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Making sense of dementia: a phenomenographic study of the information needs and behaviours of people with dementia at diagnosis

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Structured Abstract:

Purpose: To investigate the information behaviours of patients newly diagnosed with dementia.

Design/methodology/approach: Cross-sectional qualitative study, using in-depth interviews.

Findings: Reactions to a diagnosis of dementia varied and these influenced the perception of the value of information when making sense of the diagnosis. Information was avoided if participants did not feel that they could influence their situation; instead, participants relied on internal explanations to normalise their memory loss. Barriers to information seeking and use included not knowing who to speak to, perceived stigma associated with dementia, and difficulty of applying generic information to own situation. Some participants valued information that confirmed their suspicions and provided explanations.

Research limitations/implications: This study was based on a small sample size (n=13), the findings may not be generalisable to all people with dementia; however, the findings may be transferable to people who have recently been diagnosed with dementia.

Practical implications: There is not a one-size-fits-all approach to information provision for people with dementia at diagnosis, information should be tailored to individuals.

Social implications: There is a need to address the feeling of powerlessness and futility that some people with dementia experience at diagnosis, as this precludes independent information seeking and use. People receiving a diagnosis may need additional support and information pertinent to their specific circumstances, separate from the information needs of their carer(s).

Originality/value: The study provides a new understanding of the information behaviours of people recently diagnosed with dementia and how these differ from those of informal carers.

Keywords: dementia; information behaviour; information need; diagnosis; phenomenography

Article Classification: Research paper

Introduction

Dementia

With the increasing ageing population, the numbers and proportions of people with age-related health conditions, such as dementia, will increase over the next 30 years. Dementias are a range of conditions caused by chemical and pathological changes in the brain, due to underlying neurodegenerative diseases (McKeith and Fairburn, 2001). The symptoms of dementia include memory loss, cognitive decline, confusion, difficulties with problem solving, reasoning and communication, impaired ability to cope with activities of everyday life, such as personal hygiene and cooking, and changes in personality or behaviour (Knapp and Prince, 2007). Dementia is often associated with old age, affecting one in six people over the age of 80 and one in 14 people over the age of 65 (Knapp and Prince, 2007).

Dementia is caused by neurodegenerative diseases that progressively damage and destroy brain cells; however, the different types of dementia lead to different patterns of

brain damage, which therefore have different symptoms and affect people in different ways (Arendt and Jones, 1992). The most common form of dementia is Alzheimer's Disease, which accounts for 50-75% of cases of dementia (McKeith and Fairburn, 2001): this is characterised by development of plaques in the white matter of the brain. In contrast, vascular dementia is caused by strokes that restrict the brain's oxygen supply; it is estimated that this accounts for approximately 25% of dementias (McKeith and Fairburn, 2001). Other causes of dementia include dementia with Lewy bodies, fronto-temporal dementia, Parkinson's disease, Huntington's disease and Creutzfeldt-Jakob disease (National Institute for Health and Clinical Excellence, 2006).

World-wide, there are an estimated 24.3 million people with dementia: it is predicted that there will be 4.6 million new cases of dementia every year (Ferri et al., 2005). The incidence of dementia is also predicted to almost double every 20 years, to 42.3 million in 2020 and 81.1 million in 2040 (Ferri et al., 2005). In the UK, the numbers and proportions of older people are increasing and are predicted to do so until at least 2033 (Office for National Statistics, 2009). There are approximately 820 000 people with dementia in the UK, which have been estimated to cost the UK economy £23 billion per annum (Luengo-Fernandez et al., 2010). It is predicted that this will increase to one million people by 2025 and 1.7 million by 2051 (Knapp and Prince, 2007).

Dementia is therefore a growing health issue, not least because of the mounting economic cost of dementia and the increased pressure on health and social care services. At a personal level, there are health, social and economic impacts on people who have dementia and their family members and friends, who often act as informal and unpaid carers (Schulz et al., 1995; Comas-Herrera et al., 2003; Knapp and Prince, 2007). The National Institute for Health and Clinical Excellence guideline on dementia emphasized the importance of recognising and meeting the needs of informal carers a priority (National Institute for Health and Clinical Excellence, 2006).

In 2009, the UK Department of Health published its National Dementia Strategy. One of the aims of this strategy was to establish a memory clinic in every town to aid the diagnosis and management of dementia by creating a central hub through which the provision of services and information could be co-ordinated (Department of Health, 2009). Providing good quality information for people with dementia and their carers was highlighted as a priority.

Information needs and information behaviours

Information about dementia, concerning the diagnosis, prognosis and the help and support available can come from many sources, including verbal and written explanations given by health professionals (Mastwyk et al., 2014), diagnostic information sheets, information leaflets from the Alzheimer's Society, as well as informal sources of information, such as family and friends and, increasingly, the media. Understanding if, and how, people with dementia need, seek and use these different types of information is important, as research has shown that many people with dementia want to be fully informed about their diagnosis (Pinner and Bouman, 2003a,b; Beattie et al., 2004; Harman and Clare, 2006), although others may prefer not to know (Corner and Bond 2004). Although some research has specifically focused on the information needs of carers of people with dementia (Thompson and Lovestone, 2002; Wackerbath and Johnson, 2002; Wald et al., 2003; Robinson et al. 2009), limited empirical data has been gathered about the information needs and behaviours of the person with dementia (Mastwyk et al., 2014; Lecouturier et al., 2008). It is important to develop a better understanding if support services for people with dementia are to adopt a patient-centred approach and provide services according to the person-centred care model of dementia treatment (Kitwood, 1997).

To enable health professionals and health care services to facilitate access to information in an appropriate format and at the right time, there must be recognition that people with dementia are a heterogeneous group, who have different needs and preferences for information about their diagnosis and prognosis, modulated by their existing ideas about dementia. By studying the information behaviours of people with dementia, patient-centred information strategies can be tailored to the needs of the individual.

Study aims and objectives

The overall aim of this study was to develop a better understanding of how people recently diagnosed with dementia need, seek and utilise information.

More specifically, the objectives of this study were to:

- Examine the information needs and information seeking of people with dementia and their carers at diagnosis.
- Describe the ways that information is used to help people with dementia make sense of their diagnosis.

- Identify the barriers that these people experience in receiving and using timely and helpful information.

This paper focuses on the information behaviours of people with dementia at the time of diagnosis. The following section outlines the methodology used to undertake the study and the methods of data collection and analysis. The paper describes the main findings and then discusses them in relation to the literature. Implications for practice and for information support for people with dementia are discussed and the conclusions summarise what this paper adds to knowledge.

Methods

Research Design

A number of assumptions about the nature of information and information users contributed to the selection of research methodology for the study. First, information does not exist as an objective entity, but is subjectively constructed by the individual and imbued with unique meanings in the way that it is interpreted and used (Dervin and Nilan, 1986; Dervin, 1992; Dervin, 2003). The aim was not to prescribe beforehand what constituted information, but to allow the participants' subjective views of what constitutes information to arise from asking them to describe and reflect on their experiences of making sense of a diagnosis of dementia. Second, whilst previous studies have identified categories of information needs in carers of people with dementia, this was done without awareness of the situation in which they arose and understanding of the accompanying feelings and attitudes of the patient. Therefore, the aim was to generate contextually rich and situated data by asking people with dementia to reflect on their experiences, with the assumption that inferences could be made about information needs, seeking, sharing and use that could be analysed and interpreted using qualitative approaches.

The underlying ontological position for this study was that the social world is constituted in, and of, people's experiences and that it is in discovering the relationship between the phenomena in question and the individual's experiences of them that meaningful data can be generated (Mason, 2002); in this study, this related to the people's experiences of experiencing a diagnosis of dementia. The corresponding epistemology was that the phenomena could be investigated by asking people to reflect on their experiences of experiencing symptoms of dementia, of seeking support from healthcare professionals and receiving a diagnosis, to generate data that would then be analysed within an interpretivist paradigm. This approach recognised that understanding and

knowledge are constructed socially and experientially and acknowledges the role of both the participant and the researcher in creating that meaning (Silverman, 2005).

Sense-Making was initially considered as the methodological approach for the study because it has been widely used in studies of information behaviour and encompasses a theoretical and a methodological approach (Dervin and Nilan, 1986; Dervin 1992; Dervin, 2003). However, previous research employing Sense-Making (e.g., Odhiambo et al., 2003; Williams et al., 2003; Hepworth, 2004) utilized the micro-moment timeline interview (Dervin, 1992) for data collection. This was felt to be inappropriate for people with dementia because it relies on participants being able to recall 'critical incidents' and to describe each step of the sense-making process in detail. A common feature of dementia is short-term memory loss and cognitive impairment; recalling the level of detail required for the micro-moment timeline interview could have created major difficulties for the person with dementia (Harland, 2010). Although a focus of the study was in developing an understanding of the process of sense-making (in relation to people diagnosed with dementia), it does not have to be intrinsically linked to the Sense-Making methodology (Solomon, 1997). Instead, phenomenography was selected as a useful methodological approach for this study (Marton, 1981, 1986; Bowden, 2005), to investigate the experiences of information behaviours in the context of making sense of a diagnosis of dementia.

The aim of phenomenography is to reveal variation in experience of phenomena in the human world, and this offered a suitable methodological approach, which fitted with the underlying ontology and epistemology outlined above. Furthermore, phenomenography has been used successfully in information behaviour research, e.g., to study conceptions of information literacy (Bruce, 1997) and information seeking (Limberg, 1999) and health research, e.g., to investigate the experience of professionals involved in providing care to people with dementia (Albinsson and Strang, 2002).

Recruitment

It was decided that potential participants would be recruited through the UK National Health Service, as it was necessary to recruit people with dementia and their carers as soon as possible after diagnosis. Participants were recruited from a memory clinic in South Yorkshire, UK that specialised in the diagnosis and treatment of people with dementia. At diagnosis, the memory clinic consulted with the patient and their relative, or carer, at the same time, providing information about diagnosis and drug treatments to both parties simultaneously, in written and verbal form. They also provided

written information about the support available to patients and carers from social services and information about state benefits, such as attendance allowance. Patients with a diagnosis of dementia and judged by the memory clinic as able to give informed consent were invited to participate. Three to four weeks after the diagnosis was confirmed, the person with dementia and their carer had a routine follow-up appointment with the memory clinic nurse to ensure that the diagnosis had been understood by the patient and their carer and to provide further support. It was during this meeting that people with dementia and their carers were invited by the memory clinic nurse to participate in the study.

Interviews

In-depth semi-structured interviews were conducted with 13 patients in their own homes, after a diagnosis of dementia had been confirmed. Interviews are the most frequently used method of data generation within phenomenography (Booth, 1997). An interview guide was developed in relation to the aims and objectives of the research. The objective was to encourage the participants to talk about their experiences of making sense of dementia before, during and after diagnosis, focusing, in particular, on aspects of information need, seeking and use as defined by the participants. Participants were asked to describe the process of getting a diagnosis of dementia, focusing on moments of uncertainty, their accompanying actions, feelings and emotions and the perceived value of information in shaping their experience of making sense of their situation and their understanding of dementia. Participants were asked about their experiences before, during and after diagnosis, and follow-up questions focused on how information helped or hindered them in making sense of their situation.

Qualitative Analysis

Data were analysed using the phenomenographic method (Marton, 1981) to identify variation in experience. The research was descriptive and interpretative, the aim was to describe the experiences of people with dementia according to principles of phenomenographic analysis and to interpret and explain the differences and similarities reported. Phenomenography does not have a strict protocol for data analysis; however, the guidelines developed by Dahlgren and Fallsberg (1991) and Sjostrom and Dahlgren (2002), helped to guide the analysis process. The seven steps were familiarization, compilation, condensation, grouping, comparison, naming and contrastive comparison. These were undertaken in an iterative way (Sjostrom and Dahlgren, 2002), rather than purely sequential, in order to ensure that the critical aspect of variation was identified.

How these were operationalized is described in further detail below and is illustrated in Figure 1. Phenomenographic analysis is based on an inductive approach to data analysis (Bowden, 2000), and therefore it is important not to impose a framework on the data as in deductive analysis (Pope et al., 2000). The categories of description should emerge from the data and the data, therefore, should provide the evidence for their existence (Bowden, 2005).

Interviews were transcribed verbatim shortly after the interview and read and re-read several times in order to develop familiarity with the data (Step 1 above (Dahlgren and Fallsberg, 1991; Sjoström and Dahlgren; 2002)). Following these readings, notes were made, which were then compared across the transcripts to identify variations in people's experiences. Sections from the interview transcripts that contained significant and pertinent information were initially highlighted in the text and then extracted and compiled (Step 2). Key excerpts of text were identified, extracted from the transcripts and grouped together to form a pool of data. For longer sections of text, the data were condensed to ascertain the central part of the meaning that was conveyed (Step 3) (Sjoström and Dahlberg, 2002). A preliminary analysis was conducted on all the data which had been extracted, which resulted in the pooling of data by the labeling and grouping of similar excerpts to create an initial coding framework consisting of pools of meaning into which the data was sorted (Step 4). The technique of constant comparison was used to analyse each extract with all other extracts in the pool of data to identify similarity or variation in what was being expressed (Step 5). The overall categories, as well as the features contained within categories, in such a way as to demonstrate their meaning, or essence (Step 6). This process of naming was iterative; as the analysis proceeded, the names of the categories changed as the aim was to label them in such a way that they successfully captured the conception that they were describing. The final stage of analysis (Step 7) was the production of the description of each of the categories, focusing on their 'unique character' and also the resemblances between categories (Dahlgren and Fallsberg, 1991). This stage, therefore, consisted of articulating the referential aspects of each conception in its category of description, using quotations directly from the interviews to illustrate the main features of the category.

Excerpts were coded using NVivo to facilitate data management and an iterative process of category construction began, linking experiences of information need and behaviour to the overall way in which the diagnosis was perceived by the participant (Harland, 2010). These categories form the findings of the study. Phenomenographic

analysis aims at description; however, once it had been completed the findings were linked back to theories of information behaviour, in order to interpret the results.

Research Ethics and research governance

A favourable research ethics opinion was provided for the study by a UK National Health Service (NHS) Local Research Ethics Committee and research governance approval was obtained from the local NHS Trust.

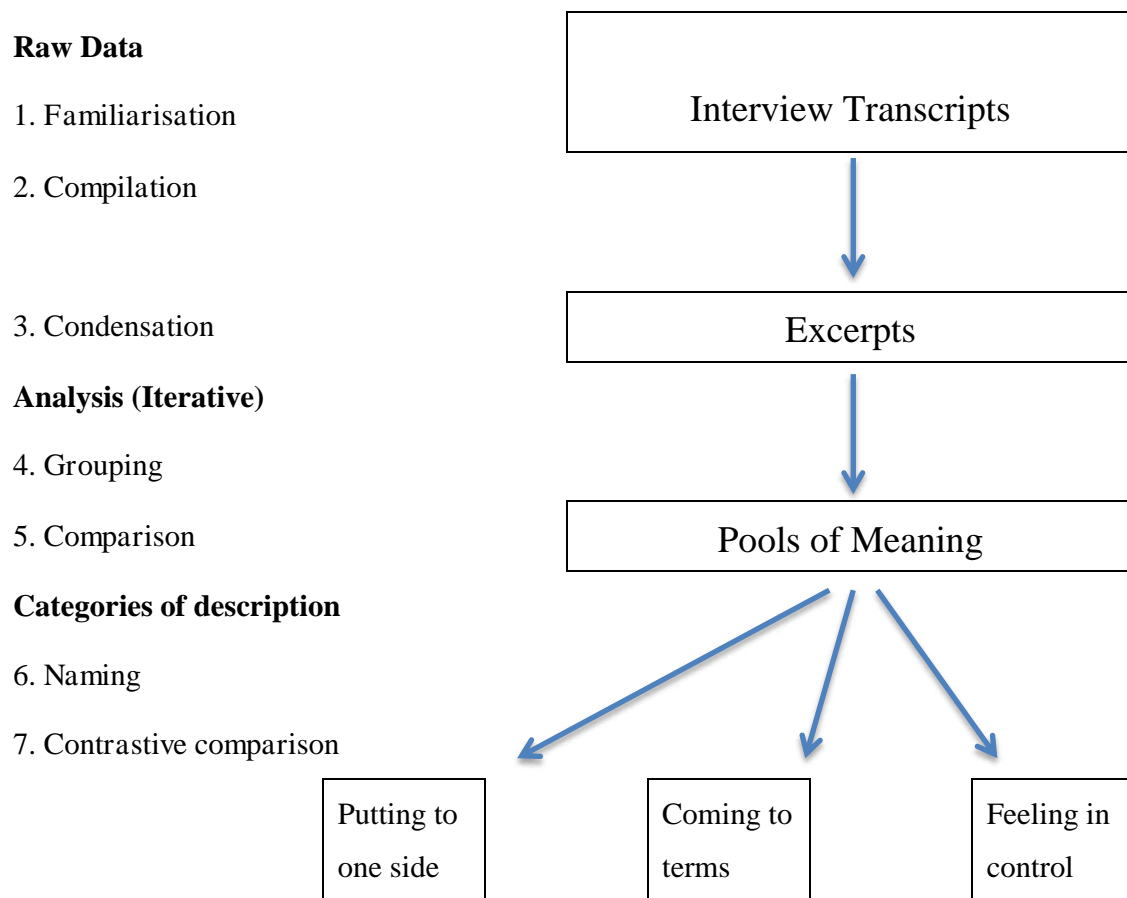


Figure 1: Process of phenomenographic analysis to develop categories of description

Results

Characteristics of the sample

A total of 13 people recently diagnosed with dementia were recruited to the study. Eight of the participants has been diagnosed with Alzheimer's disease (AD), two with vascular dementia (VaD), and three with mixed Alzheimer's disease and vascular dementia, diagnosed using ICD-10 (International Classification Disease) criteria (World Health Organisation, 2016). The age of the participants ranged from 66 years to 90 years.

Findings

Qualitative analysis of the interviews showed that the participants differed in how they reacted to their diagnosis; these differing attitudes had implications for information behaviours. Most participants wanted to set their diagnosis to one side as they tried to continue with their life as normal and reported minimal needs for medical information. Some participants were in the process of coming to terms with their diagnosis: although they accepted it, they needed additional reassurance and advice about how to cope as they struggled to fit the diagnosis with their own circumstances. A minority of participants felt more in control after a diagnosis was given as it confirmed their suspicions that there was something not quite right; they were the most active users of information.

Putting to one side

The majority of participants had put their diagnosis of dementia and the information they received to one side during the diagnosis process. Some participants maintained this approach at the time of interview. Although they demonstrated a tacit acquiescence that they had received a diagnosis, there was also a sense that they did not really believe it, or that it was irrelevant to their life. Some participants acknowledged that their memory had deteriorated prior to diagnosis, although they had not regarded it as a particular problem, and it was often explained as age-related memory loss:

“No I never thought, you know, my sister, she 's 90 next month, and she forgets things you know, she says “oh where 's so and so ” and what have you. I must admit I don 't think I've ever really, we 've said oh what do you call so and so, Mr What-Not, but nothing really worrying at all.” **Participant 7, Female with VaD/AD, 80**

“Oh no, perhaps I wondered what was happening to my memory, but I never had a thought that it was anything like this.” **Participant 4, Male with VaD, 80**

“They said it would be better if I went to the memory clinic. I don’t know. There you are you see. I don’t know that I’ve had any particular problems. It’s not as good as it was, but there you don’t expect it to be when you’re in your eighties? One of those things, anno domini”. **Participant 1, Female with AD**

Receiving medical attention was something that was perceived as happening almost by chance. For example, one participant described how the referral to memory clinic had occurred serendipitously because she had seen a leaflet in her doctor’s surgery entitled “How can I help my memory”:

“I’d got it [leaflet] on my knee when we went in, and he said have you been looking at that, and I said oh we have been and he said do you forget? And I said sometimes yes and he said what do you forget and I said oh well sometimes names and umm, so he you know he didn’t say much about it at all, you know, put it away and carried on with everything and next thing we knew he’d referred us on.” **Participant 7, Female with AD/VaD, 80**

When asked if the information in the leaflet was useful, she did not think so, because she felt that it was normal that older people forget. However, the excerpt suggests that there was a latent need for information as the leaflet caught her attention, even though she was not certain why the doctor had arranged an appointment at the memory clinic. Although there was a latent information need, as participants acknowledged changes in their memory, they did not experience this as an active need, as memory loss was not perceived to be a medical problem.

Participants reported a feeling of detachment during the diagnosis process. They did not recognise their symptoms as problematic, but attributed them to ‘normal’ age-related memory loss. As a result, medical intervention had usually been sought at the insistence of a close family member.

The memory clinic was viewed as a place to go to have tests performed, but participants rarely reported that they sought information actively from the memory clinic staff. One participant recalled that although she had wanted to know why they were performing a test, she had not asked as she just wanted to get home as soon as possible. Notably, most participants who wanted to put their diagnosis to one side and not think about it also reported negative connotations associated with the word ‘dementia’ and were therefore reluctant to be identified as having the disease.

“I don’t think that I worry about it; Nothing that I can do. You think with dementia, you hear dementia you think you’re, you think somebody’s raving mad, but you think I’m not raving mad so blow it”. **Participant 1, Female with AD**

This was accompanied by disinclination to disclose their diagnosis to anyone but close family members because of the negative stereotypes they felt were associated with it.

“No, I can’t say that I do talk about it. I go out with friends every Thursday walking in Derbyshire and they’ve never said anything to me about it either. Now whether they’ve thought about it I can’t tell you, but they haven’t said anything to me about it.” **Participant 10, Male with AD**

“I think to myself Alzheimer’s you can’t have Alzheimer’s, you know? I told everybody, family that does know don’t go telling everybody about this; don’t mention Alzheimer’s and me”. **Participant 7, Female with AD/VaD, 80**

“I’ve not told any of me friends, I don’t feel as though I want to talk to any of them about it. They know I forget, but that’s it. I don’t feel as though I want to talk about it to anybody, my family know, but that’s as far as it goes.” **Participant 12, Female with VaD, 79**

This unwillingness to discuss their diagnosis of dementia is understandable given the stigma associated with mental health conditions, and also perhaps with long-term progressive illnesses, such as dementia, which have to be treated and managed, but for which there is no cure.

Participants were also passive recipients of information, such as leaflets and books that were given to them by the memory clinic and the Alzheimer’s Society. Information about dementia was often perceived as a physical object, such as a patient information leaflet, which was extraneous to the person with dementia. Some participants reported that they put them to one side or hid them away as they were not considered pertinent and could not provide answers.

“I did have some but I don’t know where I’ve put it, yes I did have something come, but I don’t think there was anything that I didn’t know. Yes, yes, hmmm, hmm...it was just a case of looking at it and putting it on one side”. **Participant 6, Female with AD**

“I don’t read about it, no, because I feel like there’s nothing really that I can do, I mean what can you do, can you take a medicine and all of a sudden your brain starts

working, I mean it copes alright with a some things and not so well with others”.

Participant 9, Female with AD

Information from medical professionals and support groups was therefore peripheral to helping people make sense of their diagnosis and in some cases was considered futile, as it was felt that nothing could be done. Instead ‘normal life’ was maintained by carrying on regardless of their diagnosis of dementia, which often meant that information was avoided.

Coming to terms

Although the most usual response of participants was to ‘put it to one side and not think about it’, a few participants, in the weeks following diagnosis and at the time of the interview, were more actively trying to make sense of the diagnosis by using information from external sources. In their attempts to come to terms with their situation, some participants reported reading the literature that they had been given or remembering things that they had been told at diagnosis. However, coming to terms with a diagnosis was reported as a difficult process and information, particularly about the prognosis, did not always seem relevant and was therefore not considered helpful.

“They go to great pains to say well this could happen, but don’t worry about it and I think well I’m not at that stage yet to understand what you’re talking about. But I don’t know what day it is- it’s very difficult really”. **Participant 13, Male with AD**

Recalling what they had been told by medical professionals or their carer and what they had read, participants reported an ongoing struggle to fit the information that they were given to their own personal circumstances.

“You’ve got to fit it to your own situation haven’t you, when [my wife] was telling me about it, I couldn’t get with it. You know, it’s very difficult isn’t it when you feel like me and its, you think to yourself, surely I’m not going to get like that, I’ve more about me than that, that’s what I keep saying to myself. There you go, you don’t know do you. I mean could I become really, uhhh, disabled over night, that sort of thing, does that happen?” **Participant 2, Male with AD**

Information caused uncertainty and raised further questions. Sometimes these were discussed after the diagnosis with close family members, but a number of participants reported a need to have further discussions with medical professionals or dementia experts to understand how this generic information was applicable to their specific circumstances. At the time of interview, this need had not been met. Unmet

affective needs for information and support were also reported by one participant who did not feel that written information could help her to cope with her situation and who wanted someone to speak with:

“What could I read that would help me? It’s not going to help me stop feeling like this. May be if I could talk to someone who understands what I’m going through that would help, but where would I find them?” **Participant 3, Female with AD**

Other participants were able to discuss their diagnosis with family and friends, particularly selecting those people who had experience of caring for a person with dementia. This was a particularly useful source of information to gain additional advice about how to cope with their condition and what to expect. Information was both potentially helpful, as it could increase knowledge about dementia, but also challenging, as people attempted to fit it to their own understanding of who they were and of how it might affect them in the future, particularly the implications for their behaviour. Participants who were coming to terms with dementia appeared to be more likely to read the information that they had been given and to discuss it with family and friends, but also to experience a need for emotional reassurance and support that was not always met.

Getting information about dementia to fit with participants’ existing perceptions was difficult, particularly because they often focused upon negative information about the future. Adjustments were required in order to try to come to terms with the diagnosis:

“I rejected it mentally, I thought to myself, god, it’s not that bad, I do exactly the same as I used to do before, I remember the same things as I used to do before, but of course as you go in life you realise that you can’t remember these things, that’s where I’m at.” **Participant 2, Male with AD, 78**

In contrast to the conception of ‘putting to one side’ the diagnosis, trying to overcome the uncertainty caused by the diagnosis was experienced as a gap that required active information seeking and use to bridge the gap; however, making sense of this information was difficult.

Feeling in control

A few participants reported feelings of relief that they had received a diagnosis, ranging from one participant who was ‘thrilled’ because she just knew that there was something wrong to another participant who felt relieved as having a diagnosis gave her an explanation of the deterioration that she had experienced in her memory.

“Well I’ve gotten used to it now, sort of accepted it now, nothing else I can do, I feel safe about it all, not worrying about it, now I know what it is.” **Participant 12,**

Female with VaD

Some participants brought their memory problems to the attention of their GP of their own accord, rather than at the insistence of a family member.

“Well I’d been to my doctors you know, and as I walked out I said what about my memory, I’ve got some problems, and he said have you really and I said yes. So he had me there answering some questions and I couldn’t answer them all and he said would you like to be tested further and I said oh yes, it would stop me worrying so he put me forward to the Memory Clinic.” **Participant 12, Female with VaD**

One participant reported that she had actively sought information about dementia by reading books as she recognised the symptoms from caring for her grandmother. She used this to challenge her GP’s assertion that there was nothing wrong with her.

“I said I’ve read in lots of books that it is heredity and I’m doing exactly what my grandmother did. And she said “oh it’s ridiculous I haven’t heard anything like this” and I said “I know that I’ve got it”.” **Participant 8, Female with AD**

Prior recognition of deterioration in memory and independent seeking of medical intervention seemed to prepare participants for their diagnosis, which, in turn, resulted in more active seeking and use of information after diagnosis. Instead of presenting a challenge to internal coherence, information had the potential to be beneficial as it increased knowledge and understanding of dementia. In contrast to participants who had set their dementia to one side, for these participants, information leaflets that provided medical information were valued: they helped understanding by providing facts about what was happening in the brain. The activity of reading was itself experienced as beneficial as it was seen as keeping the brain active. Written information was therefore viewed as a valuable resource that could be referred to as the need arose.

“Well it explains things about what’s happening to you and how it happens to other people, you know. I don’t feel as bad now about it as when I first found out, I’m used to it now, you don’t feel as panicky as when you first find out do you? Reading about it keeps your mind going doesn’t it? I can just pick up and read when I feel like it.”

Participant 12, Female with VaD

“To be honest I can’t remember what I’ve read, but I’ve got it here and I can refer to it. I think that anything that you’re given is to be useful and should be looked at.”

Participant 11, Female with AD

Information was felt to be reassuring because it reported the experiences of others and could be consulted as the need arose. This resulted in a changed understanding of the situation and helped to facilitate their acceptance of the diagnosis.

Some participants who felt in control also spoke of a willingness to attend support groups and a dementia café as they felt that speaking to others in the same situation would be useful.

“I shall enjoy it, I really will, because I’m used to elderly people and it will be nice for me to have someone to talk to, it’s nice to have someone to talk to, knowing that they’re not going to make fun of you or create problems for you, which will be nice, because I don’t know of many people I could speak to, I need to speak to other people in the same position. You have to be careful, but you could perhaps go there and learn things.” **Participant 8, Female with AD**

Another participant did not speak about going to a specific group for people with dementia; however, many of her friends had dementia, and so she had learnt from their experiences and could consider what the future might hold as a result. One friend in particular, she indicated that she wanted to see:

“When I see her, no, it won’t be tomorrow, but when I do see her, I’ll have a chat with her, but I don’t know when that will be.”

Interviewer: “Why do you want to talk to her about it?”

“It will be good to hear what she has to say, find out what she knows about it because she’s my friend, I can trust her.” **Participant 6, Female with AD, 84**

Some participants clearly appreciated the chance to talk with people in similar circumstances and the opportunity to acquire new information and knowledge was of particular value, because it was based on their own experiences. The fact that they perceived this to be a safe environment, in which they could share their own experiences and feelings, without fear of ridicule, was also important. Although at the time of interview participants had not yet done this, they had received all the information that they needed to know about the services available and spoke of it as something that they would use in the near future. Information about dementia could therefore be seen as

empowering and was sought and used to help the person with dementia take charge of their situation and to feel more in control.

Discussion

People with dementia have different needs for information. Participants used and understood information given to them in different ways, dependent on their reaction to the diagnosis, their existing perceptions of dementia and the extent to which they felt that they could influence their situation. The people with dementia in this study actively attributed different meanings to dementia and understood dementia in different ways. This affected their experience of making sense of dementia which, in turn, impacted on information behaviour. This confirms Dervin's (2005) proposition that the value of the same information to different people is likely to vary, according to how they conceive of their situation and the nature of the gap that they experience (Ford, 2015).

Some participants avoided information, a phenomenon discussed more generally by Case and Given (2016), if it was seen as a challenge to their way of life or if finding out more seemed to them to be futile. Although participants in this study needed, sought and used information from their carers to maintain functioning in their daily life, many avoided information from other sources. The normalisation of memory loss, as part of the ageing process, and accompanying denial of the illness has been identified in other studies capturing the subjective experiences of people with dementia (Aggarwal et al. 2003). Clare (2002; 2003) argued that seeming a lack of awareness of being diagnosed with dementia may be a coping strategy, and should not be viewed solely as a physical symptom of the disease. At diagnosis, people may not need, or seek, additional information, because it can make them feel upset or worried about the future (Leydon et al., 2000; Williams et al., 2003) and, instead, they avoid information. Spink and Cole (2006) also suggested that a diagnosis of any illness does not necessarily lead to the person seeking and using information, as might be expected. Information avoidance may be adopted as a coping strategy (Case and Given, 2016), particularly, as in this case, when a person who has been diagnosed feels powerless to help or change their situation.

Many participants did not consider written information to be useful and, for example, did not seek information from specialists at the memory clinic, although recent work has suggested that written information from doctors was helpful (Mastwyk et al., 2014). Ley (1988) questioned the value of written information, because it does not bring about behaviour changes, and Rees and Bath (2000a) suggested that written information can be hard to understand. This study concurs with the conclusions of a number of other

commentators in the 'patient empowerment' discourse (Dixon-Woods, 2001), that information should be provided to all, even if it is only perceived as beneficial by a few, to provide explanations and increase understanding. Other participants in our study were more active information seekers, and required further support to understand how the information that was provided fitted with their own situation, particularly with regard to the potential progression of the disease. The time of diagnosis is very important for both patients and carers (Lecouturier et al., 2008), and these participants indicated that they were not ready to ask these questions at the diagnosis, but required additional support in the following weeks. Finally, a minority of participants viewed information as beneficial as it helped them to feel in control of their situation. They viewed dementia as a medical condition and found that information helped them to make sense of the changes that they were experiencing. These participants were more likely to read the literature that they had been given and to want to discuss their diagnosis with others in a similar situation.

A further interesting finding that emerged from this study was the importance of privacy and the person's desire to retain autonomy and control of their personal information. Although it was not one of the objectives of the study to examine this, in some interviews it emerged while discussing issues relating to sharing information and experiences with others. On the one hand, the people diagnosed with dementia showed a reluctance to share information with other people, e.g., friends in social settings, and were keen for family members not to discuss their condition with other people, because of their desire for privacy and concern about what others may think. On the other hand, some of the participants felt that talking about their condition with people with dementia was an opportunity to find out more from people who were in a similar situation, and with whom there might be greater understanding and empathy. Trust was important in these acts of sharing, and underpinned their desire to be careful with their information. The person's sense of privacy, and desire to keep control of their personal information remained important to them. However, not sharing this information with others, may also have resulted in limited access to informal information channels such as family and friends.

Comparison with previous studies

Robinson et al.'s qualitative study (2005) of the information needs of carers of people with dementia reported extensive needs for information prior and during diagnosis. It found that carers were often active information seekers, who utilised a number of different sources as they sought answers to their questions and who felt relieved at the confirmation of a diagnosis as they could begin to make plans for the future. The people

with dementia in our study, unlike the carers in Robinson et al.'s study, tended to be passive recipients of information with less motivation for seeking information independently and, in many cases, who were more reluctant to find out about the future. This suggests that health professionals need to be sensitive to the differing needs of carers and patients.

Two studies have considered the ways in which people make sense of a diagnosis of dementia or mild cognitive impairment (Lingler et al., 2006; Langdon et al., 2007). Both these studies reported that participants were uncertain about whether it was a disease or age-related memory loss, and indicated that normalising symptoms as age-related memory loss resulted in information about dementia being avoided. People with mild cognitive impairment did not use health care professionals as a main source of information, but instead made sense of their diagnosis internally, based on their existing perceptions of dementia and personal experience. Our research concurs with this research, and found a similar process occurs for some people with dementia, although our study adds to this in reporting that they do not seek or use external information because they felt it would be pointless, as they could not change their situation.

Another study found healthy older people were reluctant to approach their GP if they were experiencing some memory loss (Corner and Bond, 2004), as they felt that it would be futile and that nothing could be done to help them. This study found that this feeling remained amongst the participants even after they had been diagnosed and received information from medical professionals and the Alzheimer's Society.

Leydon et al.'s (2000) study of the information behaviour of cancer patients found that they did not independently seek information as they had faith in their doctor's knowledge about the treatment that was available. This study, in contrast, found that people with dementia were more likely not to seek information because they did not quite believe the diagnosis that they had been given and they did not feel that either they or their doctor could offer any intervention that would help. This study accords with previous research regarding women diagnosed with breast cancer, who did not want additional information when they were coming to terms with a diagnosis (Rees and Bath, 2000b); the findings in this study add to this in identifying other reasons why people diagnosed with dementia did not want information.

Explanations and implications for clinicians and policymakers

At diagnosis, some people with dementia may downplay their memory problems and want to continue their lives as normal. They are not receptive to the information provided, particularly because they are not able to influence their situation. Information avoidance is often a part of health information behaviour, and although it might be expected that people would need and use information to help to manage their disease, they are less likely to do so if it is a challenge to their way of life, causing disruption and uncertainty (Johnson et al., 2001; Spink and Cole, 2001; Case and Given, 2016). Professionals working with people with dementia should be aware that this may be the response to receiving a diagnosis, and should consider how they can present information positively and in a way that attempts to overcome feelings of futility.

Some people with dementia do want to find out more or require additional support as they try to come to terms with their situation; they did not always feel that they had sufficient support after diagnosis. Follow-up appointments, perhaps in the home so that the person with dementia feels at ease, should concentrate on the needs of the person with dementia by trying to give more personalised information. Consideration should be given as to whether information, particularly about the prognosis, should be given all at once, or in stages (Mastwyk et al., 2014); information overload can increase confusion and uncertainty among people coming to terms with their diagnosis.

While, for some participants, patient information leaflets and booklets were an important source of information and support (Mastwyk et al., 2014), for others they were put to one side and not looked at. Support services should not assume that because they provide written information that it will be used, but they should also recognise that some people with dementia do value this resource.

Information can help people to feel more in control of their situation, to know what to expect and to help them prepare for the future. However, few of the participants in this study wanted to know about the prognosis and those who did find it often raised further questions. This has implications for their family carer, who may have to take on increasing responsibility for gathering information and making plans, thereby increasing the caregiver burden. For people with dementia, the initial reaction may be to reject the diagnosis, and only later may be more willing to accept new information.

Support and self-help groups are valuable in providing information and support to people with chronic illnesses. They may be less successful for some people with dementia, as this study showed an unwillingness to discuss the diagnosis with people other than medical professionals and close family, because of the perceived stigma. However, some

people felt that discussing their illness with people with a similar condition was helpful, in that it was a safer environment, and because they might learn from their experiences. Professionals should create environments in which people are encouraged to share their experiences and overcome the negative connotations that accompany a diagnosis of dementia. If people with dementia feel uncomfortable discussing their situation in group settings, then it may be that one-to-one support is required.

Strengths and weaknesses

This qualitative study has gathered experiential data from the time of diagnosis. Some memory clinic attendees, who were eligible to participate, declined to do so as they did not want to think about the diagnosis or discuss it further. These participants may have experienced information needs, seeking, sharing and use in different ways to those who participated. In addition, during the nine months of recruitment, the memory clinic underwent considerable changes due to re-organisation in the NHS, which meant that for a number of months the number of new referrals to the clinic decreased dramatically, impacting on the recruitment to the study. The relatively small sample size may therefore limit the extent to which the findings can be generalized to other people with dementia. Qualitative research seeks to yield findings that are transferable to others in similar circumstances, and we feel the results are applicable to people who have recently been diagnosed with dementia. Other studies have employed a similar sample size (Lingler, et al., 2006; Beattie et al., 2004). This paper reports the experiences of people referred to a memory clinic for diagnosis; however, some people do not have access to this service and many people with dementia are not diagnosed until the later stages of the disease. They are likely to have quite different needs for, and access to, information, although their undiagnosed status makes them hard to reach. Furthermore, the sample was self-selecting and not random, and those who did not choose to participate in the study may have presented different views and experiences.

Unanswered questions and future research

This study reports the information behaviours of people with dementia just after they have received a diagnosis: a longitudinal study that followed participants over the course of the disease would aid understanding of how information needs and behaviour change over time and with the progression of the disease. It would also be useful to examine how current theories of information behaviour and, in particular, health information behavior, can help develop a better understanding of this group of people. This study examined the experiences of people receiving a diagnosis and asked about the

value of information from their perspective, however, further research could measure how information seeking and use impacted on their health outcomes, e.g., their quality of life, as well as benefits for carers.

Conclusions

Although information from external sources can be used to help make sense of a diagnosis, people often rely on their internal beliefs and existing perceptions of dementia; consequently information given by health professionals will often be put to one side and not considered. For those that did need and use information to try to come to terms with dementia, some found the information they were given caused anxiety about the future and did not meet current needs. Understanding individual preferences for information of people with dementia requires bespoke information packages, distinct from the information given to carers. Developing strategies to encourage information acquisition (by overcoming feelings of futility) may help the person with dementia to feel more in control, to take a more active role in the management of their condition and to plan for the future.

Meeting the individualised needs of people with dementia is an important part of practising person-centred care. People with dementia may avoid information about their diagnosis due to the negative connotations associated with the word 'dementia', and with mental health problems more generally. This paper shows that people newly diagnosed with dementia report feelings of powerlessness and futility when they receive a diagnosis which can preclude independent information seeking and use. However, some people with dementia can use information about the diagnosis to provide an explanation of their symptoms, helping them to feel more in control of their situation. It is important for health professionals to appreciate that people with dementia need information which is relevant to their situation and that might be quite different from that which they give to their carer(s).

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