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Article:

Sbaffi, L. orcid.org/0000-0003-4920-893X and Hargreaves, S. (2022) The information trust formation process for informal caregivers of people with dementia: a qualitative study. Journal of Documentation, 78 (2). pp. 302-319. ISSN 0022-0418

https://doi.org/10.1108/JD-01-2021-0014

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The information trust formation process for informal caregivers of people with dementia: a qualitative study

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Abstract

Purpose

This paper provides new insights on trust formation during information seeking processes of informal caregivers of people with dementia and identifies the sources of information deemed as trustworthy by caregivers.

Methodology

The study adopts a phenomenological qualitative approach in the form of in-depth, semi-structured interviews with a sample of 20 informal caregivers.

Findings

Caregivers trust sources that are perceived as authoritative and particularly value the information and advice provided by other caregivers. Trust in information can be divided into subjective and objective, but both are important precursors to the actual use of the information. The information available to caregivers is sufficient in quantity but inadequate in terms of ease of use, clarity and usefulness. Often, some key information needs remain unsatisfied due to the lack of timeliness, relevance and personalisation of the information.

Originality

This paper contributes to a more comprehensive prospective on caregivers' information trust formation processes, which takes into account both the characteristics of the information and caregivers' individual factors.

Practical implications

This paper provides recommendations for information and healthcare providers on how to improve communication with, and information relevance for informal caregivers of people with dementia.

Keywords: Dementia, Informal caregivers, Trust, Information sources, Information seeking behaviour, Information use

1. Introduction

In 2018, for the first time on record, people aged 65 and above outnumbered children under five years of age globally (United Nations, 2019). However, living longer comes at a price, in the form of more morbidities (Case and Deaton, 2017), as the ability to delay the aging process resulting in truly healthy living is yet to be mastered (Crimmins and Zhang, 2019). In 2012, the World Health Organization declared dementia as a public health priority and “the leading cause of dependency (i.e. need for care) and disability among older persons in both high and low-medium income countries” (World Health Organization, 2012, p.8). This increase in the number of people that will develop disability and dependence through dementia translates in a comparable increase in the number of caregivers needed to look after them.

This paper adopts the definition of informal caregivers provided by Chiao et al. (2015, p.341): “Informal caregivers are non-professional people who provide care in a home setting for another person and who usually deliver care to people with disabilities and people with dementia”. This typology of caregivers is mostly composed of family members, either living with the patient or in a different household, who share an emotional bond with the relative living with dementia (hereafter RLwD).

The role of informal caregivers is multi-layered and challenging, as they have to balance the impact of dementia on their family while fulfilling the needs of their care recipients (Cabote et al., 2015). In spite of the recognised importance of caregivers, research shows that they still report many unmet needs when it comes to accessing and securing trustworthy information (e.g. Myrick, 2017; Mason et al., 2020). Despite the increasing number of sources providing information and support to informal caregivers of RLwD, they can feel inadequately informed and ill prepared to fulfil their role (Allen et al., 2020). Although the ubiquitous accessibility of the Internet has promoted online health resources to the main source of information for the majority of people (e.g. Shaffer et al., 2018), there is still value in information received through other means of communication, such as word of mouth (Gresham et al., 2018) and printed material (Heinrich et al., 2016). However, what information do caregivers trust and why? Research on this topic is sparse and, because of the perceived risk of ‘getting it wrong’ associated with the information identified, it shows that caregivers struggle to identify and use trustworthy information (Hussein et al., 2018).

For informal caregivers, accessing trustworthy information is crucial because they experience the additional pressure of doing the right thing by their loved ones, as they are often required to act on their behalf (Pecanac et al., 2018). Information needs of caregivers are different from those of the RLwD (Martzoukou and Abdi, 2017), but this issue becomes even more important as dementia progresses and the RLwD becomes more reliant on the caregiver to make choices and decisions (Taylor, 2016).

In addition, and linked to the understudied problem of trust, other issues such as quantity, personalisation and timeliness of the information appear to hinder the fulfilment of caregivers’ information needs. Caregivers’ emotional status can change rapidly because it is highly dependent on that of the RLwD; with the progression of the condition, the quality of life of both RLwD and caregiver can deteriorate suddenly and it is often at these times of change that caregivers need most support and information. Werner et al. (2017) have shown how caregivers can face problems with both information underload (i.e. insufficient or unavailable information) and overload (i.e. excessive amount of information). Rutkowski et al. (2020) concluded that the problem with unmet information needs is not due to lack of information available, but to a “misalignment between information products and caregivers’ information behaviour” (p.4), which can vary in time and context.

The need for individualised information has been a long-standing one for informal caregivers (e.g. Washington et al., 2011). A recent systematic review by Bressan et al. (2020) on needs of caregivers of patients with dementia concluded that "it is crucial for family caregivers to receive timely and tailored information, especially in the early stages of dementia and during the whole disease trajectory." (p.1956). The fact that the information is available 'somewhere' is not enough for caregivers, because every situation is different in terms of stage of disease, severity of the condition, support network, geographical location, etc. In this respect, studies in Australia have identified that one third of families who care for people with dementia do not use dementia services because of lack of effective directions to the accessing of services (Stirling et al., 2010; Xiao et al., 2014). Söderström et al. (2016) reported how a more trustworthy relationship can be built between patients and healthcare providers (HCPs) via clear and satisfying communications. It appears, however, that the problem of the gap in individualised information and resources is widespread and far from being solved and is also deeply linked to the issue of timeliness of the information.

Research has shown that there are 'events' in the life of caregivers of RLwD which require the acquisition of more and/or specific information. The time of diagnosis is one such event (e.g. Ducharme et al., 2014; Lee et al., 2019; Longstreth et al., 2020) and consensus has not been reached on whether caregivers seek, and are able to obtain, sufficient information at this time. The complex nature of dementia, both in terms of prognosis and patients' health deterioration rates, leads to varied experiences among caregivers. The vast array of symptoms manifesting at different points in time renders the identification and adoption of relevant information very challenging. A study on eHealth interventions to support dementia caregivers (Christie et al., 2019) reported how only a small proportion of such initiatives was available at the right time in the caregivers' journey. Leslie et al. (2020), in a Canadian study conducted with family caregivers, revealed that timeliness of information and communications with HCPs is a key dimension of effective caregiving. The emotional status of caregivers at any specific point in time is also crucial because it influences the ways in which they seek and retrieve information (Savolainen, 2015).

Many studies have identified trust as a key factor influencing the health information seeking process (e.g. Diviani et al., 2020; Jackson et al., 2019; Chen et al., 2018). Specifically, Rowley et al. (2015) developed the Trust in Online Health Information scale featuring constructs such as brand, content, credibility, ease of use, recommendation, style, usefulness and verification. In a later study (Rowley et al., 2017), these authors concluded that the factors most influencing trust formation are content/credibility (objectivity, impartiality and accuracy of the information), brand (well recognised 'name'), ease of use (how easy and fast it is to find the information), recommendation (from family and friends) and familiarity (previous positive experience with the same sources). A systematic literature review by Sbaffi and Rowley (2017) also included the concept of authority (well recognised and knowledgeable author/creator of the information) among the main factors influencing health information trust judgements.

As summarised by Harland and Bath (2008) in their critical review, two main paradigms have been identified in information science to help improve information provision to caregivers of RLwD: system-centred and user-centred approaches; the first (e.g. Information Transmission Model) make assumptions on the types of information that caregivers require, the way and timing in which it should be provided, but they only view caregivers as a homogenous group, without considering individual preferences. In contrast, user-centred approaches (e.g. Information Seeking Behaviour Model) recognise the uniqueness of each caregiver and that information needs are subjective and dependent on many factors. Such latter approaches are, hence, more 'granular' and effective in addressing caregivers' information needs. Nevertheless, system-centred approaches have still the benefit of attempting to optimise strategies for delivering the best information overall, which is particularly useful in current western societies where the amount of information available can easily become overwhelming and difficult to discriminate (Kim, 2020). In other words, such approaches are still useful to lay ground, general rules to what represents trustworthy information. In light of the above reported complexity of trust formation processes, this study aimed to identify common behavioural traits that could be used as the baseline for a new approach to trustworthy information provision to caregivers of RLwD, while taking into consideration caregivers' unique and deeply personal experiences. Therefore, the research questions that the study sets out to answer are:

RQ1. What are the sources of information that informal caregivers of RLwD perceive as trustworthy?

RQ2. How do informal caregivers of RLwD judge the quality and trustworthiness of the information?

2. Methodology

2.1 Research Design

A phenomenological approach was applied to this study with the aim to gain a deeper understanding of the participants' life and individual caring circumstances (Smith and Shinebourne, 2012). This approach is usually adopted with small and fairly homogeneous samples and attempts to identify both differences and similarities of experiences. Therefore, in-depth, semi-structured interviews were carried out on a sample of 20 informal caregivers from different age groups and genders and covering a range of caring responsibilities. Initial participants were recruited via researchers' personal contacts, but subsequently the recruiting strategy developed into snowball sampling. The interviews were carried out until saturation of the themes identified was reached (Saunders et al., 2017) and particular attention was paid to the prevalence of the themes and their relevance to the research questions. After an initial short demographic questionnaire, participants were asked to describe their experience of caregivers and their main responsibilities, and then to describe their information seeking journey at different stages of their caring role, including at diagnosis (if received), at times of crisis, and in everyday life. All interviews were then manually transcribed and analysed following the principles of interpretative phenomenological analysis, according to which themes were first extracted from each interview and then from the whole sample. Both authors worked on comparing the themes emerging in the group to bring different perspectives to the interpretation of the data. All transcripts were checked for any identifying feature which might have compromised the anonymity of the participants and a pseudonym was allocated to each of them. The study was granted ethics approval by the University of Sheffield.

2.2 Participants

People aged 18 and over who currently or recently had experienced caring responsibilities at the time of the interviews were invited to participate in the study. Prospective participants could live with the RLwD (primary caregivers) or elsewhere (secondary caregivers). All participants were located in the North West region of England, UK.

3. Results

3.1 Overview

The interviews, conducted between July and October 2019, lasted between 20 minutes and 1 hour and 25 minutes (mean=50 minutes). Specifically, 15 women and five men ranging from 45 to 92 years of age (mean=65) looking after either a spouse/partner or a parent participated to the research (Table 1) and their caregiving experience ranged from 6 months to 10 years.

[Table I here]

Nine participants were already retired at the time of the interviews and the mean age for this group was 78.8 years; all of them were caring or had cared for a spouse mostly on their own; ten were in either part time or full time work (mean age=52.9) and looked after a parent, except for one who cared for his wife. Finally, 14 respondents claimed to be in good health, while the remaining six, five women and one man, reported to be in fair health.

3.2 Analysis of the themes

The interpretative phenomenological analysis of the interviews returned three main themes and seven sub-themes, which are discussed below.

[Table II here]

3.2.1 Theme 1: Assumptions about information sources

The participants described the sources of information they accessed in order to care for both their needs and those of their RLwD, and the processes they undertook to assess the quality of these sources. It was evident from participants' accounts that there were differences in how much they questioned the trustworthiness of sources and the information they received. The following sub-themes describe the assumptions made by participants allowing them to make such judgements on trust.

Subtheme 1a: Trust in official websites

A short-hand method of accessing trustworthy information (both online and offline) used by caregivers was to access information from sources perceived as credible. Within the online context, participants discussed how they accessed information from Internet sites considered trustworthy, commonly describing this in terms of legitimacy, expertise, relevant and reliable information, and organisations perceived to be acting in the best interests of people. This classification included sites provided by official organisations, such as local councils or the National Health Service (NHS), and specialist dementia organisations, such as Dementia UK and the Alzheimer's Society. Many of the participants limited searches solely to these sites, because they felt confident about the veracity and quality of the information they provide:

> "With the AS [Alzheimer's Society] because it's the funded charity that it is, I felt fairly confident with them, and then the NHS website I see that as a trusted source of information and so I felt fairly confident with both those sources." (Carrie)
>
> "Well, it is the NHS, you have got to think that that has been reviewed and carefully put together. And Age UK, it's their raison d'etre, isn't it really?" (Quentin)

The careful choice of website reflected the responsibility placed on caregivers to ensure that they accessed reliable information as this informed the care they delivered to their RLwD. In the following quotation Thomas, who has been caring for his wife affected by early onset dementia, explained the importance of accessing appropriate online resources that 'make sense' to him:

> "If I looked something up I remember going only to NHS websites because this is a serious matter, not like looking up who won the world cup in 1950, you need to make sure that what you read makes sense."

In addition to online resources specific to dementia, most participants accessed local council websites for practical information about services:

> "The council website, because you got to know about services, and the AN [Admiral Nurses], and practical thing like who is your parents' GP." (Olivia)

However some participants identified limitations to the information provided by these trustworthy official organisations, with Karen (a former nurse caring for her father) expressing the view that the support and services available were sparse and difficult to navigate:

> "…in the end you just have to find it [information] 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."

This last comment reflects the view shared among caregivers that information, even when authoritative and reliable, can still be difficult to locate and access.

Subtheme 1b: Trust in professionals

Participants reported varied experiences with respect to healthcare providers (HCPs). Some believed that the information they received from HCPs was trustworthy as it came from a legitimate source:

> "You can't really trust any information that you find on the Internet. It's just putting your trust in what the professionals believe, at the end of the day." (Olivia)

Participants who had regular contact with the same HCP described how relationships developed in time and information sharing took place within this trusted context:

> "I think it was the information that was brought to us by Jack [Admiral Nurse] in conversations. He told us how to access some services, he also rang some people up for us, so that level of service was really fantastic for us. My dad trusted him. He was from [the same county as father], he talked in a very matter-of-fact way and that personal relationship was really important. And we knew that if something needed doing, then he would get it done." (Nina)

In contrast, some participants lost faith in HCPs who they felt had not supported them enough:

> "He [husband] used to get up a lot and walk about in the night and that sort of thing and so we went to the doctors. The doctor couldn't give me any advice on anything on what to do. What he did give me was just some tablets." (Irene)

This is mirrored by Elly's recount:

> "GPs not so good…maybe it's just my experience of them…it's all pull your socks up and, you know, they are not very helpful generally we found so we didn't use them much only use them to get updated diagnosis and assessments."

In many situations, participants reported that general practitioners (GPs) played an inadequate support role and had deficits in their knowledge of dementia:

> “She [mother] was on morphine, which I don’t think it’s necessarily a good thing. In addition, I don’t think doctors always know what to do with people with dementia.” (Olivia)

Participants also described a tendency by GPs to be reactive to situations rather than offer proactive advice. Some of the participants felt that their GP had not properly informed them about the health of their RLwD, attributing this perceived reticence to an unwillingness to talk openly about the situation of their relative, either to avoid upset, or because the presence of the RLwD hindered an open discussion:

> “I think they [GPs] don’t want to upset people. I think difficult conversations are difficult conversations and they are human and time pressures on the NHS and upset him of course. Because if I am sitting there with him, he is not going to want to say you know this could happen and this could happen.” (Diana)

In one extreme case, Karen described her upset when trying and failing to get support and worrying about her mother coming to harm:

> “They got this social worker, oh don’t even get me started, was not even worth answering the phone in the first place, never mind coming and visiting, she was useless. She didn’t do anything. Eventually I put an official complaint in because she was so unhelpful. She wasn’t giving me any information, she was just like ‘oh well we will come and assess her. We will come in two weeks and we will do another assessment’. Assessment after assessment after assessment.”

Caregivers’ accounts highlighted communication and relational problems with HCPs, which are common not just in diagnoses of dementia, but in many other long term and chronic conditions (e.g. Maneze et al., 2019).

3.2.2 Theme 2: Checks and balances

When looking for information, caregivers applied both common sense and caution, exercising their own judgment in assessing the reliability and trustworthiness of the information. This approach was considered to be particularly important when searching for emotionally demanding topics such as disease progression and end of life care.

Subtheme 2a: Searching for sensitive topics

For participants seeking information on sensitive topics or medical issues, such as medication, co-morbidities and disease prognosis, the need to access reliable information from trustworthy sources was considered to be particularly important. Some of the participants who had searched more widely for information described negative emotional impacts from accessing sources which provided more information than they were happy to receive:

> “You frighten yourself silly with some of it. I mean, I hope I’m not stupid and I do know the outlook, the outcome, but because we have got this heart failure now I just think that, I can’t see him having much longer than a year.” (Helen)

The necessity to protect themselves from reading too much information was a key motive for limiting online searches to official sites which were perceived as more sensitive to caregivers’ needs. Some participants did not view the Internet as a suitable source for these types of searches, and instead sought this information in face-to-face conversations with trusted people:

> "I think it is the personal contact with all these people [ANs, support group members, etc.], they are eager to help. A lot of the times these days people aren't given the time. You know, you go to the doctors and you have 10 minutes. And I said to him [GP] the other day, 'I've only got 10 minutes', but he said yes, but if you think it is important I make the time." (Angus)

Personal interactions are crucial to caregivers, who deeply value the time and effort that other people dedicate to listening to them. They particularly appreciate patience and constructive support, which make them feeling valued as individuals (Erdelez et al., 2019).

Subtheme 2b: Commercial sites

Participants were particularly cautious about commercial websites, viewed as untrustworthy because the information available is motivated by profit, rather than genuine support. This view was informed by visiting websites offering paid-for products rather than free of charge support services. Caregivers were wary and highly critical of sites and organisations that they felt to be seeking to take advantage of their RLwD:

> "I think the thing that's easiest to find is out is anything that's commercial […]. The difficult things to find are the things that don't charge money, which cost the state money, are much more difficult to find especially with all the cuts. So the commercialisation of care." (Elly)
>
> "Yes, I wanted a kind of authoritative source, because there is a lot of hoodwinking of older people in terms of support services, because I've been through this both with my dad and my mum, hearing aid that you don't need, that are massively expensive. So I think you as a carer need to know that information sources are kind of quality assured, verified." (Diane)

Other caregivers who accessed the Internet spoke about the large amounts of unverified and for-profit sources of information that they encountered in their information seeking journey which left them feeling frustrated and dissatisfied.

3.2.3 Theme 3: Information 'management'

The caregivers described an ongoing process of gathering information to make sense of what was happening to their RLwD, and to determine any actions that needed to be undertaken. This ongoing process of information 'management' was usually achieved by 'navigating' their way through the information and services available and relying on their own instincts.

The task of information management was a laborious process, with accounts of seeking information from numerous organisations and services, in systems that were commonly perceived as both difficult to understand and disjointed. Failed queries often led to participants take on finding information for themselves.

Subtheme 3a: Filtering information

It was evident from participants' explanations that information is not accepted at face value, but rather there is a filtering process to assess value and discard information that does not make sense to them:

> "I think probably I just ignored any rubbish advice because I do it my way". (Karen)
>
> "People advised me to lock the door because she [mother] would keep going wondering. Just lock the door, lock her in. Which I didn't think was safe because it is not good locking someone in the house, she hadn't got the key to get out if there's a fire or anything. And

> that was from the social worker! So some advice that you got from the social worker was just like, really, are you qualified to say that?” (Diane)

The action of having to filter information, although reported by most participants as being at the heart of their information seeking strategies, has also an associated element of stress, due to the need to rely on one’s own judgement. Some participants, reported how they did not really receive any advice, nor suggestions on sources of health information from their healthcare providers, but they would have actually welcomed this option (Tonsaker et al., 2017).

Subtheme 3b: Trusting what ‘feels right’

Caregivers make choices based on their instincts for what is trustworthy, following the idea that some things ‘ring’ true and others do not. For Jane, this assessment was based on a gut feeling of what she felt was right for her RLwD:

> “Well that’s it you see, you just have to trust it. It’s a feeling if somethings not right, if it is not right. I was quite comfortable really with the treatment he got.”

Another key method of information assessment commonly used by participants was to compare the presentation of dementia described in sources with the symptoms shown by their RLwD. Gill, for example, described how she used this measure to assess the trustworthiness of a book, in parallel to checking the qualifications of the author:

> “You don’t know that you can trust it other than it was written by someone that looking around she had a lot of experience, she had been a doctor, so you assume that you know what they are talking about and the way it was written it was exactly as my dad is with some of the things, I mean he isn’t aggressive but he does have hallucinations and things like that. And I mean it just, and it was obvious that that was how we should deal with things.”

This matched her experience, giving her the confidence to apply the techniques presented in the book. This concept of trusting what feels right resulted in individual practices in information seeking. In this respect, many of the caregivers expressed a preference for face-to-face interactions and Fred described a laborious information seeking process about repeat prescriptions because of his mistrust of technology:

> “Well I suppose you could have done it over the computer. I used to go to the surgery because they used to give you a whole sheet of papers [repeat prescriptions] of different things on it, and you had to put a tick on what you wanted and take it to the surgery who then sent it up to the pharmacist and you had to go and collect them. Well I didn’t mind doing that because it is my distrust of all these modern gadgets and if I want to go and ask something I can go an ask somebody.”

Another example of ‘in person’ information seeking was about care home admissions, a difficult and important decision to make when the dementia condition progresses to the point of requiring full time professional assistance. In this instance, caregivers did not trust the views of others and emphasised the vital importance of undertaking visits to make the right choice for their RLwD:

> “We always went to see what they were like first. He never went into where we hadn’t been to look round, and we looked round about four [care homes]. To me, the only one that was suitable in the end was the one that he went into.” (Irene)

For many caregivers, their role did not just cover functional aspects but, because of their strong affective bond with the RLwD, it also had a protective aspect requiring them to act as custodians of the patient's wellbeing.

Subtheme 3c: Lived experience

Recommendations from others who had first-hand experience of caring for a RLwD (i.e. lived experience) were considered to be particularly valuable and trustworthy by caregivers. In the following quotations Marie and Thomas explain how confident they felt about the information provided by fellow carers because they knew it had already been quality checked via first-hand experience:

> "If I had not known [friend at support group] then I would not have got all the phone numbers that she had, but she had been looking after her mum for years and years and over time had picked up loads of information. And like I say she gave me a hand written list, everything on, and don't bother with them, don't phone them you will get no help there. And it's those sort of things that help more than anything else." (Marie)

> "It's all right somebody sitting in an office telling you, oh you need to do so and so, but unless you have been in this situation, yes 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 so and so, such and such." (Thomas)

Caregivers attending a weekly support group spoke about how much they valued being able to talk to other carers and seek answers to questions.

> "I ask the ladies here [support group], the carers here because to be honest they are the font of knowledge, you know and they point me in the right direction." (Stella)

This peer-to-peer communication functions not only as a means for trustworthy information exchange, but as a reassurance that caregivers are doing the right thing, as others before them have done the same and, in doing so, benefitted the RLwD.

4. Discussion

This section aims to answer the research questions set at the beginning of the research project and to offer a contextual framework leading to trust formation and information use.

4.1 What are the sources of information that informal caregivers perceive as trustworthy?

Caregivers' need for and acquisition of information varied from scattered and generic to detailed and personalised. In many cases, they follow their instincts and exercise their own judgements with respect to what is deemed trustworthy based on common knowledge. For example, they agree that well known websites such as the NHS, Dementia.co.uk and Alzheimer's Society can be considered reliable sources of information and caregivers have usually known about them even before their RLwD's diagnosis. Commercial and privately-owned sites are to be accessed with cautions or discarded altogether, as their motives are viewed as predatory; this is in agreement with Seckler et al. (2015), who concluded that health sites focussing on the sale or advertising of products are viewed as untrustworthy.

Caregivers' relationship with HCPs can be difficult. While, on the one hand, such a relationship is positive and nurturing with professional caregivers and support services (e.g. Admiral Nurses) with whom caregivers can establish a connection over time, on the other hand encounters with GPs and doctors have been less satisfactory, with caregivers reporting varying degrees of disappointment due to poor GPs' engagement and willingness to fully explain the condition, its consequences and support available. This is, in some ways, similar to the findings reported by Maneze et al. (2019), who highlighted how inconsistent information not targeted to the needs of individuals negatively impacted their ability to self-manage diabetes. Although in the present paper an altogether different medical condition is been discussed, Maneze et al.'s message about doctors needing "time to provide simple explanations and assisting patients in navigating reliable web resources is becoming a vital role of healthcare professionals to reduce knowledge gaps" (p.2) remains valid and applicable to dementia patients and caregivers. In fact it has been demonstrated by Söderström et al. (2016) that improving communications between patients and doctors can lead to higher patient's perceived trust in healthcare.

Past research has reported on the positive effect on caregivers' quality of life deriving from peer to peer support groups (e.g. Chappell et al., 2017), but this study has gone a step further and shown how caregivers place their full trust in the information provided by people in their same situation. Other, more experienced caregivers, would have gone through similar stages and faced similar needs, particularly if living in the same geographical area, therefore relying on this kind of first-hand information is particularly useful for less experienced caregivers. Studies by Erdelez et al. (2019) and Balog et al. (2020) have also shown how the experience and advice of peer caregivers is highly valued.

As Peterson et al. (2016) observed, and as also found in this study, caregivers go through phases of denial, particularly at the time of the diagnosis, which affects negatively their ability to seek and identify relevant information. Unsurprisingly, in the early stages of caring they do not deem it necessary to ask questions about themselves and their role in the treatment and management of their loved one's condition but, in time, it becomes clear to most of them that they too need support. Knowing that other people go through similar situations promotes a sense of community in caregivers and prevents, or at least controls, feelings of isolation and helplessness.

Over time caregivers build up support networks to fulfil information needs, but this process is very personal and depending on available resources, individual preferences, and support needs. Experiences differ, from caregivers feeling that their information needs are met to others describing a difficult and arduous process undertaken to fulfil them, some of which remain unmet, often due to lack of personalisation (Maneze et al., 2019; Alzougool et al., 2017). For all caregivers there is a high emotional and physical cost to caring, as they seek to fulfil information needs whilst also negotiating the loss of their loved-one, and attempting to weigh their own needs against those of their relative.

4.2 How do informal caregivers judge the quality and trustworthiness of the information?

In some instances, the information received both at diagnosis and later on during the progression of the condition could be overwhelming in quantity as well as confusing in quality. Caregivers experience frustration and crave simplicity and focus. Iribarren et al. (2019) reached the same conclusion and stressed the importance of identifying specific information needs. The Internet is a well-used channel, particularly by caregivers with better technological proficiency, but it is not the only one; for example, books written by authoritative authors are still considered valuable (e.g. Heinrich et al., 2016).

It emerged, in fact, that caregivers trust two specific typologies of information above others: a) that provided by other caregivers and people with past caring experience. Caregivers value the opinion and advice of people who have already been in that situation and understand it first-hand. This form of social influence appears to enhance people's resilience and coping mechanisms (Teahan et al., 2018); b) well recognised government channels such as the NHS, local council websites and national dementia organisations. What attracts caregivers to these resources is their documented and long history of undisputed authority.

Peterson et al. (2016) made a clear distinction between medical (i.e. condition-specific) and caregiving information; however, the results of this study show how caregivers tend not to make this differentiation as timing of either one is far more crucial. The timeliness of the information has emerged from most of the interviewees as significantly lacking in their experience as information seekers. Although this is not directly related to trust in information, it begs the question of whether the ability to find the right information at the right time would contribute to build trust in what information is either actively retrieved or passively obtained. This aspect does not only concern information, but it relates to other forms of support and services that are available to caregivers (Ducharme et al., 2014; Prusaczyk et al., 2019), hence permeating most of their daily life. This is a worrisome result confirming that the situation has not really improved for people who are now entering their role as caregivers.

Returning to the argument about HCPs, this study revealed that some caregivers are poorly informed about their loved one's dementia diagnosis. Communication of information also includes appropriate information by HCPs that matches a patient's level of understanding in a stepwise format and in a timely fashion starting from the time of the diagnosis (Sakai et al., 2019; Soni and Freeman, 2018). This study showed, however, that, when diagnosed, some patients and their caregivers are provided with limited or no information about the condition, its course and treatment options. It is debatable whether providing information at that time would be effective or not, as people might not be prepared to accept a dementia diagnosis immediately. While it is important to stress that dementia is a condition without cure, it is equally important to build hope and positivity at the time of delivering bad news to patients to help them develop both physical and emotional strength and resilience (Choe et al., 2019).

The distrust in HCPs is mainly due to their inadequacy to provide emotional and practical advice to the patients and their caregivers, but also to their reticence to dwell too much on details of a life-limiting condition. Bailey et al. (2019) also stated that delivering a diagnosis of dementia is a challenging task for which doctors should be provided with evidence-based training and supervision to prepare them for these emotionally taxing situations.

In conclusion, trusting information usually depends on multiple and interconnected factors (e.g. Sbaffi and Rowley, 2017), primarily authority. In this study, respondents have expressed discomfort and frustration when faced with too much information, either received or self-procured and rely only on a few selected resources which would be well known even to people unaffected by dementia, as seen in the previous section. Caregivers have neither the time nor, often, the will to peruse large quantities of information, which tends to increase their anxiety (Khaleel et al., 2020), and this is also another reason why the advice of other caregivers is so highly reputed.

4.3 Caregivers' information trust formation process…or more than that?

One of the most interesting findings of this study is that trust in information has distinctive connotations for caregivers, and is a concept which encapsulates two intertwined aspects: *objective* *trust* (the information is accurate and authoritative and not factually misleading) and *subjective trust* (the information is useful in terms of being sufficiently personalised/emotionally acceptable/balanced/intelligible). Arguably, a piece of information might be trusted in the sense of being authoritative etc., but deemed not useful if its emotional impact would be unacceptable, or if it is accurate but not sufficiently personalised to the caregiver's specific needs at a particular point in time. Trust in information is, therefore, not the ultimate goal for caregivers, but a means to reach information acceptance. Indeed, the ultimate purpose of information is to be 'accepted' and hence likely to be used/adopted. Figure 1 shows a diagrammatic representation of the process followed by caregivers when selecting, trusting and, ultimately, accepting, information.

[Figure 1 here]

This theoretical vision of trust formation draws its foundations from Dervin's Sense-Making framework (Dervin, 2015), but it also includes aspects of system-centred paradigms, which aim to "optimise strategies for delivering the best information, as decided by the authoritative information transmitter" (Harland and Bath, 2008, p.468). The interpretation of the findings through the lens of the sense-making framework came as a natural progression from the analysis of caregivers' words who, in numerous occasions throughout the interview stage, mentioned the need for and importance of 'making sense' of information in the context of their own experience. In general terms, sense-making suggests that people use their own approaches and principles to make sense of the world; however, in particular situations or at specific points in time, people may experience a gap in their knowledge, when their intrinsic sense making fails them, which stimulates information-seeking processes to bridge such gap and reach the outcome (acceptance and use). In the context of this study, caregivers are exposed to a variety of information sources, each with an associated essential level of credibility and authority (left side of diagram in figure 1). In everyday circumstances, caregivers tend to use a range of factors to assess the trustworthiness of the information, including the recognised reputation of a source, the living experience of others in similar situations and their own judgement. This can be defined as 'objective trust', which is formed on well-established criteria for assessing the quality of the information. In this respect, it is interesting to note how the lived experiences of other, often more practised, caregivers, is considered as trustworthy as the information and advice provided by healthcare professionals and national dementia organisations, as it offers a form of evidence-based information and advice which has already been 'tested' by other people. Throughout their journey as caregivers, particularly at moments of change, which demand a higher than normal emotional investment, like the time of diagnosis, a drastic deterioration in the RLwD's condition, or end of life care, people's own sense-making (or, in other words, own intuition and judgement) of what information is appropriate/acceptable becomes unsteady and additional factors (caregiver related factors in figure 1) come into play in helping them decide what information to trust (subjective trust) and, ultimately, to use. These two forms of trust are closely dependent on each other and both appear to affect caregivers' decision to accept and use the information.

The complex setting in which caregivers dwell is reflected in the equally complex process leading to the selection and use of trustworthy information and, as at today, existing models of information seeking behaviour, whether system-centred or user-centred, are not sufficient for describing characteristics specifically connected with the various needs of people, not just in caregiving roles, but in more general terms (Berget et al., 2020). Therefore, a more integrated model taking into account both general and individual aspects of information seeking behaviour with the aim to offer tangible solutions, is required. This paper offers an attempt at contextualising the information journey that caregivers of RLwD embark upon at different times and in different circumstances through the application of both system- and user-centred paradigms' key principles.

4.4 Practice Implications

The following set of recommendations is primarily directed at local health authorities, local councils and national dementia associations as they are the first and main port of call for many caregivers seeking information.

- It is important for HCPs to establish and maintain a positive and supportive relationship with caregivers and their RLwD from an early start to stimulate a sense of security and being 'looked after' by a knowledgeable source, which, in time, could help limit feelings of helplessness and frustration. In this respect:
    - The time of diagnosis is important to share key, basic information about the condition and immediate care, but it should be followed up by a separate appointment with the main RLwD's caregiver and/or other family members to guide them through practicalities, and offer advice and emotional support.
    - At diagnosis, HCPs should dedicate more time to understand the information needs of the patient and caregiver in front of them and adjust support and advice to their emotional status at that time. Additional training should be provided to HCPs to navigate these situations.
- There is no urgent scope for the creation of new dementia information and support resources. However, existing information should to be better organised, more clearly signposted and updated regularly. All local council websites should offer a space dedicated to dementia services available in the area in a clear layout. Most of them already have this, but the information is difficult to locate and navigate.
- The emotional status of caregivers is as important as that of the RLwD and a crucial element to consider when delivering, presenting or revising dementia information resources.
- The national resources already available should provide dedicated sections with information related to common 'life events' and what to do in such circumstances, for example by advising on basic first aid, and organise information in hierarchical order from national interventions to regional and local support (even just by simply listing all local authorities websites with dementia-related pages).
- Local clinics, memory clinics and pharmacies should have printed copies of contact details of key local support services, including, for example, dentists and opticians offering home visits, and more mundane services (such as mobile hairdressers/barbers and cleaning services) and to reinforce the information available online.

5. Conclusion

This study aimed to understand how informal caregivers looking after RLwDs assess and trust information related to dementia and its implications for their life and that or their loved ones. It showed that caregivers deploy a number of strategies ranging from exercising their own judgements, to recognising the authority of well-known resources and relying on peer advice. Nevertheless, unsupportive relationships with HCPs, online and physical sites of commercial nature, insensitive and impersonal information undermine their sense of control and, consequently, trust in information.

This study contributes to the scarce volume of empirical research evaluating information needs of informal caregivers of people with dementia. It proposes recommendations on how the healthcare system could better inform caregivers and offers practical advice to new caregivers as provided by their peers. This study, however, also comes with limitations. First, it was limited in scope, data collection and sample size. Second, it only covers a limited geographical area in the North of England. Third, it took into account both primary and secondary caregivers, whereas separate studies on each typology could have provided a different picture. Fourth, a full theoretical framework on information trust and acceptability needs to be fully developed with a more varied and numerous sample of caregivers.

Future studies should focus on further expanding on and understanding the caregiver related factors leading to information trust formation, also taking into account aspects such as caregivers' incognizance of their information needs, which did not emerge in this study but warrants consideration. However, the future challenge will be finding effective solutions which harmonise such granular, time-sensitive and event-based needs with the support that can be realistically provided to caregivers at national, regional and local level.

References

Allen, F., Cain, R. and Meyer, C. (2020) "Seeking relational information sources in the digital age: A study into information source preferences amongst family and friends of those with dementia", *Dementia*, Vol. 19 No. 3, pp. 766-785, doi: https://doi.org/10.1177%2F1471301218786568

Alzougool, B., Chang, S. and Gray, K. (2017) "The effects of informal carers' characteristics on their information needs: The information needs state approach", *Informatics for Health and Social Care*, Vol. 42 No. 3, pp. 261-273, doi: https://doi.org/10.1080/17538157.2016.1221409

Bailey, C., Dooley, J. and McCabe, R. (2019) "'How do they want to know? 'Doctors' perspectives on making and communicating a diagnosis of dementia", *Dementia*, Vol. 18 No. 7-8, pp. 3004-3022, doi: https://doi.org/10.1177%2F1471301218763904

Balog, K.P., Tanacković, S.F. and Erdelez, S. (2020) "Information support system for Alzheimer's disease patients' caregivers in Croatia: a phenomenological approach", *Information Research*, Vol. 25 No. 4, doi: https://doi.org/10.47989/irisic2011

Berget, G., MacFarlane, A. and Pharo, N. (2020) "Modelling the information seeking and searching behaviour of users with impairments: Are existing models applicable?", *Journal of Documentation*, doi: 10.1108/JD-04-2020-0049

Bressan, V., Visintini, C. and Palese, A. (2020) "What do family caregivers of people with dementia need? A mixed-method systematic review", *Health & Social Care in the Community*, Vol. 28 No. 6, pp. 1942-1960, doi: https://doi.org/10.1111/hsc.13048

Cabote, C.J., Bramble, M. and McCann, D. (2015) "Family caregivers' experiences of caring for a relative with younger onset dementia: A qualitative systematic review", *Journal of Family Nursing*, Vol. 21 No. 3, pp. 443-468, doi: https://doi.org/10.1177%2F1074840715573870

Case, A. and Deaton, A. (2017) “Mortality and morbidity in the 21st century”, *Brookings papers on economic activity*, No. 1, pp. 397-476, available at: https://data.nber.org/mortality-and-morbidity-in-the-21st-century/casetextsp17bpea.pdf

Chappell, M., Zdanowska, J., Cashmore, J., Oliver, G. and Cooper, J. (2017) “Peer support for carers of people with dementia”, *Mental Health and Social Inclusion*, Vol. 21, No. 2, pp. 110-118, doi: https://doi.org/10.1108/MHSI-12-2016-0038

Chen, X., Hay, J.L., Waters, E.A., Kiviniemi, M.T., Biddle, C., Schofield, E., Li, Y., Kaphingst, K. and Orom, H. (2018) “Health literacy and use and trust in health information”, *Journal of health communication*, Vol. 23 No. 8, pp.724-734, doi: https://doi.org/10.1080/10810730.2018.1511658

Chiao, C.Y., Wu, H.S. and Hsiao, C.Y. (2015) “Caregiver burden for informal caregivers of patients with dementia: A systematic review”, *International nursing review*, Vol. 62 No. 3, pp. 340-350, doi: https://doi.org/10.1111/inr.12194

Choe, E.K., Duarte, M.E., Suh, H., Pratt, W. and Kientz, J.A. (2019) “Communicating Bad News: Insights for the Design of Consumer Health Technologies”, *JMIR human factors*, Vol. 6 No. 2, p. e8885, doi: https://doi.org/10.2196/humanfactors.8885

Christie, H.L., Martin, J.L., Connor, J., Tange, H.J., Verhey, F.R., de Vugt, M.E. and Orrell, M. (2019) “eHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready?”, *Internet Interventions*, Vol. 18, p. 100260, doi: https://doi.org/10.1016/j.invent.2019.100260

Crimmins, E.M. and Zhang, Y.S. (2019) “Aging populations, mortality, and life expectancy”, *Annual Review of Sociology*, Vol. 45, pp. 69-89, doi: https://doi.org/10.1146/annurev-soc-073117-041351

Dervin, B. (2015) “Dervin's Sense-Making Theory” In: *Information seeking behavior and technology adoption: Theories and trends* (pp. 59-80). IGI Global.

Diviani, N., Zanini, C., Jaks, R., Brach, M., Gemperli, A. and Rubinelli, S. (2020) “Information seeking behavior and perceived health literacy of family caregivers of persons living with a chronic condition. The case of spinal cord injury in Switzerland” *Patient education and counselling,* Vol. 103, pp. 1531-1537, doi: https://doi.org/10.1016/j.pec.2020.02.024

Ducharme, F., Kergoat, M.J., Coulombe, R., Lévesque, L., Antoine, P. and Pasquier, F. (2014) “Unmet support needs of early-onset dementia family caregivers: a mixed-design study”, *BMC nursing*, Vol. 13 No. 1, p. 49, doi: https://doi.org/10.1186/s12912-014-0049-3

Erdelez, S., Tanacković, S.F. and Balog, K.P. (2019) “Online behavior of the Alzheimer's disease patient caregivers on Croatian online discussion forum” *Proceedings of the Association for Information Science and Technology*, Vol. 56 No. 1, pp. 78-88, doi: https://doi.org/10.1002/pra2.8

Gresham, M., Heffernan, M. and Brodaty, H. (2018) “The Going to Stay at Home program: combining dementia caregiver training and residential respite care”, *International psychogeriatrics*, Vol. 30 No. 11, pp. 1697-1706, doi: https://doi.org/10.1017/S1041610218000686

Harland, J.A. and Bath, P.A. (2008) “Understanding the information behaviours of carers of people with dementia: A critical review of models from information science”, *Aging and Mental Health*, Vol. 12 No. 4, pp. 467-477, doi: https://doi.org/10.1080/13607860802224300

Heinrich, S., Uribe, F.L., Roes, M., Hoffmann, W., Thyrian, J.R., Wolf-Ostermann, K. and Holle, B. (2016) “Knowledge management in dementia care networks: a qualitative analysis of successful information and support strategies for people with dementia living at home and their family caregivers", *Public Health*, Vol. 131, pp. 40-48, doi: https://doi.org/10.1016/j.puhe.2015.10.021

Hussein, T., Boger, J. and Rudzicz, F. (2018) "The impact of design on feelings of trust of online information for family caregivers of people with dementia", In *Proceedings of the 32nd International BCS Human Computer Interaction Conference*, Vol. 32, pp. 1-6, doi: 10.14236/ewic/HCI2018.125

Iribarren, S., Stonbraker, S., Suero-Tejeda, N., Granja, M., Luchsinger, J.A., Mittelman, M., Bakken, S. and Lucero, R. (2019) "Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer's disease and related dementias", *Informatics for Health and Social Care*, Vol. 44 No. 2, pp. 115-134, doi: https://doi.org/10.1080/17538157.2018.1433674

Jackson, D.N., Peterson, E.B., Blake, K.D., Coa, K. and Chou, W.Y.S. (2019) "Americans' trust in health information sources: trends and sociodemographic predictors", *American Journal of Health Promotion*, Vol. 33 No. 8, pp. 1187-1193, doi: https://doi.org/10.1177%2F0890117119861280

Khaleel, I., Wimmer, B.C., Peterson, G.M., Zaidi, S.T.R., Roehrer, E., Cummings, E. and Lee, K. (2020) "Health information overload among health consumers: A scoping review", *Patient education and counseling*, Vol. 103 No. 1, pp. 15-32, doi: https://doi.org/10.1016/j.pec.2019.08.008

Kim, S. (2020) "Caregivers' Information Overload and Their Personal Health Literacy", *Western Journal of Nursing Research*, doi: https://doi.org/10.1177%2F0193945920959086

Lee, K., Puga, F., Pickering, C.E., Masoud, S.S. and White, C.L. (2019) "Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review", *International journal of nursing studies*, Vol. 96, pp. 119-131, doi: https://doi.org/10.1016/j.ijnurstu.2019.02.007

Leslie, M., Gray, R.P. and Khayatzadeh-Mahani, A. (2020) "What is 'care quality'and can it be improved by information and communication technology? A typology of family caregivers' perspectives", *Scandinavian Journal of Caring Sciences*, doi: https://doi.org/10.1111/scs.12837

Longstreth, M., McKibbin, C., Steinman, B., Slosser Worth, A. and Carrico, C. (2020) "Exploring information and referral needs of individuals with dementias and informal caregivers in rural and remote areas", *Clinical Gerontologist*, pp. 1-13, doi: https://doi.org/10.1080/07317115.2019.1710735

Mason, N.F., Francis, D.B. and Pecchioni, L.L. (2020) "Health Information Seeking as a Coping Strategy to Reduce Alzheimer's Caregivers' Stress", *Health Communication*, pp. 1-10, doi: https://doi.org/10.1080/10410236.2020.1824665

Maneze, D., Weaver, R., Kovai, V., Salamonson, Y., Astorga, C., Yogendran, D. and Everett, B. (2019) ""Some say no, some say yes": Receiving inconsistent or insufficient information from healthcare professionals and consequences for diabetes self-management: A qualitative study in patients with Type 2 Diabetes", *Diabetes research and clinical practice*, Vol. 156, p. 107830, doi: https://doi.org/10.1016/j.diabres.2019.107830

Martzoukou, K. and Abdi, E.S. (2017) "Towards an everyday life information literacy mind-set: a review of literature", *Journal of Documentation*, Vol. 73 No. 4, pp. 634-665, doi: https://doi.org/10.1108/jd-07-2016-0094

Myrick, J.G. (2017) “The role of emotions and social cognitive variables in online health information seeking processes and effects”, *Computers in Human Behavior*, Vol. 68, pp. 422-433, doi: https://doi.org/10.1016/j.chb.2016.11.071

Pecanac, K.E., Wyman, M., Kind, A.J. and Voils, C.I. (2018) “Treatment decision making involving patients with dementia in acute care: a scoping review”, *Patient education and counseling*, Vol. 101 No. 11, pp. 1884-1891, doi: https://doi.org/10.1016/j.pec.2018.06.017

Peterson, K., Hahn, H., Lee, A.J., Madison, C.A. and Atri, A. (2016) “In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers’ education needs, barriers, and preferences”, *BMC geriatrics*, Vol. 16 No. 1, p. 164, doi: https://doi.org/10.1186/s12877-016-0338-7

Prusaczyk, B., Olsen, M.A., Carpenter, C.R. and Proctor, E. (2019) “Differences in Transitional Care Provided to Patients With and Without Dementia”, *Journal of gerontological nursing*, Vol. 45 No. 8, pp. 15-22, doi: https://doi.org/10.3928/00989134-20190530-02

Rowley, J., Johnson, F. and Sbaffi, L. (2015) “Students’ trust judgements in online health information seeking”, *Health informatics journal*, Vol. 21 No. 4, pp. 316-327, doi: https://doi.org/10.1177%2F1460458214546772

Rowley, J., Johnson, F. and Sbaffi, L. (2017) “Gender as an influencer of online health information-seeking and evaluation behaviour”, *Journal of the Association for Information Science and Technology*, Vol. 68 No. 1, pp. 36-47, doi: https://doi.org/10.1002/asi.23597

Rutkowski, R.A., Ponnala, S., Younan, L., Weiler, D.T., Bykovskyi, A.G. and Werner, N.E. (2020) “A process-based approach to exploring the information behavior of informal caregivers of people living with dementia”, *International Journal of Medical Informatics*, Vol. 145, p. 104341, doi: https://doi.org/10.1016/j.ijmedinf.2020.104341

Sakai, K., Takeda, M., Shimizu, S., Takahama, T., Yoshida, T., Watanabe, S., Iwasa, T., Yonesaka, K., Suzuki, S., Hayashi, H. and Kawakami, H. (2019) “A comparative study of curated contents by knowledge-based curation system in cancer clinical sequencing”, *Scientific reports*, Vol. 9 No. 1, pp. 1-8, doi: https://doi.org/10.1038/s41598-019-47673-9

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H. and Jinks, C. (2018) “Saturation in qualitative research: exploring its conceptualization and operationalization”, *Quality & quantity*, Vol. 52 No. 4, pp. 1893-1907, doi: https://doi.org/10.1007/s11135-017-0574-8

Savolainen, R. (2015) “The role of emotions in online information seeking and sharing”, *Journal of Documentation*, Vol. 71 No. 6, pp. 1203-1227, doi: 10.1108/JD-09-2014-0129

Sbaffi, L. and Rowley, J. (2017) “Trust and credibility in web-based health information: a review and agenda for future research”, *Journal of medical Internet research*, Vol. 19 No. 6, p. e218, doi: https://doi.org/10.2196/jmir.7579

Seckler, M., Heinz, S., Forde, S., Tuch, A.N. and Opwis, K. (2015) “Trust and distrust on the web: User experiences and website characteristics”, *Computers in human behavior*, Vol. 45, pp. 39-50, doi: https://doi.org/10.1016/j.chb.2014.11.064

Shaffer, K.M., Chow, P.I., Cohn, W.F., Ingersoll, K.S. and Ritterband, L.M. (2018) “Informal caregivers’ use of internet-based health resources: An analysis of the health information national trends survey”, *JMIR aging*, Vol. 1 No. 2, p. e11051, doi: https://doi.org/10.2196/11051

Smith, J.A. and Shinebourne, P. (2012) “Interpretative phenomenological analysis”. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (p. 73–82). American Psychological Association, doi: https://doi.org/10.1037/13620-005

Söderström, E., Eriksson, N. and Åhlfeldt, R.M. (2016) “Managing healthcare information: analyzing trust”, *International journal of health care quality assurance*, Vol. 29, pp. 786-800, doi: 10.1108/IJHCQA-11-2015-0136

Soni, A. and Freeman, E. (2018) “G14 (P) Understanding young people with diabetes: using experience based co-design to provide a patient-centred diabetes transition service”, Archives of Disease in Childhood, Vol. 103 No. 1, p. A6, doi: http://dx.doi.org/10.1136/archdischild-2018-rcpch.14

Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P. and Robinson, A. (2010) “Measuring dementia carers' unmet need for services-an exploratory mixed method study”, *BMC Health Services Research*, Vol. 10 No. 1, p. 122, doi: https://doi.org/10.1186/1472-6963-10-122

Taylor, H.J. (2016) “What are ‘Best Interests’? A critical evaluation of ‘Best Interests’ Decision-Making in Clinical Practice”, *Medical Law Review*, Vol. 24, pp. 176-205, doi: https://doi.org/10.1093/medlaw/fww007

Teahan, Á., Lafferty, A., McAuliffe, E., Phelan, A., O'Sullivan, L., O'Shea, D. and Fealy, G. (2018) “Resilience in family caregiving for people with dementia: A systematic review”, *International journal of geriatric psychiatry*, Vol. 33 No. 12, pp. 1582-1595, doi: https://doi.org/10.1002/gps.4972

Tonsaker, T., Law, S., Ormel, I., Nease, C. and Bartlett, G. (2017) “Engaging caregivers: exploring perspectives on web-based health information”, *Family practice*, Vol. 34 No. 4, pp. 479-484, doi: https://doi.org/10.1093/fampra/cmw084

United Nations (2019) “Aging”, available at: https://www.un.org/en/sections/issues-depth/ageing/

Werner, N.E., Stanislawski, B., Marx, K.A., Watkins, D.C., Kobayashi, M., Kales, H. and Gitlin, L.N. (2017) “Getting what they need when they need it: Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms”, *Applied clinical informatics*, Vol. 8 No. 1, p. 191, doi: https://doi.org/10.4338/ACI-2016-07-RA-0122

Washington, K.T., Meadows, S.E., Elliott, S.G. and Koopman, R.J. (2011) “Information needs of informal caregivers of older adults with chronic health conditions”, *Patient Education and Counseling*, Vol. 83 No. 1, pp. 37-44, doi: https://doi.org/10.1016/j.pec.2010.04.017

World Health Organization (2012) “Dementia: a public health priority”, available at: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

Xiao, L.D., Wang, J., He, G.P., De Bellis, A., Verbeeck, J. and Kyriazopoulos, H. (2014) “Family caregiver challenges in dementia care in Australia and China: a critical perspective”, *BMC geriatrics*, Vol. 14 No. 1, p. 6, doi: https://doi.org/10.1186/1471-2318-14-6

Table I. Demographic characteristics of the sample (frequencies).

Gender	Male	5
	Female	15
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 RLwD	Wife	4
	Husband	5
	Mother	7
	Father	3
	Mother and Father	1

Table II. Themes and sub-themes emerged from the interpretative phenomenological analysis performed on the interview data.

Themes	**Sub-themes**
1. Assumptions about information sources	1a. Trust in official websites 1b. Trust in healthcare professionals
2. Checks and balances	2a. Searching for sensitive topics 2b. Commercial sites
3. Information ‘management’	3a. Filtering information 3b. Trusting what ‘feels right’ 3c. Lived experience

Figure 1. Theoretical representation of caregivers information trust formation