7 (with great difficulty).

Participants were asked a number of questions about their cancer diagnosis. This included reporting on their: time since diagnosis in years, cancer type diagnosed with (open text response), and whether they experienced any other chronic health conditions (open-text response).

### 3.5.2 Cancer Treatment and Decision Making Process

The second section of the survey was concerned with the treatment decision making process, the amount of treatment options which were available to respondents, how well informed the participants were of their treatment options, the type of information searching which the participants were involved in, as well as their subjective experience of the support provided by their health professional. The questions used in this section were adapted from The PiCTure Study (Prostate Cancer Treatment, *your experience*; Drummond et al., 2018) and The 9 Item Shared Decision Making Questionnaire (SDM-Q-9: Müller, Hahlweg, & Scholl, 2016).

Respondents were asked to describe their primary treatment, to state how long ago they undertook the treatment and to note whether the treatment was currently ongoing in open-text style response boxes. They were also asked whether when making their decision, was there more than on treatment option available, was there anybody else they spoke to about their treatment options and whether they feel they had enough time to make the decision. Additionally, the participants were asked if they sought a second medical opinion prior to making a treatment decision, if the possibility of side effects affected their decision, whether they sought information about treatments online (if yes, how much time they spent doing so, marked on a scale of 1 (very little time) to 7 (a lot of time)) and how well informed they felt at the time of the decision. In all cases, respondents indicated either “yes” or “no”. Lastly, the participants were asked to rank in terms of importance the three people who mostly influenced their decision regarding treatment from.

The SDM-Q-9 (Simon et al., 2006), a valid and reliable tool (Kriston et al., 2010; Nejati ey al., 2019) requires participants to indicate their agreement with nine statements relating to their treatment decision-making process, e.g. “my doctor made clear that a decision needed to be made”, “my doctor wanted to know exactly how I wanted to be involved in making the decision”. More specifically, the questions related to the involvement the participant and their doctor had in the decision. Participants were asked to indicate their agreement with the statements on a scale of 1 (Completely Agree) to 6 (Completely Disagree). At least seven items must have been completed in order to extract a score from the SDM-Q-9. No score was computed if less than six items were completed, as it is not recommended to do so (Kriston et al., 2010). In order to convert the scores into a 0-100 scale, 1 was subtracted from each item, the items were added and the sum was multiplied by 20/9. A score of 0 indicated high perceived SDM and a score of 100 indicated low perceived SDM. The SDM-Q-9 has good internal consistency (Calderon et al., 2018; Kriston et al., 2010; Rencz et al., 2019)., with a Cronbach alpha coefficient in the current study of 0.92

### 3.5.3 Decision Regret

The Decision Regret Scale (Brehaut et al., 2003) was used to measure the subjective feelings participants had about their treatment choice. The scale is a valid and useful tool which indicates health care decision regret at any time point (Brehaut et al., 2003). Questions required participants to think about the decision made surrounding treatment. Specifically, they were asked to rate their agreement with five statements: ‘It was the right decision’, ‘I regret the choice that I made’, ‘I would go for the same choice if I had to do it over again’, ‘The choice did me a lot of harm’ and ‘The decision was a wise one’. The participant was asked to indicate their agreement on a scale of 1 (Strongly Agree) to 5 (Strongly Disagree). Items 2 and 4 (‘I regret the choice that I made’ and ‘The choice did me a lot of harm’) were reverse coded (O’Connor, 1996). The score was converted to a 0-100 scale by subtracting 1 from each item and multiplying it by 25. To obtain the final score, the items were summed and averaged. As a result, a score of 0 indicated low regret and a score of 100 indicated very high regret (O’Connor, 1996). The Cronbach alpha coefficient in the current study was 0.87.

### 3.5.4 Quality of Life

Quality of Life (QOL) was measured using two instruments - the global health score of the EORTC QLQ-C30 (Aaronson et al., 1993; Ayana, Negash, Yusuf, Tigeneh, Haile, 2016; Kaasa et al., 1995) and the EQ-5D (EuroQol Research Foundation, 2018), both of which have been commonly used to assess the QOL of cancer survivors and both of which are valid scales (Nicklasson & Bergman, 2007; Obradovic, Lal, & Liedgens, 2013). Investigating the relationship between QoL and regret was one of the central aims of the current study, and while the EORTC QLQ-C30 and the EQ5-D measure the same phenomenon, they do so in different ways. The rationale for including both measures in the study was intended to give a more comprehensive understanding of the specific aspects of participants’ QoL and to provide more opportunity to investigate their relationship with regret.

Firstly, participants were asked to indicate how they rated their physical wellbeing and quality of life in the past month, using a scale ranging from 1 (very poor) to 7 (excellent).

Following guidelines, an average of the measures of perceived physical condition over the past month and perceived QoL over the past month was computed to gain a global health score. Secondly, using the EQ5D, participants were asked to indicate whether they experienced any problems associated with their mobility, self-care, usual activities (work, study, housework, leisure, or family activities), pain/discomfort and anxiety/depression on the day of the survey. Responses allowed participants to report no problems, or a slight, moderate, severe, or extreme problem in each of the domains. The answers were firstly coded by assigning a number to each answer ranging from 1 (I have no problem with…) to 5 (I have an extreme problem with…). Following an established procedure (EuroQol Research Foundation, 2018), the scores were further simplified into a binary variable with 0 indicating no problem with an aspect of well-being and 1 indicating some problem (ranging from slight to extreme).

### 3.5.5 Social Support and Support Services

This section of the survey was concerned with the subjective experience of the social support received by the participant before, during and after treatment. Measures were taken from The SuN Study (SuN study - Supportive care needs of survivors of head & neck cancer: O'Brien et al., 2017). Participants were asked to indicate how satisfied they were with the support they received from the people in their life at three time points: (1) while making the decision about their treatment, (2) during their treatment and (3) currently (i.e. at the time of survey completion). To do this, participants were asked to rate their agreement with the statements on a scale of 1 (strongly agree) to 6 (strongly disagree). These scores were treated as single items.

Participants were also asked whether they had used online or other support services since their diagnosis, when exactly they had used them (before, during or after treatment), and whether they felt the support service provided them with the help they needed (yes or no) (O’Brien et al., 2017).

### 3.5.6 Positive Psychological Appraisals

Participants’ optimism, resilience, purpose and autonomy were measured by items from the 4th European Quality of Life Survey (Eurofund, 2017). Participants were asked to indicate their level of agreement with five statements: ‘I am optimistic about my future’, ‘I generally feel that what I do in life is worthwhile’, ‘I feel I am free to decide how to live my life’, ’I find it difficult to deal with important problems that come up in my life’ and ‘When things go wrong in my life, it generally takes me a long time to get back to normal’. Items were rated in a scale of 1 (strongly agree) to 5 (strongly disagree). The last two statements measured resilience and as they were negatively framed, were reverse coded for the purpose of the analysis. The resilience score was computed by averaging responses to these questions, while the other items were treated independently as per the user manual.

The last question of the survey included an open-text answer box where participants were given the opportunity to add further comments. The question used here was: “Is there anything else you would like to add?”. There was no word limit, so participants were free to discuss any other aspects of their illness/treatment/survivorship or to provide information which they felt they had not been asked about throughout the survey.

### 3.5.7 Ethical considerations

The participants were individuals who had undergone treatment for cancer or who had already initiated treatment (e.g., hormone therapy). As such the participants may have been classed as vulnerable as they were cancer survivors, i.e., they had experienced a cancer diagnosis and treatment process and were no longer classed as cancer patients. As the study asked participants to answer questions regarding their experience of cancer diagnosis, treatment decision making, the treatment itself and their current quality of life, there was a risk of distress being caused by these questions with potential for this to invoke negative emotions linked to the participants’ experience of cancer. However, studies which require participants to provide information about their cancer diagnosis, treatment and well-being are plentiful, and have given important insight into the experiences of cancer patients with minimal ethical risk (Drummond, Gavin, & Sharp, 2018; O’Brien et al., 2017; Blanchard, Labrecque, Ruckdeshel, & Blanchard, 1988; Ashbury, Findlay, Reynolds, & McKerracher, 1998). The risk in this study was mitigated further by involving cancer survivors only and not current cancer patients. On completion of the survey, participants were provided with contact information of the Irish Cancer Society.

Ethical approval was gained from the Maynooth University Ethic Committee on the 14th of December 2018, reference number: SRESC-2018-139 (Appendix E).

### 3.6 Procedure

Following ethical approval, the survey was published on Qualtrics in January 2019. The online survey link revealed an information sheet (Appendix F) which contained a detailed explanation of the study. It explained the right to refuse participation or withdraw from the research at any point and for any reason. It also provided the participants with contact details for the researcher and the supervisor, in case more questions needed to be answered before the study commenced. The information sheet held details of an appropriate support groups which could be contacted if participants felt distressed following the research. The same information appeared at conclusion of the survey. The consent form (Appendix G) was presented after the information sheet and ensured the participants met the inclusion criteria. Participants were asked to tick each statement which confirmed their consent and to tick each statement which confirmed their eligibility (according to the inclusion criteria). If any of the statement were not ticked, the participants were not able to access the survey. Instead, they were taken to the final page and thanked for their willingness to participate. Unfortunately, the printed survey allowed for access without an appropriate completion of the consent form. However, all of the paper consent forms were filled out appropriately.

Participant recruitment occurred in different stages due to an unsatisfactory number of survey responses within the first month. Based on the number of variables intended to be used in the model, the initial goal sample size was 150 and every effort was made to recruit as many participants as possible. The initial plan for participant recruitment was an online search to recruit using online cancer support groups and social media. In January 2019, the survey was posted on cancer related Facebook pages and forums (with the permission of the administrators) and shared via social media. At the same time, an email containing details of the study and a link to the survey was sent to Irish cancer support groups, including the Irish Cancer Society, with a request to disseminate to their members. Those support groups which did not respond via email, were contacted by phone with a follow-up request. A number of support groups agreed to distribute the survey link amongst their service users. In addition to the survey link distribution, various hospitals and GP clinics were visited and contacted via email with a request of displaying a poster designed to advertise the study. The poster contained a link to the survey along with a QR code, which can be scanned with a phone camera allowing instant access to the survey. As this did not yield sufficient results, another step in the participant recruitment process was taken. In April 2019, the survey was printed and copies of it were distributed amongst local support groups with a request to pass them onto interested cancer survivors. The surveys were anonymous and were mailed back to the researcher. The survey was finally closed in October 2019.

### 3.6.1 Data analysis

The results of all of the surveys were transferred from Qualtrics into IBM SPSS 25. The data were coded and analysed in the following ways:

- To describe the characteristics of the sample (objective 1), and to understand the experiences of decision making in relation to cancer treatment (objective 2), descriptive statistics (e.g. means, standard deviations, frequencies) were calculated for all variables.
- To explore the associations between decisional regret and sociodemographic, health, decision making, and psychosocial factors (objective 3), correlation analyses were conducted on all survey scales and the DRS scores. Pearson’s r was used where parametric assumptions had not been violated, and Spearman’s rho where they had.
- To further meet objective 3, a hierarchical regression analysis was conducted to explore the relationship between decision regret and nine predictor variables. These variables were chosen based on theory and univariate correlations found in the previous analysis. The hierarchical multiple regression analysis was performed to assess (1) the ability of support satisfaction (at time of survey) and levels of SDM, and (2) the ability of health and psychological variables (global health score, optimism, purpose, autonomy and resilience) to predict levels of regret, after controlling for gender and ease of making ends meet, both of which were found to be significantly related to regret in the correlational analysis. Preliminary analyses indicated no serious violations of the assumptions of normality, linearity, multicollinearity and homoscedasticity.
- Finally, to contribute to objective 2 (i.e. understand the experiences of decision making), a qualitative analysis of the open-text box responses was conducted using a thematic analysis approach. The analysis was conducted in five phases: data

familiarisation, initial code generation, searching for themes, reviewing and refining themes and theme definition and labelling (Braun & Clarke, 2006). Familiarisation occurred at the beginning of data analysis when interaction with the responses occurred but further immersion occurred when the data was repeatedly read while actively searching for reoccurring themes and patterns (Braun & Clarke, 2006). From the list of ideas generated during familiarisation, codes or basic segments were extracted in order to organise the data into meaningful groups (not as broad as final analysis themes) (Braun & Clarke, 2006). The long list of codes was then scanned to find potential general themes. Those themes were then refined, defined and named.

### 3.7 Patient and Public Involvement

In June 2020, after results of Study 1 and Study 2 were analysed, feedback was sought from Irish cancer survivors as to their observations on the findings. This was done as a way of validating the results by individuals who have experienced the cancer treatment decision making, the treatment itself and its aftermath. Survivors were contacted through Irish cancer support groups or encouraged to deliver feedback on social media platforms. A brief summary of results was presented in PDF format, along with a visual depicting of findings as presented in poster format at a national conference (Appendix H). The survivors who wished to take part filled out a brief Qualtrics survey (Appendix I) which asked whether they relate to the findings of the systematic review and the cross-sectional study, or whether they feel some aspects of survivorship omitted in results. Specifically, cancer survivors were asked the following:

- If you have any opinions on the findings of this project, please comment on these below.

- Is there any aspect of cancer survivorship, especially in relation to regret, that may have been missed in this study?
- Do you relate to the findings of this study in any way?
- Do you feel like these findings have any implications for the care of cancer survivors? If so, please comment on what these implications might be.
- If there is anything else you would like to comment on, please do so below.

The survivors were also given the opportunity to contact the researcher directly and to provide feedback through email. The participants were given an open-text response boxes and were free to provide any feedback they felt was relevant. Nine responses were collected from four males and five females. Further details of the feedback achieved can be found in Chapter 6.

# Chapter 4

## Study 2 - An Analysis of the Factors Associated with Post-Treatment Regret in Cancer Survivors Living in Ireland - Results

## 4.1 Descriptive Statistics

### 4.1.1 Sociodemographic and Background Information

101 participants took part in the survey but just 92 participants were included in the final analysis, with the remaining 9 excluded due to large amounts of missing data. The sample compromised of male (n = 33) and female (n = 59) cancer survivors aged between 19 and 85 years (M= 55.62, SD = 15.28). The majority of the participants were Irish (95.7%, n = 88), had no dependent children (69.6%, n = 64) and were married or co-habiting with a partner (71.7%, n = 66). Exactly half of the participants described their highest education level achieved as secondary school or lower (n = 46), with the other half having attained a third level degree or higher (n = 46). 54.3% of the participants were not working at the time of the survey (n = 50), and 57.6% reported no employment status change since cancer diagnosis. 12% of the participants provided unpaid personal help to a relative (n = 11). Most participants reported an ease of making ends meet (M = 2.98, SD = 1.15). 21.7% of the participants also reported another chronic health condition (n = 20), with the most common being diabetes (n = 3) and asthma (n = 3). Details of the socio-demographic and background information can be found in Table 5 (categorical variables) and later Table 8 (continuous variables).

**Table 5**

*Details of categorical socio-demographic and background information of the participants*

| Variable | | N | Percent |
|---|---|---|---|
| Gender Identity | Male | 33 | 35.9 |
| | Female | 59 | 64.1 |
| Nationality | Irish | 88 | 95.7 |
| | Other | 4 | 4.3 |
| Dependent children | Yes | 27 | 29.3 |
| | No | 65 | 69.6 |
| Marital Status | Married/co-habiting | 26 | 28.3 |
| | Other | 66 | 71.7 |
| Education level | Secondary or lower | 46 | 50 |
| | Third level or higher | 46 | 50 |
| Employment status | Working | 42 | 45.7 |
| | Not working | 50 | 54.3 |
| Employment change since diagnosis | Yes | 38 | 41.3 |
| | No | 53 | 57.6 |
| Caring responsibilities | Yes | 11 | 12 |
| | No | 81 | 88 |
| Chronic health conditions | Yes | 20 | 21 |
| | No | 72 | 79 |

### 4.1.2 Cancer Type, Treatment and Health Information

Participants' cancers were of varying types, with 23 different types being reported. The two most common were breast cancer (47.8%, n = 44) and prostate cancer (16.3%, n = 11) but also testicular cancer (n = 5), bowel cancer (n = 5) and Non-Hodgkin's lymphoma (n = 3). The prevalence of all of the cancer types can be seen in Table 6 below. Time since diagnosis ranged from 1 to 22 years (M = 6.97, SD = 4.92). The treatment reportedly occurred between 6 months and 22 years ago (M = 6.5, SD = 4.92), with 13% (n = 12) of the participants reporting that their treatment was ongoing at the time of survey completion (medication/hormone therapy). Treatment types undertaken varied. While the participants were asked to report on their primary treatment, most gave details of all of the treatment undertaken, details of which can be seen in Table 7 below. The participants availed of either one or a combination of the treatments. The most common forms of treatment were surgery (including colectomy, hysterectomy, lumpectomy, mastectomy, prostatectomy, removal of ovaries; n = 35), radiation (n = 35), and chemotherapy (n = 34).

**Table 6**
*The frequency of all cancer types reported by participants in the study*

| Cancer Type | Frequency | Percent |
|---|---|---|
| Acute myeloid leukaemia | 2 | 2.2 |
| Bladder | 1 | 1.1 |
| Bowel | 5 | 5.4 |
| Breast | 44 | 47.8 |
| Cholangiocarcinoma | 1 | 1.1 |
| Chronic lymphocytic leukaemia | 1 | 1.1 |
| Colorectal | 2 | 2.2 |
| Hodgkin’s lymphoma | 1 | 1.1 |
| Kidney | 1 | 1.1 |
| Laryngeal | 1 | 1.1 |
| Leukaemia | 1 | 1.1 |
| Liver | 1 | 1.1 |
| Lung | 1 | 1.1 |
| Melanoma | 2 | 2.2 |
| Myeloma | 1 | 1.1 |
| Neuro Endocrine Tumours | 1 | 1.1 |
| Non-Hodgkin’s lymphoma | 3 | 3.3 |
| Non-melanoma skin | 1 | 1.1 |
| Ovarian | 1 | 1.1 |
| Prostate | 15 | 16.3 |
| Testicular | 5 | 5.4 |
| Waldenstrom's Macroglobulinemia | 1 | 1.1 |
| Womb | 1 | 1.1 |
| Total | 93* | 100 |

* One patient reported two types of cancer

**Table 7**

*The frequency of cancer treatments availed of by the participants*

| Treatment type | Frequency | Percent |
|---|---|---|
| Active monitoring | 1 | .7 |
| Active surveillance | 3 | 2.1 |
| Biopsy | 1 | .7 |
| Brachytherapy | 2 | 1.4 |
| Chemotherapy | 34 | 23.4 |
| Colectomy | 1 | .7 |
| External beam radiation | 2 | 1.4 |
| Hormone therapy | 5 | 3.4 |
| Hysterectomy | 1 | .7 |
| Lumpectomy | 5 | 3.4 |
| Mastectomy | 11 | 7.6 |
| Medication | 11 | 7.6 |
| Prostatectomy | 1 | .7 |
| Radiation | 33 | 22.8 |
| Radiofrequency ablation | 1 | .7 |
| Removal of ovaries | 1 | .7 |
| Resection | 1 | .7 |
| Sandostatin injection | 1 | .7 |
| Surgery (other) | 29 | 20.0 |
| Targeted therapy | 1 | .7 |
| Total | 145 | 100.0 |

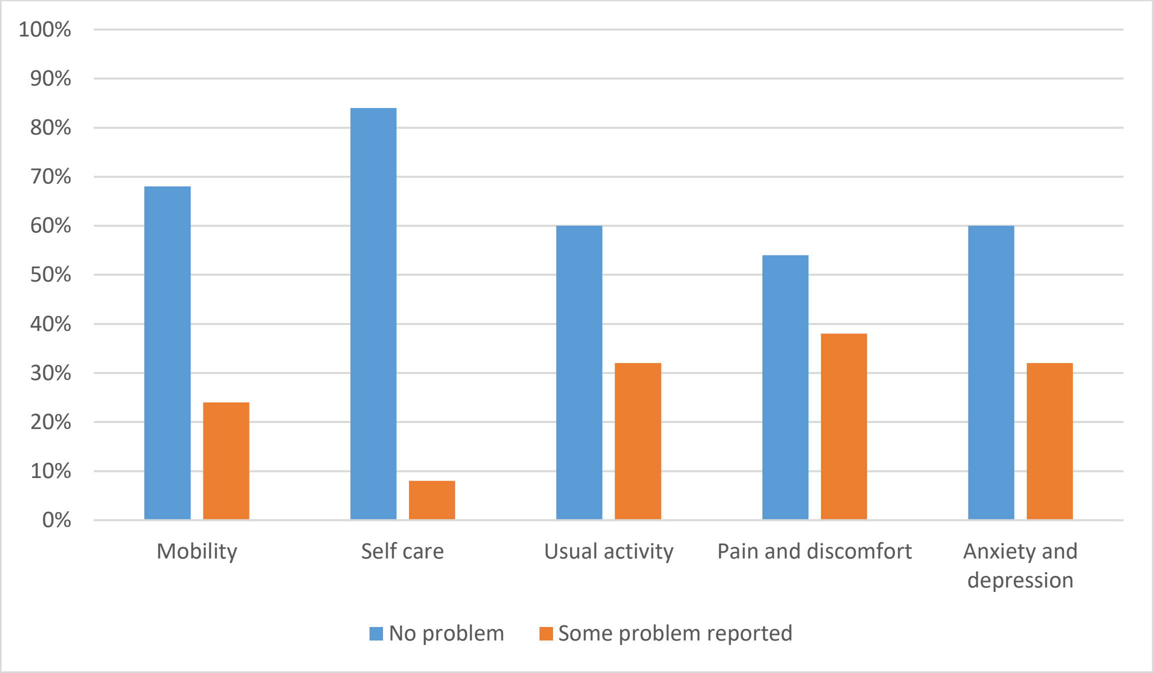
* 41 patients reported more than one type of treatment undertaken

### 4.1.3 Current Health Status and Quality of Life

Participants generally reported high levels of wellbeing using the global health score of the QLQ-C30 (M = 5.52, SD = 1.42). At the time of survey completion, using the EQ5D, most of the sample reported no problems with mobility, self-care activities, difficulty with usual activities, pain/discomfort and anxiety or depression. However, 38% of participants reported some problem with pain and discomfort and 32% reported problems with depression and anxiety. A breakdown of the frequency of problems reported with the five variables is presented in Figure 2.

**Figure 2**

*Percentage of participants who reported having no problem vs. having some problem with mobility, self-care, usual activity, pain and discomfort, anxiety and depression*

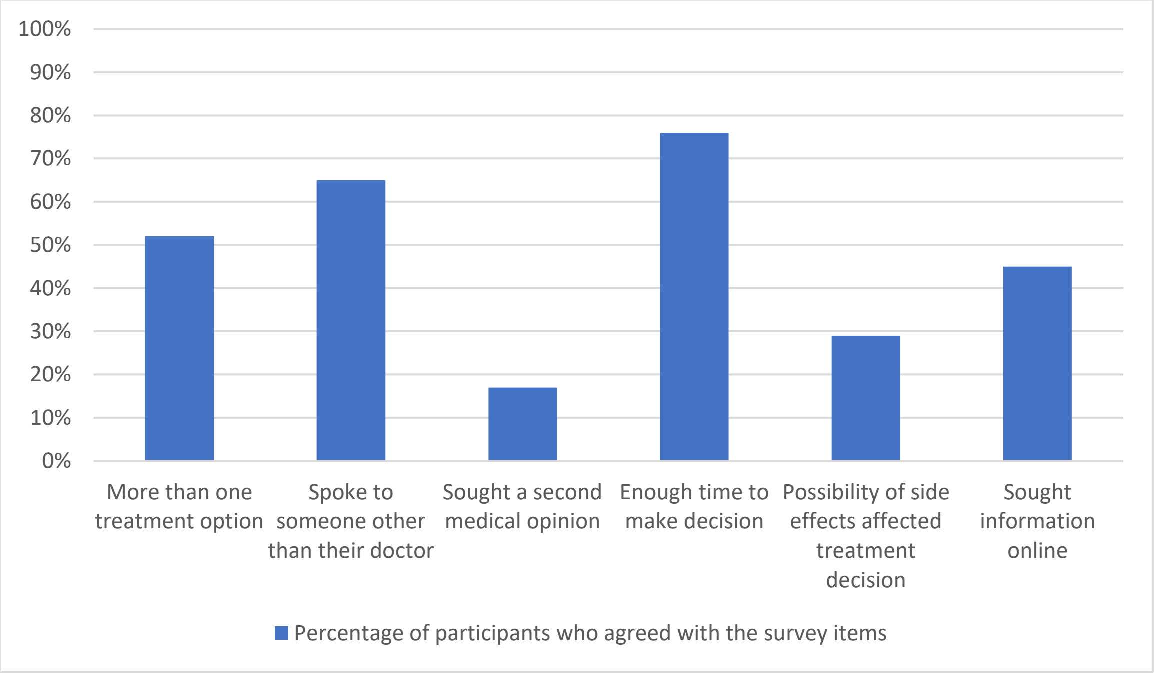


### 4.1.4 Information on the Decision Making Process

52.% of participants reported that they were given more than one treatment option, compared to 30.4% who advised only one treatment option was available and 17.4% who were unsure. 65.2% (n = 60) of the sample spoke to someone other than the doctor about their diagnosis and treatment options but only 17.4% (n = 16) sought a second medical opinion. 76.1% (n = 70) of participants felt they had enough time to make a treatment decision, implying that almost 25% felt they did not have enough time. 29.3% (n = 27) of the sample reported that the possibility of side effects strongly affected their decision, 28.3% (n = 26) felt this affected their decision slightly and 42.4% (n = 39) felt the possibility side effects did not affect their decision at all. 45.7% (n = 42) of participants reported seeking information about their diagnosis and treatment online, with the majority reporting not spending a lot of time conducting this information search (M = 2.49, SD = 2.93). An illustration of this information can be found in Figure 3 below. Most participants felt more informed at the time of the survey (M = 5.92, SD = 1.42), than at the time of the treatment decision (M = 4.56, SD = 1.97).

**Figure 3**

*Percentage of participants who agreed to survey items asking about their decision making process*



Scores on the SDM scale ranged from 0 to 100 (M = 32.39, SD = 24.34), with 0 indicating high perceived SDM. 75% (n = 69) of the participants scored below 50 on the SDM-Q-9, indicating that perceived SDM was high in the majority of the sample. 14.1% (n = 13) of the sample scored 0 and indicated very high levels of shared decision making in their experience, while 6.6% (n = 6) of the sample scored above 75 indicating very low levels of shared decision making. One participant (1.1%) scored 100 and indicated that no shared decision making took place.

### 4.1.5 Social Support and Support Services

Satisfaction with social support was high before (M = 1.42, SD = 0.93), during (M = 1.39, SD = 0.9) and after treatment (M = 1.66, SD = 1.09). Online support services were used by 30.4% (n = 28) of participants, while face-to-face support services were used by 43.5% (n = 40) of participants. Online support services were used by 10.9% (n = 10) of participants before treatment, 17.4% (n = 16) during treatment, 17.4% (n = 16) after treatment and 12% (n = 11) at the time of the survey. 10.9% (n = 10) of those who used online support services found them useful to a great extent, 16.3% (n = 15) found them useful to some extent and 2.2% (n = 2) did not find them useful at all. Other support services were used by 8.7% (n = 8) before treatment, 28.3% (n = 26) during treatment, 21.7% (n = 20) after treatment and 12% (n = 11) at the time of the survey. 20.7% (n = 19) of those who used other support services found them useful to a great extent, 18.5% (n = 17) found them useful to some extent and 3.3% (n = 3) did not find them useful at all.

### 4.1.6 Positive Psychological Appraisals

Overall, the participants displayed high levels of positive psychological appraisals, with the majority of participants displaying high levels of optimism (M = 4.21, SD = .99), purpose (M = 4.37, SD = 0.83), autonomy (M = 4.5, SD = .75) and resilience (M = 3.62, SD = 1.23).  Details of all continuous variables in the study can be found in Table 8 below.

**Table 8**

*Details of continuous variables in the study*

| Variable | M | SD | Observed Range |
|---|---|---|---|
| Age | 55.62 | 15.28 | 19-85 |
| Ease of making ends meet | 2.98 | 1.15 | 1-6 |
| Time since diagnosis | 6.97 | 4.78 | 1-22 |
| Time since treatment | 6.5 | 4.92 | 0.5-22 |
| Time spent seeking information online | 2.49 | 2.93 | 0-7 |
| Feeling well-informed at the time of treatment decision | 4.56 | 1.97 | 1-7 |
| Feeling well-informed at the time of survey | 5.92 | 1.42 | 1-7 |
| Score on the SDM-Q-9 | 32.39 | 24.34 | 0-100 |
| Score on the DRS | 21.73 | 23.4 | 0-100 |
| Global health score | 5.52 | 1.42 | 1.5-7 |
| Optimism | 4.21 | .99 | 1-5 |
| Purpose | 4.37 | .83 | 1-5 |
| Autonomy | 4.5 | .75 | 1-5 |
| Resilience | 3.62 | 1.23 | 1-5 |

### 4.1.7 Decision Regret Score

Overall, levels of decision regret were low amongst participants, with a mean DRS score of 21.79 (SD = 23.4). 73% (n = 68) of the sample scored below 30 on the DRS and this is considered a low score (Becerra-Perez, Menear, Turcotte, Labrecque, & Légaré, 2016). Only 11.96% (n = 11) of the sample scored above 50 on the DRS and this is considered a high score (Maguire, Hanly, Drummond, Gavin, & Sharp, 2017).

## 4.2 Correlation Analyses

### 4.2.1 Relationships Between Sociodemographic Factors and Regret

Correlation analysis was conducted between all variables with a focus on how these related to decisional regret (see Table 9). Gender identity had a weak positive relationship with the scores on the DRS ($r = 0.283$, $p < 0.01$), suggesting that females were more likely to experience regret than males. An independent-samples t-test confirmed this, with a significant difference in DRS found between males (M = 15, SD = 21.25) and females (M = 25.59, SD = 23.85) ($t$ (90) = -2.12, $p < 0.05$).

A positive moderate relationship was found between the measure of financial status and scores on the DRS ($r = 0.363$, $p < 0.01$), indicating that those who reported difficulty with making ends meet were more likely to experience regret. Scores on the DRS were not significantly correlated with age, nationality, children, marital status, education level, employment status, the provision of caring responsibilities or presence of other chronic health conditions.

### 4.2.2 Relationships Between Treatment Types and Regret

In Chapter 2, many studies investigated the prevalence of regret with different treatment types. Given the range of different treatment types available, and the small number of participants reporting some treatments, it was not possible to compare regret levels across the entire sample. However, a pattern emerged across the participants who scored 50 or above on the DRS (n = 11). The majority of those participants reported undertaking surgery as part of their treatment (n = 9), with some participants undertaking surgery only (n = 6), and some also availing of a combination of other treatments (n = 3).

### 4.2.3 Relationships Between the Decision Making Process and Regret

A number of aspects of the decision making process were found to have a significant relationship with DRS scores. There was a moderate positive relationship between perceived satisfaction with the time to decide on a treatment and DRS scores ($r_s = 0.475$, $p < 0.01$), suggesting that those who felt they did not have adequate time to decide on a treatment felt more regret. There was a moderate negative relationship between the perceived effect of possible side effects on the decision and the DRS scores ($r_s = -0.398$, $p < 0.01$), indicating that those who felt side effects affected their decision also felt more regret. A moderate positive relationship was found between the time spent seeking information (relating to the treatment) online and the scores on the DRS ($r_s = 0.254$, $p < 0.05$). Those who reported spending more time seeking information reported higher levels of regret, perhaps suggesting that searching for information online is not helpful (or maybe is indicative of the lack of satisfactory information found). A weak negative relationship was found between how informed participants felt at the time of their treatment decision and the scores on the DRS ($r_s = -0.216$, $p < 0.05$). A moderate negative relationship was found between how informed participants felt at the time of the survey and the scores on the DRS ($r_s = -0.328$, $p < 0.01$). These results indicate that a low perceived level of information about the cancer treatment both at the time of the decision and post-treatment correlated with decision regret. Lastly, a strong positive relationship was found between scores on the SDM scale and scores on the DRS ($r_s = 0.537$, $p < 0.01$), indicating that participants who reported a lower level of shared decision making also reported more regret.

### 4.2.4 Relationships Between Health Status and Quality of Life and Regret

There was a moderate negative relationship between global health scores and DRS scores ($r_s = -0.417$, $p < 0.01$), indicating that the better perceived quality of life reported by the participants, the lower their regret. Similar results were found in the analysis of the EQ5D scores and DRS scores, with all variables (mobility, usual activity, pain and discomfort, anxiety and depression) except self-care having a weak to moderate positive relationship with DRS. Details of effect sizes and significance values are shown in Table 9 below. This indicates that participants who reported problems with mobility, usual activity, pain and discomfort and anxiety and depression also reported higher levels of regret.

### 4.2.5 Relationships Between Social Support and Regret

The results of the correlation analysis between support-related scales and scores on the DRS indicate the importance of social support. Moderate positive relationships were found between satisfaction with social support before ($r_s = 0.305$, $p$ , 0.01), during ($r_s = 0.307$, $p$ , 0.01) and after ($r_s = 0.337$, $p < 0.01$) treatment and the scores on the DRS, suggesting that those who were satisfied with the social support received experienced less regret. However, the same results were not found in the analysis of the relationship between support service use and regret. Weak negative relationships were found between the use of support groups, both on- ($r_s = -0.241$, $p < 0.05$) and offline ($r_s = -0.207$, $p < 0.05$), and the scores on the DRS. This indicates that those who reported using online and other support services were also more likely to experience regret.

### 4.2.6 Relationships Between Positive Psychological Appraisals and Regret

Moderate to strong negative relationships were found between DRS scores and optimism ($r_s = -0.406$, $p < 0.01$), purpose ($r_s = -0.317$, $p < 0.01$), autonomy ($r_s = -0.366$, $p < 0.01$) and resilience ($r_s = -0.442$, $p < 0.01$). These results suggest that those who are less optimistic, have less autonomy, purpose and resilience also reported higher regret.

**Table 9** *Correlation matrix of all variables included in study*

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. | 14. | 15. | 16. | 17. | 18. | 19. | 20. | 21. | 22. | 23. | 24. |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. DRS score [higher = more regret] | 1 | | | | | | | | | | | | | | | | | | | | | | | |
| 2. Gender Identity [male = 0; female = 1] | -.283** | 1 | | | | | | | | | | | | | | | | | | | | | | |
| 3. Income [higher = difficulty in making ends meet] | .459** | .115 | 1 | | | | | | | | | | | | | | | | | | | | | |
| 4. Enough time to make decision [yes = 0; no =1] | .475** | .154 | .272** | 1 | | | | | | | | | | | | | | | | | | | | |
| 5. Decision affected by possibility of side effects [lower=more likely] | -.398** | -.106 | -.229** | -.268** | 1 | | | | | | | | | | | | | | | | | | | |
| 6. Time spent seeking info online [higher = more time] | .254** | .201 | -.015 | .093 | -.446** | 1 | | | | | | | | | | | | | | | | | | |
| 7. Feeling well-informed at the time of decision [higher = better informed] | -.216** | -.002 | .107 | -.329** | .045 | .226* | 1 | | | | | | | | | | | | | | | | | |
| 8. Feeling well-informed at the time of survey [higher = better informed] | -.328** | -.095 | -.337** | -.178 | -.072 | .164 | .269* | 1 | | | | | | | | | | | | | | | | |
| 9. SDM-Q-9 score [higher = less SDM] | .537** | .251* | .336** | .544** | -.242* | 0.73 | -.251** | -.31** | 1 | | | | | | | | | | | | | | | |
| 10. Global Health Score [higher = better perceived well-being] | -.417** | -.095 | -.37** | -.385** | .134 | -.193 | .121 | .351** | -.288** | 1 | | | | | | | | | | | | | | |
| 11. Support before treatment [satisfied = 0; not satisfied = ] | .305** | .048 | .197 | .255* | -.095 | -.061 | -.085 | -.284** | .117 | -.226* | 1 | | | | | | | | | | | | | |

| | | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 12. Support during treatment [satisfied = 0; not satisfied = 1] | .307** | .137 | .269* | .041 | -.095 | .196 | .033 | -.310** | .184 | -.283* | .261* | 1 | | | | | | | | | | | | |
| 13. Support current [satisfied = 0; not satisfied = 1] | .337** | -.078 | .197 | .162 | -.136 | -.024 | -.213* | -.197 | .177 | -.36** | .375** | .199 | 1 | | | | | | | | | | | |
| 14. Use of online support services [yes = 0; no = 1] | -.241* | -.347** | -.05 | -.072 | .066 | -.481** | -.212* | .035 | -.008 | .381** | -.091 | -.145 | -.112 | 1 | | | | | | | | | | |
| 15. Use of other support services [yes = 0; no = 1] | -.207* | -.199 | -.101 | .029 | -.133 | -.155 | -.174 | .184 | -.061 | .246* | .079 | -.209* | .054 | .278** | 1 | | | | | | | | | |
| 16. Optimism [higher = more optimism] | -.406** | -.04 | -.296** | -.333** | .044 | .117 | .249* | .331** | -.402** | .524** | -.279** | -.176 | -.337** | .065 | .008 | 1 | | | | | | | | |
| 17. Purpose [higher = more purpose] | -.317** | .062 | -.303** | -.284** | .034 | .111 | .134 | .343** | -.371** | .421** | -.184 | -.093 | -.344** | .013 | .047 | .733** | 1 | | | | | | | |
| 18. Autonomy [higher = more autonomy] | -.366** | .085 | -.376** | -.281** | .006 | .095 | .198 | .302** | -.366** | .321** | -.249* | -.142 | -.309** | -.001 | .12 | .668** | .68** | 1 | | | | | | |
| 19. Resilience [higher = more resilience] | -.442** | .129 | -.124 | -.276** | .192 | -.123 | .288** | .327 | -.388** | .234* | -.17 | -.074 | -.236* | .146 | .018 | .343** | .455** | .391** | 1 | | | | | |
| 20. Mobility [higher = more problem] | .294** | .028 | .216* | .241* | -.065 | -.148 | -.068 | -.267* | .221* | -.616** | .217* | .206* | .351** | -.149 | -.055 | -.612** | -.451** | -.408** | -.103 | 1 | | | | |
| 21. Self-care [higher = more problem] | .139 | -.121 | .149 | -.012 | .032 | -.140 | -.034 | -.124 | .024 | -.376** | -.063 | .130 | .188 | .053 | .060 | -.334** | -.335** | -.288** | .057 | .533** | 1 | | | |
| 22. Usual Activity [higher = more problem] | .405** | .138. | .232* | .165 | .007 | -.041 | -.062 | -.336** | .250* | -.760** | .229* | .302** | .434** | -.321** | -.220* | -.586** | -.419** | -.414** | -.160 | .731** | .350** | 1 | . | |
| 23. Pain/ Discomfort [higher = more problem] | .353** | .189 | 287** | .288* | -.054 | -.031 | -.072 | -.322** | .336** | -.672** | .393*** | .308** | .398** | -.289** | -.090 | -.602** | -.430** | -.387** | -.130 | .781** | .362** | .753** | 1 | |
| 24. Anxiety/ Depression [higher = more problem] | .507** | .156 | .217* | .351** | -.109 | .241* | -.144 | -.411** | .429** | -.596** | .247* | .464** | .513** | -.435** | -.194 | -.446** | -.412** | -.319** | -.331* | .315** | .382 | .490** | .480** | 1 |

Statistical significance: *p < .05; **p < .01

### 4.3 Regression analysis

Hierarchical multiple regression analysis was performed to assess (1) the ability of support satisfaction (at time of survey) and levels of SDM, and (2) the ability of health and psychological variables (global health score, optimism, purpose, autonomy and resilience) to predict levels of regret, after controlling for gender and ease of making ends meet, both of which were found to be significantly related to regret in the correlational analysis. The number of variables included in the model was led by consideration of statistical power and their nature was led by the study aims - to explore the associations between sociodemographic, health, decision making, and psychosocial factors and the experience of decisional regret. More specifically, the key goal of the study was to examine how (1) aspects of the decision making process, and (2) psychosocial factors, influenced regret, after controlling for known sociodemographic associates. It is for this reason that a hierarchical regression analysis was deemed the most suitable analytic approach for investigating this. The regression model can be found in Table 10 below.

Preliminary analyses indicated no serious violations of the assumptions of normality, linearity, multicollinearity and homoscedasticity. Gender and ease of making ends meet were entered at step 1, explaining 24.6% of variance in decisional regret. Ease of making ends meet was statistically significant at this step ($\beta = .45$, $p < .001$), suggesting that those who found it easier to make ends meet reported experiencing later regret. Support satisfaction at time of survey and SDM-Q-9 scores were entered at step 2 of the model, explaining 38.9% of variance in decisional regret. The variables entered at step 2 explained an additional 14.3% of variance ($R$ squared change = .143, $F$ change (2, 83) = 9.69, $p < .001$). Both social support satisfaction ($\beta = .27$) and SDM ($\beta = .28$) significantly predicted regret at this step. Significantly those reporting higher support satisfaction and a higher level of SDM were less likely to experience regret. After entry of global health score, optimism, purpose, autonomy and resilience at step 3, the total variance explained by the model as a whole was 49.4% (*F* (9, 78) = 8.47, *p* = .01). The last 5 control measures explained an additional 10.6% of the variance in regret (*R* squared change = .106, *F* change (5,78) = 3.26, *p* < .001). In the final model, only three measures were statistically significant: global health score (*β* = -.28, *p* = .019), score on the SDM-Q-9 (*β* = .23, *p* = .019) and resilience (*β* = -.23, *p* = .011). Those with higher QoL scores, reporting greater SDM and higher resilience experienced less regret.

A post-hoc power analysis was conducted. Given the sample size of 92, an alpha level of 0.05, a medium effect size (f2=0.15) and 9 predictors, the power of the model was 0.68. This suggests that the model was underpowered given the small sample size, which is a limitation of the study.

**Table 10**

*Hierarchical regression model*

| **Variables** | **B** | **p** | **t** | **B** | **SE** |
|---|---|---|---|---|---|
| **Step 1** | | | | | |
| Gender | .152 | .115 | 1.594 | 7.365 | 4.621 |
| Income [higher = difficulty in making ends meet] | .450*** | .000 | 4.727 | 9.150 | 1.936 |
| ***$R^2$ Change = .246*** | | | | | |
| **Step 2** | | | | | |
| Gender | .132 | .146 | 1.468 | 6.396 | 4.356 |
| Income [higher = difficulty in making ends meet] | .261 | .008 | 2.698 | 5.310 | 1.968 |
| Support satisfaction at the time of survey [satisfied = 0; not satisfied = 1] | .270** | .004 | 2.941 | 25.462 | 8.657 |
| SDM-Q-9 score [higher = less SDM] | .280** | .004 | 2.930 | .269 | .092 |
| ***$R^2$ Change = .143*** | | | | | |
| **Step 3** | | | | | |
| Gender | .059 | .503 | .673 | 2.854 | 4.241 |
| Income [higher = difficulty in making ends meet] | .163 | .130 | 1.531 | 3.323 | 2.170 |
| Support satisfaction at the time of survey [satisfied = 0; not satisfied = 1] | .234 | .071 | 1.833 | 17.197 | 9.380 |
| SDM-Q-9 score [higher = less SDM] | .182* | .019 | 2.399 | .225 | .094 |
| Global Health Score [higher = better perceived well-being] | -.276* | .019 | -2.402 | -4.538 | 1.889 |
| Optimism [higher = more optimism] | .023 | .880 | .151 | .536 | 3.548 |
| Purpose [higher = more purpose] | .222 | .104 | 1.645 | 6.274 | 3.815 |
| Autonomy [higher = more autonomy] | -.165 | .141 | -1.488 | -5.139 | 3.453 |
| Resilience [higher = more resilience] | -.232* | .011 | -2.592 | -4.406 | 1.700 |
| ***$R^2$ Change = .106*** | | | | | |
| **Adjusted $R^2$ = .436** | | | | | |

*p<0.05, **p<0.01, ***p<0.001

## 4.4 Thematic analysis

The last question of the survey (“Is there anything else you would like to add”) was answered by 24 of 92 participants. A qualitative analysis of these responses was conducted using a thematic analysis approach.  The way in which the participants chose to answer this question can be described in two themes: ‘being thankful’ and ‘expressing dissatisfaction’. These themes will now be detailed and illustrated with exemplar quotes.

### 4.4.1 Theme 1: ‘Being thankful’

As the participants of the current study were cancer survivors, with only a number of them currently undergoing treatment in the form of medication, the theme of being thankful for their current health status was evident: ‘*It’s good to be alive.*’ (Participant 44, female, age 71); ‘*I feel lucky that the cancer was removed so quickly and with no complications.*’ (Participant 88, male, age 77). The participants were also thankful for the medical staff: ‘*I found my GP who knew me very well to be decisive and strongly suggested which consultant I should attend. I thank him for that regularly.*’ (Participant 60, female, age 73); ‘*Thank God for the doctors, consultants, nurses and thank God I got over the cancer.*’ (Participant 35, male, age 76).

The support received was also important to the participants: ‘*While my future is uncertain my present is wonderful, thanks to the support I get.*’ (Participant 19, male, age 72); ‘*I believe that the positive work of cancer support centres is a major asset in the recovery journey.*’ (Participant 20, male, age 64); ‘*Finding a local cancer support centre during my treatment was a lifeline to me. Being able to avail of counselling, support groups and complementary therapies at a very difficult time in my life was huge and most importantly meeting other cancer survivors was inspirational.*’ (Participant 21, female age 41); ‘*I was lucky to get counselling at St Luke’s for anxiety caused by my diagnosis. I had panic* *symptoms sleep problems and I don't know how I would have been without the counselling.*' (Participant 77, female, age 48).

One participant displayed gratitude for the current research being conducted: '*I am happy that someone is doing research into the psychological aspect of cancer survivorship.*' (Participant 10, female, age 47).

### 4.4.2 Theme 2: 'Expressing dissatisfaction'

Some participants voiced their dissatisfaction with various aspects of their journey through illness as well as their current health status. Some participants pointed out the lack of psychological support available: '*At the time of my diagnosis I was not aware of emotional support. The front line medical treatment was excellent but psychological support was non-existent.*' (Participant 3, male, age 64); '*At the time of my illness and treatment there was very little support in my area except in St Luke's in Dublin where I completed my radiotherapy. Nothing local.*' (Participant 30, female, age 71).

Many participants expressed their regret about not being involved enough in their treatment decision making: '*I feel I wasn't really given a choice in my treatment was just told what was going to happen because the cancer was advancing and everything was happening really quickly.*' (Participant 24, female, age 48); '*I wish I was more involved when choosing my treatment but it all happened too fast and I trusted the specialists.*' (Participant 33, male, age 32); '*Not enough time given at initial consultation when diagnosed. Felt rushed into decision. Difficult to make decision which goes against conventional approach.*' (Participant 41, female, age 63). Some participants reported the negative side effects of their cancer treatments: '*The chemotherapy has destroyed me.*' (Participant 22, female, age 56); '*The surgery left me with visible scarring which I found difficult to accept for many years.*'

(Participant 36, female, age 28); '*Chemo given even when it interferes with quality of life.*' (Participant 41, female, age 63).

A number of participants voiced their dissatisfaction with the health-care professionals: '*I wasn't provided with full or adequate information by my doctors. I struggle now as a result.*' (Participant 78, female, age 52); '*My surgeon arrived up at the bed and said, "It's amazing what a hissy fit will do". On the day I was being discharged I felt she had no interest in me or my recovery. I saw her once after that.*' (Participant 12, female, age 47).

### 4.5 Conclusion

The results of the current study inform us of the strength of the relationships between a number of factors and regret in cancer patients. Significantly, cancer survivors who reported more SDM, higher QoL scores and higher resilience also report lower levels or regret. This result is mirrored in the qualitative analysis of the open-text responses, where participants discussed their experiences of decision making, physical and psychological wellbeing and satisfaction with support received. Further discussion of these results can be found in Chapter 5.

Ten cancer survivors were presented with the results of this study as well as the results of the systematic review in Chapter 2. Their feedback is discussed in Chapter 6.

# Chapter 5

## Study 2 - An Analysis of the Factors Associated with Post-Treatment Regret in Cancer Survivors Living in Ireland - Discussion

## 5.1 Overview

The current study had three core objectives:

1. To describe the characteristics of a sample of Irish cancer survivors who have undergone treatment.
2. To understand the experiences of decision making in relation to cancer treatment.
3. To explore the associations between sociodemographic, health, decision making, and social factors and the experience of decisional regret.

Results uncovered a number of interesting findings relating to the experience of cancer survivors in Ireland. Findings highlight both the positive and negative aspects of life after recovery from cancer and may encourage further research aimed at helping cancer survivors increase their physical and psychological wellbeing. Most importantly, findings show the important role of the treatment decision making process in survivor wellbeing and highlight the factors which are associated with the emergence of decisional regret in cancer survivors, thereby meeting the study objectives. In the following sections, these results are discussed in more detail.

## 5.2 Characteristics of Sample

The participants in this study were cancer survivors recruited through cancer support groups in Ireland. They reported a range of cancer types, cancer treatments, treatment decision-making processes, experiences of illness and feelings post-treatment. The study included participants of various ages who came from an array of socioeconomic backgrounds. Both negative and positive attitudes towards their cancer experience were reported – including different attitudes towards healthcare professionals, the treatment decision-making process and the social support received. This highlights the considerable diversity in the experiences of Irish cancer survivors.

The number of survivors included in the final analysis was 92. There was a slight gender imbalance in the sample as 64% were female and 36% were male. Studies suggest that males are more likely to develop cancer than females, despite a shorter life expectancy (Dorak & Karpuzoglu, 2012), suggesting that the sample was not quite in line with population norms. While 47.8% of the sample were breast cancer survivors, 16.3% were prostate cancer survivors. This is broadly consistent with the NCRI 2019 report (O'Connor et al., 2019) which shows that the majority of Irish female cancer survivors had breast cancer (35,125; 23% of all cancer survivors), while the majority of Irish male cancer survivors had prostate cancer (39,539; 20% of all cancer survivors). The next most common cancer for both genders in Ireland is colorectal cancer (9,205 female, 11,420 male; 12% of all cancer survivors), similarly, in the current study the third most represented cancer type was bowel cancer (5.4% of participants). However, other common cancers were not well represented in the current study, e.g., melanoma skin, corpus uteri, or cervical cancers. This suggests that the sample may not be fully representative of Irish cancer survivors, however data captured experiences from a range of survivors with different sociodemographic backgrounds and treatment experiences.

## 5.3 Experience of Regret

Overall, levels of treatment-related regret amongst participants were low which mirrors the results of previous research (Karuturi et al., 2019; Shakespeare et al., 2017), and is also consistent with the findings of the systematic review described in chapter 2. The levels of regret in the current study varied, with the majority of participants experiencing no regret or very low levels of decisional regret. However, 11.96% of the participants scored over 50 on the DRS (0-100 scale), indicating that a small portion of the sample experienced greater regret about their cancer treatment than most. Despite the low number of survivors with high regret scores, research suggests that it is important to acknowledge the difficulties some cancer survivors face, even after their illness. It has been found that regret can be long lasting with studies reporting regret in patients between 1 and 15 years post-treatment (Cusatis, Tecca, D'Souza, Shaw, & Flynn, 2020; Cuypers, Lamers, Kil, van de Poll-Franse, & de Vries, 2019; Taneja, 2017). Some studies report that regret levels remain stable over time (Martinez, Resnicow, Graff, Hamilton, & Hawley, 2015) while other show that regret increases with time post-treatment (Diefenbach & Mohamed, 2007). While the current study was unable to examine how regret may have changed over time, no relationship between regret and time since diagnosis was found in the analysis.  High levels of regret were evident in recently diagnosed survivors (1 year), as well as those who had been diagnosed as many as 25 years ago.

### 5.4 Sociodemographic and Health-related Risk Factors

Like other studies of this nature (Lavery et al., 2012; Resnick et al., 2013; Sheehan, Sherman, Lam, & Boyages, 2008), the analysis of sociodemographic correlates of regret in cancer survivors allows for a clearer understanding of who may be at risk of experiencing it. The current study initially found that females reported more treatment regret than males. However, gender did not remain as a significant predictor of regret in the regression analysis. It is possible that any gender differences that emerged between regret levels did so due to other factors like differences in QoL, psychological wellbeing or social support. For example, studies suggest that females often report lower wellbeing and QoL than males – this is true for cancer patients (Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000) and patients of other illnesses (Bisegger, Cloetta, Von Bisegger, Abel, & Ravens-Sieberer, 2005; Emery et al., 2004; Mrus, Williams, Tsevat, Cohn, & Wu, 2005). While the difference in regret levels between males and females was found, it is difficult to state whether this result mirrors other findings in literature. This is due to the large volumes of studies which concentrate on one cancer type only – typically breast and prostate cancer (Advani et al., 2019; Maguire, Hanly, Drummond, Gavin, & Sharp, 2017). Studies of cancer types which affect both genders rarely investigate the difference between regret in males and females (Criswell, Owen, Thornton, & Stanton, 2016; Goepfert et al., 2017). Future research should explore this issue further as knowledge on gender differences in the experience of regret can be valuable to healthcare providers. Supports may also be tailored according to needs of each gender.

Correlation analyses in the current study found that those who report difficulty in “making ends meet” reported higher levels of decisional regret. 31.5% of participants reported some level of financial difficulty, which highlights that this is a problem for a considerable number of cancer survivors. Financial status was also the only statistically significant variable at step one of the regression analysis, indicating its importance even when controlling for gender differences. Financial difficulty is often found to be associated with regret in cancer patients, including financial toxicity, which refers to problems related to the cost of medical care (Sangha et al., 2018; Sangha, Bossick, Coleman, Su, & Wegienka, 2019). Financial difficulty and financial burden of treatment in cancer patients has also been linked with lower levels of social, physical and emotional wellbeing (Barbaret et al., 2017), lower HRQoL (Chen et al., 2018) and is even a higher risk factor for mortality (Ramsey et al., 2016). Some patients choose to not take prescribed medication as the cost is too high (Alice, Banegas, Tucker-Seeley, & Yabroff, 2017).

It is important to note that the financial burden of a cancer diagnosis varies by country and depends on the level of financial aid provided by each government. In Ireland, a public/private healthcare system exists, with those on lower incomes less likely to be able to afford private health insurance which may limit their access to certain services (Murphy, Bourke, & Turner, 2020). While the HSE and voluntary hospitals are used by most cancer patients, some may opt to be treated in a private hospital where medical care must be covered by the patient or paid through their health insurance. The presence of additional costly medical resources available to a smaller percentage of the Irish population creates an unfair divide between cancer patients (Johnston et al., 2019). Apart from private medical services not being available to those with financial difficulties, cancer patients with lower incomes may struggle with travelling to medical appointments or availing of support services which are not in close proximity, ensuring a healthy diet, which can often be more expensive, or as mentioned above buying prescribed medication. Financial difficulty may increase the risk of regret post-treatment as well as many other negative outcomes.

The correlation between sociodemographic factors and regret, especially that of the link between regret and financial difficulties, should allow healthcare professionals to identify patients who are most at risk of experiencing this negative feeling. The findings may also aid the tailoring of supports accordingly, for example by ensuring people have access to appropriate supports and resources, and that they are not disadvantaged based on financial situation (Carrera, Kantarjian, & Blinder, 2018).

A number of aspects of physical and mental health correlated with decision regret. Lower perceived health scores and perceived QoL scores as well as problems with mobility, usual activity, pain and discomfort, anxiety and depression had a relationship with regret in this study. In our sample, most survivors experienced a good QOL, however a substantial minority reported problems with usual activity, pain, anxiety and depression, suggesting ongoing need for support for these groups. As discussed previously, regret is considered to be a negative side effect of cancer treatment as it is often linked to lower QoL and HRQoL (Clark et al., 2001; Davidson et al., 2007). The significant association between the global health score (which tested quality of life) and scores on the DRS in the final regression model was therefore not surprising, as studies of oncology populations more often than not present a relationship between poor physical and psychological wellbeing and regret (Becerra Pérez, Menear, Brehaut, & Legare, 2016; Hoffman et al., 2017; van Stam et al., 2018). Poorer physical wellbeing, which can reduce psychological wellbeing, can often also stem from side effects of the cancer or the treatments chosen (Christie et al., 2015). Survivors can experience side effects of cancer and treatment long after diagnosis – the treatment for one illness can cause other serious health-related issues. For example, androgen-deprivation therapy may result in higher risks of bone fractures, diabetes, dementia, coronary heart disease or sexual dysfunction in prostate cancer survivors (Nguyen, Lairson, Swartz, & Du, 2018). This again highlights the importance of healthcare professionals providing all necessary information to cancer patients, especially that of the negative side-effects of the illness and the chosen treatment.

## 5.5 The Experiences of Decision Making Related to Cancer Treatment

An important aim of this study was to understand survivors' experiences of various aspects of the treatment decision- making process. In line with expectations, a number of aspects of the treatment decision-making process correlated with higher levels or regret: feelings of not having enough time to decide on a treatment, feeling like the possibility of side effects affected the treatment decision, more time spent seeking information online, a low perceived level of being informed before and after treatment and a lower level of shared decision-making. Score on the SDM-Q-9 (Simon et al., 2006) was also one of the only three significant predictors of regret in the regression analysis.

From the qualitative analysis of the survey results, it is also evident that the treatment decision-making process as well as interactions with the healthcare professionals play a role in the overall experience of cancer survivors, which fits with findings of previous research (Wilson, Ronnekleiv-Kelly, & Pawlik, 2017). A number of participants in the survey expressed their dissatisfaction with the way they were treated by their doctors through the open-text response option – some felt they did not have enough time to make a decision, were not involved enough or were not given a choice of treatment but simply told what to do (Baunacke et al., 2020; Tenja, 2017). All of these findings suggest the importance of viewing the cancer patient as an individual who can and should be involved in their treatment decision if that is their preference. Their views, knowledge and feelings should be acknowledged regardless of their level of medical expertise. Patients and survivors are increasingly voicing their need to be more involved in the decisions surrounding their illness (Matsen, Lyons, Goodman, Biesecker, & Kaphingst, 2019), especially the decision concerning the treatment type which can impact individuals in many positive and negative ways.

The relationship between the treatment-decision making process and the emergence of regret has been continuously highlighted in literature and the results mirror those of the current study. For example, a study of 804 prostate cancer patients found that a lack of discussion of all treatment options has been linked to higher levels of regret (Holmes et al., 2017). Participants who underwent a discussion of all available treatment options with their healthcare professional were less likely to experience regret and this was confirmed by multivariate analysis controlling for a number of factors including age, race, marital status and education (Holmes et al., 2017). Again, this finding highlights the importance of involving the patient in their treatment decision and being open and transparent about their treatment options. It is understood that more regret is typically displayed by patients who feel their views are not taken into account, they experience little shared decision-making or their role in the decision-making is not matched with their preferred role (Wang et al., 2019; Wilding et al., 2020; Yamauchi, Nakao, & Nakashima, 2019). This was also evident in the findings of the current study.

Regret has also been recently linked with unmet expectations and those expectations have been linked with a passive role in decision making and decisional conflict (Wollersheim et al., 2020).  A way to manage expectations again links to ensuring that patients are provided with enough information (e.g. awareness of potential side effects). The current study found that information of side effects plays a role in the treatment decision making as 57.6 % participants reported that the possibility of side effects affected their decision.

As discussed in Chapter 2, one way of ensuring the patient receives sufficient information and understands the consequences of their decision is the use of decision aids which, amongst other positive outcomes, lead to a decrease in decisional conflict and post-treatment regret (Aning, Wassersug, & Goldenberg, 2012; Berlin et al., 2019; Søndergaard et al., 2019). This is a widely used intervention amongst healthcare professionals in oncology and other medical areas, which often proves very successful in allowing patients to make an informed treatment decision (Leinweber, Columbo, Kang, Trooboff, & Goodney, 2019). Poor literacy and numeracy, especially health literacy, affects regret levels post-treatment (Joyce et al., 2020), and decision aids may also be useful for those who receive low scores on these domains. However, more work in the area of decision aids for cancer patients is needed, especially in terms of the use of communicative aspects in the aids (Vromans et al., 2019). A systematic review of decision aids for prostate cancer patients revealed some issues found, like the lack of visual aids to communicate statistical information to patients who may not fully understand it, lack of interactive methods to highlight the preferences held by the patients, inclusion of biased tables to compare treatment or issues with suitability or accessibility to the decision aids (Vromans et al., 2019). Another limitation of research in this area is the overall focus on prostate cancer decision making, with less emphasis on other cancers (Jones et al., 2018). This may be due to the many treatment options available for prostate cancer patients. However, patients of other cancers also face this type of decision.

Too much time seeking information has been found to correlate with regret (Yamauchi et al., 2019), as well as seeking information from internet based sources (Shaverdian et al., 2018). Almost half of the participants in the current study (45.7%)

reported seeking information online. The correlation analysis found that those who reported spending more time seeking information online reported higher levels of regret, perhaps suggesting that searching for information online is not always helpful. While the internet can be a source of knowledge, it can also be a source of false, confusing or worrying information (Alsairi, Joury, Aljuaid, Wazzan, & Pines, 2017; Moolla, Adam, Perera, & Lawrentschuk, 2019; Nghiem, Mahmoud, & Som, 2016). Feelings of receiving inadequate information, especially information of side-effects, have been linked with increased post-treatment regret (Albkri et al., 2018). Cancer survivors have also reported a need for guidance from healthcare professionals towards appropriate sources for guidelines on the importance of physical activity (Smith et al., 2017). Cancer patients should always be provided with sufficient information by their healthcare professionals, but also steered towards appropriate sources of knowledge in the form of information/support centres, appropriate websites, information booklets, information days, etc.

Just like the findings in the systematic review contained in Chapter 2, these findings suggest that a lot of care needs to be taken by healthcare professionals not only to identify those who may be more at risk of experiencing regret, but also to mitigate the possibility of its emergence by selecting an appropriate treatment decision making procedure. An identification of the preferred involvement role may also be useful, as some patients do not want to be involved in the treatment decision making (Aminaie, Lehto, & Negarandeh, 2019). However, it should never be assumed that a patient does not want to be involved, and patient preferences should be considered.

## 5.6 The Role of Social Support in Cancer Survivorship

The importance of social support in helping survivors cope is highlighted by the study results which suggest an association between lower levels of regret and higher levels of social support before, during and after treatment. Social support post treatment was also a statistically significant variable at step 2 of the regression analysis, further highlighting its potential importance. However, this association no longer appeared when accounting for other psychological factors in the regression analysis, suggesting that factors such as resilience and QOL are better predictors of regret. Family environment, having a close partner and a general support network have been continuously linked with better QoL and psychological wellbeing in cancer patients (Costa et al., 2017; Salakari et al., 2017; Thompson et al., 2017). Social support has also been linked with better physical wellbeing (Muscatell, Eisenberger, Dutcher, Cole, & Bower, 2016). However, social support must remain in place even after cancer-treatment in order to maintain emotional-wellbeing (Drageset, Lindstrøm, Giske, & Underlid, 2016; Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2017). In the current study, satisfaction with social support was high before, during and after treatment. However, slightly less participants reported satisfaction with the social support received post treatment than before or during it. This may be due to the lack of understanding by members of society of the physical and emotional burden a cancer diagnosis leaves even after treatment and well into survivorship. The knowledge of importance of social support highlights the need of ensuring that support mechanisms are put in place for survivors. Information days for family members, partners or carers of those with cancer may be successful in creating an understanding of the need for support and ensuring that support systems remain in place even during survivorship.

Perception of loneliness, which does not necessarily imply the lack of social support, was not measured in the current study, however an analysis of literature revealed its importance as it has been shown to correlate with QoL, HRQoL and mental health in cancer patients (Hyland et al., 2019; Fanakidou et al., 2018). Loneliness not only affects the cancer patient, but also the caregiver who is at risk of a decrease in HRQoL if the patient they are caring for experiences a decrease in this domain (Segrin, Badger, & Sikorskii, 2019). Loneliness affects the patient-caregiver relationship (Segrin et al., 2019). This negative feeling can extend into survivorship, with survivors naming lack of control, feelings of being alone in their cancer experience, others' avoidance and failure to recognise the effect of cancer post treatment as some of the factors related to loneliness (Raque-Bogdan, Lamphere, Kostiuk, Gissen, & Beranek, 2019). Other factors include social isolation, criticism from others related to the illness or questions about health status (Adams et al., 2016). Social support is one way of reducing loneliness and it may result in better mental health (Secinti et al., 2019). However, despite a large social support network, a cancer patient may feel lonely in the journey through illness, especially when feeling like those around them do not understand specific struggles (Adams et al., 2016). This is why support groups, both online and offline may play an important role in the lives of cancer survivors as they provide an outlet to meet others with similar experiences. Other factors that protect cancer patients from loneliness include maintaining a normal routine or thoughts and beliefs that time alone may be desirable and that it is normal for others (who are not ill) to feel discomfort around discussions of cancer (Adams et al., 2016).

While the importance of support for cancer survivors both online and offline is increasingly recognised, an interesting result was found in the current study in those who used both types of support groups. While the majority of participants did not use either, 30.4% availed of online support and 43.5% availed of face-to-face support at some stage of the survivorship trajectory. The participants who used either/both support service types experienced higher levels of regret compared with the survivors who did not use any support services. Despite the number of regretful participants in the current study being low, this finding may suggest that those who experience regret are more likely to seek support services. This contrasts with the finding that psychological distress does not necessarily equal higher use of support services amongst cancer patients and survivors (Matsui & Tanimukai, 2017). If the findings in the current study suggests that support services are not successful in mitigating decisional regret, they also contrast studies which find that both online and face-to-face support services allow cancer patients to cope better with their illness (Gottlieb & Wachala, 2007; Høybye, Johansen, & Tjørnhøj-Thomsen, 2005; Klemm, 2003). Cancer patients and survivors often praise the support services used (Villarreal-Garza et al., 2020).

The qualitative analysis in the current study revealed that some participants felt dissatisfaction at the lack of psychological support available to them at the time of their illness while others attributed their wellbeing to the support received. Cancer patients and survivors should always be notified of various support services available and that the services will cater for their specific needs. The Irish Cancer Society official website lists 38 support groups which can be found nationwide, 3 of which are aimed at children and adolescents. The support groups provide extremely valuable face-to-face help to cancer patients and survivors but online supports, especially in the form of Facebook groups and Internet forums are growing in popularity due to the ease of sharing and receiving information and are especially helpful for younger users (Huber, Maatouk, & Ihrig, 2018). The anonymity provided by online services may be perceived as an advantage, as cancer patients and survivors may feel more comfortable sharing their stories and asking questions without being known. However, many individuals attend support groups for the social aspect, as face-to-face contact is important for psychological wellbeing, especially for older cancer survivors (Huber et al., 2018).

Many of the traditional support groups were forced to move their services online or to provide support over-the-phone in-light of the Covid-19 pandemic. Their services did not stop during this time, given their perceived essential nature. It is likely that the Covid-19 pandemic has increased engagement and provision of online supports which hopefully will be sustained in the future. However, it is not yet known whether these online supports will have similar benefits to survivors as offline supports and more research is needed in this area.

## 5.7 Psychological Appraisals in Regret

In addition to social support, the analysis suggests that positive psychological appraisals may play a role in the emergence of regret, with survivors displaying higher levels of optimism, autonomy, purpose and resilience experiencing less regret. As contemporary research now aims to focus on more than just the negative aspects of illness and survivorship, more evidence suggesting the importance of positive psychological appraisals for higher QoL has emerged (Chamber et al., 2012; Ristevska-Dimitrovska, Filov, Rajchanovska, Stefanovski, & Dejanova, 2015). However, out of all of the positive psychological variables tested in the current study, only resilience remained statistically significant in the final regression model. This result mirrors literature findings which suggest the important role resilience has in higher levels of psychological wellbeing in cancer patients (Costa et al., 2017; Lai, Hung, Chen, Shih, & Huang, 2020; Li, Yang, Liu, Wang, 2016). Resilience is also known to predict QOL/wellbeing in those with chronic illness. A study which analysed factors associated with wellbeing in those with illness found that resilience was more important in the wellbeing of those limited by health than those who were not (Maguire, Hanly, & Maguire, 2019), which suggests that this may be particularly important in those more severely impacted by cancer.

Resilience has been described as a set of baseline personal characteristics or traits which equip an individual to cope with adverse experiences and protect against psychological distress (Molina et al., 2014). Resilience is influenced by characteristics such as sociodemographic factors and personal resources like hope or optimism (Molina et al., 2014). Rather than being viewed as a stable trait, resilience is considered to be a dynamic process which can developed in cancer patients (Chmitorz et al., 2018). Despite its known importance by researchers and healthcare professionals, a systematic review of 32 qualitative studies found that no cancer patients used the word resilience when discussing their coping strategies (Tan, Beatty, & Koczwara, 2019). Instead words like hope or social support were used (Tan et al., 2019). This may suggest a lack of awareness of what resilience is and a call for increased attempts at educating patients and survivors on ways to build it.

These findings suggest the potentially important role that positive psychological appraisals may play in reducing the likelihood of regret and could encourage future research to focus on finding ways to foster resilience in cancer patients (Booth et al., 2020; Rosenberg et al., 2018; Solano, de Silva, Soares, Ashmawi, & Vieria, 2016). Some research has begun in this area and higher levels of resilience have been found in patients who are physically more active (Matzka et al., 2016). Biological, personal and social factors also contribute to resilience in cancer patients and it can be modified through psychological and pharmacological interventions (Seiler & Jenewein, 2019). Resilience can also be influenced by a range of factors, examples of which include: perceived social support, less hopelessness (Somasundaram & Devamani, 2016), spirituality (Hunter-Hernández, Costas-Muñíz, & Gany, 2015), higher education level (Wu, Liu, Li, & Li, 2016), older age or male gender (Cohen, Baziliansky, & Beny, 2014).

Studies describe many interventions aimed at fostering resilience in cancer patients but also in other populations. Some examples of interventions used are: online interventions which teach basic skills to improve resilience, persistence and ability to cope (Abbott, Klein, Hamilton, & Rosenthal, 2009; Bekki, Smith, Bernstein, & Harrison, 2013), the READY programme which aims to improve positive emotions, cognitive flexibility, social support, life meaning, and active coping (Burton, Pakenham, & Brown, 2009) or the SMART programme which teaches self-care (relaxation techniques, positive thoughts, healthy eating, physical exercise) and helps participants understand the relationship between stress and physical and emotional problems (Loprinzi, Prasad, Schroeder, & Sood, 2011). However, some interventions have not been found to be successful, for example, a stress management programme and a therapeutic music video-intervention for young adults with cancer (Greup et al., 2018). A systematic review of resilience fostering techniques which occurred between 1979 and 2014 found that their efficacy is difficult to assess due to problems with the concepts, methods, designs and definitions of resilience used (Chmitorz et al., 2018). This warrants more research in the area of fostering resilience.

## 5.8 Limitations and Strengths

One of the limitations of the current study is the small sample size. The participant recruitment process proved difficult and it was not possible to find as many participants as intended, meaning that the analysis was under-powered. Females were also over-represented in the analysis. The cross-sectional nature of the study is another limitation. The data collected refers to only one time-point in the participants’ cancer survivorship. The study may have provided more useful insights into life post-cancer treatment in Ireland if it was of longitudinal nature. A potential limitation was the failure to adequately control for Type 1 errors in the analysis. Given the large amount of variables investigated, it is possible that false positive results could have occurred. Lastly, the regression analysis was slightly underpowered and this is also a limitation of the current study.

Despite the small sample size, the participants included in the study reported an array of cancer types, cancer treatments availed of as well as experiences associated with their illness. The study does provide an interesting insight into life post cancer-treatment in Ireland, describes the characteristics of a sample of Irish cancer survivors who have undergone treatment, explores the experiences of decision making in relation to cancer treatment and the associations between sociodemographic, health, decision making, and social factors and their relationship with decisional regret. The results of the study provide an insight into the feelings of regret various cancer survivors hold between 1 and 22 years post treatment. The collection of qualitative comments also gives a more personal insight in the experiences of the participants, suggesting the range of positive and negative experiences encountered.

## 5.9 Conclusion

The current study highlights the factors associated with regret in cancer survivors in Ireland. Results suggest who may be more at risk of experiencing regret and build on the findings of study 1 (i.e., systematic review). This knowledge may aid future developments of ways to identify patients most at risk of developing feelings of regret post-treatment. These issues are expanded upon in the final chapter.

# Chapter 6

# Conclusion

## 6.1 Overview

The current research aimed to explore the factors which have been found to be associated with the emergence of decisional regret in cancer patients and survivors. This was achieved by two studies. Study 1 was an inclusive systematic review of international literature and Study 2 was a survey of cancer survivors living in Ireland. From the comparison of the results from Study 1 and Study 2, it can be concluded that cancer patients and survivors have similar needs in Ireland and internationally. Similar factors associated with post-treatment regret emerged both in the systematic review and the cross-sectional survey. This chapter will briefly review these similarities and state how these findings can aid future interventions aimed at improving the wellbeing of oncology populations. This chapter also includes a PPI (Public and Patient Involvement) section, as the results of the two studies were presented to a number of Irish cancer survivors to allow for a more meaningful interpretation of the study findings.

## 6.2 Public and Patient Involvement Results

The value of public and patient involvement in the design, conduct and dissemination of research is widely recognised and even required by many funding bodies. PPI has been shown to improve the meeting of participation targets in research studies (Ennis & Wykes, 2013) and clinical trials (Crocker et al., 2018). In the current project, PPI was used in order to receive cancer survivor feedback on research results.

Nine responses were collected from four males and five females. Just like the results of both of the studies in the current project, the feedback provided varied according to individual experiences. Some cancer survivors related to the findings, while others did not. A strong trend emerging from the feedback was the overall positive comments the survivors shared about their own experience and how it differed from the regretful experiences described in the study results. The survivors commented about being happy with their treatment, being involved in shared decision making which was described as “good” and reported having no regrets. One female cancer survivor went as far as stating that people should not regret anything about their cancer experience because “there is a better survivor rate nowadays”, “there is lots of support out there through your family, friends, work mates and many cancer support groups” and “it (treatment) gives you life back”. A male cancer survivor stated that he relates to the findings of Study 2, stating: “I have a good quality of life, I shared the decision process and I am very resilient. Had I not had the above 3 positive outlooks I imagine I would have not coped as well”. These positive comments about the individuals’ own experiences are welcomed as they imply that cancer survivorship can be a hopeful time. They also reinforce the knowledge that generally, decisional-regret in cancer patients is low.

However, some regret, fear of recurrence and worry was evident amongst a number of individuals providing PPI feedback. One male survivor commented on the never-ending battle between cherishing the win against cancer and worrying that it will come back again: “Being a survivor is great but any pain or abnormality I notice I always have the fear of my cancer coming back, this never goes away”. The same individual stated that he relates to the study findings due to his own financial difficulties during treatment: “Yes especially the part about financial difficulty because I worried I would not be able to afford my treatments and medications”. A female survivor commented on her regret associated with the side effects of the cancer and chemotherapy and her wish to have been more informed at the time. Similarly, a male cancer survivor stated that while he made the correct decision by removing his prostate soon post-diagnosis, the long-term effect of losing sexual function at a young age was very difficult. Again, these comments reinforce the study findings and show that negative thoughts, feelings and experiences can be carried from the illness to survivorship.

While the current project did not find any patterns between regret and age, one female cancer survivor felt strongly about the differences in coping strategies between younger and older cancer patients. The individual stated that she was 63 when diagnosed with cancer and that she felt that it was easier than if it happened if she was younger. She also stated that "women who are young need a lot more help and counselling". This is an interesting insight as it shows how much socio-demographic factors and individual circumstances can impact cancer experiences.

All of the survivors agreed that the findings of the current research are valuable and important in the continuous journey towards better support for cancer survivors post-treatment. When asked to provide their opinions on the findings of the project, the individuals provided the following answers: "It seems like a really well done project with important findings which can help some people.", "It is great to see research being conducted on this topic. I wish more people were concerned with the psychological well-being of cancer survivors.", "As a cancer survivor I am happy to see these findings.", "I feel that a questionnaire like this should be available to all cancer survivors.".

### 6.3 Implications

The results of both the systematic review and the survey revealed that the experience of regret is typically low in cancer survivors. While this is a positive finding, it is clear that some survivors are more at risk than others. Results of the two studies presented indicate that factors associated with regret in cancer patients and survivors both in Ireland and internationally can be divided into five categories: sociodemographic factors, factors associated with health/physical wellbeing, factors related to the treatment type underwent, factors associated with the decision making process, and psychosocial factors. The findings of the project suggest that regret often does not occur as a result of or in association with one factor only, suggesting that this is a complex process. The implications of the current findings suggest that each cancer patient should be viewed as an individual who brings their own experiences, knowledge and feelings into the treatment decision making process as post-treatment regret and reduced quality of life can occur for various reasons. The findings also highlight the need for continuous care for cancer survivors, as the negative effects of cancer and its treatment can reduce wellbeing even during survivorship. Lastly, the findings of both studies may allow healthcare providers, carers or support service workers an easier identification of individuals most likely to experience treatment regret. As discussed in the previous chapter, this knowledge may alter the care and support provided according to individual needs.

A well-established concept of care for individuals transitioning from being a cancer patient to being a cancer survivor is Person Centered Care which puts the individual’s needs, values and preferences first (Loonen et al., 2018). This component of care responds to the need to view each survivor as an individual with personal experiences as well as the need to continue the provision of care during survivorship. According to its three main components, person centred care initiates, intergrades and safeguards the relationship between the healthcare provider and the survivor (Loonen et al., 2018). Initiation places the survivor’s perspective of their life experiences and health condition at the centre of care (Loonen et al., 2018). Integration allows for sharing information between the healthcare provider and the survivor with respect to the survivor’s narrative and understanding of the survivor’s preferences regarding their care (Loonen et al., 2018). Safeguarding protects the partnership between the healthcare provider and the survivor through the registration of information on the survivor’s care preferences and health concerns (Loonen et al., 2018). Person centred care has been shown to be a successful agent in creating better physical and psychological outcomes for survivors (Olesen et al., 2016; Temple-Oberle et al., 2014). The results of the two studies presented in the current thesis suggest: the need for respect to be given to cancer patients and survivors, for more choice and involvement of patients in treatment decision making, for continuous access to support for individuals and for the provision of accurate, relevant and comprehensive information by healthcare providers – patient centred care ensures all of these needs are met (Groves, 2010).

### 6.3.1 Conceptual implications

Apart from highlighting the importance of viewing cancer survivors as individuals who may need ongoing support long after completing their treatment, the results of the current research advance a number of aspects of psychological theory including theories of decisional regret (e.g., Decision Justification Theory; Connolly & Zeelenber, 2002), decision making (Theory of Risk Aversion; Breen et al., 2014) and positive psychology.

Existing theories of decisional regret attempt to explain what decisional regret is as well as suggesting reasons for its occurrence and ways that it occurs. The current research advances our knowledge of regret in cancer patients and suggests that the reasons for its occurrence are complex and rarely occur in isolation. The current research also highlights the longevity of this phenomenon, as cancer survivors in both studies displayed decisional regret at time points ranging from a few months to many years post-treatment. Lastly, the current study highlights the importance on interventions which can mitigate the occurrence of decisional regret in patients and survivors.

The current research also advances theories of decision making by showing that the process in which a decision is made can be as important as the actual decision itself in determining the feelings a person later experiences towards their choice. Shared decision making is presented in both studies as a desirable way of making health-related decisions as it has repeatedly been linked with lower levels of treatment-related regret.

Finally, the current study advances knowledge of the importance of positive psychology by highlighting the value of fostering optimism, autonomy, purpose and resilience in survivors. In recent literature, resilience is often mentioned as essential for psychological wellbeing and good quality of life. The current research highlights its importance in an oncology setting. In both studies, resilience was linked with lower levels of regret. The need for resilience building interventions has also been highlighted.

To conclude, cancer survivors and their needs must not be overlooked by healthcare professionals, support service providers or close family and friends due to their success in beating the illness. Studies have shown that survivorship can cause as many physical and psychological struggles as the illness, and that cancer survivors should continue to receive appropriate supports which can improve their QoL. The findings of this project highlight gaps in knowledge as well as gaps in supports available, particularly in Ireland.

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# Appendix A: PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review, meta-analysis, or both. | 17 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | N/A |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. | 17 |
| Objectives | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | 18-19 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | N/A |
| Eligibility criteria | 6 | Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | 19 |
| Information sources | 7 | Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | 19 |
| Search | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | N/A |
| Study selection | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | 21 |

| | | | |
|---|---|---|---|
| Data collection process | 10 | Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | 22 |
| Data items | 11 | List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | N/A |
| Risk of bias in individual studies | 12 | Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | 24 |
| Summary measures | 13 | State the principal summary measures (e.g., risk ratio, difference in means). | 24 |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis. | N/A |

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| Risk of bias across studies | 15 | Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | N/A |
| Additional analyses | 16 | Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified. | N/A |
| **RESULTS** | | | |
| Study selection | 17 | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | 23 |
| Study characteristics | 18 | For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | 27 |
| Risk of bias within studies | 19 | Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12). | N/A |
| Results of individual studies | 20 | For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. | N/A |
| Synthesis of results | 21 | Present results of each meta-analysis done, including confidence intervals and measures of consistency. | N/A |
| Risk of bias across studies | 22 | Present results of any assessment of risk of bias across studies (see Item 15). | N/A |
| Additional analysis | 23 | Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]). | N/A |
| **DISCUSSION** | | | |
| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). | 38-45 |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias). | 55 |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | 49-55 |
| **FUNDING** | | | |

| | | | |
|---|---|---|---|
| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | N/A |

*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097.
doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

# Appendix B: Mixed Methods Appraisal Tool

| Category of study designs | Methodological quality criteria | Yes | No | Can't tell | Comments |
|---|---|---|---|---|---|
| Screening questions (for all types) | S1. Are there clear research questions? | | | | |
| | S2. Do the collected data allow to address the research questions? | | | | |
| 1. Qualitative | 1.1. Is the qualitative approach appropriate to answer the research question? | | | | |
| | 1.2. Are the qualitative data collection methods adequate to address the research question? | | | | |
| | 1.3. Are the findings adequately derived from the data? | | | | |
| | 1.4. Is the interpretation of results sufficiently substantiated by data? | | | | |
| | 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? | | | | |
| 2. Quantitative randomized controlled trials | 2.1. Is randomization appropriately performed? | | | | |
| | 2.2. Are the groups comparable at baseline? | | | | |
| | 2.3. Are there complete outcome data? | | | | |
| | 2.4. Are outcome assessors blinded to the intervention provided? | | | | |
| | 2.5 Did the participants adhere to the assigned intervention? | | | | |
| 3. Quantitative nonrandomized | 3.1. Are the participants representative of the target population? | | | | |
| | 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? | | | | |
| | 3.3. Are there complete outcome data? | | | | |
| | 3.4. Are the confounders accounted for in the design and analysis? | | | | |
| | 3.5. During the study period, is the intervention administered (or exposure occurred) as intended? | | | | |
| 4. Quantitative descriptive | 4.1. Is the sampling strategy relevant to address the research question? | | | | |
| | 4.2. Is the sample representative of the target population? | | | | |
| | 4.3. Are the measurements appropriate? | | | | |
| | 4.4. Is the risk of nonresponse bias low? | | | | |
| | 4.5. Is the statistical analysis appropriate to answer the research question? | | | | |
| 5. Mixed methods | 5.1. Is there an adequate rationale for using a mixed methods design to address the research question? | | | | |
| | 5.2. Are the different components of the study effectively integrated to answer the research question? | | | | |
| | 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | | | | |
| | 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | | | | |
| | 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? | | | | |

## Appendix C: Studies Included in the Study 1 in order of Inclusion

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among men with recurrent prostate cancer. *Prostate Cancer and Prostatic Diseases, 18*(1), 38.

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# Appendix D: Survey

## SECTION A: ABOUT YOU

Please answer all the following questions by ticking the appropriate box or using the space provided.

**A1. What is your age?**

________________________________________

**A2. How would you describe your gender?**

Male ☐ Female ☐

I'm not sure/questioning ☐ Prefer not to say ☐

Other (e.g. non-binary), please specify __________________a

**A3. What is your nationality?**

Irish ☐ Other ☐

If other, please describe ________________________

**A4. Do you have dependent children?**

Yes ☐ No ☐

**A5. What is your marital status? Please tick one box**

Married ☐ Separated ☐

Never Married ☐ Divorced ☐

Widowed ☐ Living with partner/co-habiting ☐

Living in a civil partnership ☐

**A6. What is the highest level of education you completed? Please tick one box**

| | | | |
|---|---|---|---|
| Primary school | ☐ | Third level (e.g., college, university) | ☐ |
| Secondary school | ☐ | Postgraduate (e.g., masters, doctorate) | ☐ |

**A7. Which of the following best describes you?**

| | |
|---|---|
| Working for an employer | ☐ |
| Looking after family/home | ☐ |
| Unable to work due to permanent sickness/disability | ☐ |
| Self-employed | ☐ |
| Retired | ☐ |
| Student | ☐ |
| Unemployed | ☐ |

If other, please specify ___________________________________

**A8. Has your employment status changed since your diagnosis?**

Yes ☐ No ☐

**A9. Do you provide regular unpaid personal help for a family member with a long-term illness, health problem or disability? (Includes problems due to old age. Personal help includes help with basic tasks such as feeding or dressing).**

Yes ☐ No ☐

**A10. Thinking of your total monthly income: are you able to make ends meet..?**

| Very easily | Easily | Fairly easily | With some difficulty | With difficulty | With great difficulty |
|---|---|---|---|---|---|
| | | | | | |

**A11. How long ago were you diagnosed with cancer?**

___________________________________

**A12. What type of cancer were you diagnosed with?**

______________________________________

**A13. Apart from being diagnosed with cancer, have you got any other chronic health conditions you wish to mention? (If yes, please specify)**

___________________________________

## SECTION B: TREATMENT DECISION MAKING

Please answer all the following questions by ticking the appropriate box or using the space provided.

**B1. Please describe the PRIMARY treatment you underwent following your diagnosis (e.g., surgery, medication, radiotherapy, chemotherapy, etc.)**

_____________________________________________________________________

**B2. How long ago did you undertake the primary treatment?**

_____________ years _____________ months

**B3. Is the treatment currently ongoing?**

Yes ☐ No ☐

**B4. Was there more than one treatment option available to you?**

Yes ☐ No ☐ Unsure ☐

If yes, how many treatment options were available to you? _____________

**B5. Apart from your doctor, is there anybody else you spoke to about your treatment options? (e.g., family, friends, partner, children, colleague, etc.)**

Yes ☐ No ☐

If Yes, please describe who you spoke to_______________

**B6. a. Did you feel you had enough time to make a decision about your treatment?**

Yes ☐ No ☐

**b. Who were the people who most influenced your decision regarding your treatment? Rank in terms of importance.**

1.______________________________

2.______________________________

3.______________________________

**B7. Did you seek a second medical opinion prior to making a treatment decision with your doctor?**

Yes ☐ No ☐

**B8. Did the possibility of side effects affect your treatment decision?**

Yes, strongly ☐ Yes, slightly ☐ No, not at all ☐

**B9. a. Did you seek any information about your treatment options online?**

Yes ☐ No ☐

**b. If yes, how would you rate the amount of time you spent conducting online research about your treatment options? Please circle the appropriate number.**

| | | | | | | |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| I spent very little time researching my treatment options online | | | | | | I spent a lot of time researching my treatment options online |

**B10. How well informed did you feel at the time of your decision?**

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not at all well informed | | | | | | Extremely well informed |

**B11. How well informed do you feel now about the treatment you received?**

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not at all well informed | | | | | | Extremely well informed |

**B12. Nine statements related to the decision-making in your consultation are listed below. For each statement please indicate how much you agree or disagree by ticking the box beside the statement that applies to you.**

| | **Completely disagree** | **Strongly disagree** | **Somewhat disagree** | **Somewhat agree** | **Strongly agree** | **Completely agree** |
|---|---|---|---|---|---|---|
| **a. My doctor made clear that a decision needed to be made.** | | | | | | |
| **b. My doctor wanted to know exactly how I wanted to be involved in making the decision.** | | | | | | |
| **c. My doctor told me that there were different options for treating my medical condition.** | | | | | | |
| **d. My doctor precisely explained the** | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| **advantages and disadvantages of the treatment options.** | | | | | | |
| **e. My doctor helped me understand all the information.** | | | | | | |
| **f. My doctor asked me which treatment option I preferred.** | | | | | | |
| **g. My doctor and I thoroughly weighed the different treatment options.** | | | | | | |
| **h. My doctor and I selected a treatment option together.** | | | | | | |
| **i. My doctor and I reached an agreement on how to proceed.** | | | | | | |

## SECTION C: How you feel about your choice

Please think about the decision you made about your treatment after talking to your health professional. Please show how you feel about these statements by ticking the box beside the statement which most applies to you.

| | Strongly agree | Agree | Neither Agree or Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| **C1. It was the right decision** | | | | | |
| **C2. I regret the choice that I made** | | | | | |
| **C3. I would go for the same choice if I had to do it over again** | | | | | |
| **C4. The choice did me a lot of harm** | | | | | |
| **C5. The decision was a wise one** | | | | | |

## Section D: HOW YOU FEEL SINCE YOUR TREATMENT

For the following two questions please circle the number between 1 and 7 that best applies to you

**D1. How would you rate your overall physical condition during the past month?**

1 2 3 4 5 6 7
Very Poor Excellent

**D2. How would you rate your overall quality of life during the past month?**

1 2 3 4 5 6 7
Very Poor Excellent

**D3. Under each heading below, please tick the ONE box that best describe your own health TODAY**

**a. Mobility**

| | |
|---|---|
| I have no problems in walking about | ☐ |
| I have slight problems in walking about | ☐ |
| I have moderate problems in walking about | ☐ |
| I have severe problems in walking about | ☐ |
| I am unable to walk about | ☐ |

**b. Self-care**

| | |
|---|---|
| I have no problems washing or dressing myself | ☐ |
| I have slight problems washing or dressing myself | ☐ |
| I have moderate problems washing or dressing myself | ☐ |
| I have severe problems washing or dressing myself | ☐ |
| I am unable to wash or dress myself | ☐ |

**c. Usual Activities (e.g. Work, study, housework, family or leisure activities)**

| | |
|---|---|
| I have no problems doing my usual activities | ☐ |
| I have slight problems doing my usual activities | ☐ |
| I have moderate problems doing my usual activities | ☐ |
| I have severe problems doing my usual activities | ☐ |
| I am unable to do my usual activities | ☐ |

**d. Pain/Discomfort**

| | |
|---|---|
| I have no pain or discomfort | ☐ |
| I have slight pain or discomfort | ☐ |
| I have moderate pain or discomfort | ☐ |
| I have severe pain or discomfort | ☐ |

I have extreme pain or discomfort ☐

e. **Anxiety/Depression**

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

## SECTION E: SOCIAL SUPPORT

The following questions are about the support you received from the people in your life. Please answer the question by ticking the box under the statement that applies to you.

**E1. While making the decision about my treatment, I was satisfied with the support I had from other people in my life (e.g., family, friends, neighbours, etc.)**

| 1. Strongly agree | 2. Moderately agree | 3. Slightly agree | 4. Slightly disagree | 5. Moderately disagree | 6. Strongly disagree |
|---|---|---|---|---|---|
| | | | | | |

**E2. During my treatment, I was satisfied with the support I had from other people in my life (e.g., family, friends, neighbours, etc.)**

| 1. Strongly agree | 2. Moderately agree | 3. Slightly agree | 4. Slightly disagree | 5. Moderately disagree | 6. Strongly disagree |
|---|---|---|---|---|---|
| | | | | | |

**E3. Currently, I am satisfied with the support I had from other people in my life (e.g., family, friends, neighbours, etc.)**

| 1. Strongly agree | 2. Moderately agree | 3. Slightly agree | 4. Slightly disagree | 5. Moderately disagree | 6. Strongly disagree |
|---|---|---|---|---|---|
| | | | | | |

## SECTION F: SUPPORT SERVICES

Please answer the questions in this section by ticking the box beside the statement that applies to you.

**F1. Have you used any online support services since your diagnosis?**

Yes ☐ No ☐

If yes, what online support service did you use? ________________

If yes, when did you use it?
Before treatment ☐
During Treatment ☐
After Treatment ☐

If yes, do you feel the online support service provided you with the help you needed?

Yes ☐ No ☐

**F2. Have you used any other support services since your diagnosis? E.g., information days held in hospitals, cancer “buddy” scheme, a cancer support centre, a cancer support group, etc.**

Yes ☐ No ☐

If yes, what support service did you use? ________________

If yes, when did you use it?
Before treatment ☐
During Treatment ☐
After Treatment ☐

If yes, do you feel the support service provided you with the help you needed?

Yes ☐ No ☐

## SECTION G: FINALLY

**G1. Please answer the question by ticking the box beside the statement that applies to you.**

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| **G1. I am optimistic about my future** | | | | | |
| **G2. I generally feel that what I do in life is worthwhile.** | | | | | |
| **G3. I feel I am free to decide how to live my life.** | | | | | |
| **G4. I find it difficult to deal with important problems that come up in my life.** | | | | | |
| **G5. When things go wrong in my life, it generally takes me a long time to get back to normal.** | | | | | |

**G2. Is there anything else you would like to add?**

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

Thank you for your participation! If you are satisfied with the information you provided and wish to submit it, please return the survey to the researcher.

If you experience any distress following the questionnaire, you may contact the Irish Cancer Society (Cancer Nurseline: Freephone 1800 200 700 (Monday-Friday 9-5), Cancer Information Enquiries: cancernurseline@irishcancer.ie, online: www.cancer.ie). You may also contact my supervisor, Dr. Rebecca Maguire (rebecca.maguire@mu.ie), if you feel the research has not been carried out as described previously.

Any further queries?  If you need any further information, you can contact me: Aleksandra Szproch, aleksandra.szproch.2016@mumail.ie

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.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

# Appendix E: Maynooth University Research Ethic Committee Ethical Approval

**MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE**
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

14 December 2018

Aleksandra Szproch
Department of Psychology
Maynooth University

**RE: Application for Ethical Approval for a project entitled:** Exploring reflections of health-related decision making following treatment

Dear Aleksandra,

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 December 2019.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c.Dr Rebecca Maguire, Department of Psychology, Maynooth University

Reference Number SRESC-2018-139

# Appendix F: Information Sheet

**Purpose of the Study.** I am Aleksandra Szproch, an MSc student, in the Psychology Department at Maynooth University.

As part of the requirements for an MSc degree, I am undertaking a research study under the supervision of Dr. Rebecca Maguire.

The study is concerned with the experience cancer survivors had while deciding about their treatment, how they feel about their decision now and how they are feeling since undertaking their chosen treatment.

**What are the advantages of taking part?** The research has potential to inform interventions aimed at helping cancer patients make the best decisions regarding their treatment. The current research has the potential to benefit many cancer-patients in the future. The information found has the potential to help ensure that cancer-patients receive the best possible help while being faced with a treatment decision. This can minimise the emergence of decisional regret and stop the decrease of the quality of life and well-being of cancer patients/survivors post-treatment.

**What are the possible disadvantages of taking part?** If you had a negative experience during your consultation with your doctor, during the treatment decision making process or during/after your treatment, it is possible that talking about your experience may cause some distress. This questionnaire will ask you to think about those times and to answer questions accordingly.

**What if there is a problem?** If you experience any distress following the questionnaire, you may contact the Irish Cancer Society (Cancer Nurseline: Freephone 1800 200 700 (Monday-Friday 9-5), Cancer Information Enquiries: cancernurseline@irishcancer.ie, online: www.cancer.ie). You may also contact my supervisor, Dr. Rebecca Maguire (Email: rebecca.maguire@mu.ie, Phone: +353 1 4747624), if you feel the research has not been carried out as described above.

**What will the study involve?** The study will involve a questionnaire which will take approx. 15-30 minutes to complete.

**Who has approved this study?** This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

**Why have you been asked to take part?** You have been asked because you are a cancer survivor who has made a decision about their cancer treatment.

**Do you have to take part?** No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to complete this short questionnaire. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to read an information sheet and complete a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason.

**What information will be collected?** Demographic information, information about your diagnosis, information about your treatment decision making process, information about how you felt about your treatment decision, information about the social support you received before, during and since treatment, information about support groups which you have been or are currently part of, information about your physical/psychological/social well-being since your treatment.

**Will your participation in the study be kept confidential?** Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on MU PC or servers and will be accessed only by the researcher (Aleksandra Szproch).

No information will be distributed to any other unauthorised individual or third party. As no personal identifiable information will be collected, you will not be able to seek your data after the submission of the completed questionnaire.

*'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation*

*by 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.'*

**What will happen to the information which you give?** All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the PI). Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by the PI in Maynooth University.

**What will happen to the results?** The research will be written up and presented as a thesis. It may be discussed at internal group meetings, presented at National and International conferences and may be published in scientific journals. A copy of the research findings will be made available to you upon request.

**Any further queries?** If you need any further information, you can contact me: Aleksandra Szproch, aleksandra.szproch.2016@mumail.ie

**Consent:** If you wish to take part, you can simply click on the arrow below and complete the consent form. You may then complete the survey.

**Thank you for taking the time to read this**

# Appendix G: Consent Form

Please tick each statement below:

The purpose and nature of the study has been explained to me in writing. ☐

I am participating voluntarily. ☐

I understand that I can withdraw from the study, without repercussions, at any time, whether that is before it starts or while I am participating. ☐

It has been explained to me how my data will be managed. ☐

I understand the limits of confidentiality as described in the information sheet. ☐

I understand that my data, in an anonymous format, may be used in further research projects and any subsequent publications if I give permission below: ☐

I agree for my data to be used for further research projects ☐
I do not agree for my data to be used for further research projects ☐

I confirm that I am over 18 years old ☐

I confirm that English is my first language ☐

I confirm that I am at least one year post-cancer diagnosis ☐

I confirm that I have selected and undergone cancer treatment ☐

I confirm that currently I am not a cancer patient ☐

Do you agree to take part in Aleksandra Szproch's study? Yes ☐ No ☐

---

*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.*

*For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.*

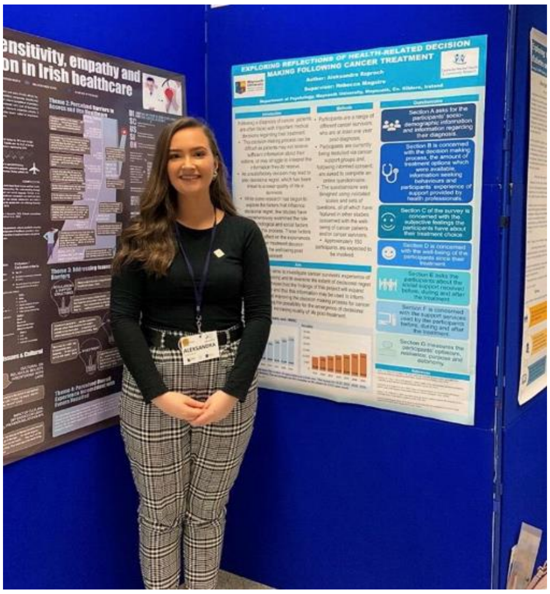
## Appendix H: Poster Inviting Cancer Survivors to Provide Feedback on Study Findings

# Are you a cancer survivor living in Ireland?

Maynooth University
National University of Ireland Maynooth

If so, we would value your help to interpret our research findings which relate to the **experience of regret following cancer treatment decisions**.

My name is Aleksandra Szproch and I am a postgraduate student at the Department of Psychology in Maynooth University, supervised by Dr Rebecca Maguire.



As part of my MSc research, I conducted two studies investigating the experience of regret felt by cancer patients and survivors following decisions over treatment. These studies aimed to find what factors are most associated with regret in oncology populations.

I am looking to present the findings of my research to cancer survivors and get some feedback or thoughts on what they mean to those living with or beyond cancer.

## Study 1: Systematic Review of Existing Research

The first study conducted was a systematic review of existing research– this involved searching databases to find published studies concerned with regret in cancer patients and survivors internationally. Appropriate studies were collected and analysed to find exactly what factors have been found to be associated with regret in oncology populations. Those factors were later grouped into five categories according to their nature:

1. *Sociodemographic factors (e.g., age, sex, income, etc.).* We found that more treatment regret was reported by cancer patients who were not married, had lower education, were not white, had a lower income or experienced greater financial difficulty.
2. *The treatment chosen.* Survivors of various cancers reported regret associated with various treatment types – there was no clear pattern found here. This finding suggests that decisions over any cancer treatment can elicit regret.
3. *Physical wellbeing.* Patients and survivors who reported poorer physical wellbeing also reported higher levels of treatment regret. This included poor physical wellbeing due to the illness and the side effects of the chosen cancer treatment.
4. *The treatment decision making process.* We found that the process in which the treatment decision is made has an impact on patient and survivor regret. Results showed that individuals mostly regretted not being involved enough in their treatment decision, not feeling informed enough about the decision they were making or that they were not informed about the side effects of the treatment.
5. *Psychological wellbeing and social support.* Results showed more regret in patients with poor psychological wellbeing and in those who received little social support.

**Study 2: Questionnaire examining experiences of cancer survivors in Ireland**

A limitation of study 1 is that findings may not apply to Irish cancer survivors. It also tended to focus on specific cancer types only. As part of the second study, I designed a questionnaire aimed at all Irish cancer survivors in order to gain insight into their decision-making experiences, their levels of treatment regret and the factors associated with their regret. Based on the responses of 92 survivors (mainly breast and prostate cancer survivors), three main factors were found to be associated with regret:

1. *Quality of life (both physical and psychological wellbeing).* Irish cancer survivors were less likely to report regret if they felt they had higher levels of physical and psychological wellbeing.
2. *Shared-decision making (when the treatment decision is made by both the doctor and the patient).* Survivors who reported that they took part in a shared-decision making strategy when deciding on their cancer treatment reported lower levels of regret.
3. *Resilience (the ability to cope well in adverse situations).* Survivors with more resilience reported lower levels of regret.

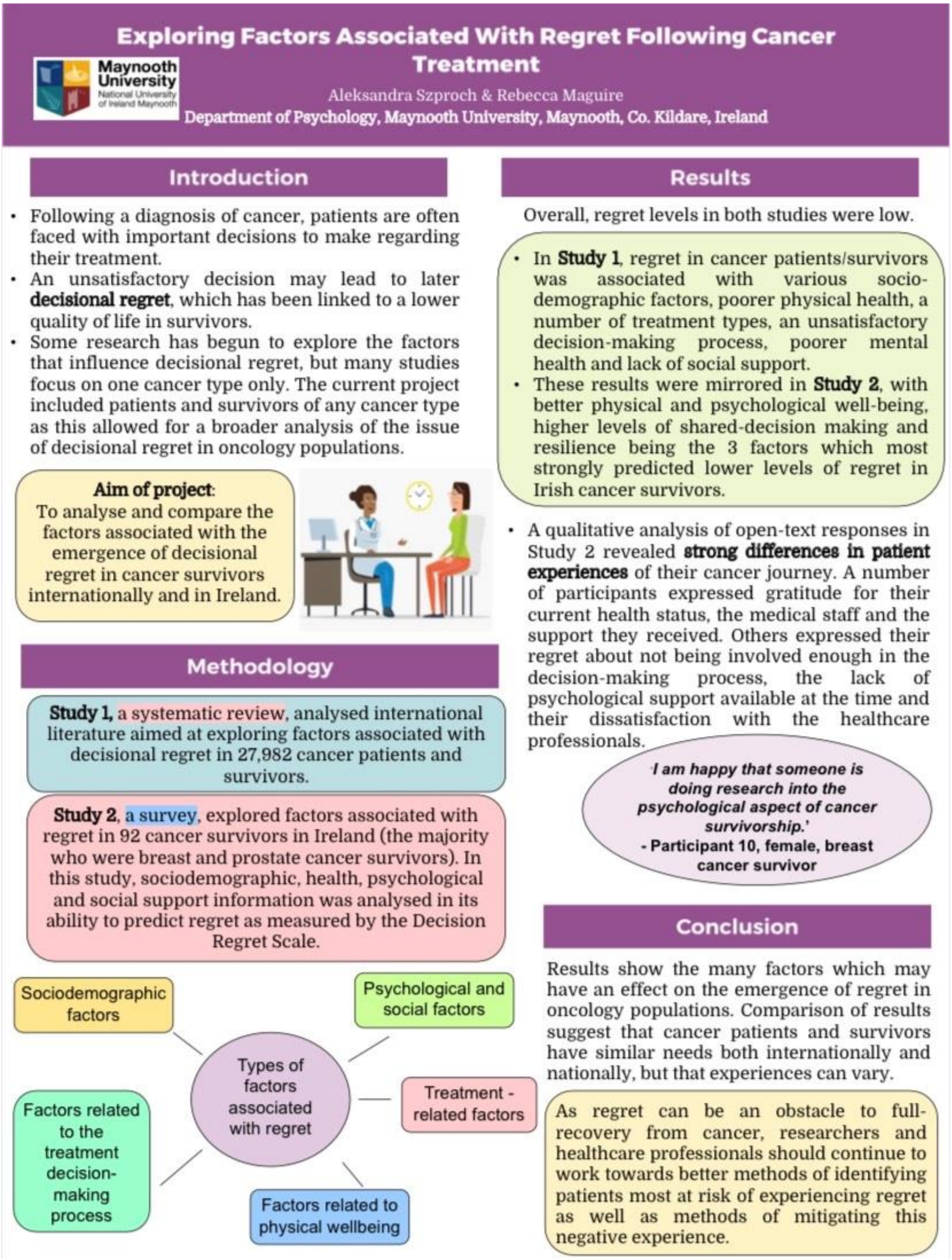
Overall regret levels were low and survivors reported a range of experiences, both positive and negative relating to their cancer decision making and the support provided to them. While females experienced greater regret than males, this difference may be due to overall differences in wellbeing between males and females.

If you have any opinion on the findings of my project, or feel that these results have missed out on some aspect of regret in survivorship, please let me know by emailing me at aleksandra.szproch.2016@mumail.ie or by clicking on the link below. PPI (Public and Patient Involvement) is important in ensuring that these findings have relevance for cancer survivors.

**Click on or copy the following link to provide your feedback:**

https://maynoothpsychology.eu.qualtrics.com/jfe/form/SV_3HKYO7rfXsOYTt3

# Research poster presented at the Psychology, Health and Medicine Conference 2020



## Exploring Factors Associated With Regret Following Cancer Treatment

Maynooth University
National University of Ireland Maynooth

Aleksandra Szproch & Rebecca Maguire

**Department of Psychology, Maynooth University, Maynooth, Co. Kildare, Ireland**

### Introduction

- Following a diagnosis of cancer, patients are often faced with important decisions to make regarding their treatment.
- An unsatisfactory decision may lead to later **decisional regret**, which has been linked to a lower quality of life in survivors.
- Some research has begun to explore the factors that influence decisional regret, but many studies focus on one cancer type only. The current project included patients and survivors of any cancer type as this allowed for a broader analysis of the issue of decisional regret in oncology populations.

**Aim of project**:
To analyse and compare the factors associated with the emergence of decisional regret in cancer survivors internationally and in Ireland.

### Methodology

**Study 1,** a systematic review, analysed international literature aimed at exploring factors associated with decisional regret in 27,982 cancer patients and survivors.

**Study 2**, a survey, explored factors associated with regret in 92 cancer survivors in Ireland (the majority who were breast and prostate cancer survivors). In this study, sociodemographic, health, psychological and social support information was analysed in its ability to predict regret as measured by the Decision Regret Scale.

Types of factors associated with regret

- Sociodemographic factors
- Psychological and social factors
- Treatment - related factors
- Factors related to physical wellbeing
- Factors related to the treatment decision-making process

### Results

Overall, regret levels in both studies were low.

- In **Study 1**, regret in cancer patients/survivors was associated with various socio-demographic factors, poorer physical health, a number of treatment types, an unsatisfactory decision-making process, poorer mental health and lack of social support.
- These results were mirrored in **Study 2**, with better physical and psychological well-being, higher levels of shared-decision making and resilience being the 3 factors which most strongly predicted lower levels of regret in Irish cancer survivors.

- A qualitative analysis of open-text responses in Study 2 revealed **strong differences in patient experiences** of their cancer journey. A number of participants expressed gratitude for their current health status, the medical staff and the support they received. Others expressed their regret about not being involved enough in the decision-making process, the lack of psychological support available at the time and their dissatisfaction with the healthcare professionals.

***'I am happy that someone is doing research into the psychological aspect of cancer survivorship.'***
**- Participant 10, female, breast cancer survivor**

### Conclusion

Results show the many factors which may have an effect on the emergence of regret in oncology populations. Comparison of results suggest that cancer patients and survivors have similar needs both internationally and nationally, but that experiences can vary.

As regret can be an obstacle to full-recovery from cancer, researchers and healthcare professionals should continue to work towards better methods of identifying patients most at risk of experiencing regret as well as methods of mitigating this negative experience.

# Appendix I: Feedback Questionnaire for Cancer Survivors

## Exploring decision making and regret in cancer survivors - call for PPI input

My name is Aleksandra Szproch and I am a postgraduate student at the Department of Psychology in Maynooth University, supervised by Dr Rebecca Maguire. As part of my MSc research, I conducted two studies investigating the experience of regret felt by cancer patients and survivors following decisions over treatment. These studies aimed to find what factors are most associated with regret in oncology populations. I would love to present the findings of my research to cancer survivors and get some feedback or thoughts on what these mean for those living with or beyond cancer.

Below is a description of our research followed by some questions.

## Study 1: Systematic Review of Existing Research

The first study conducted was a systematic review of existing research– this involved searching databases to find published studies concerned with regret in cancer patients and survivors internationally. Appropriate studies were collected and analysed to find exactly what factors have been found to be associated with regret in oncology populations. Those factors were later grouped into five categories according to their nature:

1. Sociodemographic factors (e.g., age, sex, income, etc.). We found that more treatment regret was reported by cancer patients who were not married, had lower education, were not white, had a lower income or experienced greater financial difficulty.

2. The treatment chosen. Survivors of various cancers reported regret associated with various treatment types – there was no clear pattern found here. This finding suggests that decisions over any cancer treatment can elicit regret.

3. Physical wellbeing. Patients and survivors who reported poorer physical wellbeing also reported higher levels of treatment regret. This included poor physical wellbeing due to the illness and the side effects of the chosen cancer treatment.

4. The treatment decision making process. We found that the process in which the treatment decision is made has an impact on patient and survivor regret. Results showed that individuals mostly regretted not being involved enough in their treatment decision, not feeling informed enough about the decision they were making or that they were not informed about the side effects of the treatment.

5. Psychological wellbeing and social support. Results showed more regret in patients with poor psychological wellbeing and in those who received little social support.

**Study 2: Questionnaire examining experiences of cancer survivors in Ireland**

A limitation of study 1 is that findings may not apply to Irish cancer survivors. It also tended to focus on specific cancer types only. As part of the second study, I designed a questionnaire aimed at all Irish cancer survivors in order to gain insight into their decision-making experiences, their levels of treatment regret and the factors associated with their regret. Based on the responses of 92 survivors (mainly breast and prostate cancer survivors), three main factors were found to be associated with regret:

1. Quality of life (both physical and psychological wellbeing). Irish cancer survivors were less likely to report regret if they felt they had higher levels of physical and psychological wellbeing.

2. Shared-decision making (when the treatment decision is made by both the doctor and the patient). Survivors who reported that they took part in a shared-decision making strategy when deciding on their cancer treatment reported lower levels of regret.

3. Resilience (the ability to cope well in adverse situations). Survivors with more resilience reported lower levels of regret.

Overall regret levels were low and survivors reported a range of experiences, both positive and negative relating to their cancer decision making and the support provided to them. While females experienced greater regret than males, this difference may be due to overall differences in wellbeing between males and females.

**If you have any opinion on the findings of these two studies or feel that the results have missed out on an important aspect of cancer survivorship, please let us know below or email your feedback directly to aleksandra.szproch.2016@mumail.ie.**

**If you have any opinions on the findings of this project, please comment on these below.**

**Q1. Is there any aspect of cancer survivorship, especially in relation to regret, that may have been missed in this study?**

______________________________________________________________________

**Q2. Do you relate to the findings of this study in any way?**

______________________________________________________________________

**Q3. Do you feel like these findings have any implications for the care of cancer survivors? If so, please comment on what these implications might be.**

______________________________________________________________________

**Q4. If there is anything else you would like to comment on, please do so below.**

______________________________________________________________________

**Q5. Are you a cancer survivor?**

Yes ☐ No ☐

**Q6. How would you describe your gender?**

| | | | |
|---|---|---|---|
| Male | ☐ | Female | ☐ |
| I’m not sure/questioning | ☐ | Prefer not to say | ☐ |

Other (e.g. non-binary), please specify ___________________

**Q7. If you would like to, please include any other details about yourself which you feel are relevant to this study.**

________________________________________________________________________________

**Q8. Do you give consent for your written feedback to be included in Aleksandra Szproch's MSc research thesis?**

Yes ☐ No ☐