Abstract

Background: Falls can lead to social isolation, anxiety and depression for those who fall although little is known on how informal carers manage those at risk from falling at home.

Aim: to explore the experiences of informal carers who care for an older person who is frail and at risk from falling at home

Methods: A qualitative study using thematic analysis was adopted. Data were collected via one to one, semi structured interviews.

Findings: Informal carers, experienced social isolation, significant adjustments to their working lives, a fear of further falls, tiredness, fatigue, anxiety and depression. These findings mirror those which have found that falling is considered to be a predictor of both physical and psychological changes although in those who fall rather than those who care for them.

Conclusion: This highlights the need for both community health and social care services to identify the impact of care recipient falls on the informal carer.

Key words: Falls Frail Elderly Carers Home

Key Points:

- The experiences of informal carers include a fear of further falls, social withdrawal and psychological distress mirroring those who are at risk from falling themselves.
- Caring for someone at risk from falling at home led to physical decline, a reduction in the opportunity to socialise and in some cases lower earnings.

- The relevance of this research to the design of health and social policies includes the need to acknowledge the significance of the informal carer role.
- The potential increase in the needs of the frail, older person at risk of falling at home highlights the need to identify factors that impact on the informal carer that in turn influences their ability to both care and remain independent.

Introduction

The number of adults in the UK aged 65 and over is set to increase by more than 40% over the next 20 years with 45% of those over the age of 65 living with mild to moderate frailty (BMA, 2018). Globally, it is estimated that up to 35% of those aged 65 and above fall each year with falls cited as the second leading cause of accidental deaths (WHO, 2017). Falls in frail, older people often result in a fear of further falls, reduced mobility and a loss of independence, depression, social isolation and anxiety (Bjerk et al, 2017). Increasingly, informal carers are recognised as a crucial resource for supporting long term, frailty care (NHS England, 2014b).

It is estimated that a quarter of those adults aged 45-64 in the UK are informal carers, a role impacting on their working lives, their financial security and their physical and mental health. Carers UK (2018) describe how some informal carers often feel socially isolated because of their caring responsibilities, negatively affecting their emotional and psychological wellbeing. Broese Van Groenou and De Boer (2016) argue that informal carers spend significant amounts of time undertaking emotionally and physically demanding tasks. Informal carers caring for someone at risk from falling following a stroke, have been found to experience a loss of self-confidence and a fear that the care recipient will have further falls (Kelley et al, 2010). The effects of caring

for an older person who is frail and at risk from falling in their own home is limited, and so the aim of this study was to explore the experiences of informal carers and how they fulfil the role of caring for an older person who is frail and at risk from falling in their own home.

Methods

Design

The study was conducted between January and April 2019. A descriptive qualitative design was applied as it is considered appropriate for research questions that focus on exploring experiences (Polit and Beck, 2014).

Settings and Participants

Participants were recruited with the support of the charitable organisation AGE UK. The charity identified potential participants who were provided with details of the study and then invited to contact the research team to find out more. The interviews were conducted with 10 informal carers and a purposive sampling strategy was employed initially followed by snowballing as informal carers passed on details of the study to other carers they knew. Participants were invited to take part if they had been providing informal care (not receiving any payment for their caring role) for at least 6 months for a frail, older person who had fallen at least once in the previous year in their own home. Written consent was sought before the interviews took place. Validity was enhanced by conducting the interviews with participants in the care recipient's own home. The informal carers differed in terms of age, gender and their relationship with the person at risk from falling.

The study was approved by the university ethics committee (18/NAH/033).

Data collection

An interview guide was used to explore the participant's experiences of caring for someone at risk from falling in their own home. The questions for the semi structured, one to one interviews were open ended and broad but then followed up by more in depth questioning to elicit greater detail (Charmez, 2006). All interviews were audio recorded and transcribed verbatim.

Data Analysis

The data analysis was guided by the aim of the research and thematic analysis was adopted (Braun and Clarke, 2006). The research team examined the narrative data in order to identify common themes and patterns of meaning that appeared across the transcripts. This process consisted of immersion in the data, identifying features relevant to the research, identifying broad, initial themes, refining those themes and finally combining some themes in order to represent ideas or concepts.

Ethical Considerations

Results

The findings are presented as verbatim quotes used to illustrate each theme with pseudonyms assigned to each informal carer.

Fear of Further Falls

The fear of the care recipient falling again was relentlessly present in the informal carer's thoughts. They appeared to be defined by a reduction in the care recipients and informal carers' activities as they feared the physical consequences from the care recipient falling.

'You are limited to where you can go because I'm always frightened of her falling again' (Gill).

This fear led to the informal carer's reluctance in leaving the care recipient alone. A sense of foreboding was also evident in experiences that reflected a dread that they would find the care recipient on the floor when they returned to the house.

'*If he's on his own and he falls again he wouldn't be able to get up. That's my biggest fear* (Eileen).

'It's a constant worry when I go out that she's ok and she's not going to fall' (Ron).

Several participants described the distress associated with leaving the care recipient at home with some expressing a worry that any fall might result in a physical injury or even death.

'I'm frightened he might fall again, try and get up the stairs and miss a step, come down in the night and lose his footing' (Rachel).

'Things weren't getting any better and I was getting more anxious that she was going to fall. I would worry that she would slip and bang her head again' (Ron).

'What I'm most frightened of is that he will fall again in the house and die alone with no one there with him. It's a massive worry to think that he could fall again' (Julie).

Social Consequences

Almost all informal carers expressed some social withdrawal and attributed this to the impact of caring for someone at risk from falling, associated with their unwillingness to leave the care recipient on their own.

'I haven't got a social life anymore because of dad's falls. I use to go out and do stuff but I'm so limited now because I have to make sure he's safe' (Rachel).

'I don't have any time to myself. I use to go to the gym a couple of times a week but I don't go now and I miss that' (Gill).

The social implications of caring for someone at risk from falling included limiting holiday and not continuing with social activities. This appeared to be prompted by the need for assurance that the care recipient was safe.

'We've stopped going out as much now, we don't really go anywhere now like we used to. Oh God no, we wouldn't go far, not like we used to. We'd be out all the time before he started falling' (Joyce).

'*I use to have a social life so I'm definitely missing out there. I think sometimes friends don't bother asking me to go out anymore because they know what I'm going to say'* (Rachel).

Participants described examples of social withdrawal and attributed this to the perceived increased risk of the care recipient falling. They credited retreating from social activities to their responsibilities as an informal carer.

'I've always had a good social life and for a long time I used to go out with my mates, there were 5 of us but I don't see them because I'm looking after him' (James).

'*I use to go to the pub with one of my mates but I don't go now, it's too much effort.*

'I don't go far now. I use to meet a few mates once in a while and we'd have a laugh but I don't do that anymore, it's sad but you just have to knuckle down get on with it' (Ron).

Adjustments

Informal carers described how they coped with the risk of the care recipient falling including actions taken to reduce the risk such as reducing their hours at work or giving up work altogether.

'I work part time. I've reduced my hours at work because of dad. Looking after him has impacted a lot on my work because I have to ask people to swap shifts all the time to look after dad' (Julie).

Caregiving was also viewed in terms of the changes informal carers had made to supporting care recipients such as being prepared and thinking ahead.

'I feel more relaxed about being close by and I feel more helpful knowing that I can do things if I need to. I know in the future I know I will need to input more and I know it will be easier if we don't make any plans to do things' (Sam).

While some were thinking about the changes that would be required in the future, accepting adjustments had to be made was frequently considered by some participants as part of the role of being a carer insisting that they just had to get on with it.

'It's frustrating but we'll have to get over it. It's just one of those things. You just get on with it and accept these changes are really happening. It's pointless moaning' (Joyce).

Participants' responses highlighted a process of adjustment that resulted in not participating in certain activities while others accepted the role as a normal part of any long-term relationship.

'I just have to accept that I have to adjust and make changes. Things do change as you get older anyway, you have to accept that, it's part of being a married couple. My

role is different and I'm doing things I never thought I would have to do, you just don't think do you?' (Ron)

Most participants described the changes in their lives that resulted from the care recipient falling but there appeared to be a significant level of acceptance that it was the most appropriate thing to do.

'I've put my life on hold which I wouldn't advise others to do but I'm on my own and dad's my responsibility. You just have to make changes, it's the right thing to do' (Rachel).

Physical Impact

Informal carers described their experiences of fatigue, the feeling of being inundated, anxious and other negative consequences of caring for someone at risk from falling.

'I couldn't leave him on his own. I haven't got the go in me anyway. I'm shattered and looking after him, it takes it all the energy out of me' (James).

'I'm so exhausted. I don't eat properly I know because I'm running around for dad and dashing back to the house to make sure he's ok' (Rachel).

Their experiences are vividly described with the impact on their own health being a universal concern among participants.

'I feel so stressed. I've told my doctor I'm stressed. I'm getting headaches all the time, I've had palpitations. My blood pressure is all over the place but I don't have time to get myself checked out, I'm too busy sorting dad out' (Rachel).

Caring for someone at risk from falling led some participants to a constant feeling of exhaustion. For some it was because of a change in the care recipient's physical ability following a fall.

‘I don’t sleep much these days with him getting up, neither of us sleeps actually. I lie awake sometimes thinking I have to be aware in case he needs the bathroom and then I need to make sure he’s alright’ (Joyce).

‘It’s all been a big change and I know I feel it. I feel tired and weary most of the time. It’s changed me physically, it’s draining and I’m exhausted at the end of the day. It’s tiring because she use to do it all before she fell and now it’s left up to me now’ (Ron).

Psychological Effects

Informal carers described the emotions associated with caring for someone at risk from falling at home including from frustration, anger, low mood and anxiety.

‘I get depressed and not going out doesn’t help. I’m stuck in with him on my own. What a life for us hey? (James).

‘For me as a carer it’s quite stressful. It’s so stressful thinking about all of this, the two of them falling. I’m terrified that dad will fall in the house when I’m not there to help him’ (Julie).

Some participants appeared to engage in a process of denying their feelings as a way of protecting themselves from the negative, psychological effects of caring.

‘Mentally it’s taken an awful lot out of me really, like I feel depressed and worried about what’s going to happen. I worry so much about him falling but then at the end of the day you have to adjust and that’s what I’m trying to do’ (Joyce).

Informal carers sought to explain that their feelings of frustration and anxiety were as a result of the care recipient not taking their advice. For one participant who was working, there was a sense of culpability at not being around all the time.

'I needed to go over and take her places. When I was working this was a bit difficult because I could only do that at weekends or when I was on holiday and if I couldn't take her I'd feel guilty' (Sam).

'I do resent my parents sometimes especially when they do fall and it's because they've tried to do something I've told them not to do because I know they would fall' (Megan).

The sense of isolation and loneliness appeared to be evident as some participants described the relentlessness of needing to be mentally alert when caring for someone at risk from falling. Some described the impact it had on other family members.

'It's a massive worry. I'm not sleeping, I'm not eating properly that's for sure and things got so bad recently that the doctor started me on anti-depressants. It has a huge strain on not just me but the rest of the family' (Julie).

'Being the only person mum has is overwhelming for me sometimes. It's not the physical aspects of it but it has been so mentally tiring for me' (Sam).

'You just feel absorbed into a state of depression looking after someone else, keeping a constant vigilance' (Joyce).

Discussion

Although research exists that focuses on older peoples' experiences of falls, there is limited evidence of the experiences of those caring for an older person who is frail and at risk from falling at home. An important finding from this study was that informal carers of frail, older individuals appeared to accept that the care recipient would inevitably fall again and expressed a constant fear and anxiety associated with this fatalistic view. Similar findings have been identified in previous studies (Faes et al,

2010) but in those at risk from falling, so the care recipients themselves not their carers (Host et al, 2011). While (2020) describes how this fear of falling in the older person can lead to avoiding certain activities or in some cases becoming housebound. As a consequence, While suggests this leads to an individual moving less, losing muscle strength which then increases the risk of further falls. This study suggests that informal carers' defeatist views and expectations of further falls in the frail, elderly individual they are caring for are essential to understand in the success of any falls prevention interventions including the belief that falls are inevitable, largely unavoidable and naturally attributed to a decline in health.

Evidence suggests that there is a significant association between a recent fall and fear of further falls which is then linked to a reduction in social activity and a lack of confidence for the care recipient (Boyd and Stevens, 2009). The findings from this study mirror previous studies which have identified the consequences from falling but for the care recipient including a reduction in outdoor activities, a decline in social relationships and less contact with family and friends (Roe et al, 2009). This present study has highlighted this effect with the informal carers of the frail, older person who engage in a process of social isolation following the care recipient falling at home. This echoes previous research which highlighted that older adults at risk from falling in their own home reacted to this fear of further falls by restricting their activities and reducing their participation in social events (Faes et al, 2010). In caring for those with Parkinson's disease, Hasson et al (2010) and McLaughlin at al (2010) noted that informal carers experienced social isolation, reduced social activity, physical health problems, stress and anxiety.

The impact from the care recipients falling on informal carers in terms of social identity appears to result in a reduction in confidence which reflects the consequences of falls

on those who fall themselves in terms of increased distress, anxiety and a greater risk of death (Ruthig, 2007; PHE, 2014). Although it is impossible to prevent all falls, While (2020) supports the view that some can be averted by detailed assessment by health care professionals and appropriate interventions including fall prevention programmes.

In previous research depression and acute anxiety were linked with a fear of falling in care recipients following a stroke, prompting a reduction in physical activity and social engagement (Andersson et al, 2018). An extreme fear of falling has been shown to result in reduced social activities, social isolation, depression and anxiety (Li et al, 2003) for informal carers managing those with dementia. The findings from this study echo those which have found that falling is considered to be a predictor of depression although in those who fall rather than those who care for them (Pin and Spini, 2016). In a study by Scaf Klomp et al, (2003) depressive symptoms were found to be evident in those who had experienced a fall and who exhibited functional decline as well as being less physical activity. There also appears to be a close relationship between depression and an extreme fear of falling for those who have already fallen (Iaboni et al, 2013).

There are similarities between the findings of this study and other qualitative studies that have highlighted the physical effects of falling (Terroso et al, 2014) and this study suggest that informal carers like those who fall also experience physical symptoms like tiredness and fatigue. This highlights a potential challenge for community health and social care services including district nurses in delivering integrated falls prevention interventions.

This study expands on the knowledge on falls and in particular it reveals how the consequences from falling for the informal carers of the frail, older person echoes those experienced by those who fall themselves. It adds to previous studies which suggest that falling for those care recipients leads to negative physical, psychological and social outcomes by proposing that the same consequences are experienced by family members who care for them.

Conclusion

The findings from this study provide a deeper understanding of the complex consequences resulting from the frail, elderly falling and for their informal carer. The impact of caring for an older person who is frail and at risk from falling was evident with the experiences of informal carers including a fear of further falls, social withdrawal and psychological distress appearing to mirror those who are at risk from falling themselves. The potential increase in the needs of the frail, older person at risk of falling at home highlights the importance of those working in community health and social care services including district nurses to adequately assess and identify factors or events over time that impact on the informal carer that in turn influences their ability to both care and remain independent.

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