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The experiences of older people who live with a long-term condition.

Abstract

Aim The aim of this study was to gain insight into the experiences of people aged 65 and older who have learned to live with a pre-existing long term condition.

Method A qualitative approach and the principles of narrative research were used to learn as much as possible about the individuals' stories. A focus group of five men was interviewed and two women were interviewed as a pair.

Findings Existing skills in condition management and interactions with professionals are transferable to new health needs that older people develop, but additional, age-related problems can affect management of long- term conditions. Progressive long-term conditions may become more difficult to manage with age, and it is difficult to distinguish between ageing processes and deterioration of pre-existing long-term conditions. Age-related social and financial changes and society's perception of older people may also present challenges to condition management.

Conclusion Nurses who care for older people should take into account the effects of the person's long-term condition and the ageing process when assessing their needs; understand that people may be reluctant to ask for practical assistance; explore existing support mechanisms that people have in place and their sustainability; and advocate with people to secure appropriate choices related to their health needs.

Introduction

Long term conditions are health problems that cannot be cured, such as arthritis and dementia, but can be controlled by medication and other therapies (Department of Health (DH) 2013). More than 15 million people in England have a long-term condition and this number is set to increase over the next decade (DH 2013). The population of older people in the UK is also rising, and this trend is expected to continue (Ham *et* al 2012). There is no universal definition of an 'older' person (Soule *et al* 2005), but Western society has traditionally linked this with state retirement, at around the age of 65 (World Health Organization (WHO) 2012). While changes in retirement age may mean that this alters, at present it is a common working definition.

A growing number of people now reach the age of 65 with a long-term condition that they have lived with for some time (WHO 2005). Provision for the needs of this group is therefore likely to become an increasingly important part of nursing older people. Although extensive research exists about people's experiences of living with a long-term condition, and how older people learn to manage chronic illness, specific issues may exist for older people who have such conditions that they have already learned to live with (Roy and Giddings 2012). This article therefore reports on the findings of a study exploring the experiences of people who reach the age of 65 with a pre-existing long-term condition.

Background

A plethora of evidence exists on the experiences of people who live with a long-term condition (Edwards *et al* 2008, Olsson *et al* 2008, Barlow *et al* 2009, Richardson *et al* 2009, Handley *et al* 2010, Dennison *et al* 2011, Wilson 2011). The lifestyle adjustments that people with a long-term condition, chronic illness or disability may have to make as they get older, but before retirement age, are documented (Goodwin and Compton 2004, Giddings *et al* 2007, Yen et al 2011), as are the experiences of older adults who develop chronic conditions (Gallagher *et al* 2008, Duggleby *et al* 2012). However, the experiences of people who reach the age of 65 with a pre-existing long-term condition have received less attention.

The literature provides useful pointers about the issues that older people mth pre-existing long-term conditions may have. Kralick (2002) describes how, as people learn to live " with a long-term condition, it becomes a routine element of their life: a part of 'ordinariness'. At this stage, people will usually have considerable knowledge about their condition, developed skills in self-management and the ability to participate in decision making with their healthcare providers (Edwards *et al* 2008, Barlow *et al* 2009, Handley *et al* 2010, Newcomb et al 2010, Jones et al 2011). Older people who have lived with a long-

term condition for a number of years are likely to have reached this point. However, changes to a person's situation can mean that managing the condition becomes an 'extraordinary' rather than 'ordinary' part of their life (Kralick 2002). Such changes may be associated with older age, for example, by retirement altering a person's financial status, or by the development of additional age-related health problems (Giddings et al 2007).

The management of long-term conditions in older people can be complicated by a difficulty in determining whether physical changes relate to an existing long-term condition or are a part of ageing processes (Giddings et al 2007). Alongside this, society tends to stereotype older people as being likely to have poor health or limited physical capacity (Age Concern 2008, Liu et al 2012, Fenlon et al 2013), which may result in assumptions that any difficulties that older people experience are related to age, rather than long-term health problems.

Aim

The aim of this study was to gain insight into the experiences of people aged 65 and older who have learned to live with a pre-existing long-term condition.

Method

This small, exploratory study used a qualitative approach and the principles of narrative research to gain insight into participants' stories (Moen 2006). Narrative research uses various data collection methods, including individual and group interviews (Letherby 2003). The intended method of data collection was focus group inten ews, which would allow participants to tell their own stories, but also build on one another's contributions (Webb and Kevern 2001). A semi-structured interview schedule using open-ended questions was developed so that discussions could be flexible, but still retain their focus (Overcash 2004, Cote-Arsenault and Morrison-Beedy 2005).

Two focus groups with six to eight participants in each group were planned: large enough to allow exploration of various experiences and perspectives, but small enough to enable everyone to participate (Cote-Arsenault and Morrison-Seedy 2005). Whether group membership should aim for heterogeneity or homogeneity was considered (McLafferty 2004).

It was decided to convene one group with male participants and one with female, because participants might be more comfortable discussing some aspects of a long-term

condition in this setting. However, some heterogeneity was achieved by having ng people with different conditions in each group to increase the breadth of discussion.

In the event, only five men out of a possible seven and two women out of a possible six attended the groups. As those who attended wanted to have the opportunity to share their views, and had gone to some trouble to attend, the men's experiences were discussed in a group of five and the women were interviewed as a pair, based on the same semi-structured schedule, to form case studies. The study therefore retained its narrative methodology and main areas for discussion, but adopted two different methods of data collection.

The interviews were conducted by a researcher with experience in narrative enquiry and focus group facilitation to create an open discussion, use appropriate probes, but retain the focus (Bajramoxac et al 2004, Cote-Arsenault and Morrison-Beedy 2005). The focus group lasted 90 minutes, and the discussion with the women approximately 60 minutes. All participants contributed to the discussion, and the researcher summarised what seemed to be main points at regular intervals, to check whether her interpretations matched participants' meanings.

The study involved seven participants who had lived with a long-term condition for at least five years before reaching the age of 65 and who thought that they were still enjoying a relatively healthy, active life. They were recruited using advertisements in the School of Health and Social Care service-user group and local support groups. Transcripts were analysed using thematic analysis to compare individuals' narratives, and identify themes. Two members of the research team analysed the transcripts, and then compared their findings. Themes were identified by recurrence of ideas, repetition of exact words or phrases and forcefulness of the ideas expressed (Owen 1984). A paradigmatic approach was adopted, with themes and categories developed to represent common elements across individual narratives, rather than creating a series of complete narratives (Polkinghorne 1995).

Ethical considerations

Approval to conduct the study was obtained from the university's research governance committee. Potential participants were given information about the study aim, what taking part would involve, the use of data and their right to withdraw from the study at any time. Those who wished to participate gave written consent. With participants' consent, discussions were taped and transcribed verbatim. Transcripts were anonymised by using pseudonyms and participants were advised that the research team would

regard their identities as confidential. The researcher also clarified that participants, as well as the researcher, were responsible for respecting the confidentiality of information shared by others in their group.

Findings

The findings suggest that older people with pre-existing long-term conditions have some experiences and needs that differ from the general population of people with such conditions and older people with new, but chronic, conditions. Their skills in condition management and interactions with professionals are transferable to new health needs that may develop, but additional, age-related problems can affect their management of long-term conditions.

Progressive long-term conditions may become more difficult to manage with age, and difficulty exists in distinguishing ageing processes and deterioration of pre-existing long-term conditions. Age-related social and financial changes and society's perception of older people may also present challenges to condition management.

Condition management skills Participants described how their understanding of their condition and its management had developed over time, becoming more refined with age. This understanding included developing strategies, routines and lifestyle choices that enabled them to control their symptoms or to manage their condition better than when they were younger.

> *Diane: 'You learn to live within your limitations, and, providing you keep to that, you cope. If you do something daft, well then, you know it.'*

The condition management skills that participants had developed included the ability to represent their needs to professionals and services.

> *Mike: 'I find that the older I get... the meaner [in terms of challenging healthcare staff] I get!'*

> *Paul: 'And the more functional you get, I guess?' Mike: 'Yeah... you know, I don't really get sick now... and I think a lot of the younger people don't do that.'*

Some participants also detailed their desired relationships with healthcare professionals, namely partnership in care, with their expertise about their condition respected and valued. This combination of skills, knowledge and lifestyle adjustments, accompanied by clarity over their expectations of professionals, meant that most participants no longer considered their long-term condition a dominant feature of their lives.

> *Dave: 'The condition... it's perceived in the background now. It doesn't take over my life.'*

As well as enabling individuals to manage their long-term condition, participants thought that their experience and skills helped them to manage any new conditions that they developed.

The effects of being older While many aspects of individuals' condition management improved over the years, being older could also present challenges. Some participants thought that older people tended to find it difficult to ask for assistance.

> *Anne: 'The younger generation coming along are much more able to ask for help, but the older generation can be very stubborn about accepting any help.'*

Developing additional age-related conditions was also seen as affecting existing long-term condition management, and long-term conditions that were progressive often became more difficult to manage.

> *Anne: 'The ageing has affected me in that the disability becomes more of an irritant, and also, I can't walk to the shops. I have a buggy since I can't drive [due to deteriorating eyesight]. I mean, you see, my legs didn't suddenly recover when I couldn't drive, and therefore, I had to have a buggy.'*

Participants also highlighted the difficulty of distinguishing between the ageing process and deterioration of a pre-existing long-term condition:

> *Paul: 'One of the syrriptoms of multiple sclerosis, or the side effects, is you have memory loss... but...you know... you tend to blame things on your illness when maybe, it's actually just ageing that's doing it.'*

Age-related changes in financial status and changes in the support available from family or friends, for example, if a friend or partner died, could also adversely affect participants' condition management.

> *Diane: 'The financial side does come into it...because, you know, there are gadgets available and there are things that can help us, but we can't always take advantage of them. A lot of older people don't even try because they think they couldn't afford it.'*

Some participants thought that society's views of older people compromised how they managed their condition, because they were not always listened to as well, or their concerns taken as seriously, as when they were younger, and because society expected older people to have poorer health. The result could be that treatment for long-term conditions that was

available to younger people was not equally available to them.

> *Edward: 'They feel, "Well, this person's life expectancy is not that long anyway. So why spend money doing that?"'*

Discussion

The main limitations of the study are its qualitative nature and small sample of participants, which means that the findings are not generalisable to the entire population of older people with long-term conditions. The expertise that many people with long-term conditions have, and the value they place on professionals being prepared to work in partnership with them, is well recognised (Edwards et al 2008, Barlow et al 2009, Handley et al 2010, Newcomb et al 2010, Jones et al 2011).

This study indicates that this is equally applicable to older people with long-term conditions. Like those in Roy and Giddings's (2012) study, participants in this study could transfer their existing skills, knowledge and strategies in long-term condition management to dealing with new health conditions, which could be advantageous as they reached older age. Nonetheless, these skills could be countered by generational values making them less likely to request practical, day-to-day help. This study suggests that the knowledge, skills and lifestyle adjustments that older people with long-term conditions have developed may mean that their condition management is better than when they were younger, and their condition an 'ordinary' part of their lives (Kralick 2002). However, it also highlights that additional illnesses, the physical effects of ageing and the progressive nature of some conditions, can complicate long-term condition management.

Age-associated life changes, such as reduced income or loss of significant others, can also mean that existing coping mechanisms are lost, and long-term condition management moves from being an 'ordinary' to 'extraordinary' part of their lives (Kralick 2002). This study and Giddings *et ars* (2007) work highlight the challenge of distinguishing the effects of a long-term condition from the ageing processes. As Roy and Giddings (2012) found, participants in this study suggested that healthcare staff often assume older people's health issues are related to age, rather than a long-term condition. Negative or stereotyped views of older people, which have been highlighted elsewhere (Age Concern 2008, Liu et al 2012) were alluded to by study participants, and may mean that older people do not receive optimum treatment for their long-term conditions.

Implications for practice

The findings of this study provide some insights that may be useful in informing care provision. These include:

- Assessing older people's needs includes determining whether they have any pre-existing long-term condition; how they have learned to manage any such

condition; and the possible interplay between any existing long-term condition, their age and current changes in their health.

- Older people who appear assertive and articulate about their health needs may nonetheless need encouragement to access practical assistance or support.
- The continued availability of established support mechanisms should be considered at every new interaction that older people have with healthcare services.
- Adaptations that older people have made to accommodate a long-term condition may have become so routine that they do not mention them to health professionals. It may be important, especially in times of economic austerity, to explore with older people what support they have in place and how they have accommodated their needs over the years, so as to assist them in articulating the necessity of maintaining this support.
- Negative attitudes towards older people may influence long-term condition provision and nurses working in this specialty may need to advocate for an individual's right to good quality choices about the management of existing long-term conditions.

Conclusion

A growing number of people reach the age of 65 with a pre-existing long-term condition. Understanding the particular needs of this group of people is therefore an increasingly important part of nursing older people. Working with older people who have a pre-existing long-term condition draws on the skills and knowledge required to work with condition and the ageing process when assessing needs; understand that people may be reluctant to ask for practical assistance; explore existing support mechanisms that people have in place and their sustainability; and advocate with people to secure quality choices related to their health needs older people and those with long-term conditions but there are likely to be some additional issues for this growing population. Nurses who care for older people should take into account the effects of the person's long-term condition and the ageing process when assessing needs; understand that people may be reluctant to ask for practical assistance; explore existing support mechanisms that people have in place and their sustainability; and advocate with people to secure quality choices related to their health needs.

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