

Accessing community dementia care services in Ireland: Emotional barriers for caregivers

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Abstract

Despite the benefits of utilising community-based care services (CBS) for people with dementia and their caregiver being well established, people with dementia and caregivers use fewer services in comparison to other people in need of care. While societal, cultural and logistical factors effecting caregiver use of CBS are frequently studied, research of internal emotional barriers, mental limitations created by one's own self that prevents open communication of thoughts and feelings, and their effect on CBS use is limited. This paper explores internal emotional barriers on caregivers' use of CBS within the Irish Healthcare System. Professional Healthcare Providers were also interviewed as a preliminary indicator of their awareness of these internal emotional barriers and their impact on caregivers' use of CBS. Using interpretive description methodology, interviews with 20 caregivers and fourteen dementia professional healthcare providers were transcribed and a thematic analysis methodology applied to illuminate themes/patterns within participants' subjective perceptions of caregivers emotional barriers to using CBS. Four themes emerge: reluctance to question general practitioner (GP) authority; embarrassment during level of care requirement reviews; sense of obligation to provide all care; and fear of stigma. Caregivers interviewed were reluctant to communicate concerns with professional healthcare providers (PHPs), thereby reducing the PHP's awareness of these barriers and delaying/preventing use of CBS. As key gatekeepers within the care pathway, GPs should address the uneven power dynamic with the caregiver through user-centred models of care, which actively encourage open dialogue, and receive training to identify the indicative behaviours of internal emotional barriers and empower the caregiver to communicate their feelings/concerns directly.

KEYWORDS

caregiver, community services, dementia, Ireland

1 | INTRODUCTION

Dementia is the greatest global challenge for health and social care in the 21st century with an estimated 47 million individuals diagnosed worldwide (World Health Organization, 2014). By 2050, this

number is projected to rise to 131.5 million (Prince et al., 2016). The majority of people with dementia live in community settings (Prince et al., 2013), supported by family and friends (also known as caregivers) who provide care services. As dementia is a progressive disease characterized by cognitive and functional decline, over

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time people with dementia become increasingly dependent on support services. Research has shown that community-based services (CBS), which aim to coordinate the treatment and care of people with dementia, can potentially be more cost effective than residential care (Michalowsky et al., 2019; Prince et al., 2013) and provide better health and overall quality of life for the care-receiver (Nikmat et al., 2015). Conversely, when CBS are limited, there is an increased likelihood of acute hospital admissions of people with dementia, which are linked to an accelerated journey towards long-term care and health deterioration (Donnelly et al., 2017). Therefore, it is reasonable to deduct that encouraging the use of CBS will provide a higher quality of life for the care receiver *and* a more sustainable economic option for a healthcare system with an aging population.

Despite the benefits of CBS, people with dementia and their caregivers use fewer services in comparison to others in need of care (Phillipson et al., 2014; Vecchio et al., 2016). Although medical services are frequently used, CBS, such as home support, day-care, respite or counselling, are used less often, even though these types of services may be particularly helpful (Weber et al., 2011). Several barriers to CBS use have been identified, for example, stigma within the general public (Kim et al., 2019) and healthcare system (Jack-Waugh et al., 2018), lack of information (Heinrich et al., 2016), costs associated with accessing CBS (Zhu et al., 2015), problems navigating the healthcare system (Hossien et al., 2017), and inappropriate dementia supports (Boots et al., 2015). As a result, many caregivers are reluctant to use professional support and CBS remain underutilised (Greenwood & Smith, 2015; Jennings et al., 2019). Despite their effect on caregiver's motivation to engage with CBS, little is known about the emotional barriers, mental limitations created by one's own self that prevents open communication of thoughts and feelings (Kuttappa, 2020), and their effect on a caregivers' decisions to engage or not engage with CBS (Morgan et al., 2002; Stirling et al., 2010; Taylor et al., 2016). Similarly, professional healthcare providers (PHPs) play a significant role in influencing patients' opinions on healthcare based interventions (Burgon et al., 2019; Denning et al., 2019), but little research has been done on PHP awareness of internal emotional barriers of caregivers' in relation to CBS use.

In Europe, approximately 50%–75% of all formal long-term care is provided in the community (Colombo & Mercier, 2012). Variations between EU countries in terms of healthcare and social service organisations, demographic patterns and financial systems have an impact on the distribution and effectiveness of CBS, making comparison between countries difficult (WHO, 2012). For example, how care needs are identified, accessed and distributed, and social pressure for family to provide care varies greatly between countries (Kerpershoek et al., 2019). However, there is a unifying emphasis on facilitating older people to stay at home as long as possible through CBS (Joling et al., 2015; Nilforooshan, 2018). Similarly, a key objective of the Irish National Dementia Policy is to enable people with dementia to remain at home for longer, resulting in a growing demand for CBS. The national health service agency, the Health Service Executive (HSE), provides the majority of CBS in Ireland, but it is not underpinned by legislation or provided on a statutory basis (Cahill, 2010). Instead, it is at the discretion of the community area where the person

What is known about this topic?

- People with dementia and their caregivers use fewer services in comparison to others in need of care.
- While medical services are frequently used, community services, such as home support, day-care or respite, are used less often, despite being particularly helpful.
- The body of knowledge lacks an overview of aspects related to internal emotional barriers, mental limitations created by one's own self that prevents open communication of thoughts and feelings and their effect on CBS use.

What this paper adds?

- Caregivers interviewed often did not communicate internal emotional barriers experienced in the CBS care pathway.
- Internal negative emotions are particularly impactful at GP diagnosis and in-home care needs review.
- GPs should address the uneven power dynamic with the caregiver through user-centred models of care, and healthcare professionals require training to identify the indicative behaviours of internalised emotional barriers.

resides, and the provision and cost of care vary from one area to another depending on how services are structured. Additionally, dedicated dementia-specific services are sparse in the Irish healthcare system. The use of services remains limited with caregivers often reporting that they would like to use more services but find it difficult due to lack of information and barriers to access (Begley, 2009; Brodaty et al., 2005; Weber et al., 2011). In order for CBS to be fully utilised to allow people with dementia to remain at home for as long as possible, additional research is required to identify the influencing factors on caregivers' decisions on which services they choose to engage or not engage. This research aims to better understand the complex issues regarding emotional barriers to CBS for caregivers of people with dementia, negative emotions not communicated to PHPs, and the level of awareness of these emotional barriers by PHPs.

2 | METHODOLOGY

Interpretive description (ID), originally developed within the discipline of nursing but increasingly being utilised in a variety of health research (Thompson Burdine et al., 2020), was used as it is considered an appropriate qualitative methodology for applied disciplines (Wall, 2019). ID focuses on human experience and empirical evidence and assumes the existence of multiple realities, which are context-bound, experientially based, and create intersubjective constructs through social interaction (Berterö, 2015; Glaser & Strauss, 2017; Lasiuk et al., 2013). Within this research ID was used to structure the research project approach and

illuminate themes and patterns within participants' subjective perceptions, to provide an integrative description of caregivers perceived emotional barriers to using CBS (Thorne et al., 2004).

2.1 | Data collection methods

Using a purposive sampling method of typical cases (Palinkas et al., 2015), participants were recruited through the HSE and the Alzheimer Society of Ireland (ASI) (Table 1). To participate, caregivers were required to be the primary provider of care for the person with moderate to severe dementia, for this to be their main occupation, and to currently avail/previously availed of CBS. PHPs were required to be a direct provider of CBS for those with dementia and/or their primary caregiver in the Republic of Ireland.

A semi-structured interview guide was developed to prevent leading or biased questions. Similarly, key topics for exploration during data collection were identified but not disclosed to participants to prevent bias. Sufficient flexibility was instilled in the guide to permit the introduction of new/unanticipated topics. At the end of each interview, participants were given a short summary of the

information collected to provide an opportunity to further emphasise any issues of importance not been adequately addressed and/or provide any additional information. Caregiver interviews were conducted at their place of residence or preferred location. PHP interviews were conducted at their place of work. All interviews varied in length from two to 3 hr and were recorded with participant's permission. Field notes were taken by the researcher and used to highlight points of note and reflect on findings as research progressed.

2.2 | Data analysis

In accordance with the ID methodology, a thematic analysis method was used to allow the examination of multiple perspectives of participants, highlight similarities/differences and generate unanticipated insights (Danivas et al., 2016; Nowell et al., 2017; Sundler et al., 2019). Interviews were transcribed verbatim with participant and place names replaced with pseudonyms to ensure anonymity. As each interview was completed, data gathered were reviewed and analysed allowing researcher reflection and inductive knowledge generation (Thorne, 2016). Using Nvivo software, which later facilitated data comparison across all transcripts, the researcher listened to and read the interviews until they were familiar with the content and began the thematic process by organising data into segments of similar perspectives and experiences, which precipitated formation of data patterns (Braun & Clarke, 2006). Progressive data coding, starting with broad-based codes to avoid premature interpretations progressively narrowing down to context specific information, was used to organise information into potentially thematically related groups; and verbatim quotes of significance in the context of the interview were captured (Table 2). Groups were then cross-referenced across all interviews to identify relationships. As the analysis progressed, relationships between different groups became more apparent and thematic patterns emerged that represented emotional barriers to caregiver's use of CBS and awareness of these barriers by PHPs. The author was primarily responsible for data analysis, and regular discussions were held with the research team to provide further insight into arising themes.

Information sheets and consent forms were provided to participants through HSE or ASI staff prior to researcher contact. No direct contact was made until written consent was received. Ethical approval was granted by an assembled Ethics Board of representatives from the Research Ethics Committee, Sligo Regional Hospital; Irish in Britain; The Resource Centre; and EU Social Policy and Politics Department, Institute of Technology, Sligo. Initially, the possibility of directly interviewing people with dementia was explored but was not supported by the HSE, as direct information would only be attainable from those with mild-stage dementia and full capacity to consent to the research and no/limited need or experience with CBS. Research has shown informal caregivers have significant influence on the care-receiver's ability to access CBS (Morgan et al., 2002). Therefore, research instead focused on the influencing factors on CBS engagement as perceived by caregivers of people with dementia. As significant influencers to use, PHP were interviewed to

TABLE 1 List of participants interviewed

No.	Caregiver		Healthcare professional	
	Rural/ urban	Care relationship	Role	Private/ public
1	Urban	Daughter	Old age psychiatry	Public
2	Urban	Husband	Senior social worker	Public
3	Urban	Daughter	Senior social worker	Public
4	Rural	Wife	Advanced nurse practitioner	Public
5	Rural	Daughter	Old age psychiatry	Public
6	Rural	Daughter	Clinical nurse manager	Public
7	Rural	Daughter	Clinical nurse manager	Public
8	Rural	Daughter	Old age psychiatry	Public
9	Urban	Son	Clinical nurse manager	Public
10	Rural	Daughter	Director of nursing	Public
11	Urban	Wife	Social officer	Public
12	Urban	Wife	Social officer	Public
13	Rural	Daughter	Social worker	Public
14	Rural	Son	Clinical nurse manager	Public
15	Rural	Nephew		
16	Rural	Son		
17	Urban	Daughter		
18	Rural	Daughter		
19	Urban	Husband		
20	Urban	Daughter		

TABLE 2 Identified themes and codes

Themes	Codes
Reluctance to question GP authority	Diagnosis
	Perception of dementia pre-diagnosis ^a
	Relationship/duration of care provision
	Care management CBS access
Embarrassment during care reviews	Process
	Duration & frequency
	Cognitive performance ^a
	Review environment
	Needs review ^a Needs/provision match ^a
Sense of obligation to provide all care	Carer/person with dementia relationship
	Distribution of care responsibilities
	Initial care role
	Changing care role over time ^a
	Caregiver stress
	Familial obligation
	CBS
	CBS used
	Reason for accessing CBS
	CBS positive experiences & emotions
	CBS negative experiences & emotions ^a
	Respite
	Reason for accessing respite
	Respite positive benefits & emotions
Respite negative effects & emotions	
Fear of stigma ^a	Perception of dementia pre-diagnosis
	Perception of dementia post-diagnosis

Abbreviations: CBS, community-based care services; GP, general practitioner.

^aStigma and fear of stigma identified across sub-themes. Shown in context within the table.

provide a wider context to the public dementia healthcare sector and to explore their level of awareness of emotional barriers.

3 | FINDINGS

Twenty caregivers and fourteen PHP were interviewed with four themes emerging as internal emotional barriers to CBS for caregivers: reluctance to question general practitioner (GP) authority, embarrassment during level-of-care requirement reviews, sense of obligation to provide all care, and fear of stigma. The caregivers interviewed often internalised negative emotions, i.e., did not directly communicate their emotional discomfort with PHPs at key points along the care pathway. This reduced the PHP's awareness of emotional barriers and delayed/prevented the use of CBS. PHPs were

aware of the externally communicated emotional discomfort but had limited awareness of the internal emotional barriers on CBS use.

3.1 | Reluctance to question general medical practitioners authority

GPs are recognised gatekeepers for CBS (Cahill et al., 2008; Luck et al., 2012). Due to their long-term relationships, caregivers interviewed had a high level of trust with GPs and heavily relied on them for guidance and information on CBS.

You go in, sit in front of a GP and they say, 'Oh, the mini mental is whatever, 25 out of 30' you go home and you say, 'God, am I making a fuss about nothing?' (CG13)

I think people are too busy to access the service or sometimes it might be too difficult for them to access. They don't know the proper route, lack of information. They only know the GP, and the GP wouldn't be bothered. (PHP7)

As such, GPs have considerable influence on the diagnostic process and care that patients receive. However, research has shown GPs can be reluctant to diagnose dementia due to uncertainty during early-stage dementia and are embarrassed to conduct a cognitive examination and communicate the diagnosis (Hout et al., 2000). These issues are further compounded within the Irish healthcare system by a lack of standard dementia diagnosis process for GPs (Keogh, 2017).

In hindsight, she should have been referred a year and a half before she died. It was just GPs were very reluctant to refer to the psychiatrist of older age ... I asked for the psychiatry for older age to be brought in and they didn't think there was any need for it. GPs sometimes like to manage it themselves. (CG12)

She just needed to talk and felt that she couldn't discuss these things with the GP ... She thought he'd say you were only fussing and she just felt she was inconveniencing them. (PHP14)

Due to the high regard in which GPs are held, many of the caregivers interviewed felt uncomfortable questioning the diagnosis, particularly if symptoms were in the early stages. This delayed diagnosis and prevented caregiver's use of services, as in Ireland a letter of formal diagnosis is required for CBS eligibility. As a result, additional consultation was only sought when symptoms of dementia were more prevalent and easier to demonstrate. This uneven power dynamic is further strengthened in the purposeful formulation of boundaries in the medical practitioner-patient relationship. While

aiming to protect both practitioner and patient through this separation (O'Leary et al., 2012), it increases the caregiver's reluctance to question GP authority.

3.2 | Embarrassment during requirement review

To determine care requirements, PHPs perform care needs reviews. Caregivers described the review as a 'snap-shot' as care needs are reviewed over a brief period. As a result, care requirements could be skewed if the person with dementia was having a particularly lucid or cooperative day.

[Person with dementia] performs beautifully in front of him and she'd have been so different at home. Put on the nice coat and the scarf, powdered the nose, and make sure hair is done and walks in and sits politely and quietly. (CG20)

If the person with dementia performed tasks more competently/independently within the review session than that reported by the caregiver, the caregiver felt embarrassed at being perceived as misrepresenting the situation and additionally embarrassed if the requested services were refused. In addition, caregivers reported a sense of anxiety during reviews that the person with dementia might not present symptoms or behaviour indicative of 'the worst case' care scenario and as a result would not receive the appropriate care services. This was compounded by the close relationship with the person with dementia, as there was a sense of guilt in reporting previous behaviours that did not manifest during the review.

There was moment she was very good. You would see her and she was back to herself and you'd sit down and have a cup of tea and in those good moments, they're the moments that would make you say, 'Oh, I don't want to put her in to a nursing home' ... So then, you kind of think, 'Oh, I have to maybe turn it down a few notches. (CG5)

As a result, caregivers were reluctant to request increased or additional services until the symptoms worsened and the likelihood of capturing these symptoms by the PHP in the review increased. This emotional response typically manifested in the early-moderate stages of dementia when the symptoms are harder to identify and therefore were more likely to be missed.

Supporting this view in the wider context of the Irish healthcare system, PHPs interviewed were of the opinion that CBS were insufficiently reviewed.

It's not when you need it. A lot of the time, you have to pre-empt because of the waiting lists for everything. Almost guess when you are going to need the service. (PHP3)

The brain function has just deteriorated so much but if you talk to her she could be charming and lovely and you would think well what are the staff making such a fuss about. She is fine. (PHP12)

Professional healthcare providers were aware of the logistical issues caused by the insufficient reviews but were less/unaware of the embarrassment and anxiety felt by caregivers if the person with dementia performed better than previously reported by the caregiver. Despite universally positive opinions of CBS, this reluctance to request an additional review for fear of embarrassment, resulted in fewer care reviews and lower level of CBS use by caregivers.

3.3 | Sense of obligation to provide care

Caregiver guilt is well documented (Feast et al., 2017; Prunty & Foli, 2019), while the exploration of the influence of guilt on CBS use is limited. In those interviewed, an uneven distribution of care was common, with most of the responsibility falling to a single person who often had a close relationship with the person with dementia (parent, spouse, close friend). This created a strong emotional undertone to the care provision and a sense of obligation (Hamon & Whitney, 2003) to provide all care as they 'owed' it to the person with dementia to provide 'perfect' care.

What if she was in the nursing home, you were at home for your week off but she might just think you're leaving her there. It's your mother. It's not as if you're caring for a stranger and they're gone for a week and you have a great rest. It's your mother. (CG17)

There's always the guilt thing and the fear of being a failure but you have to have time off from this particular job ... You can offer and offer and offer ... But they say 'No, I'm ok'. It's a big issue around carers, guilt, failure. It's an emotional role. It's complex. (PHP5)

Due to the progressive nature of dementia, the required amount of care increases over time and caregivers progressively struggle to provide the care themselves. As a result of this sense of obligation, it was common for caregivers to only use services at the point of feeling overwhelmed.

I had to ring the doctor, because then I knew I needed help ... We were in trouble and getting desperate. But the time lagged between when you ring them and say, 'There is something really in trouble and we need help'. (CG17).

She got married, moved into the husband's home and when she got married she had to take the mother who had dementia. She felt there was no out. (PHP9)

Consequently, service use was often associated with a sense of guilt. This was particularly prevalent for services of a personal nature (e.g., feeding, washing, toileting and shaving) as caregivers felt these services should be delivered by someone close to the person with dementia. This sense of guilt could be exacerbated by the introduction of a 'stranger' into the home to provide the service (i.e., PHPs). Due to rolling staff placements, introduction of a PHP to the home was a regular/reoccurring source of guilt that caused a reluctance to engage with ongoing and further services.

3.4 | Fear of stigma

Research has shown that dementia as a 'taboo' subject negatively affects how people care for and perceive the person with dementia and how receptive they are to accepting and seeking help (Gove et al. 2015; O'Hadhmaill & O'Riordan, 2014). Caregivers were acutely aware of the stigma around dementia. They were often afraid to tell others of the diagnosis for fear of 'being treated differently' or 'what the neighbours might say'.

Once you know that they have dementia, you look at people in a different way. (CG2)

They get embarrassed because people notice their memory problem ... maybe they are reluctant to tell people and hopefully you would be encouraging them to tell a few people for support. (PHP8)

This resulted in a care being sourced from a trusted but limited group (family, close friends) and a reluctance to use CBS, as neighbours would note the PHP attending the home. Additionally, caregivers discussed issues with the person with dementia becoming agitated and shouting due to disorientation and being negatively judged because of this behaviour.

Last summer, you couldn't go for a walk. I remember trying to go for a walk ... and [a neighbour] ringing me, 'She's [person with dementia] standing outside the door shouting'. (CG4)

I think communities are very afraid up to recently of people with dementia. Older persons with cognitive impairment should have been linked into mainstream for as long as possible so they don't get afraid of people with cognitive impairment. (PHP4)

To avoid stigma, caregivers attempted to keep the diagnosis within their social circles but did not relate this back to PHPs. Instead, caregivers could be reluctant to discuss the full extent of dementia-precipitated behaviour because of embarrassment and the resulting care requirements for fear of judgement, creating a mismatch between what CBS were required and what were provided.

4 | DISCUSSION

This study provides insight into the emotional barriers experienced by caregivers of people with dementia, which can influence their decision to engage with CBS; and the level of awareness of these emotional barriers by PHPs. It captures the complexity and impact of internal emotions (i.e., emotions not communicated to the PHPs) for both the use of CBS, and the long-term relationships with PHPs along the care pathway. Through an ID approach, participants provided their perspectives, experiences and emotional responses to CBS, with strong themes emerging. All caregivers interviewed were primarily positive in relation to the quality of CBS, but, as in previous studies (Brodaty et al., 2005; Vecchio et al. 2016), the total number of services used was relatively low, ranging between 1 and 2.

Consistent with other studies (Carter et al., 2015; Tilburgs et al., 2018), GPs are the primary point of contact for people with dementia and their caregivers for diagnosis, treatment and advice. As such, they have considerable influence on the diagnostic process and use of CBS, creating a significantly uneven power dynamic (Lang et al., 2017). Our research identified that the high regard in which the GP is held and this power dynamic, prevented questioning of the GP's authority to seek further assessment and/or second diagnosis. Recent studies have recognised this dynamic and address it through a user-centred approach to healthcare which aims to give patients greater control by enabling and involving them in the planning, organisation and delivery of care services (Abrams et al., 2019; Housden et al., 2017). This provides a more equal power balance and ultimately improves communication between practitioner and patient to ensure provision of appropriate/effective services. Though these studies explore the patient's sense of control within the healthcare system, they do not address the emotional barriers caused by the same dynamic at or before the point of access. PHPs interviewed in this research were aware of barriers affecting the logistics of accessing CBS but not the level of internal emotional barriers preventing caregivers asking for additional diagnosis reviews, care reviews and discussing changing care needs. As key gatekeepers within the care pathway, GPs must be aware of emotional barriers around authority and approach the patient-physician dynamic in a user-centred way by actively encouraging an open dialogue to identify and deliver appropriate care services. Prior research has shown that patients of empathic physicians had better health outcomes and lower levels of anxiety and were more satisfied with their care (Batt-Rawden et al. 2013; Derksen et al., 2013).

Fear of embarrassment emerged as a strong theme during care reviews if the caregiver believed they were perceived by the PHP as misrepresenting the level of care support required. Häikiö et al. (2019) discusses how a person with dementia is capable of hiding or underplaying their symptoms during the limited interactions with PHPs and the emotional effect this has for caregivers. However, Häikiö et al. identified embarrassment by the caregiver for the person with dementia resulting in unintentionally concealing needs and symptoms. In the same scenario, this research identifies a personal embarrassment by caregivers *themselves* if the person

with dementia performed tasks at a higher level than reported, as they felt they appeared to have misrepresented the extent of the symptoms. Prior research has focused on externally communicated embarrassment felt by caregivers caused by the changing/inappropriate behaviour of the person with dementia (Robinson et al., 2012; Stockwell-Smith et al., 2019), but limited research has been done on the negative effects of uncommunicated embarrassment on the caregivers as a reflection of themselves and the effect this has on CBS use. PHPs were aware of the embarrassment the behaviours of people with dementia can sometimes cause, but not in context of a service review or how caregivers felt this reflected on *themselves*. A lack of awareness of the caregiver's sense of self-embarrassment could potentially impede the healthcare professional's ability to provide high-quality, appropriate care as the care needs are not fully captured within the care review. Research has shown that PHPs directly asking caregivers about emotional duress is not effective (Yamamoto-Mitani et al., 2016). Instead, alternative means such as actively building person-to-person relationships and trust is needed for both the caregiver and professional to raise and discuss care issues. As trust can be difficult to establish, a more empathic and inclusive approach to care needs review is required, which aims to establish and maintain an open dialogue that provides opportunities to communicate currently internal emotions.

Similarly, this research identified feelings of obligation as barriers to CBS use. Due to the close relationship with the person with dementia, caregivers can have a sense of moral obligation to the person with dementia and guilt if they cannot meet the care requirements. This sense of obligation, in the form of societal, cultural or family pressure is well documented (Bieber et al., 2019; Greenwood et al., 2019; Hanssen & Tran, 2019; Werner et al., 2014). This study supports these findings and additionally highlights the need for further exploration of the additional *internal* emotional barriers resulting from these pressures which affect the caregiver's willingness to engage with CBS. In particular, the effect of the caregiver's sense of obligation on the communication of care difficulties, particularly of a personal nature, to the PHPs needs further research.

Stigma is a significant contributing factor to the avoidance of help-seeking behaviours for caregivers, delaying diagnosis and causing lower use of CBS (Vernooij-Dassen et al., 2005). This study supports research by Nolan et al. (2006) and Phillipson et al. (2014) who also identified stigma as an emotional barrier for people with dementia and their families, preventing use of necessary care and support and eventually impacting their well-being and quality of life. It is also interesting to note that the affect is not specific to dementia. In similar studies in the area of mental health (excluding dementia), caregivers derived care support from family members and close friends and less frequently from health services to avoid stigma (Ostman & Kjellin, 2003). In addition to supporting the identification of a fear of stigma as an emotional barrier to the use of CBS, this study explores its effect on the alignment of services needed and services provided. The fear of stigma combined with the fear of embarrassment at care review can have a cumulative negative effect on the identification and allocation of CBS, resulting in lower level of CBS use.

4.1 | Strengths and limitations

The use ID methodology was appropriate for the research area to interpret qualitative findings from multiple perspectives to inform healthcare policy and service provision practice and improve caregiver use of CBS (Houghton et al., 2016; Thorne, 2009). The overall sample was heterogeneous in terms of caregiver age, relationship to the person with dementia and utilisation of CBS, allowing the capture of a broad range of experiences.

Caregivers were from the west of Ireland with a low population and as a result, data collected from this group could be considered limited in perspective. While data collection was conducted in a limited location, it is likely that the findings will be of relevance to CBS elsewhere, as the emotional barriers of caregivers were identified as a critical influencing factor to CBS use, rather than the access or delivery logistics.

Data were collected retrospectively, based on caregiver recollections rather than live at the point of access as, due to confidentiality issues and codes of practice it was difficult to witness services firsthand. To gain further insight into the emotional barriers for caregivers to CBS, it is recommended that additional ethnographic research is carried out throughout or at key points along the care pathway.

4.2 | Implications for policy/practice

This research reinforces the need to understand the complex influencing factors on caregivers of people with dementia and their use of CBS. To achieve a higher level of CBS engagement, this complexity must be acknowledged and addressed. PHPs should actively recognise the key challenge of identifying the *internal* emotional barriers of caregivers and developing a model of care to overcome these barriers. Reflected in the interviews, due to the nature of non-communicated internal emotional barriers, PHPs had limited awareness of the effects on caregiver internal emotional barriers on CBS use. To overcome this, a user-centred approach is required by GPs to resolve the current power imbalance and increase the input of both the person with dementia and the caregiver in the organisation and delivery of care services. This new approach should aim to balance power dynamics, which allows GPs to retain a degree of professional distance but provide caregivers with sufficient confidence to request a more in-depth/second evaluation if needed. This is a critical point within the caregiver's journey as it is often the first point of engagement with CBS and sets expectations for future engagements. Similarly, while needs assessments are being widely used in the field of public health, internal embarrassment felt by the caregivers can prevent services from being fully utilised and/or accurately capturing the care needs. A relationship-centred care model, which creates and maintains care routines and professional boundaries but also supports a highly communicative dynamic, is required. This model should carefully balance the caregiver-PHP relationship to directly address the emotional barriers to CBS. Staff training to identify the indicative behaviours of internal concerns, embarrassment and sense

of obligation should be used to address these barriers and enhance relationship building to empower the caregiver to externally communicate feelings and concerns. In addition, a relationship-centred care model could address the issue of stigma. Creating a relationship with strong lines of communication can inform/educate caregivers and relieve anxiety and provide an opportunity to address wider community stigma caused by misinformation. Broadening user-centred design with a focus on empathic engagement at these key points within the care pathway will significantly address the issue of emotional barriers to CBS for caregivers.

5 | CONCLUSION

Despite prior research demonstrating the positive affect of community services for the people with dementia and caregivers, this group uses fewer services in comparison to other people in need of care. However, the majority of studies focus on the external aspects influencing access to and use of CBS, and little is known about caregiver's internal emotional barriers, a reluctance to communicate thoughts and feelings, which can affect their decisions to engage or not engage with CBS. This study explores the influence of *internal* emotions by the caregiver and the effect these barriers have on the use of CBS. It highlights the need of healthcare professionals to establish relationships of trust and open communication along the care pathway (i.e., GP engagement and needs care assessment) and the need for training of staff to identify internal emotional barriers that can to CBS use (i.e., self-blaming, sense of obligation and stigma). Further research should explore models of care with an appropriate balance between professional distance and open communication to allow caregivers to express concerns without negative emotional responses.

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CONFLICT OF INTEREST

None declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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