



Putting the picture together: a narrative approach to understanding the emergence of dementia in a partner

Research Summary

KEY MESSAGES:

- This study takes a narrative approach to understanding how the illnesses of dementia emerged and were experienced from the perspective of the partner without symptoms. It involves seven women whose partners experienced young-onset dementia.
- The emergence of chronic illness challenges established ways of knowing ourselves and our approaches to life. Narrative provides a means of understanding the disruption caused by illness and an opportunity to reflect on the adjustment to new circumstances.
- This study has shown how the insidious nature of dementia can present slowly and sporadically over many years, making it difficult to take action and meaning the emergence of illness may only be fully understood retrospectively.
- The way in which the symptoms presented reflected the social and individual nature of the lived experience of dementia.
- A failure by health professionals to take concerns seriously had often led to a lengthier search for answers and time to diagnosis.
- The manner in which the diagnosis was delivered and a lack of specific information had an important bearing on each of the couple's immediate responses and adjustment to living with illness.
- This study demonstrated the bounded nature of the biographical disruption created by the emergence of chronic illness for a couple. The onset of illness presented challenges to the women's way of being in the world and the relationship of the couple.
- Whilst the illness represented a break from each of the couple's previous way of being, it was experienced within what continued to be a mutually caring partnership beyond the diagnosis of dementia and reflected the interdependency of human relationships.

INTRODUCTION

This qualitative study explored how the emergence of illness was experienced from the perspective of the partner^a without symptoms. Whilst the recruitment strategy was not gender or age specific, all seven participants were women and their partners all experienced young-onset dementia^b.

This study was focused on the impact of chronic illness on the couple and the emotional experience of the woman. Through adopting a dual narrative approach^c the particular of the individual experience and commonality across stories is reflected^d.

BACKGROUND

Dementia is the umbrella term for a range of illnesses and disease symptoms. Symptoms experienced vary between individuals and the different illnesses, making dementia a complex concept which is difficult to understand (Hughes 2011). The infrequent occurrence of young-onset dementia, the insidious nature of how the illness begins and the different symptoms that are experienced, makes identification and diagnosis difficult (Rosser et al 2010).

Chrisp et al (2012) demonstrated a “bounded autonomy” in responding to the emergence of dementia, where the decision making of both the individual with symptoms and their partner is tied to the actions of the other. Bury (1982) describes the emergence of chronic illness as a “biographical disruption” that forces a person to rethink their outlook, self, relationships and behaviour. The bounded nature of dementia for a couple suggests this biographical disruption is likely to be shared by the partner without the illness.

METHODS

An interest in sharing experience, rather than the timing of the person’s diagnosis, was the key factor in recruitment. The interview process involved a thematic conversation that responded to and was shaped by the women. This process related closely with Mason’s (2010) “creative interviewing”.

Each woman told a series of short stories that represented what she wished to share at that point in time. The dual narrative approach linked these stories into a plot that encapsulated each woman’s emotional experience and located the commonality across stories into themes (Bruner 1986, Polkinghorne 1995).

^a Partner refers to spouse, partner and other co-habiting relationship.

^b Illness occurring before the age of 65.

^c Narrative analysis combined the stories each participant told into an overall plot and themed analysis brought together common elements into a category (Bruner 1986, Polkinghorne 1995).

^d For the full narratives see contact details at end of paper.

FINDINGS

Emergence of illness

The stories the women shared did not reflect a reluctance to seek answers. Rather the delay in taking action was caused by how the insidious nature of the symptoms had presented slowly and sporadically over many years. The couples took action in relation to the illness together, reflecting the bounded nature of dementia^e (Chrisp et al 2012).

Retrospective understanding was a key theme. The time period involved in the emergence of illness was over a number of years and all of the women had only fully understood how their partner's illness had emerged by looking back in time. Lived-time^f was more relevant than clock-time in the way the women shared this experience.

The stories the women shared about how the illness emerged reflected a range of experiences and demonstrated the individual and social nature of the lived experience of dementia. Whilst there were some common symptoms^g, the manner in which they were experienced varied. For some memory problems were the key identifying factor, whilst for others it was changes in their partner's ability to carry-out tasks or uncharacteristic behaviour.

Diagnosis and influence of health professionals

The women experienced a range of emotional responses to the diagnosis. Whilst some of the women described this as having been provided with an answer and having their

suspicion confirmed, other women described their response as feeling devastated. There was a common theme in the expression of how the provision of a diagnosis had represented finality and the feeling that there was no going back from it.

The way in which the diagnosis was delivered by the health professional had a detrimental impact for some. This included a lack of information and failure to provide a clear understanding of what the diagnosis meant. For some, a non-specific diagnosis or incorrect diagnosis led to a lengthy continued search for answers that would leave the woman feeling unable to respond appropriately to her partner's illness for a long period of time.

Living with illness

The emergence of illness represented a biographical disruption for the women's previous way of being and relationship with their partner. The illness had brought the emotional impact of loss and changes within the couple's relationship. It presented a challenge to the women's identity and required an adjustment in learning to approach their life in a different way.

Whilst the illness presented a biographical disruption for the couples, the continued importance of the relationship was evident. The couples continued in a mutually caring partnership beyond the diagnosis of dementia, which challenged the convention of calling the partner without symptoms 'the carer'. This reflected an "ethic of care"^h in showing how dementia is experienced within the context of relationships.

^e The decision making of both the individual with symptoms and their partner is tied to the actions of the other.

^f This represents time as the meaning given to events as opposed to a linear process determined by clock-time (Bruner 1987, 1991, Ezzy 1998).

^g Memory problems were the key factor in many of the experiences, but this was often linked to other symptoms that may not have been related to each other until after the specific diagnosis provided the opportunity to investigate the illness further through literature and information accessed via the Internet.

^h "Ethic of care" recognises the interdependency of human relationships. It does not question dependency and the need illnesses such as dementia will present for being cared for, rather it recognises care is given and received by everyone (Barnes et al 2008).

CONCLUSION

This study demonstrated the insidious and individual nature of the way the illnesses of dementia can occur. Whilst this presented a challenge for taking action, there was often a failure by health professionals to take concerns seriously, which had lengthened the search for answers.

It is important that health professionals have a greater awareness of the illnesses of dementia and how it can manifest in different ways.

It is also essential there is a considered approach to delivering what is a life-altering diagnosis.

The provision of an appropriate level of initial information and tailored follow-up is essential to support couples to adapt to, and live well with, a diagnosis that represents a break from their previous way of being in the world.

For the individual narratives of illness and further information on the study, contact:

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