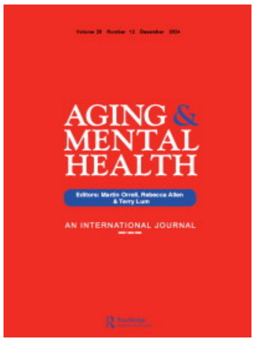

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ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/camh20

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To cite this article: A. Mahmoud, S. Raghuraman, E. Richards, S. Morgan-Trimmer, V. A. Goodwin, R. Anderson & L. Allan (22 Nov 2024): Experience of carers for older people with delirium: a qualitative study, Aging & Mental Health, DOI: 10.1080/13607863.2024.2430526

To link to this article: https://doi.org/10.1080/13607863.2024.2430526

AGING & MENTAL HEALTH
https://doi.org/10.1080/13607863.2024.2430526

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Experience of carers for older people with delirium: a qualitative study

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ABSTRACT

Objectives: There is a gap in our understanding of the experiences and needs of carers for patients with delirium and a scarcity of research on the topic in the UK. This study aims to explore the needs and experiences of carers for person with delirium and offer suggestions to support them.

Method: A qualitative interview study with carers of patients with delirium. Data were analysed using an abductive analysis approach.

Results: Fourteen carers were interviewed. We identified four themes; carers' involvement in providing care for the person with delirium, carers' perspectives of caregiving, support for carers and impact for caregiving on carers. Carers felt a responsibility to support the patient and to obtain information on delirium and its management on their own. Caregiving for a person with delirium had an emotional impact on the carer and they needed to change their lifestyle to maintain their caregiving responsibilities, as a result of the limited support they had.

Conclusion: More support for the carer in care plans with focus on emotional support, support groups for carers of people with delirium and assigning a case worker should be taken into consideration when developing interventions for people with delirium at home. These solutions may mitigate the impact of caregiving role on the mental and physical wellbeing of the carer for older person with delirium.

ARTICLE HISTORY
Received 20 June 2024
Accepted 11 November 2024

KEYWORDS
Delirium; frailty; carers; carer burnout; qualitative

Introduction

Delirium is 'an acute decline in attention and cognition' (Inouye, 2006, p. 1157), that is common in older people admitted to hospitals for acute care or after having an operation (Cotton et al., 2011; Inouye, 2006). Delirium can affect up to 50% of older people (more than 65) in hospital (BGS, 2019; NICE, 2023a). National Institute of Health and Care Excellence (NICE) guidance recommends the 4AT assessment tool for the diagnosis of delirium which consists of four items: (1) alertness, (2) Abbreviated Mental Test-4, (3) attention, and (4) acute change (Jeong et al., 2020; NICE, 2023b). Delirium management includes identifying and managing the underlying cause, effective communication and reorientation and providing reassurance for the person with delirium (Inouye et al., 2014; NICE, 2023b). Delirium is potentially a preventable clinical syndrome among older people, the development of delirium is associated with poor patient outcomes (Cotton et al., 2011) such as loss of independence, increased risk of morbidity and mortality, increased healthcare costs (Inouye, 2006) and hospital acquired complications (Cotton et al., 2011). After discharge home, patients with delirium are more likely to have poor functional and cognitive recovery (Cotton et al., 2011). Among older people with dementia, delirium is associated with increased rates of cognitive decline and mortality (Inouye et al., 2014).

The persisting symptoms of delirium after discharge from hospital cause concerns for both clinicians and carers or family members (Shrestha & Fick, 2020; Toye et al., 2014). One of the National Health Services (NHS) key priorities is to provide personalised care for older people at home without having to attend hospital or arrange for GP appointments (NHS, 2019). In the UK, NICE has produced substantial policy initiatives concerning better standards of delirium care (NICE, 2023b). However, delirium remains a major clinical problem without a corresponding public health response (Khachaturian et al., 2020; MacLullich et al., 2022).

Family members and carers can have a significant role in the management and recognition of delirium (Shrestha & Fick, 2020). Nevertheless, caring for people with delirium at home can be difficult as it is associated with stress for carers who want to do the right thing for the patient's recovery and safety (Meyer et al., 2023; O'Malley et al., 2008; Toye et al., 2014; Williams et al., 2020). Therefore, the impact of delirium may extend beyond the patient (O'Malley et al., 2008).

Caring for older people imposes demands on carers/family members (Bleijlevens et al., 2015; Meyer et al., 2023; Shrestha & Fick, 2020; Toye et al., 2014). There are variations in the burden of caregiving in different settings and different countries (Bleijlevens et al., 2015). A study showed that admission of older person with dementia to care homes decreased the burden of care on the carer and improved their psychological wellbeing (Bleijlevens et al., 2015). Given the current NHS policy that encourages people to stay in their own homes (NHS, 2019), this suggests the need for education, support and improved coping strategies that decrease the burden on the carers (Bleijlevens et al., 2015; Meyer et al., 2023; Shrestha & Fick, 2020; Toye et al., 2014). This support should be tailored to the carer's specific needs (Bleijlevens et al., 2015). A study that was conducted in Scotland, explored the experiences of older people with delirium and their carers during hospital stay (Dewar et al., 2013).

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/13607863.2024.2430526.

However, there is a gap in our understanding of the experiences and needs of carers for patients with delirium in the community and a scarcity of research on the topic in the UK (Meyer et al., 2023; O'Malley et al., 2008; Shrestha & Fick, 2020). This understanding is essential for development of evidence-based educational interventions that support carers in their role in the prevention, identification, reporting and managing delirium (Carbone & Gugliucci, 2015; Cohen et al., 2009; Shrestha & Fick, 2020). This study forms a part of a bigger project that involved the development of RecoverED intervention for older people with delirium at home that is being tested for feasibility. This qualitative paper explores the needs and experiences of carers for a person with delirium and offer suggestions to support them.

Methods

Design

A qualitative interview study with older people with delirium and their carers was conducted. Qualitative interviews allow deep exploration of participants' experiences and opinions. The Informal Caregiving Integrative Model (ICIM) (Gérain & Zech, 2019), Theory of Caring (Lin et al., 2012), and existing literature (Meyer et al., 2023; O'Malley et al., 2008; Shrestha & Fick, 2020; Toye et al., 2014) guided the analysis. The ICIM is a theoretical framework that considers determinants of informal caregiver burnout, with a key mediating role for the caregivers' appraisal of their situation and their relationship with the care-recipient (Gérain & Zech, 2019). The theory of caring consists of four categories and considers the dynamic process of care (Lin et al., 2012). The core category is My Life Changed and the other three categories (Commitment, Responsibility and Duty, and Support) are built around the core category (Lin et al., 2012). The research team are experienced qualitative researchers. SR (a female postdoctoral research fellow) and ER (internal medicine trainee) collected the data. SR and AM (a female postdoctoral research fellow and a pharmacist) analysed the data in collaboration with AL (a consultant geriatrician) and SMT (a social scientist). Ethical approval was issued by the Health Research Authority and Health and Care Research Wales (HCRW) (REC Reference number 19/WM/0362) before data collection.

Stakeholder engagement

People with lived experience of delirium and their carers and Health and Care Professionals (HCP) were consulted in the design of the study. They assisted in developing topic guide (Supplementary material 1) for the interviews.

Sampling and recruitment

The study was carried out in a teaching hospital in Devon providing acute care for older people. We employed a purposive sampling strategy (Hinton & Ryan, 2020) to capture the experiences of delirium symptoms, care and service use from the perspectives of older people with delirium and their carers. Patient-participants were screened for delirium by the admitting doctor, and confirmed in the post-take ward round by the admitting consultant. The research nurses consecutively approached and recruited patients aged over 65 who experienced an episode of delirium. Patients were diagnosed by medical team during the period of admission to an acute medical ward or orthopaedic ward during the recruitment period, as well as with the medical teams to identify cases of incident delirium in previously admitted patients. Eligible people either had capacity to consent or had a nominated consultee who could consent on their behalf. When the research nurses approached the patients, the patients were asked whether anyone was involved with their care at home and whether we were able to contact them. In cases where patients were not able to give consent, the research nurses contacted the documented next of kin. Only English-speaking participants were included in the study. Following verbal consent from a member of the clinical team, eligible participants were approached by the clinical researcher at the time of preparation for discharge. Participation was through voluntary consent and interviews with consenting individuals were scheduled 4 wk after discharge from hospital either to their own homes or a residential care facility. The researchers had no previous contact with any of the participants.

Data collection

We developed semi-structured topic guide (Creswell & Poth, 2016; Hinton & Ryan, 2020) based on a published realist review of interventions to support recovery for people with delirium (O'Rourke et al., 2021) and discussions with PPIE group members that involved lay members of the public. The topic guide enabled consistency in the data collection, with the interviews flexible enough to allow the participants to explain what was important to them (Mays & Pope, 2020). The interviews were conducted *via* telephone and audio recorded using an encrypted recorder (Hinton & Ryan, 2020). The patient and carers used the speaker mode during the phone call to allow recording of the patient's and the carer's voice. The researchers introduced themselves and explained the aim of the study to the interviewee at the beginning of each interview. The researchers engaged both patients and carers in the conversation by asking them if they need to elaborate on any of the questions, during the interview. The audio-recorded interviews were transcribed by a General Data Protection Regulations (GDPR) compliant transcriber and checked for accuracy by researchers. This paper presents the findings from the interviews that are related to carer experiences and needs from carers' perspectives.

Data analysis

In this paper, we present a sub-analysis from a larger dataset. We undertook abductive analysis that is a combination of inductive and deductive approaches (Timmermans & Tavory, 2012), and used NVivo 14.0 (QSR International Pty Ltd, 2022) to manage the data. This involved an iterative approach to analysis that used inductive and deductive coding, to facilitate a deeper understanding of carers' experiences and needs (Creswell, 2014; Mays & Pope, 2020). We coded the interviews in cycles, with inductive codes generated by two research fellows independently, identifying similar ideas or concepts that could be categorised into a code (Mays & Pope, 2020). Consequently, codes were revised by the two research fellows (AM and SR) two senior members (SMT and AL) of the research team helped resolve discrepancies and sensemaking of the codes, and reviewed findings and offered feedback. After the inductive coding, the ICIM (Gérain & Zech, 2019), Theory of Caring (Lin et al., 2012) were used to guide the deductive approach. AM used the domains of the two frameworks in conceptualisation, and grouping of the codes into categories. This enabled understanding of the relations between categories, identifying patterns in the data and themes. This enabled balance between data relating to pre-existing concepts and data based on the perspectives of the participants to create balance between data from the interviews and those based on existing literature. Finally, categories and themes were reviewed with the research team.

Results

Interviews took place between November 2021 to July 2022.

Demographic characteristics

Sixteen carers consented to participate; nine were interviewed on their own, five with the person with delirium and two withdrew from the interview. We interviewed five male and nine female carers with variation in age and relation to the participant with delirium (Table 1). Carers were providing care for recipients who were older people with delirium or had a delirium episode, and many of them had additional co-morbidities including cognitive impairment, incontinence, chronic obstructive pulmonary disease (COPD) and frailty. As the interviews were conducted four weeks after discharge from hospital, some older people may have still been delirious during the 4 wk and others have recovered but the interviewer could not assess this. The interviews lasted between 26 and 65 min (mean= 45 min).

Using the ICIM and the Theory of Caring, we identified patterns in the data about the experiences of carers and identified four themes. The themes are presented in Figure 1 and summarised below.

Theme 1: Carers' involvement in providing care to their family members

This theme explored how carers described their involvement in the caregiving for person with delirium.

Interviewing carers from different age groups and relation to the person with delirium allowed us to explore factors that led carers to be involved in caregiving and how they perceive their involvement. Also, at the time of the interview, the person with delirium status of recovery varied among the participants as perceived by the carers.

> So it took her four weeks altogether to get back, but not quite to normal. I mean, I would say 85% of normal. (Carer 11, son of the person with delirium)

> He was getting weaker, so I don't think we would ever get back to cognitive health. (Carer 1, daughter of the person with delirium)

Carers recognised the staff could not always provide support to them. Therefore, some carers felt a responsibility to support patients during their hospital stay to manage their symptoms of delirium.

> The nurses left me to it, which… which was okay, because that's what I was there for, I guess. (Carer 3, spouse of the person with delirium)

After being discharged from hospital, carers had concerns about the safety of their family members, with loss of cognition and reduced mobility seen with delirium increasing the likelihood of falls or unintentional harm to themselves or others. These concerns translated to increased carer burden, with carers having to spend more time ensuring their family member remained safe. Additionally, carers were trying to improve their family member's cognition by spending more time with them doing activities.

> As a carer, you're ultimately… you are 24 hours' responsible, and you've… and one feels that responsibility very heavily. (Carer 11, son of the person with delirium)

> We'd play Round the Clock Patience, we'd play dominoes. […] this is what we've got to do, is to keep them as stimulated as possible. (Carer 6, daughter of the person with delirium)

The type and quality of the relationship between the carer and patient were factors that may have determined carers' involvement in caregiving. For example, one carer did not want to be separated from their family member with delirium because they thought their presence could positively impact the recovery of the older person.

> The fact that I'm here has helped a lot, the fact that I haven't gone anywhere. I'm here all the time. (Carer 8, spouse of the person with delirium)

Although interviewed carers expressed their feelings of responsibility to support their family members with delirium, there was a difference in their perceived intentions for their involvement. Some were providing support to their family

Table 1. Demographic characteristics of carer participants and the person with delirium.

Carer ID	Carer gender	Carer relation to the person with delirium	Person with delirium gender	Delirium status as perceived by patient and/or carer
1	Female	Daughter	Male	Repeated episodes/ not recovered from delirium by the time of the interview
2	Female	Daughter	Male	Repeated episodes/recovered from delirium by the time of the interview
3	Male	Spouse	Female	Repeated episodes/ partially recovered from delirium by the time of the interview
4	Male	Son	Female	partially recovered from delirium by the time of the interview
5	Female	Spouse	Male	First/ partially recovered from delirium by the time of the interview
6	Female	Daughter	Male	Repeated episodes/ partially recovered from delirium by the time of the interview
7	Male	Spouse	Female	First episode / partially recovered from delirium by the time of the interview
8	Female	Spouse	Male	First episode / partially recovered from delirium by the time of the interview
9	Female	Spouse	Male	First episode / recovered from delirium by the time of the interview
10	Male	Son	Female	First episode / not recovered from delirium by the time of the interview
11	Male	Son	Female	First episode / partially recovered from delirium by the time of the interview
12	Female	Spouse	Male	First episode / not recovered from delirium by the time of the interview
13	Female	Daughter	Male	First episode / recovered from delirium by the time of the interview
14	Female	Daughter	female	Repeated episodes

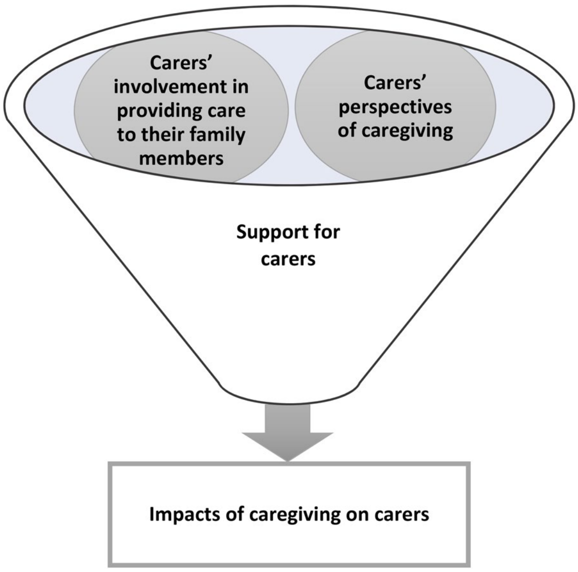

Figure 1. Themes developed using abductive thematic analysis.

members with an eye on gradual recovery or improvements in terms of independence or memory, while another carer wanted to be updated about the progress of the patient's condition all the time. Regardless of their intentions and feelings, some carers lacked choice in becoming a carer.

> A moment ago, he's just shown me he's going to the toilet, fine. I just wish he had some memory. I wish something would come back. (Carer 12, spouse for the person with delirium)

> I suppose I can't complain about any of it really, it's just one of those things that hey, got to put up with and […], just get on with life. (Carer 12, spouse for the person with delirium)

Theme 2: Carers' perspectives of caregiving

This theme explored carers' perspectives of caring for an older person with delirium

Carer for person 8 (a spouse) found that an additional demand for caregiving for the person with delirium was constant need for reassurance. This might be related to the long period of their relationship.

> So, you know, it's the partner that's sort of left at home thinking, well, what's happening, you know? But, as I say, we sat down when he came home and I said, "Look, we will do this together. If there's anything worrying you, talk to me. (Carer 8, spouse of the person with delirium)

> He was sort of very emotional and wanted to know why I couldn't stay at the hospital and saying things like… because I could only go for an hour a day and he was saying things like, "I've been looking for you everywhere," which was silly because he was in hospital, but that was part of the delirium. He just couldn't understand why I couldn't stay at the hospital and getting very… towards the end, before he came out, very emotional, very… yeah, just very worried sort of thing. That's the only way I can explain it. (Carer 8, spouse of the person with delirium)

Carers expressed a strain on their relationship with their family members due to conflicts around the level of care needs required during and after delirium. Some felt there were discrepancies between what help the carer felt was needed, and what the person with delirium felt was required.

> I mean, you've probably assessed that [name]'s a very independent lady and she's got quite a lot of plans for the future, but a lot of that does have to be tempered with a certain amount of denial of the reality of the situation. And the estimation she has of her own capabilities with the health consideration. (Carer 3, spouse of the person with delirium)

One carer who was a spouse of the older person with delirium, had to provide emotional support to other family members to help them when first meeting the patient after having delirium.

> It's a shock [for family members], and because you could only have one visitor at once, I couldn't go into the hospital with them [family members], which made it a lot harder, […], I tried to prepare them before. (Carer 5, spouse for the person with delirium)

Finally, the general health of the person with delirium, with multiple co-morbidities (e.g. COPD, dementia and cognitive impairment) sometimes necessitated increased care. This could range from domestic help to personal care, or medication management. Many of the participants in this study had complex co-morbidities (e.g. frailty) alongside their delirium, that sometimes led to additional demands on carers. Complications related to delirium, such as incontinence and mobility impairment, even if transient, could lead to loss of independence thus increasing the demands on the carer either temporarily or permanently.

> Even if I had carers four times a day, there'd still be long gaps in the day when I'd be on my own and if [redacted] fell over again, or if his pad needed changing or something like that, I couldn't do it by myself. (Carer 5, spouse for the older person with delirium)

Theme 3: Support for carers

This theme addressed practical and emotional support that was provided to the carers of person with delirium.

Most of the carers we interviewed explained how they experienced lack of support from the health and social care staff at hospital, community and care homes. Some carers wanted reassurance from healthcare staff and appreciated any form of communication with healthcare professionals at hospital or in the community.

> There just isn't any support, nobody wants to help you. … when [redacted] was at home, I spent so much of my time on the phone going round and round in circles trying to get help or advice from people, and the doctors weren't interested. (Carer 5, spouse of the person with delirium)

It was evident in the interviews with carers that regardless of the patient's condition after having delirium, the carers needed to organise the health and social care services provided to the patient because of the lack of comprehensive support in any of the settings. Therefore, one carer suggested that having one point of contact who could coordinate the access of the patient to services might support the carers.

> There's just no support there, no people just phoning or contacting me or explaining anything. It was just… it was an absolute nightmare. (Carer 5, spouse of the person with delirium)

> Just a case worker, yeah, someone who's responsible ultimately for that [access to services], […] if your mum's turning up at your door at 10 o'clock at night, you're… you… you feel that quite a lot, and not having that point of contact… (Carer 11, son for the person with delirium)

Family support was considered essential for carers, with some indicating huge value in people recognising the burden placed on them, and offering to help, not only with emotional support, but also with care tasks. Moreover, input from friends, peer support in carers groups and religious groups through the church were recognised as important sources of informal support for carers for person with delirium.

> I suppose as a carer you want people to recognise that what you're doing is quite a demanding, hard task. (Carer 10, son of the person with delirium)

> I've started to go to church around here and they've been really supportive. (Carer 6, daughter of the person with delirium)

Others appreciated support they got from a professional carer to help them with the demands of caregiving for person with delirium and improve the patient's condition.

> It (professional carer) helped [Name] a lot, and helped with the memory and the general responses, and it's helped me quite a lot, because I get a break for an hour or so both ends of the day. (Carer 3, spouse of older person with delirium)

Another form of support that carers needed was education and information sharing about the aetiology of delirium. Many carers felt they would have benefited in their understanding of their family member's condition if this were explained by a healthcare professional. Carers shared their perceptions of delirium often confusing delirium symptoms with that of dementia. Also, a carer who provides care to a person with recurrent delirium episodes, shared their need to understand if there are risk factors that increase the opportunity for delirium episodes to be repeated.

> I felt that just some information would helpful. So that we knew what to expect about [delirium] because I think initially, when family members noticed that Mum was confused, they thought, oh, it must be Alzheimer's or dementia, but then realised that it was the infection that was giving you the confusion. (Carer 4, son of the person with delirium)

> The only thing I can really say is because it is quite frightening to a partner, more information; somebody to sit down and talk to me and explain what was happening would have benefited me, because it scared me. (Carer 8, spouse of the person with delirium)

> So I guess, you know, if you have it once and it's bad what is the likelihood? Are you at greater risk of having it again or is it you're exactly the same odds? (Carer 14, daughter of the person with delirium)

One carer mentioned how they learnt from experience how to deal with delirium symptoms.

Carers acquired information themselves about delirium care pathways, rehabilitation services, and useful contacts for legal, financial and healthcare advice. Providing this information to carers on discharge may decrease the additional stress put on carers in locating this information themselves.

> Yeah, except it's just a bit difficult navigating your way through it, … everyone still has to navigate their way through the process of assessment. (Carer 4, son of the person with delirium)

> I've been studying it myself and trying to understand myself, so I've read as much as I possibly can. (Carer 6, daughter of the person with delirium)

One carer appreciated the help they got from organised carers' meetings and relevant societies in their community, and also joined an online course to educate themselves on dementia and its symptoms. However, they did not find similar activities or societies for delirium.

> The best help I've had has been from [area] Carers […] And recently they've organised some courses on dementia and I did one the other day on Zoom on types of dementia, and that was very, very helpful. (Carer 5, spouse of the person with delirium)

Although these groups and societies were beneficial in terms of emotional support and information, they are not able to make onward referrals within the healthcare system for additional support or advice. Carers indicated that there were no similar resources for delirium and recommended the provision of education and training to carers of person with delirium to provide them with advice and support on delirium management at home

> The Alzheimer's Society only really had the… they only were able to signpost me into a multitude of different agencies that might be able to provide some assistance. (Carer 11, son of the person with delirium)

Theme 4: Impacts of caregiving on carers

This theme describes the impact on the carer for a person with delirium.

Carers perceived that the caregiving role led them to change their lifestyle, needing to be available 24 h a day in order to fulfil their caregiving role.

> I had to…do a lifestyle change almost to support Mum (Carer 5, spouse of the person with delirium)

We identified a direct impact on the carer for the person with delirium. For example, they need to maintain their daily responsibilities and may not get much sleep.

> And you have to be really strong to keep going, especially if you're not getting much sleep, and I was on the go all day looking after [redacted] (Carer 5, spouse of the person with delirium)

We identified carers expressing emotional distress as a consequence of witnessing their family member suffering from delirium. This sudden change in their relative led to shock and distress in the carer and other family members, which was described as being 'upsetting' and 'scary'. Some described the feeling of 'helplessness'. Emotional distress was also seen in carers with regards to concerns for their family member's safety, the unknown trajectory of delirium, and the fear of whether it may happen again.

> It was so scary, really, because we couldn't do anything to help him. (Carer 2, daughter of the person with delirium)

> Mum's had issues in the past that have had some kind of element of delirium it's lasted 24 hours maybe longer with the recovery but this just was so immense and so acute and took so long and I felt that I'd lost her then. Sorry – [gets upset]. […] There's a fear of it happening again. (Carer 14, daughter of the person with delirium)

One carer expressed their need for a break from caregiving and stated that if this help was available it could give this carer a break from caregiving tasks.

> I am hoping that they might be able to just take [name] out, if somebody could take him out just, sounds horrible, take him off my hands for an hour so that I could just have a bit of a break. (Carer 12, spouse of the person with delirium)

We interviewed carers from different age groups and relations to the person with delirium. For example, carer 14 who was the daughter of the person with delirium could not cope with the unpredictable demands of caregiving for person with delirium with the lack of sufficient support. They found themselves no longer able to continue and approached social services for help.

> … she then got to the point where she was then vulnerable in the house and vulnerable 24 hours a day and I wasn't able to look after her 24 hours a day. So in the end I think I managed three weeks of that kind of thing continuing and I had to phone Social Services and call for help and said I can't do it. (Carer 14, daughter of the person with delirium)

On the other hand, carers 6 and 12, used the words 'prisoners' and 'stuck' to describe the emotional burden of the caregiving role on them. However, they expressed their desire to continue trying despite the burden on their day-to-day lives.

> Well, I felt as if I was stuck in a hole and I could not get out, but there you go… I'm not giving up, certainly. (Carer 6, daughter of the person with delirium)

Discussion

In this study, we identified factors that determine carers' involvement in caregiving and the demands of the caregiving role on the carer in the context of delirium. Carers perceived that there is a lack of sufficient support for them, which made the caregiving role more challenging. We identified carers' needs that can be addressed to support them to manage the demands of their role. From the interviews and existing literature, we offer suggestions of viable solutions to support carers looking after a person with delirium.

The interpersonal relationship between the person with delirium and their carer determines the level of involvement of the carer and their experience in caregiving (Gérain & Zech, 2019). From interviews we conducted, we found that caregiving for person with delirium may change the quality of the relationship due to conflicts between them and the care needs for the patient. Moreover, the trajectory of delirium and change of roles of the carer and person with delirium have an impact on the quality of relationship between them. In line with existing evidence, future research should focus on better understanding of the conflicting views between carers and person with delirium and its impact on their emotional wellbeing including the quality and stability of the relationship (Revenson et al., 2016; Shrestha & Fick, 2020).

Delirium symptoms, progression and sudden onset are factors that resulted in emotional distress for some carers (Buss et al., 2007). The physical complications associated with delirium may negatively impact the level of independence of the patient (Gérain & Zech, 2019; Revenson et al., 2016)and therefore increase the burden of caregiving. The loss of cognitive abilities associated with delirium (Gérain & Zech, 2019; Revenson et al., 2016) may raise safety concerns that can be a fundamental cause of distress for the carer (Shrestha & Fick, 2020). Carers that we interviewed stated that witnessing their family members in a state of confusion because of delirium was related to emotional distress in the caregivers. The person with delirium's constant need for reassurance and support was found to place additional demands on the carer's capacity. In line with previous studies, our study showed that the need for constant supervision at the cost of sacrificing carers' personal and professional lives could jeopardise the carers' physical and mental wellbeing (Cohen et al., 2009; Shrestha & Fick, 2020). Evidence shows that the lack of independence of the care-recipient and the impact of caregiving on the relationship between carer and person with delirium can make the carer more susceptible to burnout (Gérain & Zech, 2019; Revenson et al., 2016). For example, evidence shows that caregivers for people with delirium developed anxiety and depression as a result of their caregiving role (Bull, 2011; Buss et al., 2007). It is important to recognise that carers for people with delirium are at risk of developing long-term health conditions and this should be taken into consideration when developing interventions for people with delirium (Buss et al., 2007; Shrestha & Fick, 2020). Similar to other studies, carers in our study needed reassurance and education from HCPs in different healthcare settings (Bull, 2011; Bull et al., 2016; Dewar et al., 2013). As suggested from the interviews, providing carers with information on delirium can help them respond appropriately to symptoms, offer support to the person with delirium, have more confidence in decision making and mitigate the distress caused by witnessing the symptoms of delirium (Bull, 2011; Bull et al., 2016; Shrestha & Fick, 2020). King's Fund published in their report on social care that only 55.55% of carers in England receive, advice, information or signposting (Simon Bottery, 2024). This can be related to the current pressure on the local authorities' budget that have an impact on number of people receiving social care; in 2023 more people are asking for social care and fewer are receiving it (Simon Bottery, 2024). However, with the current limitations of staff capacity and challenges on the NHS, there could be a role for technology (NHS, 2019; NHS England, 2023; Shrestha & Fick, 2020) in supporting carers by allowing better access to information about delirium and its management at home.

Finally, carers for people with delirium indicated that the presence of other comorbidities beside delirium and lack of independence are factors that increased their caregiving responsibilities in terms of domestic help, support to take the right medication and booking appointments. In England, the proportion of carers who receive no support increased to 17.2 in 2023 and only 3% received locally commissioned care (The King's Fund, n.d.). This highlights the need to offer support with domestic tasks through respite care at home or a formal carer to allow the carer to have breaks and decrease the amount of time providing care. However, having external support may cause further distress (Gérain & Zech, 2019) because of conflicts between carer and professional carer, distrust and financial constraints in hiring professional carers. These may lead carers to take the sole responsibility for caregiving and they may avoid asking for help with their tasks (Gérain & Zech, 2019). We suggest that informal support from family, friends and organisations for carers for a person with delirium could mitigate the burden of care and its emotional and impact on the carer (Gérain & Zech, 2019). Family members and friends can provide reassurance and emotional support that carers' needs. There is support for carers of patients with dementia in the UK through Dementia UK (n.d.) and the Alzheimer's society (Alzheimer's Society, n.d.) but there is a lack of similar support for carers of persons with delirium. Such support groups could play a role in increasing people's awareness about delirium; so family members will have better understanding of delirium and the challenges of caring for person with delirium. Thus carers will be recognised and offered support. Additionally, these organisations may play a role in providing information about available care pathways to the carers to address needs. From the findings, we suggest that assigning a case worker who coordinates the care provided to a person with delirium, facilitate their access to rehabilitation and respite care would provide support for the carer. Other research has found that utilising care coordinators in providing health and social care for older people may reduce emergencies (Ho et al., 2023; Improvement Academy and Connected Health Cities, 2017; Poupard et al., 2020). Further research might be needed to identify best approach to coordinate care in older people with delirium to meet care and patient needs.

With the lack of sufficient formal support, some of the carers we interviewed attempted to meet the needs of the patient at the expense of their own wellbeing, whereas other carers admitted their limited ability to provide care and the insufficient formal support leading to sending their family members to care homes. Caregiving for people with delirium is a difficult task that makes carers entitled to be recognised by society and their preferences and needs should be taken into consideration when developing delirium management and care plans. Therefore, future research should focus on providing better support for carers to maintain their wellbeing and to allow older people to stay at their own homes to reduce costs associated with rehospitalisation and admission to care homes (NHS, 2019; Shrestha & Fick, 2020).

Strengths and limitations

A key strength for this study is that it adds to the scarce evidence on experience of carers for people with delirium and their needs. Additionally, it highlighted the needs for carers for people with delirium in the community settings in the UK.

A diverse range of participant perspectives added to the richness of information generated and gave insight into needs of carers of person with delirium and possible ways for support. It is noted that the outcomes in this research are specific to the carers and people with delirium that participated in the interviews. Additionally, as qualitative research is subjective, the outcomes could be affected by the views of the researchers and/or how the questions were worded. Although we recruited carers with a wide variety of views and experiences, our findings may not be transferable to other carers who might have different views and opinions (Creswell & Poth, 2016; Mays & Pope, 2020).

The study was conducted during the SARS-COV2 global pandemic which impacted the recruitment of participants and limited the sample size. Additionally, some carers were interviewed in the presence of the person with delirium and this might cause bias but the researchers encouraged carers to express their opinions and experiences. However, our frameworks informed qualitative research enabled exploration of carers experiences from their perspectives.

Conclusions

There is a limited support for carers for a person with delirium. Carers needed more support in terms of providing information and education on delirium ideology and management, organising access to care and services, helping with care tasks at home and emotional support. More support for the carer in care plans with focus on emotional support, support groups for carers of people with delirium and assigning a case worker should be taken into consideration when developing interventions for people with delirium to assist carers in caregiving at home. These solutions may mitigate the impact of caregiving role on the mental and physical wellbeing of the carer for an older person with delirium. Future research should focus on innovative approaches to provide better support for carers of people with delirium at home, to shift the care plan for people with delirium from person-centred into person and family centred approach (Shrestha & Fick, 2020).

Acknowledgements

We would like to acknowledge the support of the following research networks: NIHR Applied Research Collaboration South West Peninsula (PenARC) and Exeter NIHR Biomedical Research Centre. We are grateful to the RecoverED study participants for their participation in the study and to members of the patient and public involvement and engagement group for their support and contribution throughout the study. For the purpose of open access, the author has applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising from this submission.

Ethical approval

Ethical approval was issued by the HRA and Health and Care Research Wales (HCRW) on 17th January 2020 (Reference number 19/WM/0362).

Informed consent

All the participants gave written informed consent and consent to participate.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This project was funded by the University of Exeter and the National Institute of Health and Care Research (NIHR) Programme Grants for Applied Research Programme [NIHR202338]. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR.

Data availability statement

Anonymised interview data are available upon reasonable request from the author.

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