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Information seeking amongst informal caregivers of people with dementia: a qualitative study

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Abstract

Purpose – This paper both supports previous findings relating to, and presents new insights into: the information needs and the information seeking processes of a sample of informal caregivers of people with dementia (in relation to their own needs and the interrelated needs of the people they are caring for); the extent to which such information needs are and are not being met; and the factors facilitating and hindering access to the right information.

Design/methodology/approach – The study adopted a qualitative approach in the form of a thematic analysis of in-depth, semi-structured interviews with a sample of 20 informal caregivers from a range of different age groups, genders, and caring roles.

Findings – Thematic analysis identified significant informational challenges, with a common perception that information seeking was onerous, requiring a proactive approach. Further challenges arose from a perceived lack of focus on carer needs; coming up against the boundaries of professional knowledge; and inconsistent information provision across the sample. Distance carers faced specific issues. A second theme of negative impacts described burdens arising from: difficulties in accessing information from a complex array of support services; closure or change in services; and unfulfilled information needs. Participants employed strategies to enable access to information, for example, being open about their caring role; and building formal or informal support networks. It is important to address emotional as well as cognitive dimensions of information needs.

Practical implications – This research highlights a need for health and social care, practice, and policy to acknowledge and address information needs of this diverse population and build resilience. Above all, information seeking and sharing must be understood within the context of the emotional impact of caring, and recognition of these twin needs is crucial.

Originality/value – Whilst previous research has focussed on identifying specific needs and knowledge acquisition at cross-sections, a more holistic understanding of experiences is underexplored. This approach is needed to take into account broader contexts, diversity of experiences, and different caring roles e.g., primary and secondary carers, and in-situ and distance carers.

Key words: Dementia, informal carers, information needs, information seeking

Paper type: Research paper

1. Introduction

A previous paper (Sbaffi and Hargreaves, 2022) presented findings from a qualitative study of informal caregivers of people with dementia focusing on how they formed perceptions of the trustworthiness of information sources relevant to their caregiving role. This paper extends the analysis of data collected in this research to focus on perceived barriers to, and enablers of, their effective seeking and acquisition of relevant and trustworthy information, and the extent to which their information needs are, and are not being met.

In the UK, there are 670,000 informal unpaid (or family) carers looking after a person living with dementia (PLwD) (Carers Trust, 2020) and it is estimated that one-in-three people will undertake this caring role for a relative or friend within their lifetime (NHS England, n.d.). The caring role is complex and demanding, involving balancing the impact of dementia on their own lives while fulfilling the needs of their care recipients (Cabote *et al*., 2015). This rises information needs that have dual interrelated elements - the carer's own needs and those of the person they are caring for. Carers are a diverse group in terms of roles, relationships, circumstances, and the needs that arise from different stages of the caring journey (Department of Health and Social Care, 2018; Larkin *et al*., 2019; Moriarty *et al*., 2015). The role has significant informational challenges as carers play a key role in navigating support services, their own information needs, and those of the PLwD, which shift and change over the caring trajectory (Department of Health and Social Care, 2018).

Carers have diverse information needs and existing research has focussed on needs deriving from aspects of care, such as medication administration (e.g., Horne *et al*., 2018; Malloy-Weir and Kirk, 2017), management of behavioural symptoms (Werner *et al*., 2017), or dealing with co-morbidities (e.g., McWilliams *et al*., 2018). Researchers have also explored needs at different points of the caring trajectory, in particular diagnosis (e.g., Killen *et al*., 2016; Pálsdóttir, 2017). These studies showed that carers are poorly supported at diagnosis and are provided with limited information on key aspects such as emotional, financial, and practical support (Killen *et al*., 2016).

However, as noted in Sbaffi and Hargreaves (2022), although an increasing number of sources of information relevant to caregivers is available, they still report many unmet needs when it comes to accessing and securing trustworthy information (e.g. Myrick, 2017; Mason *et al*., 2020), and they can feel inadequately informed and ill-prepared to fulfil their role (Allen *et al*., 2020).

Alzougool *et al*. (2013) developed a conceptual framework of four types of information needs: Recognised Demanded (carers are aware of their information needs and want them to be met); Recognised Undemanded (carers are aware of their information needs but do not want them to be met); Unrecognised Demanded (carers are not aware of having information needs but they perceive that they might need information); and Unrecognised Undemanded (carers are not aware of potentially relevant missing information, hence cannot establish whether they need to satisfy such a need). The study concluded that there is still a considerable gap in the information available to carers and more nuanced and personalised resources should be provided.

Alzougool, *et al*. (2017) go on to identify statistically significant correlations between the reporting of these different need states and a number of individual and social variables. However, they do not proffer theoretical explanations of how or why these states might occur, or explore differences in the extent to which these information needs do or do not go on to be pursued and fulfilled - and why. A number of existing theoretical models offer potential insights into at least parts of the complex interactions between perceived needs, the intention to pursue these needs, and success or failure in so doing.

Many of these models explore strategies, processes and influences applying to people in a *recognised demanded* information state who are trying to satisfy their information needs. If the information required to resolve their need is not provided to a carer (e.g. by healthcare providers) then they must seek it out for themselves. However, a number of factors may intervene to affect their success in so doing. Different people may possess very different levels of information literacy in terms of the knowledge and skills required effectively to seek out, obtain, evaluate and use information. They may also vary in the extent to which they have access to appropriate information, and the extent to which from all available sources they choose which to trust and access, ignoring or rejecting others.

Chatman's (1999) "small worlds" theory offers insights into how different contexts and social networks may influence people in how they place trust in, and consequently use or not use particular sources of information. According to her theory, people may tend to favour - in terms of attributing them with trust and credibility - sources that are accepted within their "small worlds", a small world being a social group in which "mutual opinions and concerns are reflected by its members and in which the interests and activities of individual members are largely determined by the normative influences of the small world as a whole" (Chatman, 1999, p.213). This lens may be relevant to the extent that carers perceive themselves to be part of a coherent social group via their shared circumstances. The concept of navigating new "information landscapes" (Lloyd, 2010) may also be relevant to the extent that carers, in taking on and learning about their role, will have to navigate their way around an information landscape which is both complex and very new to them.

Attention has also been paid to people with information needs that are *recognised*, but *undemanded* not in the sense of people deferring action to satisfy them, but rather in terms of them simply not pursuing them or even actively seeking to avoid information that might relate to them. Wilson's (2022) model of information behaviour suggests a number of intervening factors that offer to illuminate such states, such as risk/reward calculation (Settle and Alreck, 1989), whereby the perceived benefit of acquiring information must justify the estimated expenditure of effort involved in seeking it to trigger information seeking. Choo (2017) provides a good review of other relevant theories that can help to illuminate this phenomenon of avoiding information. However, information that may be accurate and logically relevant to satisfy an information need may not necessarily be accepted and utilised if that information is mismatched with emotional and cognitive aspects of the needs of the information seeker.

The *unrecognised demanded* state arguably spans the two areas in that, although a specific need requiring prompt information acquisition may not be present, people may have a more general perception that health related information is needed for later use as and when required. It seems harsh to label this as evidence of an *unrecognised* info need – it may instead represent a deferred need of the type described in Krikelas' (1983) information seeking model.

The work mentioned so far relates to situations in which an information need has already been perceived. Less research attention has been paid to Alzougool *et al*.'s (2017) fourth information need state, *unrecognised undemanded*. This state corresponds with the notion of "incognizance", which has been the focus of research for example by St. Jean *et al*. (2018), who define it as "an enduring unawareness that one has a particular information need" (p.307) and go on, within the context of people with type 2 diabetes, to propose strategies for overcoming it including talking with others in similar health situations.

This need for personalised information has been long recognised by research (e.g., Washington *et al*., 2011) and goes together with addressing the importance that carers attribute to 'sense-making', that is the use of their own approaches and principles to make sense of different sources and typologies of information (Sbaffi and Hargreaves, 2022).

The current evidence base has limitations, with the majority of studies from the United States, a lack of diversity within samples, and most studies exploring a specific cross-section as opposed to the caring journey (Bressan *et al*., 2020; Francis and Hanna, 2022; Soong *et al*., 2020; Smith *et al*., 2021). Limitations in terms of the research focus have also been identified with gaps in knowledge around information needs in carer self-care (Soong *et al*., 2020); the impact of fragmented information provision between different organisations/providers (Smith *et al*., 2021); when and from whom carers prefer to receive information (Bressan *et al*., 2020); what type of information is needed and how to tailor services to individual needs (Larkin *et al*., 2022; Morrisby *et al*., 2018). These limitations point to a requirement for a broader approach to exploring information needs across carers' experiences and within different types of carers (e.g. distance carers). The study reported here adopted a holistic approach, situating carers' information needs and information-seeking behaviours within an understanding of broader contexts, such as different caring roles, family relationships, demands, and emotional needs. This holistic approach was adopted in order to take into account participants' diversity of experiences and different caring roles e.g., primary (PC), secondary carers (SC), in-situ and distance carers (Department of Health and Social Care, 2018; White *et al*., 2020).

The research set out to answer the following research questions:

> RQ1. To what extent are the information needs of informal carers (including both their own needs and those of the people they are caring for) being met?
>
> RQ2. What factors are perceived as barriers hindering the acquisition of information appropriate to support their needs?
>
> RQ3. What factors are perceived as facilitating the acquisition of appropriate information?

2. Methodology

This qualitative research adopted an inductive approach broadly based on interpretivism. In interpretivist philosophy, the goal is to view the world from the perspective of the participants, rather than the world's explanation per se (Walker and Dewar, 2000), which is consistent with the purpose of this study.

In-depth, semi-structured interviews were carried out with a sample of 20 carers from different age groups, genders, and caring roles to build a rich picture of informal caregiving information-seeking practices. Initial recruitment of participants was via the researchers' personal contacts, but the group of participants was subsequently expanded using snowball sampling and recruitment at a dementia carers support group. The sample consisted of people aged 18 and over who currently or recently had experienced caring responsibilities. They could live with the person with dementia or elsewhere. All were located in the North West region of England, UK.

A demographic questionnaire was devised to describe the sample. The interview schedule, previously piloted with two volunteers with a caring role, explored experiences of caring and information-seeking at different stages of their caring role, including at diagnosis (if received), within everyday life and at times of crisis. Participants were also asked how difficult information was to find, and if they had any unfulfilled information needs. The interview schedule was used to provide an initial focus on the key issues of concern to the study; however, questions were kept open ended, and the interviews were conducted with minimal researcher direction in relation to how interviewees chose to respond and to elaborate their answers, which is in line with the adopted interpretivist approach.

The interviews were carried out until saturation of the themes identified was reached (Saunders *et al.*, 2018). They were transcribed and analysed in NVivo, with themes first identified from individual interviews and then across the whole sample. A comparison of emerging themes was undertaken by the authors to bring different perspectives to the data interpretation. This was done through the researchers independently coding transcripts and comparing codes and themes. Any differences in coding were discussed and resolved through consensus.

Codes were grouped into themes and then reviewed and refined by rereading interview transcripts and field notes, thus ensuring a fit between the dataset and interpretation. Data interpretation was discussed in an ongoing dialog among the authors to further ensure that analysis reflected participants' experiences.

The study was granted ethics approval by the University where the research was carried out. Interviewees were informed that their participation in the study was entirely voluntary and had the right to withdraw from it at any time without providing a reason. Due to the potentially sensitive nature of some of the aspects emerging in the interviews, participants were encouraged to attend the interview accompanied by a support person if they chose to do so. Interviews would have been immediately interrupted if participants felt uneasy or became emotional and only resumed with their full agreement.

All data were fully anonymised. A pseudonym was allocated to each participant, and any potentially identifying descriptions within the transcripts were removed and replaced with broader equivalent terms.

3. Findings

The interviews took place between July and October 2019, with an average duration of 50 minutes (ranging from 20 minutes to 1 hour 20 minutes). There were 15 females and 5 males (Table 1); ages ranged from 45 to 92 years, with an average age of 65. Nine people had experience of caring for their spouse/partner, and the remaining 11 for their parents. The duration of caring ranged from six months to ten years.

[Insert Table 1 here]

Most participants caring for their spouse/partner were retired and older than the group caring for parents (mean age 78.8). Participants who were working (part/full-time) had a mean age of 52.9, and 10/11 were looking after parents, with the remaining participant caring for his spouse.

The interviews provided rich accounts of experiences of caring for people living with dementia (PLwD) and both the information needs arising from this and subsequent information seeking activities, and the extent to which needs were and were not met. The often lengthy interviews highlighted the difficult and emotional experiences of participants, and the demands of searching for information to support the needs of the PLwD and their own. In this paper we present the three main themes of: informational challenges, structural challenges and strategies that enable access to information (Table 2).

[Insert Table 2 here]

3.1. Informational challenges

3.1.1 "It is all down to me" (onus on carer)

This theme captures the common perception that day-to-day responsibilities for ensuring the wellbeing of the PLwD and accessing the information needed to undertake this role, fell on carers. This sense of being alone in caring grew over time as the dementia progressed, and was acutely felt when dealing with challenging behaviours, situations, or facing difficult decisions about future care. In parallel to this, carers worked through, and often struggled with, the emotional impacts of loss, changing roles, and impact on their own lives.

The level of engagement in information seeking varied within the sample. However, for the majority, there was a strong sense that responsibility for acquiring the information required had to be actively sought out by them:

> "...in the end you just have to find it out for yourself. I found that anyway, if you want to know anything you have to go out and find it, and you have got to fight for what you want as well I'm afraid." (Karen, PC)

Participants commonly used action verbs, such as 'fight' to emphasise their active role and the difficulties involved in information seeking.

3.1.2 Lack of focus on carers' information needs

Participants perceived that support services and information sources provided for dementia focused chiefly on the needs of PLwD with an under-emphasis on those of the carer. A good example of this was the diagnostic consultation. Some participants who were present remembered being offered an opportunity to ask questions for themselves, but many did not. Those that were given an opportunity often did not know what to ask, and at that point had little or no understanding of the impact the diagnosis was going to have on their lives:

> "I hadn't a clue what Alzheimer's was. So it was a case of walking out, didn't mention it. And then you have just got to find your own way through." (Helen, PC)

Participants often prioritised the information needs of the PLwD over their own. In the early days of caring many participants did not consider themselves to be carers, and this lack of identification hindered information seeking and focusing on their own needs. Their information needs and perspective differed from the PLwD's, (e.g., seeking information on what lies ahead; financial information; who to contact in an emergency; and when, and how to contact support services).

3.1.3 Being up against the limits of professionals' knowledge

Participants recounted numerous instances of seeking advice from professionals who were unable to provide solutions to their problems. A good example of this came from Irene, one of the oldest carers in our sample, struggling to care alone for her husband:

> "…Giles used to get up a lot and walk about in the night and that sort of things and so we went to the doctor. The doctor couldn't give me any advice on anything. What he did give me was some tablets…and the doctor said that there was nothing that they could do. It is just a progressive illness." (Irene, PC)

Negative experiences such as this were commonly reported and engendered a sense of abandonment and fatalism, with some participants describing feeling discouraged or uncertain about seeking help, and how this put the onus on them to live with problems, or to seek their own solutions. This could have the effect of forcing them to develop their information seeking skills:

> "...it feels like, as a family, you are left to your own devices. You are in that really difficult situation and it's up to you to try to solve it. It enhances your information gathering skills as

> a family. I do feel you are, to a big extent, abandoned and it's up to you to find things out." (Nina, SC)

3.1.4 Inconsistent informational support

3.1.4.1 Variation in the usefulness of information shared with them by professionals

Participants made a distinction between information sharing that they perceived as meaningful and of practical use, providing solutions to problems, and information sharing that lacked substance. The most useful information was stage appropriate and sensitive to family needs. Participants spoke about being given information that was not relevant or applicable to their needs:

> "…he (Admiral Nurse) was sort of helpful in a positive way, you always felt you made progress if you had a talk and that sort of thing. But a lot of the other times was sort of endless phone calls and things, but nothing came of it…" (Fred, PC)

Some participants were able to acquire more useful information via specialised carer-focussed support from Admiral Nurses, carers support organisations, and support groups. Others were reliant on generalised support from General Practitioners or social workers. Available support varied depending on the area where the participant lived, with a lack of support in rural areas noted:

> "So yeah, social services [in the town were] very good. GPs not so good in rural GP practices… they are not very helpful generally we found so we didn't use them much." (Elly, SC)

> "I didn't have any dementia specific nurse, there was nothing like that…" (Diane, PC)

3.1.4.2 Caring from a distance

SCs within the sample reported being kept out of the loop of information sharing. Geographical distance often meant that the information they received came via second-hand reports:

> "…it is harder as a carer-one-removed isn't it? Because actually you don't get to know the full picture. My Dad [PLwD] wouldn't always remember what he had been told. I think for my Mum if it wasn't important she didn't always pass it on….filtered from their perspective isn't it?" (Stella, SC)

The distance between the SCs and their families varied from one hour travel time (each way) to trips that would involve flights abroad. Accessing information across geographical and organisational boundaries was challenging; but cross-border information access was found to be bewildering, with participants describing not knowing how to start the process:

> "... we don't know what we need to know yet. And if they were in this country that would make it a 100 times easier, but the fact that they are not makes it 100 times worse" (Rose, SC)

Key information was withheld from the SCs within the sample, who were not informed about their relative's dementia diagnosis. This meant that they missed out on early-stage planning and important conversations:

> "…we never got the chance to have the discussions when she was still able to have them to know what she wanted." (Carrie, SC)

There was a strong sense that the SCs were standing on the outside, often unsure of what was happening, and at times unsure of their own rights to information. This was a sensitive issue with participants who had been unable to enact the Power of Attorney.

3.1.5 Unfulfilled information needs

Participants were asked if they struggled to find information. Accounts of unfulfilled information needs were common with topics such as, locating community services for housebound PLwD, information about care homes, carer support services, and information needed in emergency situations:

> "If somebody is housebound how do they get to a dentist? It seems improbable that they don't know about the service, but nobody signposted us to it." (Elly, SC)

Participants commonly described how the demands of caring or life in general left them with insufficient time and energy to find and read information. This meant that information needs could go unaddressed, and time sensitive questions remained unanswered:

> "…yeah I didn't get the information at the time [diagnosis]. But then you are sort of blindsided by having to deal with what's happening at the time, it sort of slips by and you don't eventually get it." (Olivia, PC)

3.2. Structural challenges

3.2.1 Burden of the information maze

A significant challenge in information seeking reported by most participants was in gaining an understanding of where to access information from the many and varied organisations providing support. One participant compared this to navigating a maze. Participants argued that this perceived lack of cohesive support added to their burden:

> "You see there's all different groups…if they would all come together, it's just a nightmare trying to find out one thing after another, after another. Some don't agree with this, and some don't agree with that. I don't know [said in a whisper]." (Marie, PC)

3.2.2 Burden of change

Participants described negative impacts when services they had come to rely on changed, or support structures were reorganised. This could impact the informational support they received. These changes were perceived as highly disruptive and burdensome, creating additional work to make sense of revised structures and services:

> "…they changed their goal post as well, and they say, right, you are not getting [this], these are all going to be amalgamated into one, and you have got to do this and you have got to do that. You are already coping with as much as you can cope with, without having to rejig what you are thinking about what is on offer." (Irene, PC)

The theme of change ran through participant accounts, with narratives about the closure of clinics, and services being cut. This was particularly difficult at points of transition. One participant shared that her Admiral Nurse was unavailable to provide informational support during the end of life of her mother.

3.3. Strategies that facilitate access to information

3.3.1 Openness

Many within the sample used a strategy of openness about their caring role as a key component of information seeking. Participants described this as a fruitful means of gaining informational support tailored to their needs:

> "…as soon as you say I am looking after someone with Alzheimer's they become more understanding and more helpful." (Karen, PC)

Some participants described being more reticent about sharing their needs in the early stages of their caring journey but had learnt that restraint did not unlock supportive information.

Openness was problematic in some contexts, with some of the carers reporting that they did not talk about their caring role at work due to concerns about possible negative impacts.

3.3.2 Proactivity

Proactive information gathering was the strategy employed most frequently by the carers within the sample. A key aspect of this strategy was a search for control, with information seeking undertaken to prepare for potential scenarios. A good example of this is work undertaken to prepare for potential care home admission, with some participants researching finances and care home options. This approach paid off when decision making had to be undertaken quickly:

> "…you are plunged into instant decisions that are going to completely transform your loved one's life, and if you haven't done your homework, and you don't know [which care home] might have a space that meets your standards and your preferences, you are stuck basically." (Pam, PC)

Proactive information seeking activities were prompted by professionals or other carers who gave insights into the next stage of caring; however, proactive advice was not consistently received across the sample.

3.3.3 Support networks

Participants benefited from informal and formal support networks to support information accrual. Some participants had very supportive families, working together to fulfil information needs. SCs within the sample described undertaking extensive information gathering to put in place support and to monitor the wellbeing of both parents (the PLwD and PC):

> "My mum was waking up wet, my dad needed to change the bedding and my parents were both very elderly…so I rang the Admiral Nurse and asked for some advice on pads and they told me about the different types. In the end we did manage to solve that problem and my mum was dry…" (Nina, SC)

Other participants were unable to pursue this strategy because family members had not stepped up or were busy with work/caring responsibilities.

Participants receiving regular contact from a professional spoke about valuing this constancy and the fact that the information sharing took place within the context of a trusted relationship. Sensitive and person-centred approaches to information sharing were valued, with accounts of sharing to support individual needs in ways that were respectful of the PLwD. Participants in receipt of this type of professional support felt well supported and perceived that the professional was looking out for their needs.

3.3.4 Peer-to-peer support

Participants highly valued information shared by people with lived experience of caring for PLwD and described how this helped to plug gaps in professional knowledge. This first-hand knowledge was perceived as grounded and practical, with insights coming from people who had gone through similar experiences and knew what worked for them:

> "It's alright somebody sitting in an office telling you 'oh you need to do so and so', but unless you have been in this situation, on paper they can tell you what to do, but I'd rather listen to the people who know what it is like, know how frustrating it is, and have already had that experience, and they will say don't bother with such and such." (Karen, PC)

Carer support groups were a key setting for peer-to-peer information sharing. However not all participants were aware of support groups, or able to access them.

3.3.5 Combining informational and emotional needs

A strong theme running through the interviews was the emotional impact of caring for a PLwD, and information needs for carers can be seen within this broader emotional context:

> "I think all information needs need to be seen in the light of the need for emotional support, and that goes always over and above basic information, because you can have fantastic information but if the person isn't supported, doesn't feel valued, then it won't do the job." (Pam, PC)

There were many examples of the importance of this intertwining of information and emotional needs, especially when seeking information about planning for the future and what lies ahead, or at times of crisis. At such times, the acknowledgment of emotional impacts was highly valued by participants.

In contrast to this, participants gave examples of interactions with professionals that were functional in nature, where the broader emotional impact on carers was not acknowledged, nor given time or space:

> "I used to sometimes get a home visit from the [GP] surgery, only if you asked, they never volunteered to come, ever. But they would come if you asked, whistle in, whistle out, five minutes later they were gone [laughter]." (Fred, PC)

4. Discussion

This study explored the information needs and the information seeking activities of a varied sample of primary, secondary and distance carers of PLwD. Gaps in information provision and consequent failure to have their information needs satisfied were experienced. The process of accruing information was complex and demanding (Berget *et al*., 2021), with participants describing time-consuming and intellectually and emotionally difficult endeavours to access relevant, timely, and appropriate information to fulfil their needs. These findings concur with Bressan *et al*. (2020) and Savolainen (2015).

The sample reported a lack of insight into carers' information needs by professionals or services. This need has been noted by previous studies, with calls for a greater focus on carer needs from an early stage (Dean *et al*., 2014; Department of Health, 2016), proactive information provision, and space given within interactions to answer questions (Dean *et al*., 2014; Tierney *et al*., 2019). Participants within our study struggled with balancing their own needs against those of the PLwD and required support to do so, as also reported by Bressan *et al*. (2020). The need for a broader rebalancing within services has been identified by previous studies, to ensure that carers receive equal attention and support (e.g., Robinson *et al*., 2015). Issues of access to information are broader than dementia caring roles, with Carers UK calling for all carers to be better supported and prepared for their role with easily accessible information (Carers UK, 2019). NICE (2020) guidelines state that carers have a right to information, and that information should be shared with them by local authorities and practitioners of health and social care.

Whilst all carers in the sample reported difficulties in accessing information, secondary carers providing care from a distance reported additional barriers. This study confirms key issues such as distance, accessing information across authority borders, lack of direct information provision, and questions around the legitimacy of their role created additional complexity in information seeking (White *et al*., 2020). Carers supporting PLwD living abroad faced huge challenges in accessing and making sense of information, and dealing with information potentially withheld by relatives (Czapka and Sagbakken, 2020). Guidance calls for greater awareness and recognition of diverse caring groups to enable services to acknowledge and address needs within this population (Department of Health and Social Care, 2020). A means to bridge distances should be sought, such as online access to resources and greater use of technology to foster inclusivity (e.g., Davies *et al*., 2020; White *et al*., 2020).

Participants within this study characterised their information-seeking journey predominantly as self-directed, and with a strong perception that the onus was on them to take responsibility to fulfil information needs, as found in previous studies (Parkinson *et al*., 2022; Peel and Harding, 2014). This study provided examples of strategies employed to shift the responsibility from individuals to a collective approach (Table 3). Sharing this information-seeking role within formal and informal networks can reduce the burden on individuals (Tierney *et al*., 2019; White *et al*., 2020) and the bridging of individual and community dimensions provides an opportunity to build resilience (Windle and Bennett, 2012). Approaches differed within our sample, with some participants benefitting from a whole family approach to information seeking. However, family resources and dynamics varied within the sample, and, whilst some participants preferred to be self-reliant in information seeking, for others this added to the burden. This finding emphasises the fact that approaches to reduce the information-seeking burden need to be informed by a holistic understanding of the range of individual circumstances to identify successful strategies.

This study adds further evidence to the importance of having early-stage contact with health or social care professionals to access information provision and signposting to services within trusted relationships (Hole and Harrison Dening, 2019; Maio *et al*., 2016; Stephan *et al*., 2018). The carers in our sample spoke about the value of sensitivity in information giving, taking account of the context of dementia, and the emotional impact of caring. They perceived information giving and emotional support to be intertwined, as described by Parkinson *et al*. (2022), as without this understanding it is known that information accrual can be stark, overwhelming and emotionally demanding (Maio *et al*., 2019; Sutcliffe *et al*., 2015). Emotional support from a trusted professional is perceived as vitally important (Hole and Harrison Dening, 2019). Information sharing combining practical, useful and meaningful support together with emotional support offers the potential to empower carers in what can be otherwise perceived as a powerless situation, as highlighted in previous research (Maio *et al*., 2019; Parkinson *et al*., 2022).

Access to supportive professionals undertaking a proactive role in information sharing varied within the sample, as also found in previous research (Hole and Harrison Dening, 2019; Peel and Harding, 2014; Tierney *et al*., 2019). Our findings suggest a need for the systematic provision of proactive information sharing at service level, rather than the present patchwork provision based on good practice in individual settings (Bunn *et al*., 2017). This systematic provision is of great importance to older caregivers more vulnerable to negative impacts of caring (Gridley *et al*., 2019). NICE (2020) guidelines recommend that practitioners should have the knowledge, time, and communication skills to provide carers with effective informational support.

This study offers further evidence of the need to address the interrelation of carers' information needs and those of the person they are caring for. It offers further support to the recognition that information seeking is vital in supporting the wellbeing of both PLwD and carers, and to the latter in their caring role (Bressan *et al*., 2020; Soong *et al*., 2020).

However, in accord with previous research, our findings demonstrate a gap between the information needed and what was accessed or provided (Bressan *et al*., 2020). Information seeking was constrained by factors which have been previously identified, such as limitations in scientific or professional knowledge about dementia (Aldridge and Harrison Dening, 2019), carers' stoical attitudes, or failure to perceive needs (De Poli *et al*., 2020). Information shared by professionals is of great importance, but failure to share at points of need can have negative impacts (Jurgens *et al*., 2012). Interactions are significant opportunities to build resilience in carers and, where specific solutions to problems cannot be identified, signposting to alternative sources of information is vital. A model of information giving that is proactive and supportive is, therefore, essential (Aldridge and Harrison Dening, 2019).

Participants in this study found that informal sharing of first-hand knowledge of caring for a PLwD helped to plug gaps in professional knowledge. Connections with other informal carers were highly regarded as enabling practical and empathetic information sharing, in agreement with Donnellan *et al*. (2017), Hole and Harrison Dening (2019) and West and Hogan (2020). However, lack of awareness of support groups, or access difficulties arising from the frailty of PLwD or, in the case of SCs, difficulties in accessing sessions taking place during the working week, prevented access for some. Carer guidance states that they should be provided with information about carers groups and forums (NICE 2020), and information about online support groups would enable greater access.

Another gap in information provision related to time-sensitive information, with some participants being unaware of key resources within requisite timescales. This gap highlights the requirement for proactive information sharing, as recommended by Bressan *et al*. (2020), Robinson *et al*. (2015), and Washington *et al*. (2011). In contrast to this, some participants who took the initiative to scope out future information needs, benefitted from enacting informed decision making when events dictated a rapid response (Stephan *et al*., 2018). Guidelines recommend that carers should be provided with timely information about the situation of the person they are caring for, in order to process the news, and prepare for the future (NICE 2020).

Participants also navigated a complicated 'maze' of support services, finding this process difficult to understand and laborious. In addition, a lack of information prevented access to local services, as also described by Morrisby *et al*. (2018). Participants' accounts of navigating a complex and disjointed system are mirrored in an earlier paper (Peel and Harding, 2014). Our findings add further evidence of the great need for the provision of a guide to local services, written in a clear, user-friendly way, describing what services are available, how and when to access them (Bressan *et al*., 2020; Carers UK, 2020; De Poli *et al*., 2020); a one-stop source where all information needs can be met (Sutcliffe *et al*., 2015), with professional support to facilitate navigation (Maio *et al*., 2019). Additional pressures arose from cuts and reorganisation of services at times of austerity, a finding seen in other studies (Hole and Harrison Dening, 2019; Maio *et al*., 2019; Moriarty *et al*., 2015). This required carers to navigate new structures and fall back on their own resources. The recent adult social care whitepaper (Department of Health and Social Care, 2021) puts the provision of information and advice as a core requisite in empowering carers, and outlines means to achieve this goal through accessible, local, and personalised information provision.

The findings of the study resonate with aspects of a number of the theoretical models mentioned in the introduction to this paper.

The role of emotions in information behaviour, particularly in relation to the acceptability and thus suitability of information that is not matched with emotional needs, was notable in our findings, with interviewees highlighting this important affective aspect of their information needs, and drawing attention to the fact that sometimes health professionals were not attuned to this. Also, what is threatening information for the person cared for may be also be threatening for the carer, emotionally in terms of their connection with the person they care for, and/or in terms of practical implications for their caring role. Lloyd's theoretical framework is likely to be useful in that she links her work on information landscapes with the need to approach information literacy in terms other than formal skills measurement approaches typical of the educational world, which may "narrow our understanding of the forms of information and the ways of knowing that contribute to the construction of information landscapes" (Lloyd and Hicks, 2021, p.1053).

The extent to which carers see themselves as part of what Chatman (1999) would term a "small world" would be interesting to explore further. In our study, interviewees spoke of the benefits of sharing information and experiences with others in a similar situation, and of the role of community in building resilience. To the extent that - as they take on, learn about and experience their role as carers - they perceive themselves as members of a coherent group of people in a similar situation and with similar needs to their own, and the extent to which they are thrust into an information environment that is both new to them and highly complex.

5. Conclusions and implications for future research

Whilst previous research has focussed on identifying specific needs and knowledge acquisition at cross-sections, a more holistic understanding of experiences is still under-explored. The research reported here, therefore, attempted to take into account broader contexts, diversity of experiences, and different caring roles e.g., primary and secondary carers, and in-situ and distance carers, and to explore information seeking across the caring trajectory and broader carer experiences.

5.1 Key findings

The key findings of the study can be summarised as follows:

- informal carers of people living with dementia have significant and ongoing information needs;
- there are gaps in provision and specifically for information tailored to individual needs;
- carers are a diverse group and research is needed to explore broad experiences and the impact of different caring roles on information seeking and acquisition;
- variations in informational support were experienced in different caring roles;
- information evaluation criteria used by carers include:
    - the extent to which information is perceived as emanating from a source with similar lived experience to that of the carer: there is a difference between information that might be factually correct but which is perceived to lack such experiential validation;
    - the extent to which information addresses emotional as well as cognitive needs, which is necessary in order to empower and enable carers;
- there is a need for carers with unmet information needs to develop meta-information seeking skills in the sense of:
    - realising when information is not going to be provided to them, and that the onus is on them proactively to seek it out;
    - realising that there may be alternative information sources (e.g. informal networks and peer-to-peer support) which might provide the information they require – in terms of being experientially valid, and/or addressing emotional aspects of their needs;
- a strategy of openness about their caring role can in some cases be a fruitful means to enable carers to gain informational support tailored to needs.

The study also found evidence of interactions between hindering and enabling factors – for example, a link between realisation by the carer that, in the face of inadequate informational support from professionals, the onus is on them to develop and apply their own information-seeking skills. As one participant noted: "it feels like, as a family, you are left to your own devices. You are in that really difficult situation and it's up to you to try to solve it. It enhances your information gathering skills as a family. I do feel you are, to a big extent, abandoned and it's up to you to find things out". Table 3 below summarises such factors in the form of 'barriers' and 'carer response'.

[Insert Table 3 here]

It is worth noting that there are three main typologies of issues linked to the overarching lack of information appropriate to meet carers' needs: problems arising from relationships with supporting healthcare professionals; problems with the information available and problems with the information needed. For each, carers have developed 'responses' which help them cope. However, although some of them have the potential to contribute toward the carer's longer term cognitive development (e.g. trying to develop better information gathering skills) and emotional stability (e.g. sharing the burden of information seeking with other family members), others are more ephemeral (e.g. devising strategies to make their needs known) and causes of additional uncertainty.

5.2 Implications for future research

The research was exploratory, based on a small sample of carers. As such, its findings are not generalisable, but rather suggestive of factors that may facilitate and hinder the effective acquisition of information by carers. The findings are indicative of the presence of these factors in the sample but not of their incidence in the sample as a whole or amongst any groupings within it.

Bearing in mind this caveat, this study highlighted the diversity of caring roles and identified significant challenges in accessing required information, and variations in access and informational support. Further research is needed to explore in greater depth experiences of distance carers and secondary carers.

Participants in our study were recruited from a carer support group and via personal contacts. This method enabled recruitment of carers who had benefited from accessing peer-to-peer support and information sharing, and others who had not done so, and highlighted the value of empathetic information exchange. Future research should broaden samples to include a greater diversity of experience, such as BAME and male carers. A focus on individual experiences is needed to make information provision accessible and sensitive to needs.

This study found that information seeking was a significant burden for the carers within our sample. Participants identified strategies employed to reduce this burden, such as support from formal or informal support networks. Further research is needed to find a range of strategies to support the diverse caring roles. The study confirmed barriers in accessing a range of information, such as information about services, and a lack of proactive information provision from services. Research is needed into how to translate these findings into carer-focused and proactive information provision by health and other support services.

It may also be useful in future research to follow up resonances between our findings and the theoretical frameworks discussed above to explore their potential explanatory power to help us better understand carers' information behaviour, and ways of empowering them individually and collectively to optimise their acquisition and use of information relevant to their needs.

5.3 Implications for carers and providers of information and support

Providers of information and support need to be aware of factors that may act as barriers to carers preventing them from acquiring information and support that is appropriate to their needs. They should be aware of differences between information which may be factually correct and logically appropriate in the mind of the provider – but which may, from the perspective of the carer, be insufficient for fulfilling their needs in terms of lacking experiential validity, and/or failing to address emotional in addition to cognitive aspects of their needs. Providers should be aware of the diversity of carers and proactively seek to acknowledge and address needs, such as, the provision of information specifically aimed at secondary and distance carers. An early stage contact with carers enables the development of supportive relationships for personalised information sharing.

When faced with unsatisfied information needs, carers need to be equipped with skills and strategies that can empower them to overcome barriers to acquiring information appropriate for satisfying their needs. For this they need to develop, and be helped to develop – as well as information-seeking skills - meta-information seeking skills in terms of (a) awareness that their unmet information needs could possibly be met by other means, (b) awareness that these means may include becoming proactive in terms of developing and applying new information-seeking skills. Such means also include being aware that informal as well as formal channels may be a source of information that might fulfil currently unmet needs in terms of its experiential validity and ability to address emotional needs.

6. Conclusion

This study explored the information-seeking experiences of a small sample of carers of PLwD from the North West of England and, whilst findings are not generalisable, they add further weight to previous calls for improvements in information provision and support. The inclusion of different carer characteristics increases the transferability of our findings. Information has the potential to empower carers in their caring role and in supporting their own needs. This study identified significant challenges and deficits in access, and key differences in the information needs of primary, secondary and distance carers. It is important that policy, practice, and research acknowledge the informational challenges and the need for information sharing to be undertaken with an understanding of the emotional needs of carers and their living circumstances. Within this context, information sharing and emotional support are intertwined, and practice should reflect this. The integration of professional and informal resources leading to the development of inclusive, easy-to-access and comprehensive resources which take into consideration the multi-layered nature of the carers’ role have the potential to improve resilience and enable carers to undertake their role more effectively.

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Table 1. Sample characteristics (in frequencies)

Gender	Male	5
	Female	15
Age	<50	2
	50-65	11
	>65	7
Marital status	Married/With partner	14
	Widowed	5
	Divorced	1
Education	Secondary education	3
	Post-secondary education	3
	Undergraduate and higher	9
	Vocational qualification	5
Employment	Working full time	6
	Working part time	4
	Retired	9
	Prefer not to say	1
Subjective health	Good	14
	Fair	6
Relationship with PLwD	Wife	4
	Husband	5
	Mother	7
	Father	3
	Mother and Father	1

Table 2. Qualitative analysis coding frame

First level codes (themes)	**Sub-themes**
Informational challenges	• “It is all down to me" (onus on carer) • Lack of focus on carers’ information needs • Being up against the limits of professionals’ knowledge • Inconsistent informational support o Variation in the usefulness of information shared with them by professionals o Caring from a distance • Unfulfilled information needs
Structural challenges	• Burden of the information maze • Burden of change
Strategies that facilitate access to information	• Openness • Proactivity • Support networks • Peer-to-peer support • Combining informational and Emotional needs

Table 3. Summary of carers' main barriers to information access and approaches to overcome them

OVERALL PROBLEM Lack of information appropriate to meet carers' needs (implication for researchers)	
BARRIERS (implications for information providers)	**CARER RESPONSE** (implications for carers)
Problems with supporting healthcare professionals	
Professionals providing support lack required knowledge	Realisation that the onus is on carer who has to be proactive
Professionals providing information may lack the skills to support carers	Realisation that some professionals are more supportive than others and try to focus attention on building relationships with them
Problems with information available	
Acquired information does not address emotional aspects of carers' needs	Need to develop better information gathering skills
Acquired information lacks "lived" experiential validity	Experientially-valid information may be available via networks/peer to peer support
Acquired information lacks focus on carers' needs and sufficient signposting to sources tailored to their needs	Need to device strategies to highlight their needs and those of the PLwD (e.g. openness)
Problems with information needed	
Changes/instability means information can become lacking or inappropriate to needs and information seeking can become more demanding	Need to form formal and informal support networks to share the information burden (e.g. family wide information seeking)
Fulfilling information needs is demanding for individual carers	
Information can be required at short notice	A strategy of proactive information seeking to enable greater preparedness when faced with rapidly changing circumstances
Information needs and barriers experienced by secondary and distance carers may not be recognised	Need to overcome distance and time barriers through accessing online information