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Title: Understanding informal carers’ experiences of caring for older people with a hip fracture: a systematic review of qualitative studies

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Abstract

Purpose: This systematic review aimed to reconceptualise experiences from a variety of papers to provide direction for research, policy and practice.

Method: Meta-ethnography was used to inform the review and 21 studies were included.

Findings: The analysis identified a core theme of ‘engaging in care: struggling through’, as carers who wanted to be involved in caring learnt to live with the intense and stressful impact of caring and changes to their life. The core theme is represented through three themes 1) Helping another to live 2) Adapting ways of living and 3) Negotiating the unknown.

Conclusions: The discussion identified a focus on carers of people suffering from a hip fracture, the willingness of informal carers to engage in caring and the intense experience of adapting to changes in relationships and dependency alongside a steep experiential learning

curve. Tensions exist in negotiations with complex healthcare systems as carers do not feel their expertise is valued and struggle to find and understand information.

INTRODUCTION

In an ageing society projections indicate that the prevalence of all fractures will continue to rise [1]. The increased risk of bone fractures among older people is exacerbated by decreasing bone density, deterioration in neuromuscular function and reduced functional capacity [2,3]. Hip fractures are particularly devastating with significant long-term consequences such as: disability; deterioration in walking ability; higher risk of morbidity and mortality; and higher healthcare resource utilisation and cost [1,4]. Compared to hip fractures the risk factors and consequences of other types of fractures in older people are less well known [3].

Recovering from a fracture impacts not only the older person but also family members and society [5]. Formal welfare services are often supplementary with family and friends performing core care-giving activities [6]. A family carer is defined as someone who provides unpaid, regular and substantial practical and/or emotional help to another person beyond that required as part of normal everyday life [7]. Care burden has been reported with negative consequences in physical, psychosocial and economic areas [8,9] especially among women [10-12], which suggests that gender is an important issue to consider in informal care.

The importance of carers' role and the impact of caring on the lives of carers has been examined in situations where patients have a range of conditions [13,14]. Much of the literature is in relation to chronic conditions which highlights the structural and contextual factors that impact on carer burden [15]. A fracture of a bone is often a sudden traumatic event requiring acute intervention and/or hospitalisation. In older people a fracture may have

a longer term impact on their experience of daily life and requirement for support [16,17]. Recovery may therefore reflect aspects found in chronic conditions, which compounded by any pre-existing co-morbidities might increase carer burden. Literature in acute care tends to focus on user involvement and engagement in care that identifies a greater need to work with family/carers and include them in decision-making [18]. This is particularly identified in older people [19] and those with reduced capacity such as memory loss [20].

A range of studies explore carers' experience of looking after older people with a fracture but samples are often diverse and some concepts lack clarity. The aim of this review is to draw together what is currently known about the phenomenon in order to provide guidance to direct best practice. By comparing concepts and findings from qualitative studies and subsuming them into a higher order theoretical structure, meta-ethnography can help to provide a new interpretation [21,22]. This method is currently the most widely used in qualitative synthesis in healthcare research and insights have contributed to a deeper understanding of complex processes, bringing together evidence to help inform healthcare practices and policies [23,24].

METHODOLOGY

Systematic procedures were used for the search strategy, study selection, data extraction and analysis according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [25] and following the meta-ethnography method of analysis and synthesis [22,26]. This review was registered and published in PROSPERO database (CRD42015029875).

We systematically searched for studies in five electronic databases: MEDLINE through Ovid; EMBASE through Ovid; PsychINFO through Ovid; CINAHL through EBSCOhost; and Social Science Citation Index through Web of Science. The search strategy was limited by language (English) and date (2000 to 2015) with the purpose of keeping a manageable

volume of papers that allowed us a detailed analysis. Search strategies were developed for each database using a combination of free text and thesaurus terms as appropriate, and the Boolean logic terms “or” and “and” were used to combine searches. The key terms were included in five main blocks: elderly, carer, experiences, qualitative design and fracture. Six key journals were also hand and electronically searched: Qualitative Health Research; Sociology of Health and Illness; International Journal of Nursing Studies; Journal of Advanced Nursing; The Gerontologist; and Ageing and Society. We complemented these searches by checking the reference lists of eligible studies for relevant citations. The search was conducted in March 2015. We used the reference manager software EndNoteX7 to manage the bibliography.

The inclusion criteria applied were: original and review articles; qualitative methods of data collection and analysis or qualitative elements of mixed methods research; data collected from the family/carer of people over the age of 60 with a fractured bone clinically patients under 60 years with hip fracture tend to have significant co morbidities; English language; published since and including 2000 to 2015.

Titles and abstracts were independently scanned for eligibility according to the inclusion criteria. Each article was classified as ‘include’, ‘exclude’, or ‘unclear’. The full text of articles classified as ‘include’ or ‘unclear’ was retrieved for closer examination against the criteria. Those that met all the criteria were included for data extraction. Two reviewers independently screened all titles and abstracts, full texts and differences were resolved by discussion.

We assessed each included study with the Critical Appraisal Skills Programme tool [27] which has been used in previous systematic qualitative reviews [21]. Each included article was independently appraised by two reviewers and discrepancies were discussed. The findings from the quality assessment were not used to exclude studies; however they were

used as descriptive information for the data synthesis and reported in the findings section (see table 1).

Insert table 1 here

The characteristics of the studies are summarized in table 2 which includes: aims, setting/location, sample characteristics, and data collection. This detailed information provided the context for the synthesis of our findings.

Insert table 2 here

We followed an iterative, flexible and inductive process of extraction, analysis and synthesis of the data informed by the meta-ethnography approach described by Noblit and Hare [22]. Phase 1 and 2, getting started and the focus of interest, have been identified in the systematic search for papers. In phase 3 the selected studies were read and re-read to establish familiarity. To determine the relatedness of the studies (phase 4) and translation of studies into each other (phase 5) we used thematic analysis [28]. This enabled us to identify and organise the main concepts or perspectives in the studies that Noblit and Hare [22] describe as metaphors. NVivo10 was used to help with management of the data. Listing of the concepts/themes equated to coding of each study which was undertaken by one reviewer, a second reviewer provided opportunities for reflective discussion on the developing synthesis. All relevant data were extracted and coded including concepts/themes, participants' quotes, authors' interpretations and conclusions. Coding of the studies took place alongside translation of the studies. This involved interpretation and mutual translation of the data of each study into one another and across the whole set of studies [21]. For example 'repositioning' where carers reconsidered their relationship in light of the past became one part of maintaining relationships containing other elements such as feelings of responsibility, closeness and anxiety. The process of coding and comparison across the studies enabled synthesis of the data (Phase 6, synthesising translations) and the

development of an interpretative 'line of argument' [22] building up a picture of the whole from a study of the parts (Phase 7, expressing the synthesis). The findings and discussion present the synthesis in written form although Noblit and Hare [22] support the use of a variety of mediums such as video or plays. Rigour was ensured by drawing on Lincoln and Guba's [29] notion of trustworthiness through engaging with the data, reflection on the process and identification of a clear audit trail. Saturation was achieved within the themes and categories.

Article identification

The PRISMA flow diagram (figure 1) reports the search outcome. Initial database searching resulted in 3986 hits. After examination of the full text, a final sample of 21 articles was obtained.

Insert figure 1 here

They incorporated data from 318 caregivers of older people with a fractured bone mostly in Canada and the United States of America. The papers were focused on hip fractures; 67% of the carers were women and most of them spouses or children of a person with a hip fracture. Of the studies, eight described the methodology they used as grounded theory, six as ethnography, two as phenomenology and five did not report using a methodological approach. The studies had findings that were of value and so were included, however many studies were descriptive and lacked conceptual development.

FINDINGS

Concepts identification, interpretation and mutual translation

The analysis, synthesis and higher-order interpretation of the studies identified a core concept of engaging in care: struggling through. This reflected the intense, stressful impact of caring and the process required to maintain a sense of equilibrium in their life, health and wellbeing. The core concept is represented by three themes and their categories

1) Helping another to live:

- i) maintaining relationships;
 - ii) providing support.
- 2) Adapting ways of living:
- i) living with stress;
 - ii) learning through experience;
 - iii) changing needs over time.
- 3) Negotiating the unknown:
- i) wanting to be involved;
 - ii) not knowing;
 - iii) being proactive.

The themes were interrelated and have categories presented below with representative first-order constructs of carer's quotations. Papers added to the breadth of understanding and did not negate the experience reported in other papers.

1) Helping another to live

The complexity of helping a known person to live identified the active nature of being a carer that included feelings reflecting concern for the other person in 'maintaining relationships' and an active element of 'providing support' through a range of activities. The studies conveyed the way helping was construed within the context of a close relationship between individuals. In other words, it was unlikely that helping occurred if a relationship was absent.

i) Maintaining relationships

The findings of the papers reported that carers wanted to help their relative/friend; identified as a responsibility to the other, a potential for growth in their mutual relationship but also as a necessity due to limited healthcare resources. This feeling was associated mainly with the belief that care was inherently part of the couple's relationship [30,31] or a filial responsibility [32-34] which was perceived as natural and unquestionable: "He is my father-in-law. It's my responsibility to take good care of him. After all, our parents took care of us in the same way

when we were young. Now he needs help, it's time for us to take care of him in return" [32 p.276]. Some carers experienced a positive feeling of closeness to their elderly parent through spending more time with them which allowed them to renew their connection and re-define their relationship with the awareness that they were in the last phase of life for example "it's a real gift that we have this time together" [35 p.162]. For others overcoming a health crisis together was a positive experience [35,36]. A sense of filial responsibility could also create anxiety for example: "if anything happens to him there's a little part of me that says 'You know it'll be your fault if you didn't ask those questions and deal with that.' I am under a level of stress with this. It puts me under a pressure – and sometimes my reactions might be a little more than is necessary because it's an inborn duty that I feel I have to cover all the bases or else I have failed in my duties to care for my father" [33 p.1121]. The impact of the fracture on the ability of the patient to carry out normal daily life created a temporary or permanent shift in relationships created by dependency. Byrne et al. [31] identify this as repositioning as carers reconcile the dissonance between the past and present situation. Shawler [34,35,37] described this complex process among mothers and daughters dyads: "It is kind of that old reversal thing, but not really. She's still my mom and I don't know what I'd do without her" [35 p.164]. For some spouses, this change in the relationship was uncomfortable: "I think because now he's become sort of like the child and I'm the parent. And I don't like that situation. I'd like to be an equal partner" [31 p.1380]. Caring was related to gender (i.e. most of the carers were women) [30,32,36] but broader theories around gender were not considered in the analysis of the findings of the included papers.

ii) Providing support

Providing support was identified as an important way of enacting the role of carer both in hospital and at home. Carers provided emotional and practical support to the patients, including social interaction, help with activities of daily life (eating, hygiene, etc.), transport and/or monetary issues: "Washing! She is not incontinent but because she has difficulty getting onto her legs to use the commode, or whatever, her knickers and petticoat have

been soiled. There's been getting clothes to her and making sure they are okay. She's very particular about her appearance" [33 p.1121]. Another important task was to share information about the patient within the healthcare system. For patients with memory loss, being an advocate or representative for another was one of the most important tasks [30] Aberg et al. [30] reported that all the activities provided by carers aimed to protect their relative's/friend's sense of self (how the person used to be) from the consequences of dependency and declining physical functioning.

There was a sense that their relative/friend should have the best care possible and concerns about the quality of care provided [36] or their perception of the busy workload on the wards: "The nurses don't really have time to sit and make conversation and my aunt needs conversation" [33 p.1120]. Moreover, healthcare policies of early discharge and fewer resources for rehabilitation [39-41] could push individuals to assume the role of carer: "I think that the sorrowing part that I see, is that it's just all about money, that's all it seems to be...we probably have one of the best health care systems in the world but it's cracking at the seams and you can see it. If this experience taught me anything it was that our health care system is in jeopardy now" [42 p.7].

2) Adapting ways of living

Adapting ways of living highlights how carers live with stress and gain knowledge and skills through experience using strategies that are intrinsic, interpersonal and environmental to negotiate ways of processing their emotions and enact caring work. Temporality is important as needs change over time; transitions in care require different activities and a sense of integration of the past and present.

i) Living with stress

The intense experience and the number of activities that it entailed often impacted negatively on a carer's own health. Stress, anxiety, frustration, fear, sadness, hopelessness, confusion,

and lack of time to balance the new role with their personal-life were feelings that dominated accounts: “very stressful...it was just trying to juggle everything. You know, work, making sure things were taken care of with his household, my household, visiting him every day...so, trying to juggle everything was probably the most difficult thing” [36 p.5]. Additional stress and complication were sorting out and co-ordinating the roles of other family members involved in providing care [32,40,41,43-45]; or living a significant distance away [41,45]. Some carers also found that their own frail health had impeded them from providing care [31,33,39,40] and others tried to stay healthy in order to provide care [31,37]. Carers felt lonely, lacking in self-confidence and felt they carried the whole responsibility for providing care; Rydholm Hedman et al. [42] expressed this as “suffering from care” and it was more evident among carers of patients with cognitive impairment.

ii) Learning through experience

A range of strategies were adopted by carers to transform negative experiences and give them a sense of control. The strategies reviewed were intrinsic, interpersonal and environmental. Intrinsic strategies included self-confidence [37,43], being positive, being patient [37,46], relaxation techniques [38], life philosophies or religious beliefs [37]; and being persistent and proactive to obtain information from healthcare providers [33,37,40,43,44]: “I just put my foot down and said I need this, this, this” [44 p.6]. Some carers with health professional backgrounds used it to navigate the health system and it helped them to cope with the stress linked to their lack of knowledge as a carer: “because I have medical knowledge and experience, I could fill in the gaps and ask the questions for answers I needed to know” [43 p.143]. Interpersonal strategies were “to have someone to talk to, to refer to” [43 p.145], accepting support from friends [37,38]; sharing ideas with others [37], empathy and using everyday knowledge about their relative/friend to achieve harmonious and reciprocal relationships [30,32,34] and being involved in the rehabilitation: “when I saw that she was finally getting on to walking and following exercises with the aides, the physio aides and that kind of thing was working with her, then I felt comfortable and was

able to go home” [43 p.145]. In addition, carers adapted their environment and lifestyle to meet the needs of their relative/friend [30,32,34,38]. Creating a safer environment by eliminating potential hazards gave them a sense of control of the situation and was another way of adapting.

Personal benefit was also gained from learning through experience; some carers reported that they gained beneficial knowledge of fracture prevention: “certainly this experience has made me more aware of my own bone health...additionally; I intend to make my daughter more aware of the choices she makes” [38 p.5]. Luptak [47] studied how this process influenced carers’ preferences for their future care and their narratives about ageing: “watching her grow old is actually a growing process for me. It’s maturing me. It changed my world view...with aging relatives you see what’s going to happen to you and what you have to plan for” [47 p.34].

iii) Changing needs over time

Carers’ burden and needs changed during the care transitions between hospital admission and the recovery phase [31,36,38,42,43]. Giosa et al. [43] developed a theory of carer’s support needs during care transitions connected with their emotional journey. The burden was greatest during hospitalisation and in the first two months but decreased over time with a satisfactory recovery and when carers understood their role: “I feel drained of energy every time she gets worse. Because I feel that she wants me to come every day, but I have so much to do at work and the house [purchase], so sometimes I feel that I cannot stand it when she tells me that she is worse” [42 p.455]. Byrne and colleagues [31] explained how carers responded to the fluctuating needs which were more evident once they were at home. For example, during this phase, the preparation and knowledge gleaned or not influenced how carers coped with multiple demands. During the last phase of the experience, named as ‘getting on with it’, carers strove for predictability and focused on facilitating social participation for themselves and their relatives. According to Byrne et al. [31] reconciling was

enacted by carers to integrate their past and their present and it reflected not only medical and physical aspects of rehabilitation but also a strong emotional and social component of this experience.

Adapting ways of living was an intense experience that impacted on all aspects of the individual's life and carers struggled with helping others to live. Feelings of duty, wanting the best care, opportunities for closeness were balanced with living with changed relationships, heightened levels of emotional and physical turmoil, alongside a steep learning curve and ongoing change. Interactions with healthcare systems created a further struggle within the theme negotiating the unknown.

3) Negotiating the unknown

Negotiating the unknown identified the high level of interaction required by carers in order to understand and actively manage their relative's/friend's care. Wanting to be involved in hospital care demonstrated a degree of readiness to take part in discussions and care activity. Not knowing what to do in the early stages of rehabilitation highlighted a lack of understanding of the complexity of care, the struggle to find information, including practical help, and the struggle to grasp and make sense of the range of information required. In addition, carers felt their personal knowledge of the patient had limited value and being proactive was fraught with difficulties created by a complex environment, confusing or unclear paths of communication.

i) Wanting to be involved

Carers expected to participate and be engaged in the decision-making process [40-43,48,49]. Most of the carers did not feel incorporated in this process: "No, I actually wasn't (involved). I was told kind of after the fact but I wasn't included in the discussions ahead of time even though I requested to be included in all of the discussions" [43 p.144]. For carers of patients with cognitive impairment this was a particular problem [39,42]. Being involved

and being aware of what was happening with their relative/friend in the hospital was extremely important especially in the discharge planning [41,43,44]. However studies showed that carers were not included in discharge planning [41-44]: “The hospital sent him back to the nursing home on Friday instead of Tuesday the week after” [42 p.454]. Providing carers with opportunities to express preferences and expectations in healthcare and strengthen information sharing could ensure that the needs of everyone involved in care are met [41,46]. This was described as being part of a patient’s circle of care [40,41,43-45,48].

ii) Not knowing

Receiving information from healthcare providers about their relative/friend with a hip fracture was crucial for carers so that they could cope with their role. The findings reported that carers felt uninformed and unhappy with the information shared in hospital: “Apparently she went for some x-rays and some heart tests last week and we have never even gotten any results or nothing” [41 p.7]; “My mom and us had no idea as to what was happening, what was being done, what was going to happen, etc. This was a totally new experience and unknown” [38 p.6]. Some carers also felt that the timing of information was often difficult to cope with, for example too early during the admission or too late [36,43]. Generally carers felt unprepared and needed information about pain management, rehabilitation procedures and the availability of care support [31,37,39-43,49]: “We did not really know how to proceed with my Mother's care upon discharge from the hospital” [38 p.6]. Carers required comprehensive and accurate information to reduce mismatched information about their role in the recovery phase, especially carers of people with dementia who expressed more unknowns about the progression and medication [31]. Carers needed to anticipate immediate and long-term problems [31] and to understand their role as motivators throughout recovery [36,49].

In general it was indicated that carers’ sources of knowledge were not included in care decisions or particularly valued. Limited time in hospital and care resources [38] and a heavy

reliance on their care [40], often left carers living with a sense of “not knowing what to expect or what is expected” from them [48] despite being the only ones providing continuity of care [41]. Carers have important information about the patient background (i.e. health status) [50] and they suggested that their information about the patient and their family dynamic should be assessed at hospital admission [43,44]. Despite carers’ perception that they are the “glue” some of them also felt that the healthcare providers had a more educated understanding of the patient’s condition; therefore they saw themselves as mainly receiving information but not providing it [44].

iii) Being proactive

Carers proactively sought knowledge but felt that the healthcare system placed them in a passive role, waiting for information; they struggled with their new role, with uncertainty and with feeling guilty for requesting information from busy staff [36,44,40,48]: “Every time I would ask the nurse she would have to go and look it up to come and give it to me but if I’m talking to somebody I can ask them about medication... but nobody has time to do that” [40 p.5]. Obtaining information was a struggle: “I mean it’s extremely frustrating to try and find somebody who actually knows what the situation is” [44 p.7]. Moreover, when they received inaccurate information it created a lack of trust in their healthcare providers and provoked confusion, frustration and more stress [40-42,44].

Being proactive was sometimes hindered by a lack of flexibility in arranging meetings taking into account a carer’s availability [41,36] and the lack of awareness of hospital policy: “they wouldn’t tell me anything because I didn’t have her privacy code...” [48 p.8]. As a response to the lack of information, carers mainly recommended being proactive to initiate communication and ask questions about the patient, which was easier if the carer had healthcare training or experience [40,44]: “We were pulling it [looking for information] on our own because otherwise it was just a black hole...you’re kind of thirsting for information that whole time” [43 p.144]. Written information to facilitate information sharing and minimise

errors [41,43]; and patient advocates [43,46] were also recommended. When carers were practically involved in rehabilitation sessions [41,43] or in training [30] they felt confident and more prepared to undertake care at home. This reflects that carers needed to be prepared for their role and suggests that healthcare providers should actively “build capacity to care” [43], which involves providing information and training [40].

Engaging in care: struggling through was hampered by negotiating the unknown. Carers wanted to be involved but did not necessarily feel involved. Absorbing information in a timely fashion was problematic due the amount of information, their readiness and ability to make sense of the information. Searching for information and developing understanding was a way of trying to understand their role as carer. However carers felt their views were not always valued and in being proactive often felt thwarted by conflicting information and they felt a burden to busy staff. This process may have been exacerbated by the suddenness of hip fracture without the benefit of time and experience to develop the understanding and skills involved in being a carer.

Interpretative line of argument

The line of argument identifies the core concept of engaging in care: struggling through, as an intense and all-consuming process of helping others to live, adapting ways of living whilst negotiating the unknown which includes a sense of not feeling valued within the healthcare system. The notion of struggle reflects the challenging emotional, social, and physical work that is actively required to engage in care. The active nature of the struggle is demonstrated through the themes and categories. The struggle to be involved, feel valued and gain the information required in a busy complex healthcare environment was challenging for carers. The predominant style of learning through experience suggests that further work could be explored to support this style by offering experiences that help develop understanding of the unknown and ease the degree of struggle.

DISCUSSION

The studies in this review only included hip fracture possibly due to its high prevalence, the hospital care and long term rehabilitation required, the significant cost of care and the consequences of disability [1], which were higher than any other types of fracture [2,4]. Our findings indicate that after a hip fracture relatives/friends wanted to help despite the intense nature of the experience. To cope with the role, carers learnt to adopt an extensive range of strategies and some of them were able to find benefits within their role. However as a group they would like to be more involved in decision-making and feel supported by the healthcare system.

Relatives/friends of an older person with hip fracture want to help and they play an important role by performing a wide range of emotional and practical tasks. In other conditions, the importance of the carers' help has also been highlighted [51-55]. Despite some studies that suggest carers embraced their role in variable ways [51,54,55], in part explained by the types of relationship (i.e. spouse, children, etc.) [56]; in general engaging in care was motivated by feelings of love, protection or solidarity and grounded in a belief in moral duty [9,57]. In this study, carers who were children of a hip fracture patient reported that this experience allowed them to enjoy more time with their parent. Our findings suggested that filial responsibility and gender norms play an important role in the decision about who provides care, as found in other studies [6,9,10,12,55,57] though their function and mechanism requires further study.

As in other conditions the intense experience of caring for an older relative/friend focused on adaptation and had a negative impact on carers' perception of health. For instance, stress, anxiety, frustration and lack of time were commonly reported feelings. This experience has also been found in quantitative studies that examined the impact of caring for a relative/friend with a fractured hip at home [58-60]. The negative repercussions of caregiving on health has been consistently reported in the literature and the term burden is widely

adopted to define it [9,61]. Carretero et al. [8] identified burden as a multi-dimensional concept and demonstrate how care can be converted into a degree of 'burden' for individuals depending of their circumstances. Furthermore our meta-ethnography shows that struggling to overcome negative feelings and trying to juggle everything with limited support was central to carers' experience. This also appears to be an important feeling reported by other studies [62,63]. Moreover, studies suggested that carers' mental health [64] and needs [60] are related to the degree of functional recovery from hip fracture.

With the passage of time carers learnt from their experience and their needs changed. Plank et al. [53] noted that carers' ambivalent feelings of 'being responsible for everything' varied through the discharge period. Building on Meleis's theory of transition [65] Byrne's study [31] identified several patterns within carers' transitions. Meleis et al.'s [65] notion of transitional experience was also helpful to explore aspects related to the patient-carer relationship after a hip fracture in Shawler's studies [34,35,37].

Carers developed an extensive range of proactive strategies to help them adapt. Strategies of coping and social support have been identified in the literature as key mediators of carers' stress [8]. For example, self-efficacy, personal mastery and a problem-solving approach appear to have a protective effect on a variety of health outcomes in dementia carers [66]. Clisset et al. [62] noted how family carers of older people with mental health problems in hospital responded proactively by trying to stay informed and communicate with staff. Social support and formal assistance supplied by other people was a strategy for relief for carers [8,67]. In this review formal care support was not mentioned as a strategy utilised by carers although they expressed their need for information about the availability of support.

The studies reviewed demonstrated a tension in carers' interactions with the healthcare system as they negotiated the unknown. In some papers carers struggled to assimilate information which highlights the importance of a readiness to receive information as well as receiving timely and accurate information. Moreover, lack of information sharing created a

lack of trust in the healthcare system and increased carers' stress. This resonates with research that identifies carers' information needs in order to provide care for their older family member [53,68]. The needs of carers have previously been identified as important for functional recovery and to reduce hospital readmission; therefore the importance of a holistic healthcare approach has been recommended [60].

Despite the importance of the family-centred care approach and valuing carer's knowledge our review reported that most of the carers felt excluded from the decision-making process. The involvement of family and friends as a key part of patient's circle of care is one of the core elements of patient-centred care [69] and, as in other conditions, family/friends should be included in the decisions about hip fracture care [70]. According to Bridges et al. [19] the desire of the family to be involved in the acute care of their older relative was not only to ensure her/his safety through family contact but also to have their own needs recognised by the healthcare staff.

The limitations of this review include the restriction of the search to articles published in English and the exclusion of grey literature. Also the search limited to 2000 could add a bias excluding relevant papers about the topic. A lack of studies for carers of older people with a fractured bone has limited the review to carers of an older relative/friend with a hip fracture. There were a number of methodological weaknesses identified. Firstly, the amount and the quality of data reported were heterogeneous and few studies provided substantial theoretical conceptualisation. Secondly, most of the studies included a wide range of age, carer-patient relationships, co-morbidities and both female and male participants but did not consistently report findings in relation to these variables so it was not possible to draw conclusions about the impact of relationship, gender, age or medical condition on the caregiving experience. Furthermore, the sample did not include others who are unable or who do not wish to take on the role of carer and the studies do not report if carers embrace a new role after the fracture or they already were carers of their friend/family member. This could be important to

understand identity issues and tension associated with engaging in care. Thirdly the studies largely originate from Canada and the USA which may limit transferability of findings to other healthcare systems. Fourthly there was a lack of exploration of family dynamics, expectation of care and practice norms. Future studies could consider the implications of sample characteristics more carefully, the interrelationship between social factors and experiences and focus on understanding the impact of a range of fractures in an ageing population. Longitudinal studies could identify carers' needs over time and cultural studies could identify what is happening in practice.

Conclusion

The contribution of this review is the creation of a new understanding of carers' experiences of caring for older people with a hip fracture. Engaging in care: struggling through identifies the intense nature of the caregiving experience where changing needs over time combined with juggling daily life, learning what is required, negotiating a complex health environment and feelings of being excluded from the decision-making process are core concepts of the experience. Family-centred care, shared decision-making, forms of experiential learning may provide direction to help facilitate greater integration of carers within daily care. This may enable the development of the knowledge and skills required to fulfil their role. Resources are required for innovated ways to enhance this aspect of care.

Implications for Rehabilitation

- Including relatives/carers in the umbrella of care within a family-centred approach.
- Involving relatives/carers within shared decision-making about care requirements and rehabilitation goals.
- Utilising forms of experiential learning to help the development of relatives/carers skills in relation to their role as carer.

- Providing opportunities for carers to explore ways of sustaining their own health through self-compassion.

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Declaration of interest

The authors report no conflicts of interest

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Tables and figure.

Table 1. Critical Appraise Skill Programme (CASP) assessment's results

Article	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Aberg et al. (2004)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Byrne et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Elliot et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes.	Yes
Giosa et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Glenny et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Griffiths et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Johnson et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Li & Shyu (2007)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Luptak (2006)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
Macleod et al. (2005)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Nahm et al. (2010)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Nahm et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Rydholm-Hedman & Grafstrom (2001)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Rydholm-Hedman et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Schiller et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Shawler (2004)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Shawler (2006)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Shawler (2007)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Toscan et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Toscan et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Tyrrel et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

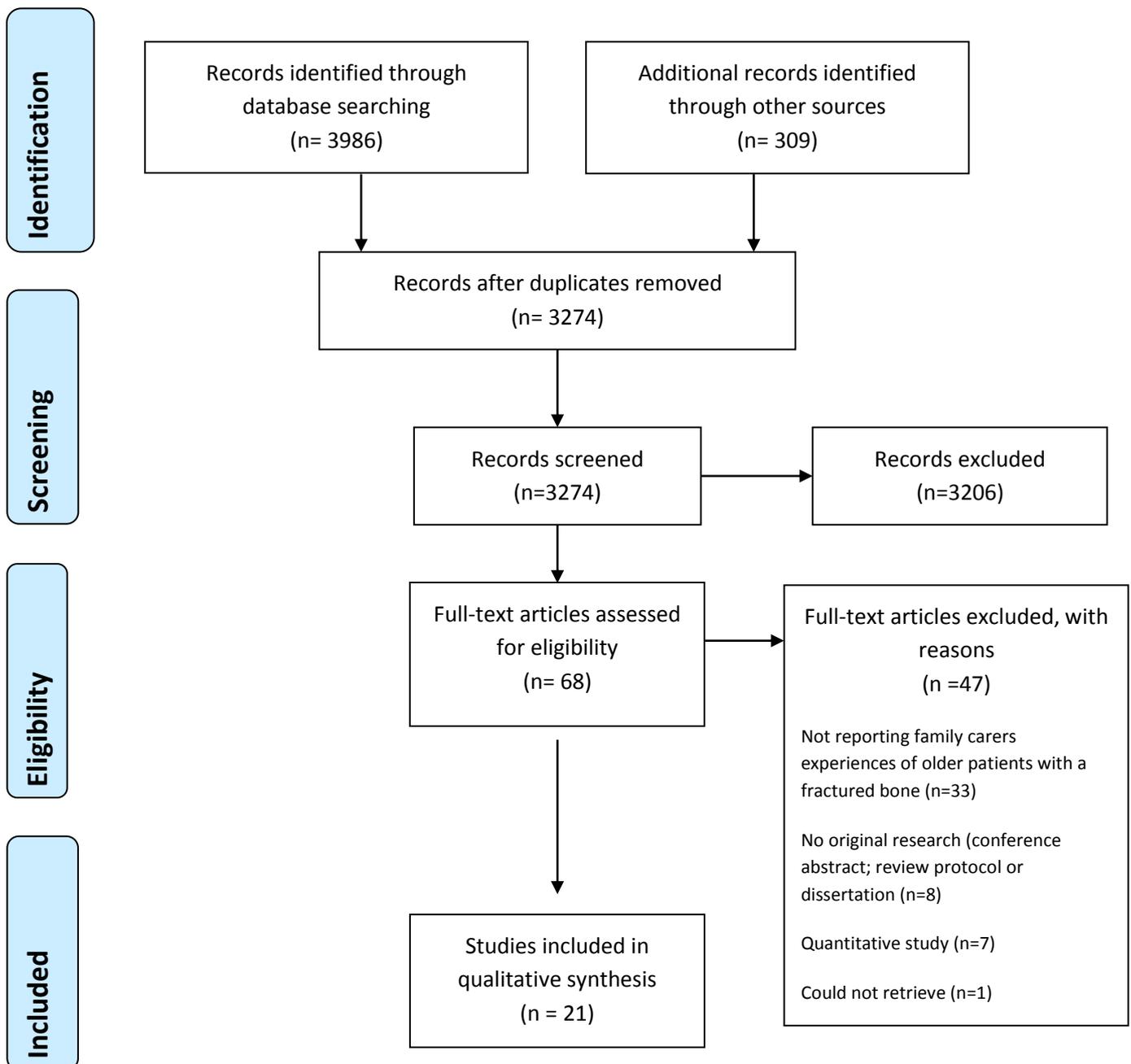
Table 2. Characteristics of included studies.

Author/Date	Objective	Data collection	Sample size and characteristics
Aberg et.al. (2004)	To investigate the perceptions of significant others, as informal caregivers, about the caregiving situation and its meaning and purposes.	Semi-structured interviews	Caregivers (N=14, 12 women) of an older person who had been undergoing rehabilitation. Relationship with the patient= 3 spouses; 9 children; 2 friends.
Byrne et al. (2011)	To develop a theoretical understanding of the processes engaged in by spousal caregivers during the transfer of their husband/wife from a Geriatric Rehabilitation Unit to home	Observations and 3 interviews at 3 points	Spousal caregiver (N=18, 9 women) of older patients with hip fracture or other conditions.
Elliot et al. (2014)	To examine the characteristics of the family caregivers' experience of communication and information sharing and identify facilitators and barriers of effective information sharing among patients, family caregivers and health care providers.	In- depth semi-structured interviews and observations	Family caregivers (N=8) of post-surgical patients through subsequent care transitions in a rural community. Relationship with patient= 6 adult children; 2 spouses.
Giosa et al. (2014)	To develop a more comprehensive understanding of family caregiver experiences of transitional care between hospital and home, and of caregiver needs for support during care transitions.	In- depth semi-structured interviews	Family caregivers (N=12, 7 women) of older adults with hip fracture, hip replacement or stroke. Relationship with patient= 4 daughters; 1 daughter-in-law; 4 sons; 2 wives; and 1 husband.
Glenny et al. (2013)	To explore experiences related to communication and information sharing during in-hospital and transitional care for older hip fracture patients through the perspectives of both health care providers and family caregivers to identify areas to target future interventions.	Semi-structured interviews and observations	Family caregivers (N=6) of older patients with hip fracture. Relationship with patients= 5 children; 1 spouse.
Griffiths et al. (2015)	To explore what patients consider important when evaluating their recovery from hip fracture and to consider how these priorities could be used in the evaluation of the quality of hip fracture services	Semi-structured interviews, individual and patient/carer dyad	Carers (N=14) of patient with a hip fracture.
Johnson et al. (2013)	To explore information transfer occurring through care handoffs executed by physiotherapist across the rural hip-fracture care continuum.	Semi-structured interviews and observations	Family caregiver (N=8) of older patients with hip fracture. Relationship with the patient= 2 spouses; 6 children.
Li & Shyu (2007)	To develop a conceptual framework explaining the coping processes of Taiwanese families after hospital discharge	In- depth semi-structured interviews	Family caregiver (N=12, 8 women) of older patients with hip fracture. Relationship with the patient= 3 spouses; 4 sons; 5 daughters-in-law.

	of an elderly family member with hip fracture and to use the Roy adaptation model to examine their interdependence relationships.		
Luptak (2006)	To explore discussions about care that took place between older adults and their families, preferences for one's own care, changes in those preferences over time, and the types of plans made.	Structured telephone interviews	Primary caregivers (N=110, 82 women) of patients with hip fracture or stroke who died between the one year interview and five year. Relationship with patients= 16 spouses; 49 children; 7 daughter in law; grandchildren 5; niece 10; other 13.
Macleod et al. (2005)	To examine the carer's role regarding early hospital rehabilitation.	Semi-structured interviews	Family caregivers (N=30, 20 women) of older patients with hip fracture. Relationship with patient= 11 daughters; 7 sons; 7 spouses; 3 sisters; 1 granddaughter; 1 niece.
Nahm et al. (2010)	To explore informal caregivers' experiences with providing care to older adults over the first 6- month trajectory of hip fracture recovery and their support needs.	In- depth semi-structured interviews	Family caregivers (N=10, 9 women) of older patients with hip fracture. Relationship with patients= 6 children; 2 spouses; 1 niece; 1 nephew.
Nahm et al. (2013)	To explore the caregivers' experiences in taking care of their family member while they were using the online hip fracture resource centre intervention	Discussion board posting	Caregivers (N=27, 18 women) of patients with hip fracture.
Rydholm- Hedman & Grafstrom (2001)	To describe the conditions for rehabilitation of older patients with dementia and hip fracture from the perspective of their next of the kin.	Structured interviews	Next of the kin (N=20, 18 women) of older patients with hip fracture and cognitive impairment. Relationship with the patients= 7 husbands; 3 sons; 4 daughters; 1 sister; 1 friend.
Rydholm- Hedman et al. (2011)	To explore how hip fracture patients' cognitive state affect family members' experiences during the recovery period.	Diaries written by family members	Family member (N=11, 8 women) of older patients with hip fracture, some of them cognitive impaired. Relationship with the patients= 2 spouses; 4 children; 1 distant relative; 2 friends; 2 nursing home staff.
Schiller et al. (2015)	To understand the recovery phase after hip fracture from the patient perspective, and identify specific messages that could be integrated into future educational material for clinical practice to support patients during recovery	Semi-structured interviews	Caregivers (N=8, 4 women) of older patients with hip fracture. Relationship with patients= 2 husbands; 2 sons; 3 daughters; 1 wife.
Shawler (2004)	To describe two related concepts that illustrate the perspective of the dyads of mothers' and daughters' relationships before a health crisis.	Individual, dyad and group semi-structured interviews, participant observation and archival material	Daughters (N=6) of mothers who fractured a hip.
Shawler (2006)	To further describe empowerment, one of the five concepts in the theoretical framework for transitions in mother-daughter relationships during health crisis	Individual, dyad and group semi-structured interviews, participant observation and archival material	Daughters (N=6) of mothers who fractured a hip.
Shawler (2007)	To develop a theoretical model illustrating aging mothers' and daughters' transitions through a health crisis.	Individual, dyad and group semi-structured interviews, participant observation and archival	Daughters (N=6) of mothers who fractured a hip.

		material	
Toscan et al. (2012)	To investigate care coordination for older hip fracture patients from multiple perspectives, including patients, informal caregivers, and health care providers to determine the core factors related to poorly integrated care when patients transition from one care setting to another.	Semi-structured interviews and observations	Informal caregivers (N=6 women) of older patients with hip fracture. Relationship with patients= 6 daughters.
Toscan et al. (2013)	To explore the experience of transitional care over the complete care trajectory for a single hip fracture patient, from multiple perspectives, including the patient, family caregivers, and relevant health care providers	Semi-structured interviews and observations	Daughters (N=2) of one older patient with hip fracture.
Tyrrel et al. (2012)	To examine the perspectives of patients aged over 65 years and their family members on the contribution of nurses to their inpatient rehabilitation	Semi-structured interviews	Family member (N=6 women) of older patients. Relationship with patients= 2 wives; 3 daughters; 1 daughter-in-law.

Figure 1: PRISMA Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

