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RESEARCH ARTICLE

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The forgotten other: supporting the caregivers of people with limb absence during the hospital-to-home transition

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ABSTRACT

Objectives: This study aimed to explore the interrelated nature of how caregivers of people with limb absence impact and are impacted by the hospital-to-home transition. Moreover, this study aimed to explore how caregivers can be better supported to fulfil their role.

Methods: A qualitative research study positioned within an interpretivist paradigm. Semi-structured interviews were conducted with 14 people with limb absence and 15 nominated caregivers. Data was analysed using a reflexive thematic analysis.

Results: Three themes were identified. (1) Lost in transition: Disconnection and divergence from hospital to home: Both service-users and caregivers described how caregivers were marginalised during the rehabilitation process, creating differing expectations regarding the service-users' functional abilities upon returning home. (2) Bearing the weight of unseen struggles: The impact of caregiving on the caregiver. Participants described the cumulative impact of caregiving on caregivers' physical and mental well-being. (3) Supporting the supporter: Participants highlighted informational, care continuity, communication, and social support gaps and described how such gaps could be addressed.

Conclusion: This study offers novel insights into the lived experiences of both caregivers and service-users in navigating the hospital-to-home transition and foregrounds how caregivers can be better supported. Centralising caregivers' perspectives can help ensure that they inform evidence-based initiatives to support integrated rehabilitation environments.

IMPLICATIONS FOR REHABILITATION

- Practitioners should be aware of the diverse ways that caregivers may experience the hospital-to-home transition to develop a more person-centred, broader, and longer-term view of the rehabilitation process.
- Including caregivers throughout rehabilitation could help mitigate against the mismatch in expectations concerning service-users' functional limitations upon returning home, ultimately improving long-term care outcomes.
- Participants suggested addressing support gaps by implementing educational material and talks, social support groups, and creating stronger links between hospitals and communities.
- To support future integrated care policies, the findings articulate a need to shift from the patient-centred ethos of rehabilitation towards viewing caregivers as partners in care.

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Rehabilitation; qualitative; community physiotherapy; limb absence; care-givers

Amputation is a major life-changing experience which alters an individual's mortality, function, mobility, mental health, and quality of life [1–6]. While rehabilitation aims to minimise these impacts, previous research has highlighted how the hospital-to-home transition can be particularly challenging, as service-users negotiate significant practical, physical, psychological, and social issues [7]. Compounding these difficulties, hospital staff (e.g., physiotherapists, occupational therapists) often lack the time, resources, or community services to sufficiently support service-users in managing the hospital-to-home transition [6,8,9]. Ultimately, this inadequate transitional care can lead to poor self-management, readmissions, and increased healthcare costs [10,11].

Central to navigating this transitional period and rebuilding life following limb absence is the support provided by others, in particular, informal caregivers [12]. Informal caregivers can be defined as those

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who provide physical, financial, practical, and emotional support, and can include partners, children, other family members, or acquaintances [13,14]. Informal caregivers are crucial to healthcare systems as they play a pivotal role in care continuity and illness management in the community. For example, previous research has highlighted how people with limb absence who perceive greater levels of available support have been shown to have a higher quality of life satisfaction, greater mobility, lower levels of depressive symptoms and pain, and better overall adjustment [2,15,16]. Such benefits are crucial to the life-time support of people with limb absence and are becoming increasingly more important as healthcare models shift towards transitioning care from the hospital to the community [17,18].

Nevertheless, despite the demonstrated valuable impact provided by caregivers in assisting people with limb absence, they are often the forgotten voice within rehabilitation services [19]. As outlined by the broader literature, informal caregivers receive insufficient support for their care of loved ones, particularly at critical junctures such as hospital discharge and the transition to ongoing support at home [18]. This inadequate support is consequential, as high rates of hospital readmissions alongside the use of Emergency Departments for non-urgent situations have been associated with inadequate preparation of informal caregivers to care for their dependents at the time of discharge [20–22]. Moreover, caregivers are reported to have higher levels of depressive symptoms and lower mental health and quality of life scores than the general population [23]. These findings contribute towards growing tensions regarding the sustainability of community–based care for people with long-term conditions, especially when those in supportive roles are themselves inadequately supported [13].

With regard to limb absence, a recent scoping review identified several unmet needs of caregivers, supporting previous research which has illustrated how caregivers feel ill-equipped to fulfil their role [11,12,14,19]. That said, there has been limited contextual insight into the nature of these unmet needs, as the literature has been dominated by quantitative methodologies [24–28]. Consequently, the lived experiences of caregivers regarding the challenges they encounter and their perspectives on how to address these challenges remain largely unexplored. These knowledge gaps make it difficult for healthcare professionals, systems and policymakers to understand their needs and experiences and support them appropriately. Therefore, the focus of this study was twofold. First, to understand the experiences of both caregivers and service-users in navigating the hospital-to-home transition and life post-rehabilitation. Exploring both service-users and caregivers' perspectives allows for a more robust and in-depth insight into the interrelated nature of how caregivers impact and are impacted by this transition. Second, to explore how caregivers can be best supported in their role. To extend previous research [12], and heeding calls to explore the cumulative impact of caregiving [29], we recruited caregivers of service-users who had diverse presentations of limb absence and were between 6 months and 10 years post-discharge.

Methods

Design and philosophical positioning

This study adopts a qualitative approach and is underpinned by a relativist ontology and a subjectivist epistemology [30]. It employs both semi-structured interviews and reflexive thematic analysis as methods of data collection and analysis. Ontologically, we subscribe to the belief that no single, mind-independent, external reality exists; rather, reality is multiple, fluid, and mind-dependent [30–32]. Epistemologically, we assume knowledge is subjective and constructed through interaction between the researcher and the participants. The authors' positioning, therefore, will have shaped both the data co-construction and the interpretations offered throughout [30–32]. The primary researcher is a physiotherapist and academic with experience in qualitative research. She was embedded within the rehabilitation setting for a day a week for 18 months; however, she acted as an independent researcher and was not directly involved in the treatment or care of service-users or caregivers at the centre.

Setting and context

This research took place at a United Kingdom–based urban amputee rehabilitation centre operated by the National Health Service (NHS). Service-users attending the centre have undergone amputation due to a variety of causes, including vascular conditions, trauma, infection, disease, or congenital defects. Service-users can attend the rehabilitation centre full time either as an in-patient (due to complex needs) or an out-patient for multiple weeks post-surgery. Rehabilitation involves group classes, educational talks, and personalised rehabilitative exercises.

Patient and public involvement (PPI)

A service provider identified a need within their service to involve, centre, and amplify caregivers' experiences of the hospital-to-home transition. This need was identified following ongoing conversations with people with limb absence within their service, who highlighted the impact of caregivers on their transition. The service providers invited academic researchers (i.e., outside-in pathway) to form a working group with them. Following several consultation meetings, the consensus was that this commissioned research would aim to understand the experiences of both service-users and caregivers using semi-structured interviews to allow both the service-users and the caregivers to tell their individual and collective story. The initial interview guide (see Appendix) was created by the research team and then refined with input from both staff and service-users. After the analysis, findings were shared with staff, service-users, and their caregivers in focus groups.

Participants

Following university and NHS ethical board approval, maximum variation purposeful sampling [33] was used to recruit fourteen people with limb absence (Table 1) and fifteen nominated caregivers. To ensure diverse perspectives, several criteria were used. Gender was considered by including both male and female participants, given that the experience of an amputation can differ across genders and that caregivers' roles can be gendered. Different types of amputations were included to capture the varying challenges for both service-users and caregivers. To extend previous research, which has been largely limited to 1-year post-discharge [12], time since amputation was also considered to help explore the cumulative impact of caregiving. Finally, a range of caregiver roles—such as wife, partner, daughter, and aunt—were included rather than focusing on a single role. Together, these criteria ensured a broad range of perspectives.

Data collection

Observation and semi-structured interviews were used as sources of data collection. The primary researcher was embedded within the rehabilitative centre, a day a week for 18 months. These observations enabled the researcher to develop contextualised understandings of both the setting and participants' lived experiences; however, the field notes themselves were not directly analysed in this study. Semi-structured interviews were conducted individually with service-users ($n = 14$), then their nominated caregivers ($n = 15$), and finally dyadically (service-user and caregiver $n = 9$) to understand

Table 1. Participant characteristics.

Service-user participant	Biological sex	Presentation	Time since amputation	Caregiver participant
Heather	Female	Quadruple limb absence	4 years	Husband [Bill]
Anna	Female	Double leg limb absence	4 years	Partner [Jack]
Leslie	Female	Double leg limb absence	6 months	Husband [Jotham]
Avery	Male	Double leg limb absence	2 years	Wife [Jane]
Dan	Male	Single-leg limb absence	2 years	Wife [Lisa]
Jamie	Male	Single-leg limb absence	18 months	Wife [Tina]
Rory	Male	Single-leg limb absence	6 months	Partner [Ailbhe]
Theo	Male	Single-leg limb absence	1 year	No supporter [lives alone]
Simon	Male	Double leg limb absence	4 years	Wife [Sara]
Christine	Female	Quadruple limb absence	3 years	Aunt [Cara]
Micah	Female	Double leg limb absence	10 years	Husband [Andrew]
Sascha	Female	Quadruple limb absence	4 years	Daughter [Jamie]
Dana	Female	Single-leg limb absence	7 years	Husband and 2 children [John, Mia, and Andrew]
Lee	Female	Double leg limb absence	4 years	Dad [Rhys]

both their individual and collective experiences. Interviews were conducted either in person at the rehabilitative centre, online or *via* telephone. Interviews lasted between 40 and 65 minutes, were recorded, and transcribed verbatim. In total, 1510 minutes of data were recorded, equating to 241,754 words of transcription.

Data analysis

A reflexive thematic analysis [34] was used to analyse the interview transcripts. This involved six stages, including the first author initially familiarising herself with the data by reading and re-reading the transcripts. Initial codes were then formed and clustered together around a central organising concept to form overarching themes, which were then discussed and further refined through critical friends' discussions and external reflections [31,35]. These themes were then reviewed against the transcripts and the entire data set. The themes were named to capture interpretative stories of the data, and finally, they were written up. In line with our overarching philosophy (i.e., interpretivism), a relativist position was used to enhance the methodological rigour and trustworthiness of the study [32]. Trustworthiness of the data was attended to by using "thick descriptions" and illustrative quotations to support interpretative findings and enhance the naturalistic generalisability of the study [35,36]. Analytical rigour was further attended to through self-reflexivity [37], where the first author engaged in reflexive journaling, reflecting on her biases and assumptions and how they may have influenced the data analysis. These reflections were shared, and initial interpretations of the data were discussed with the rest of the research team. These critical friend discussions helped the first author revisit and deepen her interpretations by posing challenging questions, offering a theoretical sounding board, and providing alternative perspectives [31]. Finally, external reflections were sought by sharing the findings with staff, service-users, and caregivers through member reflection focus group interviews. Incorporating PPI enhanced the rigour of the study by ensuring that all aspects of the study, from the design to the findings and recommendations, were grounded in the experiences of those living with, caring for, or supporting those with limb absence.

Findings

Three themes were identified. (1) Lost in transition: Disconnection and divergence from hospital to home: Both service-users and caregivers described how caregivers were marginalised during the rehabilitation process, which created differing expectations regarding the service-users' functional abilities upon returning home. (2) Bearing the weight of unseen struggles: The impact of caregiving on the caregiver. Participants described the cumulative impact of caregiving on caregivers' physical and mental well-being. (3) Supporting the supporter: Participants highlighted informational, care continuity, communication and social support gaps and described how such gaps can be addressed

Lost in transition: Disconnection and divergence from hospital to home

This theme reflects how caregivers felt disconnected from service-users during rehabilitation, which shaped the way caregivers emotionally experienced the transition and led to differing expectations regarding the service-users' functional limitations upon returning home.

Across interviews, caregivers described feeling marginalised during the rehabilitation process, depicting themselves as "the forgotten people," who are "on the sidelines looking in" (Sara). This perceived relegation was further compounded by noticeable changes in their loved ones, who appeared increasingly self-focused and emotionally withdrawn. For example, Bill, a caregiver, noted, "She focused on herself so much to get well, it felt like no one else mattered. I don't ever remember [patient] asking me how I was getting on at home at all." Taken together, this emotional separation left many caregivers feeling increasingly isolated in navigating the amputation experience, despite it being transformative not only for the service-user but also for themselves, as Sara, a caregiver, articulates, "You feel very lonely, and very out of it… because at the beginning you think well, I've lost my life now, as much as he's lost his life, and it's not that life is over, but you've got a different life, and you think, am I prepared for this life? Is he prepared for this life? And instead of preparing for it together, we've prepared for it separately."

Alongside this emotional disconnect, participants expressed how caregivers had limited insight into the rehabilitation process which left caregivers feeling unprepared to care for service-users upon returning home, as Bill, a caregiver, describes, "You really want to get involved and to be there…but no one ever asked, do you want to see how to transfer her from a chair to the bath, or how to get her up if she falls out of her chair, and how the hell am I meant to know that, no one ever offered to show us how to do that."

This limited involvement during rehabilitation often resulted in a divergence in expectations, particularly regarding the service-users' capabilities upon returning home. In some cases, service-users described how caregivers overestimated their functional capabilities, placing unrealistic expectations on them. Alternatively, some service-users described how caregivers became overprotective, preventing them from engaging in day-to-day tasks and inadvertently impeding their recovery, as one service-user, Rory, demonstrates: "When I came home, it was like no, you can't do that, you can't do this. To save the arguments, and we did argue first of all, I basically sort of gave up a bit because they didn't know what I could do.… They probably felt left out on that part of my journey… and I've said to the hospital that family should be more involved. If they had experienced exactly what I had done in the gym or whatever, they might have understood more, and perhaps I would be further down the road now and not gone backwards."

Ultimately, these disconnects, both in expectations and emotional connection, created conflicts and impacted service-users' progress towards long-term functional independence.

Bearing the weight of unseen struggles: the impact of caregiving

This theme relates to the emotional, physical, and social burden experienced by caregivers. This caregiver labour was characterised by increased workloads as they assumed additional roles and responsibilities, as Avery, a service-user, describes: "She's [wife] had to take on all of the stuff I used to do as well as the roles she was doing herself, whilst trying to hold her job down. So, that was a lot for her, and I just felt sick not being able to help and the frustration of seeing her struggling to do everything."

Moreover, other caregivers described struggling to deal with the emotional fluctuations associated with limb absence, as Cara, a caregiver, describes, "Taking her in, it's turned our lives upside down. At the beginning, she was so angry, so in denial, so upset, I didn't know how to deal with it. I've never lost a limb before, so I didn't know how to help her." While attempting to provide the best support for their loved one, caregivers simultaneously grappled with significant changes in their own lives following the amputation. They articulated a shift in their shared life expectations and conveyed feelings of constraint, as many previously enjoyed activities were no longer accessible to them. For example, Jotham, a caregiver, describes, "Our lives and our life together and all of the plans we made for it are gone for both of us… before the accident, we used to travel loads, we were a very active couple, and that's obviously stopped now for both of us… even though I could go off on my own, I don't want to, we never really had separate lives, so I've now become as restricted in a really weird way."

This sense of loss and overwhelm was further amplified by the conflicting sense of guilt that caregivers experienced as they believed that their struggles were less valid because they had not experienced limb absence themselves. Moreover, they aimed to suppress these emotions for fear of upsetting their loved one, as Ailbhe, a caregiver, describes: "I was upset and depressed, but if I told him how I was feeling, he would have took it that that was because of him and that I didn't want to be with him anymore, so you can't really explain how you feel without upsetting them, and so you just don't bother saying anything at all."

For some caregivers, the demands of their caregiving role subsided over time, as their loved one began to reclaim some of their previous roles and responsibilities, and they adapted to life post-amputation. In other cases, the cumulative impact of the caregiving role began to take its toll on caregivers' mental and physical well-being, as they felt increasingly confined by their role and the weight of being the patient's only source of physical, social, and emotional support. To expand, some caregivers described how, while the service-user had regained functional independence, they continued to avoid social engagement years after the amputation. This persistent social withdrawal often led service-users to become increasingly dependent on a single supporter, hindering their ability to maintain their own social connections and personal relationships, as Cara, a caregiver, demonstrates: "It amazes me how independent she has become… but she's still so dependent on me in lots of ways. She still doesn't speak to any of her old friends, and people ask for her all the time, but she doesn't pick up the phone, even years on…so I'm her main source of contact and all of my days off from work are spent with her, and it's affected my relationship with my husband quite a bit."

In other cases, both caregivers and service-users described how the gradual withdrawal of social support left them feeling increasingly isolated and ultimately placed their mental and physical well-being at risk, as Bill, a caregiver, depicts: "Although we are very strong, we don't really have anyone around us. I think a lot of people help at the beginning and then it all just sort of fades away, and people assume that we are fine, even though we're not… It's a bit scary at times, because we had a scare the other day, where I had a tummy issue, and I was in so much pain, but I was too scared to go into the hospital and leave her on her own…so it showed a real vulnerability to our situation."

These findings underscore the importance of equipping caregivers with the training and resources to provide care for people with limb absence, as well as ensuring that caregivers have adequate emotional and social support themselves. In terms of caregiver support, both service-users and caregivers emphasised the importance of caregivers broadening their social support network, seeking additional resources (e.g. personal assistant for service-users), and maintaining their own individual identities and social networks, as Sascha, a service-user describes: "I've made sure, and I think this is really important, I made sure he still goes out on his own and leaves me… He does things on his own, and I do things on my own. We have our own groups of friends that we can sound off to, and I think that's so important so that it doesn't feel all-consuming."

Supporting the supporter

Across interviews, both service-users and caregivers highlighted four gaps in transitional care for caregivers and outlined recommendations for bridging these gaps (Table 2). First, participants described an information gap, in terms of caregivers' understanding of the practical, safety, and financial implications of an amputation and the need for evidence-based or trustworthy information. For example, Simon, a caregiver, describes, "There is so much to figure out, like how to adapt your home, or how do you even buy clothes to fit the leg, and there just needs to be more information given, because you end up googling all this stuff and it doesn't always give the best advice." Second, participants described gaps in care continuity. For example, some participants highlighted how they felt they had limited contact with the hospital post-discharge and wanted access to community therapy to enable them to continue their rehabilitation, which they felt would reduce the caregiver burden. Finally, gaps in communication between health care providers and caregivers were described, alongside gaps in emotional and social support. To address these gaps, participants described wanting access to peer support groups alongside professional medical advice delivered through educational talks or one-to-one sessions prior to discharge. For example, Dana, a caregiver, described, "I think if you were able to have a one-off session with the medical team as a formal drop-in or Q&A session it would be great and even to have it with other caregivers… the staff have so much knowledge and learning from other people in similar positions would help too, just to get that support and shared experience that other people are struggling too rather than being left on your own to figure it out." Throughout interviews, participants highlighted several recommendations for bridging these support gaps, which are outlined in further detail below (Table 2).

Table 2. Suggestions on bridging gaps in transitional care.

Informational support gaps	Care continuity gaps	Communication gaps between families and HCPs	Emotional and social support gaps
More information concerning the practical, safety, travel considerations associated with an amputation, as well as information on financial entitlements and relevant resources	More formalised check-ins as to how they are getting on	Supporters to be invited to educational talks and the rehabilitation gym	Access to more support groups/ buddy systems
Frequently asked questions available in a booklet or online or access to a resource where they can ask questions	More prolonged support in the community after discharge/ signposting to resources within the community	Service-users to be educated on the impact on the support network	Access to more lived experience – how have other people dealt with it [Patient & Supporter perspective]
A documentary film highlighting the transitional process/filming patients to show progress		Educational session or monthly Q&A sessions for the supporters	

Discussion

Transitioning from hospital to home and rebuilding life following limb absence is a critical period for not only the individual with limb absence but also their caregiver. While service-users go through a comprehensive rehabilitation programme designed to maximise their function and quality of life, caregivers are often sidelined, leaving them feeling underprepared for the demands of their role upon hospital discharge [12]. As the provision of care migrates from the acute settings to the community, centralising the role of caregivers is becoming increasingly more important to ensure the sustainability of integrated care models [13,18]. Understanding the needs and perspectives of caregivers is therefore timely. Our study helps extend the research by providing nuanced and contextualised insights into the interrelated nature of how caregivers impact and are impacted by this transition process. Moreover, our findings provide insight into the unmet needs of caregivers and their perspectives on how such unmet needs can be addressed. By foregrounding the lived experiences of caregivers and service-users, it can help ensure that their voices and perspectives become foundational in the development of evidence-based practice and policy to support integrated rehabilitation environments [38].

Our findings outline four main gaps (i.e., information, care continuity, communication, emotional and social support) in transitional care, and caregivers' and service-users' suggestions on how they can be addressed. Gaps in informational support alongside communication gaps between health care workers and caregivers have been identified in previous research [39,40]. Therefore, our findings help underscore the significance of providing informational support to caregivers regarding the activities of daily living, *via* educational talks and material, and by including caregivers more throughout the rehabilitation process. Drawing from the broader caregiving literature, previous research has highlighted how educating caregivers about the aspects of their care can help improve the quality of care they provide by enhancing their knowledge, practices, and attitudes as well as reducing the caregiver burden [41,42]. Our findings also extend the literature by outlining the impact of communication gaps on rehabilitation outcomes. Caregivers highlighted how they felt marginalised during rehabilitation, leading them to feel disconnected from their loved ones, and ultimately unprepared for their transition home. Caregivers' limited involvement during rehabilitation also created a mismatch in understanding regarding the service-users' functional capabilities and limitations, ultimately impacting long-term recovery outcomes. Such findings validate the need to include caregivers as partners in care throughout the rehabilitation process. This collaboration is essential to help maintain care continuity and optimise recovery outcomes for people with limb absence.

Regarding care continuity, participants called for greater support in the community and greater connections to community services. Such gaps in support could be addressed by creating greater links with local charities or through social prescribing services that address service-users' non-medical needs (housing, debt, loneliness) by linking them to local assets [43]. Finally, our findings support previous research by highlighting how caregivers experience gaps in both social and emotional support [14]. Previous quantitative research has highlighted how caregivers experience higher depressive scores and lower mental health and quality of life scores than the general population [23]. One study highlighted how 80% of caregivers of people with limb absence referred to a need for psychological counselling following their loved one's discharge from hospital [27]. That said, to date, there has been limited insight into the nature of this distress for caregivers. Therefore, our findings extend the literature by highlighting caregivers' conflicting emotions as they negotiated the significant changes in their lives and accompanying feelings of loss. However, these emotions were conflated with and amplified by a sense of invalidation and guilt, as they hadn't experienced limb absence themselves. Adding to this quagmire was the temporal and cumulative aspect of caregiving, a relatively underexplored facet, as most studies examine only the first-year post-discharge [14,39]. Indeed, while for some caregivers the demands of their role subsided over time as their loved ones began to reclaim some of their previous roles and responsibilities. For others, the caregiving burden increased over time, as the caregivers described becoming increasingly confined by their caregiving role, and this confinement, coupled with dwindling social support, added to the cumulative impact of their perceived caregiving burden.

Clinical implications

Overall, the findings of this study help foreground the importance of supporting caregivers in their role by reinforcing previous quantitative findings [24–28,44] regarding the unmet needs of caregivers, whilst enriching understanding of the contextual and interrelated challenges of caregivers. Moreover, our findings centralise caregivers' and service-users' perspectives on how such challenges or needs can be addressed. Firstly, the findings outline the need for more informational and educational support for caregivers. Given that caregivers are key actors in managing transitional and life-long care of people with limb absence, it is the responsibility of health care workers and systems to ensure that caregivers are equipped with the knowledge and skills to fulfil their role by promoting a collaborative partnership throughout the rehabilitation process. Secondly, the findings underscore the need for more prolonged support within the community and better links to local services to help reduce the fragmented nature of care. Finally, the findings outline the need to provide emotional and social support to caregivers to help safeguard them against burnout and health issues and to ensure that they have the capacity to maintain continuous care for people with limb absence. Similar to previous research, the caregivers and service-users in our study advocated for the implementation of peer support groups [45]. Peer support groups are an inexpensive method that can help facilitate the exchange of knowledge, promote shared experiences, and reduce social isolation. Given the benefits articulated by previous research of the capacity of peer support groups to improve the knowledge and understanding of caregivers, improve psychological well-being, and reduce the burden of care [45], peer support groups offer a useful and viable starting point for health care workers and systems aiming to provide support to caregivers.

Limitations and future directions

The findings of the study should be interpreted in the context of a number of limitations. The findings are limited by a lack of longitudinal design, including multiple interviews with patients and caregivers over time. The interviews were also conducted with participants from one rehabilitation centre. Further research could expand the scope of the study to explore participants' views from multiple rehabilitation centres. Doing so may allow for more diverse and nuanced perspectives to emerge. Future research should also focus on designing interventions and implementing co-design resources that act on the suggestions put forward by the participants in this study.

Conclusion

Overall, this study offers novel insights into the lived experiences of both caregivers and service-users in navigating the hospital-to-home transition, highlighting how caregivers influence and are affected by this process. Moreover, this study foregrounds how caregivers can be better supported to fulfil their role. Centralising the caregiver's role can help ensure that their voices and experiences become foundational in the development of evidence-based practice and policy to support integrated rehabilitation environments.

Author contributions

CRediT: **Ciara Everard**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Software, Writing – original draft, Writing – review & editing; **Ross Wadey**: Conceptualization, Funding acquisition, Methodology, Resources, Supervision, Writing – review & editing; **Kimberley Humphrey**: Data curation, Methodology, Project administration, Resources, Software, Writing – review & editing; **Melissa Day**: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Equity, diversity and inclusion statement

The study included male and female participants from diverse socio-economic and ethnic backgrounds. The author team included three females and one male, early career researchers and researchers from multiple disciplines (psychology and physiotherapy). Participants' accessibility and geographical needs were accounted for by giving them multiple options to engage with data collection (in-person, online, or telephone). The study is targeted towards those with limb absence and those caring for people with limb absence, a largely underrepresented population, thus this work explicitly aims to improve inclusion and diversity within this field.

Ethical approval

This study received ethical approval from the NHS Research Ethics Committee and the University of Chichester Ethics Committee. Participants gave informed consent to participate in the study.

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Data sharing

Data are available upon reasonable request.

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