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## Title Page

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The experiences of patients and spouse-carers in the daily-management of care at the end of life: findings from a phenomenological study

Abstract

Background: Home is the preferred location for most people with advanced disease and at the end of life. A variety of care professionals work in community settings to provide support to this population. Patients and spouse-carers are rarely accompanied by these sources of support at all times, and have to manage independently between their care professional contacts.

Aim: To explore how patients and spouse-carers manage their involvement with care professionals in the community setting.

Method: Interpretive phenomenology informs the design of the research. Sixteen interviews were conducted with patient and spouse-carers. Interviews were recorded and transcribed verbatim. Data were analysed using phenomenological techniques including Template Analysis.

Findings: Patients and spouse-carers are interdependent and both parties play a role in co-ordinating care and managing relationships with professional care providers. People actively make choices about how to manage their situation, and develop and modify managing strategies based on their experiences.

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Conclusions: When daily-management is effective and care professionals acknowledge the dyadic nature of the patient and spouse-carer relationship, people have confidence in living with advanced disease.

Key words

Caregivers, Palliative Care, Patients, Primary Health Care, Qualitative research, Self-management.

## Background

Life expectancy is increasing (WHO, 2013) and healthcare is continually evolving to meet the changing needs of populations and communities. Deaths from communicable diseases are decreasing, but the implications of an aging world population are increases in the complex diseases of aging, such as heart failure, Chronic Obstructive Pulmonary Disease (COPD), cancer and multi-morbidity. Many people now live for longer with advanced diseases (AD) (where disease is in the advanced stage and treatment focusses on symptom management) (Economist Intelligence Unit, 2010). Health care systems must respond to this changing demographic of society and support people to maintain their quality of life for as long as possible (Davies and Higginson, 2004). Although most people across Europe die in hospital (Davies and Higginson, 2004) people who are living with AD towards the end-of life frequently cite home as their preferred place of care and death (Gomes et al., 2013). Indeed, most people in the last year of their life will receive a significant component of their care in the community setting (Andersson et al., 2006, Hughes-Hallett et al., 2011, Rutten et al., 2012), even when they then get admitted to hospital at the very end of life.

There are significant variations in the models of care around the world to support people at home who live with AD. For many people who have been identified as having AD, end of life care is provided under the palliative approach. However, specialist hospice-palliative care service availability varies greatly throughout the world (Wright et al., 2008). Regardless of model

of care, when patients are in the home environment they will generally only be accompanied by care professionals<sup>1</sup> for some of the time.

Patients and spouse-carers have to 'front line' manage their illness independently between their contacts with care professionals. If this is to be done effectively then the patient and spouse-carer need to be competent in their own care in the face of fluctuating health, and in dealing with complex symptoms. They also need to have good knowledge of resources (DeVito Dabbs et al., 2013). All of these roles and responsibilities allude to the concept known as 'self-management'. There is ambiguity present in the terminology used to describe self-management, which often also incorporates a number of other closely related concepts such as self care and self-help (Johnston et al (2009), Johnston et al (2014)). A recent concept analysis identified that supported self-management is a professionally facilitated process which is *'linked to the outcomes of the patient's actual and potential capacity to meet their identified needs'* (Johnston et al 2014). Self-managing can also be understood as a naturally occurring process whereby people are engaging in action and decision within their own context at all times. This is a dynamic process in which consumers of care (patients and spouse-carers) are knowledgeable about their own body, experiences, values and beliefs, and will access information from a wide range of sources to meet their self-perceived needs (Kendall et al (2011)). These will include health and care services, but also person and setting specific resources such as friends, community, and the internet. In this paper, we focus on the latter model of

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<sup>1</sup> 'Care Professionals' is used to denote all professionals involved in caring for and supporting someone at the end of life. This might include people from health, social and voluntary organisations.

self-managing, but argue that the notion of 'self' management for people with AD is problematic, as research has repeatedly shown that where patients have indicated that they have a carer, then their experiences are inevitably interconnected (Higginson et al 1990, Jo et al 2007, Seamark et al 2004). We have chosen to use the term 'daily-management' to differentiate this from the focus purely on 'self'. We define daily-management as those activities that are undertaken by the patient and carer to manage their lives.

We have identified no current research investigating the patient and spouse-carer experience in relation to daily-management of care professional contacts in the last year of life, and this paper aims to meet this gap in the literature. We draw upon qualitative interview data from a larger study that explored the lived experiences of patients and their spouse-carers who received their care from a range of care professionals.

### Methodology

This paper explores the daily-management of care professional contacts undertaken by patients who have high likelihood of dying within 6-12 months, and their spouse-carers. The study used phenomenological methodology to illuminate the lived experiences of patients and spouse-carers. The method was informed by the work of Van Manen (1990), whose 'human science' hermeneutic approach aims to challenging every day thinking and ways of behaving and therefore contribute to improvements in practice (Van Manen 2011). Van Manen's method is heuristic rather than prescriptive, and he suggests that the specific method needs to be suitable to the phenomena under investigation. This approach enables flexibility to suit the needs of

research working with vulnerable populations. Phenomenological research is underpinned by the phenomenological attitude (consideration of how the world is experienced rather than how it is already theorised and conceptualised), which is achieved by various processes including the phenomenological reduction and the vocative dimension (van Manen 1990). The phenomenological reduction is a method in which the researcher aims to overcome '*subjective, or private preference, inclinations or expectations*' and to '*strip away*' (van Manen 1990 p. 185) theories and scientific ideas that may prevent them from coming to terms with experience as lived. The 'vocative' dimension emphasises the role of language in the analysis of text and the creation of phenomenological descriptions. In addition to the phenomenological attitude, empirical methods (recruitment and data collection) are required to access actual examples of lived experience and reflective methods (analysis and interpretation) required to explore these lived experience examples.

#### *Recruitment and data collection*

##### *Participants:*

We identified people with AD and in the last year of life by using the Prognostic Indicator Guidance (PIG) (GSF, 2011). The PIG is a tool included as part of the Gold Standards Framework, a UK program for improving end-of-life care. The PIG includes diagnostic guides that contain pathological indicators and 'the surprise question', which recognises intuitive understanding in health professionals, and asks them to consider whether they would be 'surprised' if the individual were still alive in six to twelve



months. Further eligibility criteria required participants to be over eighteen years old, English speaking, and receiving care from two or more community healthcare services. Carers had to self-identify as being the main informal carer for someone with an anticipated prognosis of twelve months or less. Although not an initial inclusion criteria, all carers who participated were also the spouse of the patient, a situation that we acknowledge through the use of the term 'spouse-carer' to describe these participants

Community nursing teams (district nurses, specialist palliative care nurses, and disease specific specialist nurses) identified eligible patients and carers and gave them an information pack about the research. The pack included a reply slip to be returned to the researcher if further information was required. When the reply slip was received, a researcher would contact the patient and carer to discuss the research and obtain written consent to participate.

Participant characteristics are summarized in Table 1

Table 1. Participant characteristics: the dyads

<b>Patient ID</b>	<b>Sex</b>	<b>Age</b>	<b>Diagnosis (patient's perspective)</b>	<b>Care professionals on chart</b>	<b>Spouse-carer ID</b>	<b>Sex</b>	<b>Age</b>	<b>Care professionals on chart</b>
P2	Male	67	Prostate cancer and 'growth' on spine	2	C2	Female	68	11
P3	Male	63	Lung cancer with metastatic disease	5	C3	Female	62	5
P5	Male	70	COPD	2	C5	Female	62	4
P7	Female	64	COPD and diabetes	6	C7	Male	65	3
P9	Male	65	Heart failure and diabetes	8	C9	Female	64	7
P10	Male	76	Heart failure, kidney failure, early stage dementia.	8	C10	Female	? <sup>2</sup>	12
P11	Female	60	Parkinson's disease	5	C11	Male	63	5
P12	Female	68	Parkinson's disease	7	C12	Male	68	3

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<sup>2</sup> C10 did not provide her age.

*Interviews:*

Eight patient/carer dyads participated in the research. All interviews were undertaken in the participants' homes and lasted between 31 and 99 minutes. Patients and spouse-carers were interviewed separately, as the aim was to explore their personal perceptions of receiving and managing care from the perspective of each dyad member. In one interview the patient came and sat in the same room as the spouse-carer whilst the interview was being undertaken, and in two others the spouse-carer or other family member periodically interrupted the interview. The presence of these people did not appear to substantially divert the course of the narrative of the participants, and was reflected upon during analysis of data. A semi-structured topic guide was used to ensure that relevant areas had been discussed within the participants. The data were collected in 2010 and all participants lived in the north of England.

It has been suggested that people with AD do not always know the names or roles of the people who are providing their care (QNI 2011). It was anticipated that participants in this research may have difficulty describing the array of services involved in their care, and reflecting on their experiences of this complex care situation at a time when they were experiencing multiple and rapid changes in their health and circumstances. Visual mapping techniques, such as ecomaps, genograms (Rempel et al 2007) and Pictor charts (King et al 2010) have been used in health and social care research to help elucidate a graphical representation of family, social and professional relationships. Although these techniques all aim to elicit information about relationships and interactions, Pictor was felt to be the most appropriate

technique for this research as it facilitates exploration of role perception, and relationship dynamics across networks of care (King et al, 2013). It is also a relatively simple technique to use with people who may have complex health problems.

Pictor involves the creation of a 'chart' detailing the people involved in a given care situation, which becomes the basis of the ongoing interview. Participants were asked to consider all of the services and/or people involved with helping them to live with their illness. These were written on arrow shaped 'post-it' notes and arranged by the participant on a large sheet of paper in a way that helped them to discuss their experiences of the care situation. They were advised that they could use the space on the paper, and/or the direction of the arrows to demonstrate roles and relationships but that this was not compulsory. As the charts were being created, the participant discussed their rationale for the location of the arrows, and the created chart became the basis for the ongoing interview. A carer creating a Pictor chart can be seen in figure 1, and a completed Pictor chart can be seen in Figure 2. Further discussion of the use of Pictor with people affected by AD can be found in Hardy, King and Firth (2012) and King et al (2013).



Figure 1. A carer creating a Pictor chart. (picture copyright Beth Hardy).

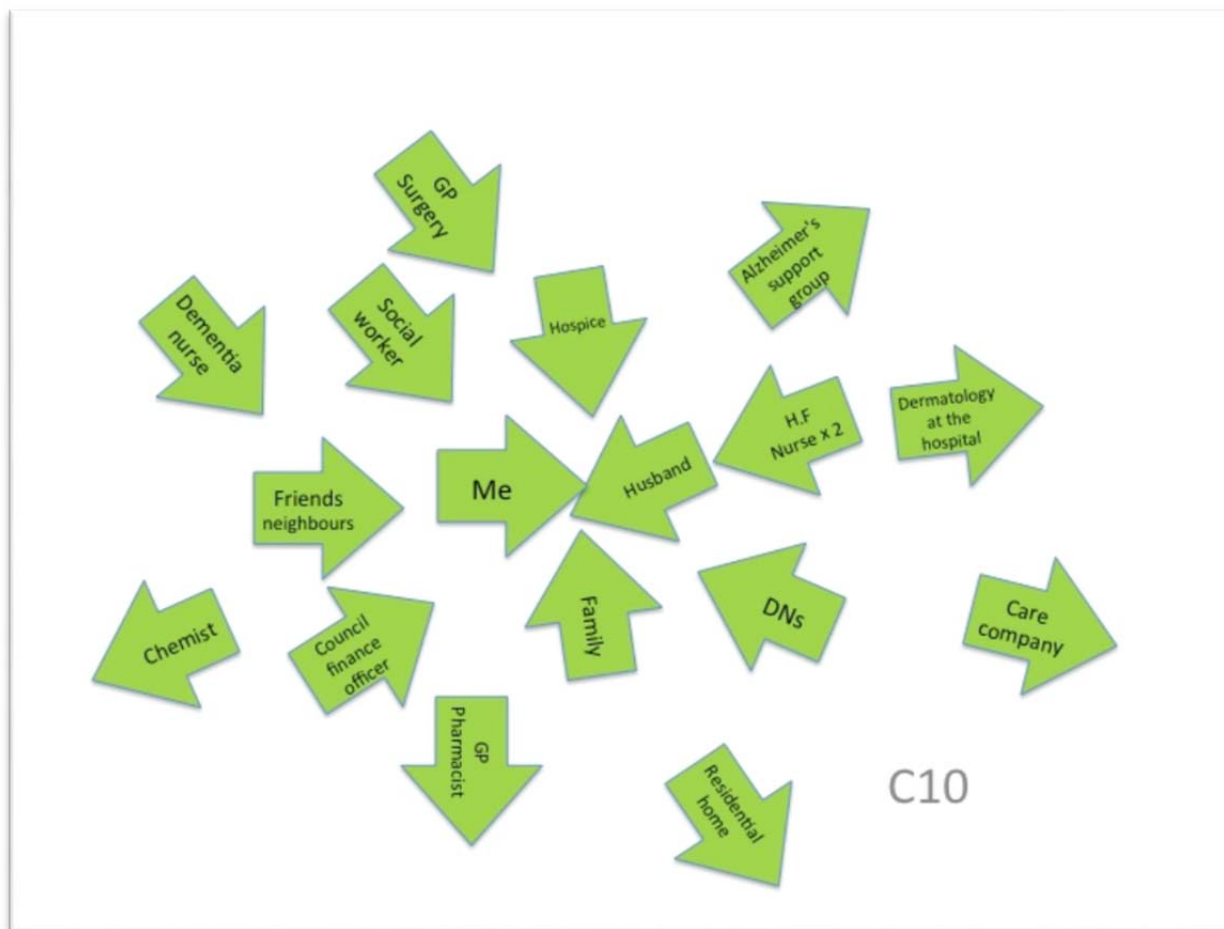


Figure 2. Example Pictor Chart: C10, whose husband had heart failure and early stage dementia.

*Data analysis and interpretation:*

Interviews were recorded and transcribed verbatim. Pictor charts were imaged and retained. All detail that alluded directly to the participants' identity was removed from transcripts and charts and replaced with pseudonyms. Phenomenological methods of analysis and interpretation were employed. This involved a thematic analysis, following the Template Analysis style (King, 2012) to manage the large amount of thematic data that were generated. Template Analysis is a technique that involves developing a hierarchical template of themes that are used to support interpretation and writing up of

findings. The template is developed in an iterative process whereby it is initially based on the coding of a sub-set of transcripts, and then modified as further coding is undertaken. Despite the template being 'hierarchical', the hierarchy does not necessarily indicate a hierarchy of importance; rather, it is a way of organising the data that allows the researcher access into the participants experience so that they can then explore the meanings within the text. A further advantage of Template Analysis is that it allows the researcher to create an audit trail of the analysis stage of the research, and document how themes were identified and thinking evolved (King, 2012). Thus the process of revelation and the decision trail is documented (Rapport, 2005).

Interpretation of the thematic data involved utilising the hermeneutic circle. The parts and whole nature of a phenomenon were considered by moving between the developing template, the original participant narratives, field-work notes and diaries, the created Pictor charts, and developing interpretations of the phenomenon, whilst trying never to lose sight of the individual accounts and contexts (Crist and Tanner, 2003). Writing, and re-writing, was central to this interpretive process as a method for developing ideas and exploring concepts.

Pictor charts were considered alongside the interview transcripts. These charts do not aim to be objective representations of participants' support networks, but rather they capture such networks as experienced by interviewees. As such charts were used as a tool to 'signpost' the researcher to areas of the data that may be of interest. For example it was noted on most of the charts that patients and spouse-carers would place themselves adjacent to each other. This observation encouraged the researcher to

consider how patient and spouse-carer considered their relationship dyad within the context of care in the community setting.

Emerging findings were discussed with professional and lay-members of the steering group, and with practicing care professionals in a process of collaborative reflection on the development of the findings (van Manen 2011).

*Ethical considerations and permissions:*

The study was granted ethical approval from the NHS Research Ethics Service (ref: 09/H1310/52).

Findings

People discussed between two and twelve services that were providing their care, and described varying levels of involvement and success in managing their own care and care contacts. The findings are presented in relation to three themes 'A dyadic approach to managing' 'everyday choices' and 'managing strategies'.

*A dyadic approach to managing*

Living with AD significantly affected both the patient and the spouse-carer. Spouse-carers however did not always identify with the use of the term 'carer' to formalise their role. They were wives and husbands involved in a situation that affected them and their partner.

I'm his wife, primarily. And I want to be his wife for as long as I can.  
So that's.... I do care for him, I am his main carer, but I would be  
anyway as his wife wouldn't I? C9



Patients realised that their illness had impacted upon their partner and acknowledged that they were unable to manage without them.

My (husband) is the first person (to support me) because he's here all the time, and he's with me. P11

The caring role was an extension to the marital relationship, and previous managing behaviours continued and evolved to meet the new demands of the situation. People drew on skills such as knowledge of the healthcare system and previous experience of managing people as they attempted to ensure that the care needs of the person with AD were met.

(wife) does that (arranging prescriptions and appointments). Because she works in system (as a doctors receptionist) so she's knows when I'll want them. P5

Both patients and spouse-carers took on aspects of organizing and arranging care. However, it was often the case that formalized organization of care was left to the spouse-carer:

(wife) is in touch with the clinic, the hospital, the doctors, the erm, pharmacy, and she's, she keeps a check on me like medication and everything...

P10

Spouse-carers stepped into this role, alongside the personal care they often provided. In addition, they also took on activities that were previously undertaken by their spouse, such as household management (finances, cleaning, shopping) and maintaining the home. This could sometimes be a

considerable source of distress to the patient who could no longer undertake such tasks.

Well, she does the things that carers do when the carers aren't here. If I get messed up she cleans me up. She does this bladder flush everyday. She does everything. If I'm wet, cos sometimes I dribble from here even though I've got a catheter. Sometimes she's changed the whole bed -the carers will do it when they come but if they've just gone, say, and this happens she has to change because I can't stay in it for a number of hours until they come again. And when I think about her having to look after the garden it upsets me it does... (starts crying) when I think I was so fit, so fit up to 7, 8, 9 months ago when this first started, my goodness, what a change its brought. Mind you, I try to help her by... I'll do the vegetables, things like that for dinner. P2

### *Strategies for managing*

Strategies for managing included keeping records of phone numbers and names of individual services, and knowing effective pathways to access these services. Knowing how to contact services, and anticipating that they would respond in a timely manner were of great comfort, and enabled people to continue to feel that they could independently manage their care, with the confidence that extra support was available if required.

We don't need them (the nursing team) to be coming in all the time. Not everybody would think the same way as us, obviously, but I just feel that we would be taking them away from patients further down the line that need them more than we do at this moment in time. And

we've also got the numbers, so if we do need to ring anybody we've got the numbers. C3

Confidence in the effectiveness of strategies was an essential component of people's belief in their ability to cope with illness. Where management strategies were utilised to obtain healthcare, but failed, the patient and spouse-carer could find themselves in a situation that felt out of their control. This is highlighted by a C3 who described her attempts to obtain assistance for her husband in the out-of-hours period. He had recently received chemotherapy, had developed persisting hiccoughs, and could not eat.

But that was on the Friday, but on the Saturday I rang the emergency doctors, because of course all the surgeries are closed, and they sent a nurse out and gave them an injection, which didn't do any good, and I rang again. And all Saturday night I must have spoken to 13 or 14 different people on the phone. And at certain point you get away from the emergency doctors to NHS direct. Horrendous. Absolutely horrendous. C3

Ultimately, the spouse-carer got hold of their regular specialist nurse after the weekend and a hospital admission was arranged. However, this incident had led the spouse-carer to decide that in future they would bypass community healthcare services during the out-of-hours period and obtain emergency admission to hospital instead. People were experientially learning how to manage their situation, and daily-management strategies were evolving to overcome hurdles that were faced.

### *Everyday choices*

Patients and spouse-carers identified many people and services that were involved in their care; some of whom were more closely involved than others. Who is involved may be partly the patient or spouse-carer's choice; the patient and their spouse-carer try to utilise the people who they find most useful to meet their needs. Amongst the plethora of services involved in care, people make decisions about who to contact to address their issues. These decisions are multi-faceted, and based on a range of factors such as previous experience of a service, personal knowledge and preference, advice of peer networks, confidence in care, availability, personal relationships, and a sense of being known. The use of these individuals may be to the exclusion of other services that may also be available, or may involve bypassing services that would be the 'correct' ones to use.

I'm supposed to ring her (practice nurse), and it's supposed, they're supposed to be all involved but I find I get on easier ringing (respiratory nurse specialist)... Oh to be honest, I don't like the practice nurse. P7

In addition to personal preference, people chose to use the services that they anticipated would be best able to manage the problem with which they were seeking help:

BH: If you had any problems whom would you contact?

C2: It would depend on the problem wouldn't it; if it's medical and I think the nurses can deal with it... Well nurses first, I've got their

number and I ring them. And if I can't find them it's the receptionist. If I wanted the GP I'd have to go through the receptionists, and I'm sure I'd get one. I don't have any worries about that.

Relationships with healthcare staff were nurtured when they might prove to be beneficial in the future. C2 described how she had developed positive relationships with the receptionists at her community medical centre. These people were her gatekeepers to the family doctor and the district nurses, services she hoped to access quickly at any point if her husband required them.

Individual practitioners were chosen (where possible) based on the confidence that the patient and spouse-carer had in their knowledge of the condition, combined with their ability to resolve the problem in a way that was acceptable to them.

P12: you do tend to pick, erm, those people (Doctor at the community health centre)...

BH: Right, which er, people sorry?

P12: The people who you can talk to and get on with, who you feel know perhaps a little bit about you and the er, the disease.

Patients and spouse-carers were continually making choices about how to manage their care. Assessing the significance of a symptom, deciding

whether assistance is required, choosing which service to use to address their issue, and considering whether to follow advised courses of action.

For all participants, the managing role was not an optional aspect of care; rather it was part and parcel of their lives living with illness. Successful daily-management helped people to feel in control of their situation and gave them a sense of safety and security living with AD in the home environment. .

### Discussion

Daily-management is grounded in the context of everyday life and the interdependency of patient and carer (Pickard and Rogers, 2012). Everyday choices and managing strategies are developed within the dyadic (patient/carers) relationship, and may be made with or for another person. As Kellehear (2007) describes, it is perhaps unsurprising that people take on a management role in their own care, as people who have spent a lifetime managing their own lives, coordinating families, managing budgets and resources, do not suddenly lose these skills because illness has entered their lives.

This research has demonstrated the active role that spouse-carers take in daily-management. The impact of a spouse's illness upon family carers has long been acknowledged, and carers are known to take on many roles including the provision of physical care, household management, organization of financial affairs, and the adoption of roles which were previously undertaken by the ill person (Ugalde et al., 2011, Stajduhar et al., 2010). Our findings resonate with those of Lawson et al (2012) who explored the effect of transitions between environments of care on caregiving by family members.

In their study, family caregivers were found to be advocating for patients by drawing on their view of the situation gained through their supportive presence, and their experience of coordinating the patient's care. Other studies have also identified that a primary concern of carers is obtaining the best care possible for their loved one (Cain et al., 2004, Funk et al., 2009). Carers undertake proactive information searching, and perceive themselves as acting as a go between for the various services involved in the care situation to compensate for a perceived lack of communication between these services (Hasson et al., 2010).

Our research demonstrates that people make choices about when to use health care and about which health services to utilize, and that these decisions are modified in light of new experiences. However, people can find it hard to assess the legitimacy of their problems and decide when assistance is required, particularly when the option is to contact a care professional with whom there is not an existing relationship, such as in the out of hours period (Aldred et al., 2005, Richards et al., 2011). When people have had a negative experience of a health care service, then there can be reluctance to utilize the service in the future (Exley et al., 2005, Worth et al., 2006).

When daily-managing is effective, people feel confident in living independently, however where daily-management choices and strategies fail to elicit an accepted response then the patient and carer may feel a breakdown in their sense of safety in the home environment. Previous studies have considered 'self' management, but we suggest that in AD, it is important to consider the dyad, as daily-managing is undertaken between both patient

and carer. We propose that 'daily-managing', which considers the context of the individual dyad, may be a more useful descriptor of these activities.

### Implications for practice and further research

People with AD generally prefer to remain being cared for in community settings, where they have to manage independently between their professional care contacts. Confidence in daily-management strategies engenders confidence in managing illness. Care professionals need to be aware of patients and spouse-carers daily-managing practices, abilities and expertise, as well as factors that may impact upon their choices and decisions regarding healthcare. Lack of awareness of these factors may contribute to inappropriate service use, and a breakdown of the relationship between service users and care professionals. The promotion of effective daily-management by patients and spouse-carers living within their own homes should be an aspiration of health services. This might include supporting the patient and spouse-carer to learn new disease and situation management techniques (as in supported self management), but should also acknowledge and develop existing strategies. This should not be seen as an attempt to reduce the involvement of healthcare for these populations, but rather as a method of empowering people to be confident to be able to incorporate illness within their lives.

This paper has focused on the patient and spouse-carer dyad in AD. The extensive role of the spouse-carer in daily-management has been demonstrated. This has implications for people who live alone, or who cannot depend upon a carer. Further research is needed to explore the daily-



management of people who live alone. Investigation into methods of promoting daily-management in the context of both individuals and the dyad, and evaluation of the outcomes of effective daily-management, will commence the process of evidence based practice in this emerging area of care for people with AD and at the end-of-life.

### Strengths and limitations

Phenomenology is a science of 'plausible insight' (Van Manen, 1990), and aims to give voice to human experience and understand the meanings associated with experience rather than provide causal explanation (Van Der Zalm and Bergum, 2000). Findings are not intended to be generalizable, however, the rigorous phenomenological methods employed in this research have led to insights that have transferability to other people with AD at the end of life.

### Conclusions

Our research has demonstrated that the patient and carer dyad is making choices and developing strategies to manage their care professional contacts. When these are successful, a sense of safety and security is achieved, and people have confidence in living with their illness. Further research is required with people affected by AD as to the best ways to support effective daily-management.

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