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Informal care at times of change in health and mobility: a qualitative study

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Abstract

Introduction: relationships between people with health problems and their partners, families and friends are usually described as ‘informal care’. Using a qualitative examination of older people’s descriptions of their relationships with partners or other significant friends or relatives at times of change in health and mobility (walking), we questioned whether ‘informal care’ is an appropriate label.

Methods: seven men and eight women aged between 58 and 85 years (mean 72.4 years) were recruited on grounds of having difficulty walking. Participants were interviewed on four occasions each. Nine of the interviewees lived with partners, four of whom were also interviewed. Whether living alone or with a partner, all participants discussed key social relationships. Analysis was performed using standard methods of qualitative inquiry, including thematic and narrative case study approaches.

Findings: the participants had several ways of coping with health changes and the onset or escalation of immobility. These included working together to ensure recovery, working together to maintain independence and experiencing and recognising considerable difficulty coping with change. Adaptation within relationships reflected the experience of abrupt or gradual change as well as expectations for the future. Participants did not describe their relationships in terms of ‘carer’ and ‘cared for’.

Conclusion: means of coping with changing circumstances in mobility and health are inextricable from the work that goes on within partner, familial or friendship relationships. As older people seldom describe their relationships with significant others as ‘care’, it may be more appropriate to discuss informal care provision with patients by using the language of relationships.

Keywords: caring, caregivers, disability, elderly, older people, qualitative research

Introduction

In the UK, difficulty walking—locomotor activity limitation—is the most common form of disability and its prevalence increases with age [1]. Older people do not experience limitations in isolation, but do so in contexts of partners, family and friends. When an older person needs support in daily life, then these relationships are often described as ‘informal care’. UK policy on health and care for older people emphasises continued residence at home, in the context of appropriate support [2]. It has been well recognised that ‘carers’ also require support and assistance [3]. In the UK, the greater part of caring responsibilities falls upon people in the 45–64 age group, with 24% of people reporting that they are carers. The proportion of people aged 65 and over who are carers is also high at 16%. The heaviest load of informal caring responsibilities falls on partners or children [4].

There is a sizable literature in social and health sciences exploring the intricacies of informal care. Research has examined the perspectives of ‘carers’ as well as of those who are ‘cared for’. It has been shown that carers experience disruption when they adopt the role of carer, but this takes place alongside a sense that caring for a family member during an episode of ill health is a ‘normal’ state of affairs [5, 6]. Women are more likely to be carers than men, and formal care services model themselves on traditional female domestic roles within the home [7]. The emphasis on caregiving as a female pursuit has provoked exploration of men’s roles as caregivers. It has been suggested that men caring for their wives adjusted to their new roles by orientating themselves according to one of four types: ‘worker’; ‘labour of love’; ‘sense of duty’ or ‘at the crossroads’ [8]. In the context of palliative care, older people prefer to receive care from family members rather than from outsiders [9]. Despite extensive work on care, there has been little work examining such relationships from both sides at once [10].

Furthermore, little attention has been paid to how older people themselves define ‘care’. In research and writing about disability among younger age groups it is clear that terms such as ‘care’, ‘carer’ and ‘caregiving’ are inappropriate ways of characterising relationships between people with disabilities and their significant others. For example, autobiographical accounts of living with disability show that relationships are not described in this way [11–13]. This echoes comments from people who express surprise that their role in familial relationships means that they are described as carers [14]. Framing relationships as ‘care’ may be extremely disempowering for people living within those relationships [15, 16].

In this study we explore the forms that relationships of care take and examine whether older people use terms such as ‘care’ to describe their relationships with significant others.

Methods

In this longitudinal qualitative interview study there were 15 participants. Fourteen participants were interviewed on four occasions each, and one was interviewed twice. The

study was designed so that follow-up interviews with each participant took place roughly two months apart. This was so that the interviews would capture change over a 6 month period. Nine of the participants were living with their spouses; we interviewed four of them. This study design generated 62 interviews in total.

The 15 participants comprised seven men and eight women, aged 58–85 years with a mean age of 72.4 years. All participants were white and lived in, or near, a large English conurbation. The participants were purposively sampled on the study’s behalf by two hospital consultants on the basis that they had older age and problems in walking (Table 1). The participants were not selected to represent the general population but provided a sample of older people who were in receipt of secondary care at the time of recruitment. Participants gave their written consent to participate and be audio-taped.

The first interview with each participant included an interviewer-administered questionnaire containing questions about household status, health, activities, service use, neighbourhood and sources of support. As answers to these questions contained considerable detail, these first interviews were also audio-taped and formed part of the qualitative dataset [17]. Topics in subsequent in-depth interviews included health, personal history, mobility, daily activities, aids and appliances, use of services, social networks and change over time. Addressing these topics enabled discussion about sources of support.

The interviews were audio taped and transcribed. The transcripts were anonymised and transferred into the software package, ATLAS.ti. Transcripts were analysed using standard methods of qualitative thematic analysis. First, transcripts were coded inductively according to themes that arose from the data. The data within key themes, in this instance relating to relationships and support, were then scrutinised and compared within and between cases to arrive at a theoretical account [18]. To ensure that the data retained meaning and was not decontextualised, respondents’ case narratives, as well as the extracted themes, were integral to understanding the data [19]. All initials used here refer to pseudonyms and any potentially identifying details have been altered or omitted to preserve the anonymity of participants.

Findings

Ways of dealing with change

Table 1 outlines participants’ health and the main providers of help in the home. All had experienced changed health over recent months or years. We found that it was hard to ascertain key sources of help through formal questions alone, as these often elicited responses that did not include those people who provided daily or regular help. Nine out of 15 participants lived with partners. In all but one instance, partners were key sources of support for these nine participants. Family, friends and neighbours provided help and support for those who lived alone, and two of the single participants were in receipt of formal services (home care).

Table 1. Participants' health and relationships

Participant	Gender	Age	Main health conditions reported at first interview	Main sources of help in the home (and living circumstances)
1 (Mr A)	M	68	Two strokes, 6 years previously and in the year prior to interview; aortic aneurysm, 2 years prior to interview; diabetes; breathing problems; 'borderline' high blood pressure	Wife (lived with wife)
2 (Mr B)	M	68	Stroke during the year of the interview; high blood pressure; underactive thyroid	Wife (lived with wife)
3 (Mr C)	M	70	High blood pressure; rheumatoid arthritis since 5 years prior to first interview	Wife (lived with wife)
4 (Mrs D)	F	73	High blood pressure; restless legs syndrome; vascular disease since 8 years prior to interview; rheumatoid arthritis since the year prior to interview	Daughter, sister and neighbours (lived alone)
5 (Mrs E)	F	81	Osteoarthritis for 30 years; rheumatoid arthritis since year prior to interview; start of cataract in right eye	Husband and children (lived with husband)
6 (Miss F)	F	67	Osteoarthritis since 4 years prior to interview; rheumatoid arthritis since 4 years prior to interview	Friends (lived alone)
7 (Mrs G)	F	58	Breast cancer, 5 years prior to interview; osteoarthritis since 13 years prior to interview; nodal arthritis since 3 years prior to interview	Husband (lived with husband)
8 (Mr H)	M	78	Two strokes, 3 years and in the year prior to interviews; diabetes; tendonitis	Friends (lived with wife)
9 (Mrs I)	F	64	Osteoarthritis; osteoporosis; rheumatoid arthritis since 4 years prior to interview; diabetes	Formal services and daughter (lived alone)
10 (Mrs J)	F	81	Two 'mini-strokes'; knee-replacement surgery; lung lobectomy; osteoarthritis; possibly rheumatoid arthritis (unsure of onset dates)	Daughter (lived alone)
11 (Mrs K)	F	85	Stroke in the year prior to interview; both hips replaced 16 years prior to interview	Formal services and neighbour (lived alone)
12 (Mr L)	M	81	Paget's disease; arthritis; asbestosis; 'minor' stroke; 'minor' heart attack; hip-replacement surgery 8–10 years prior to interview (unsure of most onset dates)	Friends (lived alone)
13 (Mrs M)	F	76	Osteoarthritis for 'some years'; rheumatoid arthritis in the year prior to interview; recent arrhythmia; high blood pressure; past depression	Husband and children (lived with husband)
14 (Mr N)	M	66	Osteoarthritis (especially knee) led to retirement 18 years prior to interview; depression; varicose veins stripped 19 years prior to interview	Wife (lived with wife)
15 (Mr O)	M	70	Paget's disease diagnosed 20 years prior to interview; lung cancer 26 years prior to interview; osteoarthritis during year prior to interview; osteoporosis since 18 years prior to interview; heart attack and subsequent heart problems 24 years prior to interview; high blood pressure since 26 years prior to interview; 'borderline' asthma	Wife (lived with wife)

We identified three main ways that participants dealt with recent changes in their health and mobility in the context of these relationships. These were (i) working together to enable recovery, (ii) working together to maintain independence and (iii) difficulty in coping.

Working together to enable recovery

Working together to enable recovery was a central theme in descriptions of many relationships, whether with partners or friends and family.

Mr B, who lived with his wife, had had a stroke 6 months prior to the first interview. Over the course of the interviews his mobility improved, and he talked about his friends coming to visit. He and his wife talked about the efforts they made to bring the world inside in therapeutic terms:

Mr B: Got two friends coming this afternoon haven't we?

Mrs B: Yeah and they come quite often. I just try to encourage that because it just gives . . .

Mr B: Forces me to have a conversation with somebody different, you know

Interviewer: Yeah

Mrs B: Well not force you, but it's just . . .

Mr B: Well no, but it's good for me

Mrs B: Bringing the world in here isn't it really?

Mrs I, who lived alone, received professional home care services but also received help from her daughter who visited regularly:

We're more like sisters than I'm her mother. Yeah. And there's nothing too much for her, because she does my washing and all my fetching. The mattress keeps coming off and she's always doing that [tying mattress onto bed base]. There's nothing you can ask her and she'd say no.

Working together to maintain independence

A second key theme was emphasis on retaining independence. Although independence is often taken to mean individual self-reliance, some participants defined it as an attribute of couples or dyads.

Mrs E lived with her husband. During the interviews, her mobility initially declined following previous hip surgery. Revision surgery then rectified some of her problems and her situation improved markedly. Mrs E stressed how she and her husband worked together to perform everyday

tasks. When asked who would help her in the home if needed, she said:

The children would come and do it. But they don't have to do anything because we do it all between us . . . I mean to cook a meal, my husband prepares it all and I sit out there on my stool and I cook it, by the cooker.

Working together to retain independence was not just an attribute of couples. Those who received help from close friends or family also described maintaining independence in the context of those relationships. However, the assistance of friends and family also entailed certain constraints, for example participants, described that they did not want to inconvenience others. Mrs D received help from her daughter, neighbours and sister and described how although their help enabled her to get out and about, she curtailed the amount of time that she spent doing things, unless she was with her sister:

When I'm out with people and that, I sort of um—apart from my sister—I do what I've got to do and I get home, I don't sort of hang about or look about or anything. I sort of go to the shops, come out the shops and come back home again because I've got a lift, because I don't like to keep people waiting.

Difficulty coping

Coping with changes in health and mobility was not necessarily straightforward. Although isolation was a problem for some of those who lived alone, living in a couple did not necessarily make things easy or smooth. One participant (Mr H) spent little time with his wife, while others struggled with their responsibilities to look after one another.

Difficulty coping with change in circumstances often proved a great emotional strain. For instance, Mr O lived with his wife, and his mobility and health had declined greatly over the last few years; he lived with increasing pain. Mr O explained that he did not like asking for help and often found his own way around everyday tasks within the home. However, his wife said that she did look after him, including lifting him up after falls and helping when he wanted to go out. When interviewed, she explained that she knew how to do practical tasks, but that she found it hard to cope emotionally: 'Nobody wants to say this because they shouldn't, but you plod on year after year because you have to'. She added that the situation had turned her into an 'old woman before time'.

Even those who ostensibly worked with others to deal with changed circumstances sometimes struggled to cope. This was the case for all participants: they talked about difficulties as well as their successful strategies. For example, while Mr and Mrs B (above) talked about how they tried to enhance recuperation, Mr B also described their disappointment with some of the changes in their married life since his stroke:

But when the cold weather came I was very disappointed that [Mrs B] couldn't sleep with me, because I just disturbed her night's rest.

Abrupt versus gradual change

Coping took place in the context of different sorts of changes in health: sudden, gradual and a combination of both. Participants reported a variety of conditions ranging from those with sudden onset (e.g. stroke, aortic aneurysm) to those that had progressed gradually over several years (e.g. Paget's disease, osteoarthritis). All participants reported more than one condition (Table 1).

Participants who had experienced gradual decline in health and mobility often saw little potential for significant improvement. Even the availability of potentially helpful interventions was not always a solution. For instance, Mr N reported that he had refused a knee operation because of fears of complications. Although his mobility was so limited that he and his wife had recently moved to a bungalow, he persevered living with the pain and difficulty.

Those who experienced sudden onset of a condition, such as stroke, and who received good prognosis for recovery found it easier to consider their interactions with significant others as an arena for hard work to cope and to achieve recovery. This was the case for all participants with good prognosis. For instance, Mr A talked about his wife's help:

Well she's a marvel really . . . Well I'm 16 stone and she's got to bathe me and that's one hell of a weight to lift, but she . . . does it. Mind you, she's had training, because she used to work in the old people's [home], and she went on different courses there. So I mean she knows what she's doing.

For all participants, it was not merely the rapidity of onset of a condition that affected adaptation. Instead, sequelae and prognosis were central to this process. However, adaptation and ability to envisage improvement were formulated in the context of relationships, and these were subject to flux as was health and mobility. Adaptation to any type of change took place in the context of pre-existing relationships and we found that prognosis and expectations of improvement were crucial to emotional coping.

The language of 'care'

Participants were embedded within networks of help, and these sometimes involved both receiving and giving help. Although all participants received assistance and help from spouses, family or friends, none of them spontaneously described these relationships as 'care'. Participants only used terms 'care' or 'carer' to describe their relationships when prompted by the interviewer or in the context of descriptions of health care encounters. For example, Mrs B said that her GP had told her that it was important to 'make time for yourself and have sort of regular breaks, and make other people involved in [Mr B's] care'. She added that she found it difficult to consider involving other people because many of the tasks involved were 'personal care'. Participants reserved terms such as 'carer' or 'care' for discussion of professional services, such as those provided by home care.

Instead of talking about care, participants described the detail of the help that they received, ranging from assistance with gardening to help with intimate tasks such as bathing.

Participants did talk about receiving or asking for help, but more usually care was discussed as help or in terms of working together as described above.

Although some participants described how they looked after other family members, either in the past or present, this was also not presented with the language of care, but was talked about in terms of visiting or of lives bound up with one another:

Mrs D: I moved up in[to] this house to look after my Mum . . . I was living over the other side of town . . . and when she was very ill . . . I managed to get this house, which is the nearest I could get . . . to go down there every day and see to her.

Mrs G: Our whole life since [retirement] has been bound up with our two mothers. We didn't expect them—it's an awful thing to say—to still be alive when we were retired.

Discussion

It is well known in qualitative research that general or hypothetical questions—such as 'Who would you ask if you needed help?'—may elicit 'public' responses that tell only part of the picture [20]. Instead, the data regarding sources of help stems from participants' descriptions of real events and help received in concrete circumstances. Although it may be tempting to classify people according to their style of coping, our study found considerable change and overlap between types of strategies. This echoes work with male caregivers which showed that there were 'several different caregiver types in the speech of single narrators' [21]. Categorising caregivers according to personal orientations may be questionable. Instead, people's relationships alter both subtly and significantly alongside fluctuations in health and mobility. This indicates that classifying couples or individuals according to one or other type may not reflect their experiences over time nor the nature of changes in relationships at times of mobility change.

Participants' circumstances and modes of adaptation were underpinned by diverse experiences of change in health and mobility and therefore of expectations for the future. There is already considerable evidence about the dynamics of disability in older age. For instance, it has been shown that over time, although some people become more disabled, others remain the same and others become less disabled [22, 23]. It has been suggested that those who experience gradual physical changes see those changes as 'obstacles to be worked around', but that when change is abrupt, challenges are more extreme and may be more difficult to accommodate [24]. However, sudden events (e.g. stroke) may be accompanied by a good prognosis for recovery. After the initial shock of the event has subsided it appears that the expectation of recovery may mean that even these abrupt circumstances become more manageable than conditions that are gradual but with poorer prognosis. We suggest that how people cope or adapt to change is related to expectations for the future.

Nobody described their relationships with spouses or other relatives or friends in terms of 'care'. Instead, participants

described these relationships by talking about working together or in terms of strain and difficulty. Discussions of 'care' seemed to only arise in response to institutional framing of those relationships as care. Although the circumstances of each individual were unique, instead of depicting their relationships as 'care', what mattered most was the change in their relationships with others. While constructs such as 'care' have an important role in claims about rights and responsibilities, it seems sensible to remember that such language does not necessarily echo that of the everyday life or older people.

The limitations of this study include the small sample size and the reliance on self-report of health conditions. However, the longitudinal nature of the study and the amount of data generated enabled exploration of the detail of participants' lives as well as an appreciation of the texture of change over time. While it is not new to explore coping and adaptation styles and strategies concerning chronic illness [25], it is important that such work includes the relationships within which this coping takes place. Future work might further explore relationships with a larger sample and by including more family members and friends in research. Also, inclusion of health and social work records and clinicians' perspectives might prove valuable in exploring how encounters with health and social services modify the coping process.

Correspondence between changing abilities and styles of adaptation is multifaceted, complex shifting and hinges on expectations for the future. As older people seldom describe their relationships with significant others as 'care', it may be important to approach the subject of care with patients by using the language of relationships rather than that of 'informal care'.

Key points

- Relationships and expectations for the future may be key to how people cope with mobility and health status change in later life.
- When discussing service needs with older people it may be more acceptable to frame relationships as relationships rather than as 'care provision'.

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Conflicts of interest

There are no conflicts of interest in this study. Frenchay and Southmead Local Research Ethics Committees (LRECs) provided ethical approval for this study.

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