“Nobody ever asked how I was”: the hidden mental health burden of caring for someone with spinal cord injury

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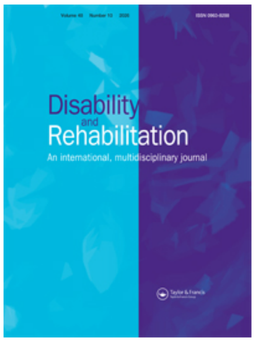

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"Nobody ever asked how I was": the hidden mental health burden of caring for someone with spinal cord injury

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ABSTRACT

Purpose: This study aimed to understand how caregivers of people living with spinal cord injury (SCI) experience and carry secondary trauma, and how this shapes role identity and emotional wellbeing. It focused on the psychological toll of caregiving, highlighting needs that remain unsupported.
Materials and Methods: Twenty-three SCI caregivers participated in in-depth semi-structured interviews. Data were analysed using Reflective Thematic Analysis to understand recurring emotional and psychological challenges across the caregiving journey.
Results: Five themes emerged: (1) SCI reality uncovered, confronting the gap between expectations and lived reality; (2) Shared traumatisation, describing caregivers' exposure to acute trauma and emotional burden alongside the person living with SCI; (3) The sidelined supporter, reflecting systemic invisibility across care contexts; (4) Masking mental health, involving the concealment of personal distress; and (5) Demanding a discharge toolkit, underscoring the desire to access adequate post-discharge support. Caregivers described persistent emotional suppression, role loss, and social isolation.
Conclusion: Caregivers carry emotional strain that is internalised, and rarely acknowledged. Their needs are frequently silenced, by their own efforts to stay strong and systems that overlook them. Addressing this burden demands the embedding of dedicated caregiver support into rehabilitation, with sustained attention to the emotional demands of long-term care.

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Unpaid carer; psychological wellbeing; emotional suppression; neurological injuries; secondary trauma; support systems

➤ IMPLICATIONS FOR REHABILITATION

- Caregivers perceived that supporting a person living with spinal cord injury involved sustained psychological strain that was often unacknowledged and unsupported within rehabilitation pathways.
- Caregivers described the hospital-to-home transition as fragmented and emotionally challenging, particularly due to insufficient information, limited mental health support, and a lack of structured follow-up after discharge.
- Addressing caregivers' mental health needs requires the integration of formal support at the point of discharge alongside ongoing access to peer-based networks and outpatient rehabilitation services.
- Rehabilitation services should broaden their focus to include caregivers as active stakeholders whose wellbeing is central to the sustainability of home-based spinal cord injury care.

Introduction

Spinal cord injuries (SCI) bring about profound, life-altering effects on the injured individuals and their families [1]. The sudden and unexpected nature of SCI often leaves families and caregivers unprepared for the emotional and psychological toll of caregiving [2]. Individuals living with SCI, along with their families and social networks, must navigate significant physical, emotional, and social adjustments to accommodate the changes brought on by the injury [1,3]. Families, friends, and caregivers frequently find

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themselves adapting their lives to offer ongoing assistance with daily activities, personal care, and emotional support [3]. However, caregivers' mental health needs receive limited attention, despite being critical to quality of life [4]. Though becoming a caregiver is a major turning point in one's life trajectory [5], adjusting to caregiving is a long term and evolving process rather than a short term period of adjustment [6].

This transition into a long-term caregiving role is often accompanied by significant emotional, psychological, and practical consequences [1,7]. Caregivers often face the sudden onset of caregiving responsibilities without adequate knowledge of SCI-specific needs, contributing to emotional distress and psychological strain [8]. This limited preparation and guidance at the point of transition into caregiving is associated with caregiver burden, alongside reduced social participation and disruption to daily life [3,9–11]. Caregiving responsibilities are also associated with adverse effects on employment among unpaid carers, particularly during midlife [12]. Despite experiencing significant distress, many caregivers feel reluctant to seek help, viewing their needs as secondary to those of the person living with SCI [3]. Caregiver burden, defined as the perceived emotional, social, and physical strain associated with caregiving roles [13], is associated with reduced quality of life among caregivers of people living with SCI [14]. This burden is often compounded by caregivers suppressing their own emotional needs in order to protect the injured individual, a process linked to social withdrawal and isolation over time [6,15]. Despite the scale of these challenges, research and service provision tailored to the mental health needs of caregivers of individuals living with spinal cord injury remain limited [4,14,16].

Beyond emotional and mental health challenges, caring for individuals with spinal cord injury is associated with substantial financial strain. Evidence from the State of Caring 2025 survey of 10,539 unpaid carers in the UK indicates that caring responsibilities frequently affect employment, with 35% of carers in work reporting reduced working hours and 20% reporting a move from full-time to part-time employment [17]. In addition, 62% of carers report regular out-of-pocket spending on caring costs and 49% report cutting back on essentials such as food, heating, or transport [17]. These financial pressures are accompanied by widespread financial anxiety, with 74% of carers reporting concern about the impact of caring on their future finances, highlighting the close interaction between financial strain and psychological stress among unpaid carers [17].

Understanding the needs of informal caregivers is important given the scale and dynamic nature of unpaid care. In the UK, Census 2021 data indicate that approximately 5.8 million people provide unpaid care to a family member or friend at any one time [18]. Longitudinal analysis of national survey data shows that caregiving roles are frequently assumed, with an average of 4.3 million people becoming unpaid carers each year between 2010 and 2020, equivalent to approximately 12,000 people per day [19]. Evidence from studies of spinal cord injury caregiving indicates that many caregivers experience ongoing psychological strain linked to insufficient support and limited coping resources, underscoring the need to address caregivers' mental health needs alongside those of individuals living with spinal cord injury [3].

However, there remains a gap in understanding the specific mental health experiences of caregivers of individuals living with SCI, particularly in the UK. Existing research has largely focused on the person living with SCI, leaving the psychological struggles and mental health needs of families, friends and caregivers underexplored. This study explored the experiences of families, friends, and caregivers of individuals living with SCI, with a particular emphasis on their mental health support needs and the psychological toll of caregiving. By focusing on the lived experiences of caregivers, this research provides a deeper understanding of their needs and lays the groundwork for future research, practical support measures, and the development of targeted mental health interventions to address the psychological challenges faced by caregivers of individuals living with SCI.

Methods

This analysis was informed by a reflexive qualitative approach underpinned by a constructivist epistemological position, which recognises that meaning is actively constructed through engagement between researchers and data [20]. Reflexive Thematic Analysis was used as an analytic method, with themes constructed through the researchers' interpretative engagement with caregivers' accounts rather than treated as pre-existing within the data. All authors are trained in Health Psychology with experience in qualitative health research and none had a prior clinical or personal relationship with participants.

Study design

A qualitative study employing semi-structured interviews was conducted, guided by Reflective Thematic Analysis [20]. Qualitative research is a valuable method in health research as it addresses the "how" and "why" research questions, providing in-depth insights into experiences, phenomena, and context [21]. It allows researchers to explore complex human experiences that are not readily captured through quantitative measures. By focusing on everyday social practices and lived experience, qualitative research extends understanding of how concepts operate in real-world contexts [21]. Reflective Thematic Analysis (RTA) was particularly suited to this study, as it enabled the identification of patterns and themes related to caregivers' lived experiences, capturing the nuances of their mental health support needs and caregiving challenges [20].

Participants

Participants for the study were recruited through three pathways:

i. Referral from a large-scale survey: UK-based Spinal Injuries Charity, the Spinal Injuries Association, conducted a study on the experiences of individuals living with SCI. As part of the recruitment strategy for the current study, each participant had the option to provide their caregiver's contact information for inclusion;
ii. Social media posts hosted by the Spinal Injuries Association;
iii. Purposive sampling through referrals from the Spinal Injuries Association clinical staff, who informed unpaid caregivers about the study and provided study information to those who expressed interest. Clinical staff did not select participants based on demographic or caregiving characteristics. Their role was limited to informing potentially eligible caregivers about the study and facilitating contact where caregivers chose to express interest.

The inclusion criteria for participant sampling were individuals aged 18 years or older, living in the UK, able to provide informed consent, and self-identifying as an unpaid caregiver providing regular practical, emotional, or care coordination support to a person living with spinal cord injury, consistent with the UK definition of a carer [22]. Caregivers included family members, close friends, and significant others whose support provision was directly responding to the spinal cord injury. Participants were excluded if the spinal cord injury was due to an active cancer or malignancy, to isolate reflections on caregiving experiences associated with SCI rather than cancer treatment.

Qualitative research does not rely on statistically representative samples. Instead, it prioritises context-specific insights over generalisability [23,24]. It has been suggested that sample sizes in qualitative studies can be guided by the concept of information power, which posits that the more information a sample holds that is relevant to the research aims, the fewer participants are required [25]. The study was guided by the principle of information power, which emphasises the relevance, depth, and quality of the data in relation to the research aim rather than the attainment of saturation [25]. This approach is consistent with reflexive thematic analysis, where saturation is not treated as a guiding analytic principle and is considered conceptually incompatible with the generation of themes as interpretative analytic constructions [20,26,27]. No *a priori* sample size was set. Information power depends on factors such as the specificity of the study aim, the characteristics of the sample, the quality of the data, and the analytic approach [25]. Participants were recruited through multiple pathways to access caregivers with varied caregiving experiences, rather than to achieve statistical representativeness or maximum variability.

Data collection continued until the interviews were judged to provide sufficient depth and breadth to address the research objectives. As interviews progressed, later interviews contributed fewer novel insights while adding depth, nuance, and variation to existing analytic patterns, indicating that the dataset was sufficiently rich for reflexive thematic analysis, where analytic adequacy is judged by interpretative depth rather than code or theme repetition [20,26,27]. In total, 23 participants provided detailed and information-rich accounts that supported the development of meaningful and robust themes.

Five men and 18 women, ranging in age from 26 to 83 years, were interviewed (see Table 1). The gender distribution was expected, as women are more likely than men to assume informal caregiving roles [28,29]. This pattern is notable given epidemiological evidence showing that spinal cord injury incidence is substantially higher among men than women [30].

Of the 23 participants, 12 were spouses of people living with SCI, five were parents, two were siblings, one was a daughter-in-law, and three were non-family caregivers.

The average time that the participants had been caring for people living with SCI was seven years and eight months, with the shortest time as a caregiver being six months and the longest, 25 years. Participant demographics are presented in Table 2.

Data collection

A 12-item semi-structured interview schedule (See Table 3) was created to invite participants to share their views on: (i) possible causes of mental health problems following SCI and the impact it has on them as caregiver, (ii) what services they believed were required to improve the management of mental health for caregivers of individuals living with SCI, and (iii) their experiences of mental health services and how well they met the needs of the caregiver.

This study formed part of a broader programme of qualitative research exploring experiences of spinal cord injury from both the perspectives of individuals living with SCI and their unpaid caregivers. While the experiences of people living with SCI have been reported elsewhere (Finlay et al., [31]), the present

Table 1. Participant characteristics.

Characteristics of caregivers	$N = 23$
Sex	
Male	5
Female	18
Relationship to person living with SCI	
Spouse	12
Parent	5
Sibling	2
Children	1
Non-family caregiver	3
Age (range; mean)	26-83; 57.35

Table 2. Participant demographics.

Pseudonym	Gender	Age	Relation	Injury type of person living with SCI	Time caring for person with SCI
Alice	Female	60	Spouse	Incomplete tetraplegia	5 years 6 months
Lucy	Female	54	Spouse	Incomplete tetraplegia	8 months
Scott	Male	60	Spouse	Incomplete paraplegia	7 years
Emily	Female	26	Spouse	Incomplete paraplegia	6 months
Marc	Male	48	Parent	Incomplete tetraplegia	2 years 6 months
Kate	Female	66	Spouse	Incomplete tetraplegia	1 year 6 months
Jessica	Female	62	Spouse	Incomplete paraplegia	9 years
Tiffany	Female	53	Sister	Incomplete tetraplegia	2 years 4 months
Sarah	Female	63	Parent	Incomplete paraplegia	6 years
Harry	Male	70	Parent	Complete tetraplegia	18 years
Victoria	Female	83	Parent	Incomplete tetraplegia	13 years
Jacqueline	Female	54	Non-family caregiver	Incomplete tetraplegia	5 years 6 months
Megan	Female	64	Non-family caregiver	Incomplete tetraplegia	10 years
Sandra	Female	49	Non-family caregiver	Incomplete tetraplegia	1 year 3 months
Jack	Male	53	Brother	Incomplete tetraplegia	10 years
Rebecca	Female	56	Parent	Incomplete tetraplegia	1 year
Lauren	Female	58	Spouse	Incomplete tetraplegia	20 years
Sam	Male	56	Spouse	Complete tetraplegia	21 years
Grace	Female	45	Spouse	Incomplete tetraplegia	14 years
Rachel	Female	37	Spouse	Complete tetraplegia	1 year 2 months
Angie	Female	60	Spouse	Incomplete tetraplegia	25 years
Nancy	Female	69	Spouse	Incomplete paraplegia	3 years
Kelly	Female	59	Daughter-in-law	Incomplete tetraplegia	11 months

Table 3. Interview schedule.

Semi-structured interview schedule
1. Can you tell me about what has happened to your partner/friend/family member's mental health since they had their Spinal Cord Injury?
2. What do you think are the main areas which we need to address for improving mental health for people with SCI as a whole?
3. How has your partner/friend/family member's mental health been supported since their SCI (if at all)?
4. Can you tell me about some barriers your partner may have faced or experienced in seeking support for their mental health since their SCI?
5. Can you tell me about some things that may have encouraged your partner to access mental health services?
6. Thinking about your situation, what informal support did your partner/friend/family member actually use or receive?
7. Thinking about your situation, what formal support did your partner/friend/family member actually use?
8. What do you think would increase the likelihood of your partner/friend/family member to seek more support for their mental health?
9. If you could design a system for improving and managing mental health after SCI, what would it be like? How would it work?
10. Supporting someone with mental health challenges after SCI can be challenging. How has it affected you?
11. What do you think would make it easier for you to seek more support for your mental health?
12. Is there anything about SCI mental health and mental health services that we've not discussed that you would like to explore further?

analysis focuses specifically on caregivers' accounts. Although several interview questions referenced the mental health of the person living with spinal cord injury, these were designed to elicit caregivers' reflections on their own emotional experiences, perceived responsibilities, and support needs within the caregiving role, recognising the dyadic and relational nature of caregiving following SCI. Questions focusing explicitly on the caregiver were also included, and the analytic focus throughout remained on caregivers' accounts and interpretations rather than on the experiences of the person living with spinal cord injury. In line with reflexive thematic analysis, questions were treated as flexible prompts, and themes were constructed through engagement with caregivers' narratives rather than derived directly from the interview structure [20].

Interviews were conducted *via* Zoom ($n = 19$) or telephone call ($n = 4$). Interviews lasted between 38 and 75 min ($M = 51.6$, $S.D = 10.8$) and were audio-recorded and transcribed using the encrypted artificial intelligence system Otter.ai, with all transcripts subsequently reviewed for accuracy by the research team. The semi-structured nature of the interview schedule allowed interviewers to respond flexibly to areas of relevance raised by participants and to probe responses in greater depth [32]. All interviews were conducted by two authors (AM & LD), both of whom hold advanced qualitative research methods training and received additional project specific training prior to conducting interviews.

Participants received information sheets *via* email, detailing their rights to withdraw or end the interview at any time during the session or within 48 h after participation without providing a reason. Written consent was obtained prior to the start of the interviews. During transcription, all identifiable features were anonymised, and participants were asked to choose their own pseudonyms [33]. Research ethics approval was obtained from the University of Reading and University of Buckingham.

Data analysis

Transcribed data were analysed by the research team using an inductive thematic approach, with NVivo software used to support data management and organisation. Initial codes were generated to capture recurring features of caregivers' accounts and represented individual experiences, challenges, and support needs. These included, for example, lack of preparedness, emotional suppression, feeling overlooked, and difficulties accessing support. Themes were developed inductively using reflexive thematic analysis, in accordance with Braun and Clarke [20]. Familiarisation with the data involved repeated reading of transcripts and initial note-taking to capture early analytic observations. Coding focused on identifying meaningful features of caregivers' accounts relevant to experiences of caregiving, support, and adjustment. Initial themes were generated by grouping related codes that shared semantic and/or conceptual patterns. Themes were then developed and reviewed through iterative comparison across transcripts and discussion within the research team. Refining, defining, and naming themes involved clarifying the boundaries and focus of each theme to ensure internal coherence and distinction between themes. Finally, themes were written up using illustrative data extracts to support analytic interpretation. Thematic development was led by one researcher but included iterative discussions with the research team to refine the thematic map and ensure alignment between themes and the data [20]. A reflexive journal was maintained throughout the analysis, and transcripts were carefully reviewed to ensure comprehensive and nuanced interpretation of the data. These strategies were implemented to enhance the credibility and dependability of the analytic process [20,34].

Results

Results demonstrated five core themes representing a diverse span of challenges that significantly impact the mental health of family, friends, and caregivers: (1) *SCI reality uncovered;* (2) *Shared traumatisation; (3) The sidelined supporter*; *(4) Masking mental health; and* (5) *Demanding a discharge toolkit*. Themes are outlined individually with quotes that represent and support each theme. Additional quotes for each theme are presented in Online Supplementary Materials S1.

SCI reality uncovered

All participants described having limited understanding of spinal cord injury prior to the injury occurring. While individuals living with SCI were in hospital, family members and friends spoke about trying to make sense of the injury and its implications, often drawing on general assumptions about illness, recovery, and rehabilitation. During this period, many participants expected recovery to be more straightforward, anticipated some continuity with pre-injury routines, or assumed that the specialist support available in hospital would continue once the individual returned home. These expectations were shaped by a broader lack of public understanding about SCI and its consequences. For many caregivers, the full extent of the physical, emotional, and practical challenges only became apparent after discharge, when they returned home without the structured support of the hospital environment.

> This is a bit of a sweeping statement. I mean, people know about strokes in general, people know about heart attacks, people know that people have spinal injuries, but I had no idea that even a really minor injury can have such a devastating consequence. I think that’s a societal education thing. Kate, 66, Spouse

Receiving medical information about SCI in a manner that assumed prior knowledge, left participants confused and distressed. For some participants, limited understanding of medical terminology and insufficient explanation were described as contributing to emotional distress and mental health difficulties during the early stages following injury.

> So, the doctor talked to me. Very matter of fact, as if I understood what he was saying. In fact, I still have the notes on what he said, ‘Oh yes your partner has got C-2 C-3 incomplete injury’, like I knew what he was saying. I thought at that point, incomplete, was it was a bad thing. Nobody explained to me that it was a good thing, which is I find incredible. So unfortunately, my mental health issues started by the way I was treated at the hospital. Lucy, 54, Spouse

Accessing information about SCI was described as a significant stressor for mental health. Having a lack of prior knowledge about SCI but also being unable to obtain that knowledge from the appropriate sources left friends and family members feeling frustrated.

> I can remember coming home [from hospital] on several occasions with lots and lots of questions and never being able to get hold of this person [patient liaison] to ask what does this and that mean? I don’t feel there was the right communication. There might have been more communication between staff and patient because they are there all the time, but, I think family and relatives, they need that clarity or explanations because, you know, I’ve never come across anybody with a spinal cord injury before. Jessica, 62, Spouse

Additionally, aside from friends and family having a lack of understanding and clarity about SCI, the general consensus was that their wider social circle also had varying expectations of what SCI entails. This had an impact on both the person living with SCI and those around them.

> I think one of the biggest problems is probably friends and family because they see it as only a back injury. ‘Oh, you’re not better yet’. No, you don’t get better you actually get worse. You know because other things go on. We’ve had friends and family move away from us because they don’t know or understand it. Scott, 60, Spouse

Shared traumatisation

Participants described experiencing acute shock and emotional distress at the onset of spinal cord injury, highlighting how the traumatic event extended beyond the injured individual to affect caregivers' own mental health. For many, this initial trauma was marked by sudden exposure to distressing information, loss of control, and a sense of being unprepared for the consequences of the injury.

> The doctor walked past, and I just said, 'how is she?' And he just said, 'oh she'll be paralysed for life.' Well, my legs went from under me. I just bent down and couldn't stand up. I mean, if it had been the normal me, I'd have like exploded at him, the way that he said it, I was completely floored by that. Victoria, 83, Parent

This early shock often evolved into a broader sense of shared trauma, as caregivers confronted the realisation that their own lives, identities, and futures had also been fundamentally altered. Although caregivers experienced this change differently from the person living with SCI, participants described the emotional impact as equally profound.

> Because, yes, it's a life changing thing for him, but it's a life changing event in a different way for me as well. This isn't how I imagined my life; it is a massive thing for me too. Alice, 60, Spouse

Shared traumatisation was further characterised by a growing sense of responsibility and emotional burden, particularly during the early stages of injury. Caregivers described feelings of helplessness, despair, and moral responsibility for the injured person's survival and wellbeing, which intensified their own psychological distress.

> At the beginning of his spinal injury, it [suicidal ideation] happened two days into his injury, I felt the same. How will I cope with this? I can't cope with it. And actually, selfishly, probably my first thoughts were 'now I can't kill myself' because I'm his only support, and that was a very scary place to be. Kate, 66, Spouse

Beyond the caregiver–partner relationship, participants described how the trauma of SCI reverberated across the wider family system. Managing children's fears, altered family roles, and disrupted routines added further emotional strain and reinforced the sense that the injury had reshaped family life as a whole.

> When my husband had the accident, our children were obviously a big concern as well. And when he was still in hospital, I realised that my children didn't think he was coming home again. But you know, my whole purpose was really about keeping life quite smooth and simple for them. What I also struggled with the children was that my husband wasn't living at home. I found that quite hard that I was adapting to being a single parent when I wasn't a single parent. We found that quite traumatic. Rachel, 37, Spouse

Over time, shared traumatisation also affected relationships with extended family members. Participants described misunderstandings and relational tensions that arose when others struggled to comprehend the practical and emotional consequences of the injury, adding to caregivers' emotional burden.

> I think it would have really benefitted his parents and my parents to understand the impact [of SCI] on us. My mom and dad are very protective of me, and I think they're trying to do their best to look out for me in this situation. They don't fully understand what's going on. But I think if they knew more, they'd probably help us in a different way. My husband doesn't go to my parents anymore. At first they saw it as a bit of a shunning as we've done all this for him and actually, he can't even come around. But the truth is he doesn't feel comfortable sitting on the sofa for long periods of time. He can't get into the house because it's got stairs so it's just sitting and explaining to them that it's got nothing to do with them and it's actually the physical restrictions that he can't get over when he visits. Grace, 45, Spouse

The sidelined supporter

Whereas shared traumatisation captured caregivers' exposure to the emotional impact of spinal cord injury itself, this theme focuses on caregivers' experiences of being overlooked and marginalised within care systems, relationships, and wider social contexts. Despite the central role they played in supporting the person living with SCI, participants described how attention and concern were directed almost exclusively towards the injured individual, leaving caregivers' own mental health and support needs largely unrecognised.

> No, no, it was all about [Person living with SCI] I never had support during the journey. It [caregiver mental health support] was never highlighted to me. Sarah, 63, Parent

The sidelining of caregivers extended beyond mental health support and into physical, relational, and identity related needs. Participants described how aspects of intimacy, partnership, and bodily connection were often overlooked as they transitioned into caregiving roles.

> I mean, I went from being his wife to his carer. And I know we joke about that. We still joke about it now but that's what it was. You know, there was no intimacy, there was no sex, there wasn't even physical touch. He got framed to his wheelchair. So, there was nothing and I think to have that part literally cut off, from being this loving couple to just being this carer, mentally that was quite difficult to accept. Angie, 60, Spouse

Caregivers also described difficulties prioritising their own wellbeing in contexts where the person living with SCI remained the primary focus of professional and social attention. This contributed to challenges implementing self-care and seeking support.

> I know that I need to look after myself in order to be able to look after [Person living with SCI]. But it's just so hard to do that. I don't feel able to do that when the whole time it's about focusing on the person you're looking after, and everyone else is focusing on them. So, we usually tend to put yourself at the end of the list. Yeah, I think I would ask for more help if I felt that there was sort of a better understanding of what I'm struggling with. Alice, 60, Spouse

Beyond healthcare settings, participants described feeling overlooked within their wider social networks. Friends, family members, and community contacts often focused their concern exclusively on the injured individual, leaving caregivers feeling invisible and emotionally unsupported.

> It sounds awfully selfish, but people will contact me and it's always 'How's [Person living with SCI]? How's [Person living with SCI] getting along?' It's not like I like to talk about myself, but I just think the people who care for people are also affected and sort of overlooked really. Alice, 60, Spouse

The sudden transition from spouse to caregiver takes a profound emotional and psychological toll, particularly when caregivers feel unsupported and unacknowledged. Participants often described feeling invisible in their struggles, as attention and concern were directed almost exclusively towards the injured individual.

> I kind of wasn't ever asked about me if I'm being honest. You know my life changed; our lives changed overnight. One day you're a wife and the next you're a carer. Sometimes you just kind of think "well I can't do this," but I can't say that to anyone. The impact that the injury has makes people go "oh my god I would never have known just quite how hard this is for you." People talk to my husband and ask, "How are you? How are you doing? ." But no one ever asked how I was. I do get very lonely and sad about it all the time and very angry and frustrated. Nancy, 69, Spouse

For some caregivers, this lack of recognition also posed a barrier to accessing mental health support. Participants described how their own psychological needs were deprioritised within systems designed to support the person living with SCI.

> Although our solicitor and people on our side of the fence are caring about me and have been asking them to pay for a psychologist for me also, that doesn't seem to be a thing. It just seems to have been like swept under the carpet the multiple times they've asked. And I'm thinking, it's not just him, like, I've been off work for six months. How do you think he gets out and does things? Emily, 26, Spouse

Masking mental health

In order to shelter and protect partners who are living with SCI, often, unpaid caregivers report masking their own mental health needs. Since the experience of trauma is shared, the masking can also occur bi-directionally, with the person living with SCI also trying to ease the burden on their family/friend/partner. Participants described a shared masking of psychological difficulty within the caregiving relationship.

> I think he doesn't tell me things because he doesn't want me to worry. He has kept things to himself, and he didn't want to tell me, which was quite concerning. And so, I think he doesn't want to worry me. Alice, 60, Spouse

More commonly discussed was the masking of one's own mental health needs by the unpaid caregivers. Even though participants discussed feeling drained and tired, they felt unable to express these feelings. Instead, the role required them to mask their feelings in order to be able to support the person living with SCI. Masking individual mental health needs was described as a mechanism to protect both people living with the SCI and caregivers of SCI from further mental burdens.

> The first one [comment on a support group] resonated with me. It was like 'the best place to cry all day is in the shower, you can hide in the shower.' And then there was like 50 comments going 'Yeah, we all cry in the shower' and I cried, that's why I read it. Lucy, 54, Spouse

Caregivers often experienced an internal conflict between expressing their own frustrations and maintaining a positive, supportive role for the person living with SCI. They felt compelled to suppress their own feelings in order to protect the care recipient.

> If I'm just genuinely feeling fed up or there are things that need doing and I don't want to do it, and I've got no motivation, or I just don't want to, sometimes I feel like if I say that, it's going to drag him down because he feels guilty, because he sees the fact that I feel like that it's his fault. He thinks that I feel demotivated because my life is as it is because of him. So therefore, I don't say that to him. Sometimes I feel like I can't say it, because then not only do I feel fed up, but then I've also got to cope with him not wanting to speak because he's gone down into a dump mood again. Lauren, 58, Spouse

Concealing their own health issues and emotional struggles from their family was reported by all participants. Nancy expressed her personal fear of falling ill as a significant source of her stress, reflecting her anxiety about how such an illness would impact their future.

> I've been on antidepressants, since he came home, I've never told him. I've not been able to tell my husband anything. I had a stomach ulcer as well, which he doesn't know about. I've had quite a few physical problems due to stress. But I've always had to hide it away, even the kids don't know about it. I live in fear of getting ill because I don't know what would happen, how would we cope? So yeah, I suppose that has impacted on me quite a bit. Nancy, 69, Spouse

Demanding a discharge toolkit

Participants described a clear need for structured information, guidance, and support at the point of discharge to support caregivers' mental and physical health as individuals transitioned from hospital to home. Support was deemed essential from the point of discharge and throughout the care trajectory, with caregivers' needs being dynamic and necessitating multiple forms of assistance. They felt there was a lack of adequate support provided during discharge. This impacted the mental health of caregivers since they too were left alone without the support that was provided in the hospital.

> I don't know it was a couple of months; I think it's about four to six weeks, and then they just shoved him out to sink. So, where's the support then? And it's kind of like 'it's not our issue now it's on to your council.' And that was the bit that was lacking because you know there's no transition from hospital to home. It was kind of a battle nobody was really interested in. So, that does affect your mental health, and I think without my nephew, we would have really, really struggled. Sarah, 63, Parent

A comprehensive discharge package, including both practical and emotional support for caregivers and families, was described as something that would have been beneficial for post-discharge adaptation.

> And I certainly wasn't offered anything [at discharge]. I think perhaps it would have been useful to have something when you leave, kind of like an exit pack. Because they leave you on your own. They did absolutely nothing for the discharge. We need to talk about things like trying to put packages together, for carers and families together. Not just for mental health but support for anything. So practical and emotional support really. Lauren, 58, Spouse

The absence of practical guidance and emotional preparation to support someone living with SCI created significant challenges for caregivers when the injured individual returned home. Many participants described how the lack of clear pathways for assistance and resources left them feeling overwhelmed and unsure of how to navigate their new roles, which impacted their mental well-being.

> I think some information should be available through an online tool or system that you can access when you discharge from hospital or even before being discharged from hospital. Because there are a lot of things we needed to put in place before we came home. And I think a lot of the unknown stemmed from the fact that he was being discharged into our home. There was no way of getting upstairs. This impacted us and some support would have made a massive difference. Rachel, 37, Spouse

A gap in reality emerged when participants returned home, exacerbated by the inadequate comprehensive support provided at discharge.

> I felt they had support while he was at the hospital. I felt they had support with different therapists when he was at the rehabilitation centre, and then that was it. Yeah, you're on your own, and you're like "oh my God, how can you do that, he still needs help." We need a better structure. Better transition after discharge, that's the main thing. I just felt we'd been ditched and that's when we saw his mental health decline, because I'm sure he thought nobody really cares. Sarah, 63, Parent

Both formal and informal support were described as essential across the caregiving trajectory, with different forms of support needed at different stages. Formal support was described as particularly important in the early stages following injury to help caregivers process their experiences.

> We need formal support to just check in right away. You know, [Person living with SCI] in a way, had a less traumatic beginning. He certainly had a very traumatic time in hospital, but he was unconscious and asleep for 17 days. So, bless him, he got out of the pretty bad bit sleeping. Whereas you know, like dealing with police calls and waiting to find out if your partner's even going to survive was hard. You're just on your own. Emily, 26, Spouse

In the absence of structured discharge support, participants described how gaps in discharge preparation shaped the types of formal and informal support they sought once they returned home. In particular, caregivers emphasised the need for healthcare professionals with specific knowledge of spinal cord injuries during the post-discharge period, noting that while many professionals can offer generic support, those with personal or professional experience of SCI could provide more effective assistance.

> It's identifying a counsellor, or a medically qualified psychiatrist or psychologist who can understand what spinal cord injury is. There are counsellors out there, that have got spinal cord injured spouses, so they get it. Marc, 48, Parent

The benefits of formal services at the beginning of an injury were described as being more concrete and individualised to each person's needs.

> When you are feeling mentally down, to know that a week on Thursday, or two weeks on, you're going to be seeing somebody professional to talk about it for the foreseeable future, is more beneficial than maybe being in a chat room on the WhatsApp group and chatting to people. When it's more formal it's more tailored to the individual's needs. Jack, 53, Brother

As caregivers continue their care journeys, informal support was described as an important tool to support mental health needs. Even though having support from friends and family was described as beneficial, all participants highlighted the importance of being able to talk to individuals who have been through or are going through a similar situation people and understand SCI.

> And I think, the other day when I spoke to people on the Backup Zoom Lounge. I think that's really helped because you're talking to people who know what you're talking about because they are going through it at the same time. People can sympathise. And with others and it's no disrespect to them, but they don't understand. They really don't understand because they aren't going through it. Tiffany, 53, Sister

Participants also saw the opportunity to contribute to support groups and offer guidance to other families, leveraging their own experiences to assist others facing similar challenges.

> The two or three years while [Person living with SCI] had this accident, say you're linking in with people who've got the same issues, same feelings, and you know maybe have a chat about it, I think it probably

> would have benefitted me. Now I know [Person living with SCI] has come through and is doing quite well. Maybe I can, if I did go on to a support group, provide some sort of help to somebody else, other families.
> Lucy, 54, Spouse

Discussion

Families, friends, and caregivers play a central role in the lives of individuals with spinal cord injuries (SCI), yet their unique experiences and mental health support needs remain underexplored, including in the UK context. This study addresses this gap by uncovering the multifaceted challenges caregivers face, including the disconnect between expectations and the realities of SCI, the shared emotional burden of trauma, the invisibility of caregivers' struggles, emotional suppression, and inadequate support systems. By examining these underexplored dynamics, this research highlights the critical need to prioritise caregivers' mental health and practical needs, ultimately enhancing their well-being and the quality of care they provide to individuals living with SCI.

Knowledge about SCI plays a crucial role in shaping the experiences of caregivers, as highlighted by the theme "SCI reality uncovered." The current findings identify a significant lack of knowledge about available resources and formal training as key barriers for caregivers, as also demonstrated by Jeyathevan et al. [3]. Limited awareness of SCI and its implications often exacerbates the challenges faced by caregivers and their broader networks. Confronting the immediate shock and long-term consequences of SCI [6] contributes to the emotional burden experienced by caregivers. Increased public knowledge about SCI, its nature, impact on caregivers, and broader implications for families, could better prepare those affected, addressing gaps in understanding identified in the current findings. Melin et al. [35] emphasise the importance of providing critical information to individuals living with SCI, caregivers, and stakeholders, such as healthcare professionals and personal care assistants. The current findings underscore the potential for public awareness campaigns to disseminate this information in rehabilitation settings, mitigating the effects of weak SCI knowledge on caregivers and their networks and easing the transition into their altered roles.

The current study revealed that caregivers of individuals living with SCI often experience a profound and complex sense of grief, not only for the physical abilities lost by the injured person but also for the life they once knew. Participants described living in an ambiguous space between their past life and the uncertain future, which heightened feelings of prolonged grief and emotional distress. This grief was further shaped by the shared trauma experienced by both caregivers and the individual living with SCI, creating a persistent need for support to address the resulting emotional and mental health challenges. These findings align with previous research documenting the significant implications of caregiving on physical, mental, and social well-being [14,29,36]. Consistent with studies that highlight feelings of isolation and loss of identity among caregivers [9,14], this study further emphasises the complexity of grief that caregivers experience as they navigate the dual roles of mourner and caregiver [15]. The shared trauma uncovered in this research can have a significant detrimental impact on caregivers' mental health, leading to emotional distress, feelings of isolation, and a persistent need for support.

The theme of "The sidelined supporter" illustrates how negative emotions experienced by caregivers are amplified by feelings of abandonment and being overlooked. Participants reported a persistent sense of being overlooked by professionals, with their needs frequently disregarded. The onset of spinal cord injury is often marked by confusion and uncertainty regarding the injury itself and the necessary next steps [37]. During this critical period, caregivers frequently feel isolated in their emotional struggles and face challenges in accessing adequate support. This phase, sometimes referred to as the "birth" of a caregiver, represents a crucial opportunity to identify individuals in need of assistance [6]. Previous research has consistently emphasised the importance of providing information, knowledge, and training to those involved in the care of individuals living with SCI [16,35]. The present study further highlights the need for healthcare providers to acknowledge and address the unique needs of caregivers, particularly during this early formative period. By recognising the "birth" of a caregiver as a pivotal moment, healthcare professionals can foster open communication, provide timely support, and equip caregivers with the resources they need to navigate their roles effectively. Doing so can not only mitigate the negative emotional experiences of caregivers but also enhance the overall quality of care provided to individuals living with SCI.

Highlighted in the theme of “Masking Mental Health,” emotional awareness among caregivers of individuals living with SCI was not always openly expressed. While empathic capacity is often viewed as important for supporting caregiving relationships and shaping emotional responses [38], caregivers frequently reported suppressing their emotions to shield the care recipient from additional guilt or distress. Though intended as a coping mechanism, this emotional suppression often left caregivers feeling isolated and contributed to the neglect of their own mental and physical health. While prior research highlights the role of emotional awareness and empathic understanding in shaping caregiving experiences [38,39], this study reveals a more nuanced reality. Emotional awareness may heighten guilt, compelling caregivers to prioritise the emotional well-being of the care recipient over their own. Additionally, this study revealed that caregivers experienced feelings of guilt and emotional distress when struggling to adjust to their changed circumstances, consistent with research documenting caregivers’ experiences of suffering and self-blame [40]. This dynamic underscores the need for caregivers to strike a balance between empathy and self-care. Suppressing emotions to protect the care recipient can have detrimental effects on the caregiver’s mental health. This study highlights the potential value of incorporating caregiver-identified supports during rehabilitation, such as emotion coaching, reflecting caregivers’ expressed need for emotionally focused guidance and support during adjustment to spinal cord injury [3].

Formal and informal support systems are essential in assisting caregivers of individuals living with SCI, particularly during the discharge and post-discharge period. Participants highlighted significant challenges, including insufficient guidance from healthcare professionals, a lack of practical and emotional preparedness, and difficulties managing emotions during the transition home. These findings align with Jeyathevan et al. [3], who emphasise the importance of structured support during key caregiving transitions. In the UK, post-discharge follow-ups often focus solely on individuals living with SCI, neglecting caregivers’ needs. Expanding these follow-ups to include caregivers and providing essential information and resources during hospital stays could foster smoother transitions and alleviate emotional and practical burdens.

Peer support also emerged as a critical resource for caregivers. Consistent with prior qualitative research, caregivers described peer support as reducing feelings of isolation and providing emotional reassurance and a sense of solidarity [3]. Informal networks, including family, friends, and community groups, play an important role as caregiving progresses [3,9]. These networks help provide practical and emotional resources, aligning with evidence that community support and social resources are associated with reduced caregiver distress and lower perceived burden [41,42]. Improving access to peer and community-based networks in the UK could significantly enhance caregivers’ well-being, offering familiarity, reassurance, and support throughout their journey.

Our data highlight three critical areas for attention. First, targeted education and psychoeducation for caregivers and their immediate networks is essential to mitigate the shock and confusion experienced at the onset of spinal cord injury, equipping caregivers with the knowledge needed to navigate their role more effectively, particularly during the early “birth” of a caregiver stage. Second, caregivers require sustained and enhanced support systems that extend far beyond the onset of injury, recognising that caregiving is not a single event but a long-term trajectory with fluctuating mental health impacts. Finally, this study underscores the importance of targeted interventions that directly address caregivers’ emotional and psychological needs, including emotion coaching, peer support, and structured assistance from family and friends.

Future research should focus on improving the management of the hospital-to-home transition, particularly the immediate needs of caregivers in assessing and managing secondary complications of spinal cord injury, such as tissue injury and autonomic dysreflexia. Additionally, understanding the role and coordination of home care services in the UK, particularly involving nurse practitioners, dietitians, and physiotherapists, will be crucial. By equipping caregivers with the necessary clinical knowledge and support, the overall caregiving experience and the recovery process of the care recipient can be significantly enhanced.

Limitations

Despite the strengths of the study, including in-depth engagement with a clearly defined caregiver population, a focused examination of experiences across the caregiving trajectory, and a reflexive analytic process that prioritised meaning-making and interpretation, there are a few limitations. Firstly, as a retrospective study, it is vulnerable to recall and observer bias, relying heavily on participants' memory and self-reported data. Many participants reflected on experiences from the onset of injury that occurred years ago. However, the consistency of reported views across participants, regardless of the time since injury, suggests these findings represent systemic issues rather than isolated experiences. Triangulating these findings with prospective studies could further validate the persistence of these challenges. Secondly, the sample may not be fully representative of the broader SCI caregiver population due to the high proportion of female (~80%) and spousal caregivers (~55%). However, this composition aligns with evidence from the general population showing that unpaid caregiving roles are more commonly undertaken by women [19], as well as SCI-specific research indicating that caregiving is frequently assumed by spouses and partners [6,43]. Future research could extend this work by exploring caregiving experiences across additional caregiving relationships and contexts.

While many of the issues raised mirror those reported in other countries [3,6], caregivers in the UK described context-specific challenges shaped by the organisation of healthcare and post-discharge support. National data show that over half of unpaid carers report needing more support from the NHS, and only 14% are asked about their ability to provide care at hospital discharge, despite a legal right to be involved in this process [17]. Future research should examine how differences in healthcare policy and service structures influence caregiving experiences across national contexts.

Finally, in line with a reflexive qualitative approach, it is important to acknowledge the role of the researchers in shaping the analytic process. All authors are trained in Health Psychology, which informed the interpretative lens through which caregivers' accounts were analysed and prioritised, particularly in relation to mental health, support needs, and caregiving roles. While reflexive thematic analysis does not aim for researcher neutrality, ongoing reflexive practices, including team discussions and reflexive journalling, were used to critically examine assumptions and interpretations throughout analysis. This approach is considered a strength of the study, enabling theoretically informed and contextually grounded interpretation, while also recognising that alternative readings of the data are possible.

Conclusion

This study uncovers the often-hidden realities of caregiving for individuals with spinal cord injuries (SCI), revealing a multifaceted interaction between emotional distress, isolation, and systemic gaps in support. Building on prior research, these findings delve deeper into the pervasive impact of shared trauma, the unexpected and unprepared nature of caregiving roles, and the significant gaps in available resources. These insights highlight the need to view caregivers as integral to the SCI care framework, ensuring their experiences and needs are prioritised and psychoeducation interventions are targeted at them, alongside the person living with SCI.

In the UK, where this research was conducted, caregivers consistently reported feeling overlooked by healthcare providers and expressed a need for more structured and ongoing support. By exploring the experiences and challenges faced by caregivers, this study provides key areas where tailored interventions could be developed to support the mental health and well-being needs of caregivers. Healthcare systems that address these needs can enhance the overall well-being of caregivers while improving the quality of care for individuals living with SCI. This research underscores the critical importance of a caregiver-focused approach, ensuring that caregivers receive the resources and mental health support necessary to sustain their roles effectively and promote positive outcomes for both themselves and the individuals they care for.

Author contributions

CRediT: **Adam Madhani**: Data curation, Formal analysis, Investigation, Methodology, Resources, Validation, Writing – original draft, Writing – review & editing; **Margaret Tilley**: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision; **Phoebe Brook-Rowland**: Data curation, Investigation, Methodology, Resources, Validation; **Louisa Dosanjh**: Data curation, Investigation, Methodology, Resources, Validation; **Katherine A. Finlay**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing.

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Data availability statement

The data that support the findings of this study are available from the corresponding author, KF upon reasonable request.

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