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Understanding Caregiver Stress to Inform Community-Based Stress Monitoring and Supportive Interventions: A Qualitative, Descriptive Study

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ABSTRACT

To inform community-based stress monitoring tools and supportive interventions, this study aimed to understand caregiver stress as experienced by a diverse group of informal caregivers guided by the Pearlin's stress process model. We used a qualitative descriptive design conducting semistructured interviews with informal caregivers (≥ 18 years) currently or previously caring for an adult with health issues at home. Data were analysed using the framework approach. We recruited 27 caregivers (19 current and 8 former) from various geographic locations within the United Kingdom. In terms of background and context, poor caregiver health increased stress whereas prior employment in health or social care, and access to trusted supports and resources reduced stress. Common primary stressors included rapidly changing or palliative care care-recipient needs, loneliness and loss (i.e., loss of their normal life, or of the life and future plans they had expected). Family conflict, occupational/economic strains and social/recreational life constraints were important secondary stressors. Guilt contributed to intrapsychic strain resulting in low self-esteem and feelings of role captivity. Few participants discussed positive elements of caregiving such as mastery or gain. Stress mediators included coping strategies such as taking control, humour, taking brief respite, social activities, access to peer and other forms of social support, and trusted support for caring. Common outcomes of stress included exhaustion, physical injuries, weight loss, difficulty sleeping, depression and anxiety. Despite growing recognition of issues facing informal caregivers and policies or services put in place to support them, our data indicate key stressors remain. Future supportive initiatives should reflect dynamic and individual caregiver needs, thereby enabling caregivers to prioritise their mental and physical wellbeing and receive brief respite from caregiving responsibilities. Stress monitoring tools and accompanying supportive interventions, if codesigned with caregivers with lived experience, offer the potential to identify high-stress periods, enable timely interventions and guide more efficient resource allocation.

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1 | Introduction

Increasing complexity of long-term healthcare needs and ongoing constraints on the healthcare system has resulted in an exponential rise in the need for family, friends or significant others to provide caregiving in the home (henceforth referred to as informal caregivers). The most recent (2021) census for England and Wales identified over five million people who are informal caregivers providing essential care in the home at no cost to the healthcare system [1]. This is estimated to save the National Health Service approximately £193 billion each year [2]. Yet, despite their crucial role, these informal caregivers often face considerable burden and stress due to the physically and psychologically demanding nature of their caregiving responsibilities [3, 4].

Caregiver stress is defined as the emotional, physical and psychological strain associated with providing sustained, often intensive, care to someone with significant health needs [3, 4]. As Pearlin and colleagues outlined using the stress process model [5], caregiver stress includes the domains of the background and context of stress, primary and secondary stressors, stress mediators and manifestations of stress. Pearlin's application of the stress process model to caregiving, published in 1990, provides a comprehensive framework to understand mechanisms by which stressors lead to health outcomes, whilst also taking into consideration the caregiving characteristics and context and potential stress mediators, thereby reflecting real-world caregiving experiences. Pearlin's model remains a dominant and widely used theoretical framework in stress research conducted in diverse populations including caregivers.

Regardless of competence or support, most caregivers encounter stress leading them to feel overwhelmed at times, particularly if the care recipient is exhibiting challenging behaviour, has high care needs or is on a palliative trajectory [6]. Burnout, depression, physical illness, loss of social networks, low levels of quality of life and financial concerns are common [7]. Decreased caregiver well-being directly impacts on their capacity to provide care in the home. This may result in the care recipient being transferred to long-term residential care if their informal caregiver is no longer able to assume this role [8]. Recognising the issues faced and providing support to stressed caregivers is therefore essential [9].

Caregiver stress is frequently overlooked and unmonitored by healthcare professionals, society and caregivers themselves, with symptoms of stress often left untreated [7, 10]. Various validated instruments are available to assess caregiver stress. Yet, they are infrequently used outside of a research context. Additionally, these self-report tools do not measure stress in real-time and in the real-world caregiving context to inform the need for supportive interventions. Stress monitoring poses other challenges. First, stress is subjective, dynamic in nature and responsive to various and individualised mediators [11]. Second, stigma is attached to admitting stress and need for support. Third, caregivers have concerns about identifying the care recipient as a source of stress and burden [12]. Finally, usual methods to measure stress such as self-report questionnaires (e.g., Zarit Burden Interview [13]) are collected at discrete timepoints (i.e., at baseline and study completion) and therefore do not capture dynamic stress. Furthermore, self-report questionnaires can be influenced by recall and social desirability bias [14].

Given the above challenges of stress monitoring and informed by the Pearlin's stress process model, this study aimed to characterise caregiver stress from the perspectives of a diverse group of current and former informal caregivers. These data provide a contemporary, nuanced understanding of the lived experience of caregiver stress that can inform the design of caregiver stress monitoring tools, including emerging digital technologies as well as community-based support strategies to alleviate stress.

2 | Materials and Methods

2.1 | Study Design

We conducted a descriptive qualitative study using semi-structured interviews with informal caregivers. During the interviews, we asked participants about their experiences and perceptions of caregiver stress. We also asked their views on the potential role of novel stress monitoring methods. These data are published elsewhere [15]. We aimed to generate in depth understanding of the daily realities and stressors caregivers face, as well as the supports they find helpful or lacking. This understanding will inform future development of stress monitoring tools and support strategies that are grounded in the real-world experiences of caregivers and that are sensitive to the diverse factors influencing stress.

We chose a qualitative descriptive design as this provides direct participant accounts making findings accessible to health and social care practitioners and policy makers. We adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines in the preparation of this manuscript [16].

2.2 | Participants

Our inclusion criteria comprised adult informal caregivers (≥ 18 years) who were currently or previously caring for an adult or child in the home with long-term health issues. We did not apply a time restriction in terms of when caregiving occurred if the caregiver recipient had either died or recovered. This allowed a greater number of caregivers to participate to provide a diverse perspective of caregiver stress. We excluded people whose caregiving role was for a healthy child and those with a professional (paid) caregiving role. To describe our participants' sample, we asked them to identify the primary health condition of their caregiver recipient most responsible for their caregiving responsibilities.

2.3 | Recruitment

We used a multimodal recruitment strategy and convenience sampling while aiming for sample diversity. We contacted previous participants of an online peer support programme for caregivers of people with motor neurone disease (MND) and family members of our advisory group for research into recovery from intensive care. We used snowballing methods, social media (X), patient charities (ICUSteps, MND Association), the King's College London weekly research volunteer e-circular and E-Carewell, a University of Ulster research programme exploring digital support tools for carers. Interested caregivers expressed interest via email to the research team (SS or EF) in response to our recruitment materials and were then screened using the above inclusion criteria.

2.4 | Interview Guide Development

We developed the interview guide (see Supporting Information (available here)) iteratively among the study team. Interview questions 1–4 (reported in this study) were deliberately open-ended to explore participants' experiences of caregiving, caregiver stressors and support received (including peer support). Subsequent interview questions were more focused on ascertaining perceptions of various novel digital technologies to measure stress (these data are reported elsewhere [15]).

Before formal data collection commenced, we conducted a pilot interview of the interview guide, to ensure the questions had clarity, were in a logical order and elicited the required information (data were retained for analyses). Feedback from the pilot interview led to minor changes (e.g., we did not ask question 7, "Have you ever used technology to support you in your caring role? If yes, what?" because the participant did not understand what this meant.)

2.5 | Data Collection

We conducted one-on-one interviews (February to August 2023) over video using Zoom or telephone call dependant on participant preference. Remote interviews enabled us to recruit participants from various geographic locations and to schedule at times that accommodated their caregiver responsibilities. Participants choose their preferred mode of interview to promote comfort and encourage open, honest reflection on what can be a sensitive topic.

All interviews were conducted by a nurse researcher (Sian Saha) with interview training and experience. Sian Saha had no prior relationship with participants, although some were previously interviewed following their participation in a digital peer support randomised controlled trial [17]. Participant demographic information was collected at the start of each interview. Interview field notes were made with interviews digitally recorded, professionally transcribed and subsequently anonymised by the research team (Sian Saha). We maintained a clear audit trail of interviews, data charting, study group meeting minutes and data analyses. Participants were given a £15 gift voucher in lieu of their time. Transcripts were not returned to participants for member checking to avoid further burden to participants; no participants withdrew their data. We discontinued interview recruitment when the study team considered that no new data were being identified and we had reached sufficient information power [18] for our relatively narrowly focused aim and participant specificity.

2.6 | Data Analysis and Conceptual Framework

We conducted a framework analysis [19] informed by Pearlin's stress process model [5]. In this model, there are four domains with multiple subdomains. The domains are (1) background and context (with subdomains comprising caregiver characteristics, caregiving history and access to and use of resources/supports); (2) stressors including primary stressors (with subdomains of cognitive status and problematic behaviours, activities of daily living (ADLs) dependencies and hardships of caregiving, i.e., overload and relational deprivation) and secondary stressors (with subdomains of family conflict, occupation/economic strains, social life/recreational constraints and intrapsychic strains including low self-esteem, role captivity and mastery/competence/gain); (3) mediating conditions (with subdomains of coping and social support) and (4) outcomes (with subdomains of physical, cognitive and mental health manifestations of stress). Together, these domains and subdomains formed the structure of our matrix and coding.

The framework approach [19] allowed us to compare and contrast data whilst maintaining the context of the individual participant views. When applying the framework approach, we followed the procedures of (1) transcription; (2) data familiarisation; (3) coding; (4) developing a working analytical framework; (5) applying the analytical framework; (6) charting data into the framework matrix and (7) data interpretation. Using a deductive approach, data were coded independently by two research team members (Sian Saha and Emily Flowers) using the comment and highlight functions of Microsoft Word and then charted using Microsoft Excel. Two senior authors (Louise Rose and John Rooksby) reviewed and coded 40% of the transcripts. Data and coding were discussed by the team (Sian Saha, Emily Flowers, Louise Rose and John Rooksby) at monthly meetings until agreement was reached that the codes fit the data. The final codebook was reviewed by the wider study team (Joan Condell, Faith Matcham, Alexander J. Casson, Chee Siang Ang and Tony Robinson). Finally, quotes illustrating the domains and subdomains were chosen.

We used the following demographic key for these illustrative quotes to represent participant age category, care recipient relationship and whether the care recipient had MND or another health condition: participant age: 18–40 = A, 41–65 = B, > 65 = C; care recipient: spouse = 1, sibling = 2, parent = 3, grandchild = 4, grandparent = 5; MND = a, and other health condition = b.

2.7 | Ethical Approval and Informed Consent

We obtained research's ethics approval from the King's College London Minimal Risk Committee (reference no: MRA-22/23-34473). All participants were informed about the study aims, their rights as participants and confidentiality of their responses. Written (by returning a signed consent form) or verbal informed consent (audio recorded prior to the interview) was obtained before interview.

3 | Findings

We recruited 27 caregivers from across the United Kingdom including the devolved nations, most of whom were aged 41–65 (63%) and female (70%). Participants were mainly White British (70%), and the majority had completed tertiary or postgraduate education (74%). Caregivers most often supported a spouse or parent (81%) and were caring for individuals with diverse health conditions, including MND (33%), post-ICU recovery (22%) and dementia (19%). Caring demands were substantial, with over half providing 10–24 h of care per day, and most (70%) were still in an active caring role (see Table 1 for demographic details). No parent caregivers of children with long-term health needs responded to our recruitment methods, meaning that the caregiver relationship 'child' was not included. Interviews ranged from 15 to 49 min (mean 33 min).

TABLE 1 | Demographics of interview participants.

	n
Age	
18–40	2
41–65	17
> 65	8
Gender	
Male	8
Female	19
Ethnicity	
White British	19
Asian or Asian British	2
Black, African, Caribbean or Black British	3
Mixed or multiple ethnic groups	2
Other ethnic group	1
Level of education	
Some primary school	0
Completed primary school	0
Some secondary school education	0
Completed secondary school education	5
Some tertiary (college or university) courses	2
Completed college or university undergraduate level qualification	13
Completed graduate degree (Masters and above)	7
Employment	
Retired	10
Full-time work	10
Self-employed	6
Part-time/casual work	1
Student	0
Unable to work/receiving unemployment benefits	0
Other	0
Person cared for	
Spouse	11
Sibling	3
Parent	11
Child	0
Grandparent	1
Grandchild	1
Friend	0
Primary care recipient health needs	
Motor neurone disease	9
Recovering from ICU admission	6
Dementia	5
Learning difficulties	3
Ageing	2
Parkinson’s	1
Previous stroke	1
Still have a caring role	
Yes	19

(Continues)

TABLE 1 | (Continued)

	n
No, previous caregiver	8
Number of hours caregiving	
10–24 h a day	15
5–30 h week	4
1 h week	1
Variable depending on need	6
No data	1
How long caring?	
< 1 year	4
1–5 years	14
5–10 years	5
> 10 years	4
Previous experience of peer support	
Yes	15
No	12

We identified that the following domains and subdomains of the Pearlin's stress process (summarised in Table 2) were relevant to our participants' experiences of stress.

3.1 | Domain 1: Background and Context of Stress

In the Pearlin's model, background and context of stress includes subdomains of caregiver characteristics, caregiving history and available resources. Findings within this domain highlight the personalised and dynamic nature of caregiver stress that any form of stress monitoring or stress targeting intervention needs to accommodate.

3.1.1 | 1a. Subdomain: Caregiver Characteristics—Age

We identified different perspectives towards caregiver stress related to the age caregiving commenced. For example, participants commencing a caregiving role as a young adult (i.e., age 18–25) reported that they initially did not grasp the enormity of caregiving responsibilities.

> "*I think when I looked after my mother I was very young, and I don't think I really understood what I was doing to be quite honest.*" (ID11B2b)

Participants who commenced a caregiving role as a young adult described the stress of having to juggle caregiving with other life responsibilities such as education and finding a career.

> "*I was only maybe seventeen years old. It was a lot of responsibility for me to have and a lot of pressure because at that age, trying to work on yourself and trying to focus on yourself and like, I was going through a time of [exams].*" (ID18A3b)

Conversely, older participants considered their caregiving situation as an accepted responsibility and a social expectation and did not specifically acknowledge stress (or the need to monitor stress) arising from it.

> "*I think it's, for people probably of my age, they won't acknowledge stress.*" (ID25B2b)

3.1.2 | 1b. Subdomain: Caregiver Characteristics—Occupation

Participants who had a healthcare or managerial-type occupational background described how they used this knowledge to negotiate the healthcare system. This knowledge also gave them a better understanding of what caregiving entailed thereby relieving stress somewhat.

> "*I knew my way around health because I was working as a social worker... I knew more about how to ask questions and how to stand up and say, "Look, I want an answer to this.""* (ID17C1a)

Participants who had occupations exposing them to high levels of stress also saw this as helpful in managing their own stress.

> "*I've seen all sorts of very nasty stuff* [in previous employment] *and I don't get stressed.*" (ID12C1a)

3.1.3 | 1c. Subdomain: Caregiver Characteristics—Caregiver Health Status

Participants described how their own health shaped their response to their caregiving situation with worsening health increasing their stress, perception of burden and ability to cope.

> "*I know I'm not coping too, too well at the moment. I've got a lot of things on, I've got a sixteen year old son, I'm not one hundred percent well myself and everybody comes to me for everything.*" (ID13B5b)

TABLE 2 | The Pearlin's stress process: A summary of domains and relevant identified subdomains.

Domain	Subdomains
Domain 1: Background and context of stress	Age Occupation Caregiver health status Relationship to care recipient Care needs of the care recipient Access to and use of resources
Domain 2: Primary stressors	Cognitive status and problematic behaviours Activities of daily living dependencies Hardships of caregiving
Domain 2: Secondary stressors	Family conflict Occupation/economic strains Social life/recreational constraint
Domain 2: Secondary stressors—intrapsychic strain	Low self-esteem/loss of self Role captivity Competence, mastery and gain
Domain 3: Mediators	Coping Social support
Domain 4: Outcomes—manifestations of stress	Physical Cognitive Mental

3.1.4 | 1d. Subdomain: Caregiving History—Relationship to Care Recipient

Stress was perceived differently depending on a participant's relationship to the care recipient and whether they embraced their caregiving role or felt forced to do it as no one else was available or would take it on.

> *"Especially having no family or siblings, I'm the only one, and my obligation obviously in this case was my mother … Your priority lies there, and then you're left with sort of the aftermath."* (ID8B3b)
>
> *"From my perspective, I was really happy to deliver care on my own. It was something that we had discussed from the beginning. So I made a promise and I stuck to the promise really."* (ID3C1a)

Stress was further influenced by previous conflict with the care recipient, creating a barrier to overcome when providing care. This also led to feeling unappreciated.

> *"Daddy would be in a temper or something, you're learning how to manage that, because you have all the triggers that happen with your childhood."* (ID21B3b)

3.1.5 | 1e. Subdomain: Caregiving History—Care Needs of the Care Recipient

Participants reported that they experienced stress when care needs changed rapidly, particularly those caring for individuals with MND which has a rapidly palliative trajectory. Conversely, stress was mitigated by hope of recovery for those participants caring for individuals on a recovery trajectory.

> *"And then when he was diagnosed, it was like a bomb hitting us both. It was stressful from the beginning because we knew that it was certain death"* (ID17C1a)
>
> *"When he came home, it was such a good feeling that he was getting over it"* (ID23B1b)

3.1.6 | 1f. Subdomain: Access to and Use of Resources

When discussing accessing resources for their care recipient, participants spoke about trust. When trusted support was available, stress was reduced. Trust in the caregiving provided by others enabled participants to take a break that resulted in, an albeit temporary, stress reduction.

> "*Thankfully I've got a very, very, very good [professional] carer, who I trust, I'm not very trusting with people looking after my nan but I don't know what I'd do without her to be honest with you"* (ID13B5b)

In contrast, when caregiving support was offered or provided from a source they did not trust, having to accept this support increased their stress levels. Accessing external supports created additional burden due to the preparation needed to hand over their caregiving responsibilities, as well as overwhelming anxiety from leaving their care recipient with someone whom they did not trust.

> *"My mum and dad weren't comfortable with carers … My dad* [who was the primary caregiver for mum] *got so stressed about what they were doing, what he had to get out for them in the morning, even though I'd set it up all the night before"* (ID9B3a)

Participants described accessing external networks that reduced their feelings of stress and isolation including community-based programs run by healthcare professionals, charities or hospices and carers' networks providing practical, emotional and informational support from peers (i.e., other caregivers in similar situations).

> *"The hospice were extremely useful ... They were always available on the phone. That took a lot of stress away ... because it was really difficult getting hold of other healthcare professionals"* (ID24C1b)

Conversely, lack of local community resources, complexities of getting care packages in place and interacting with organisations involved in the provision of in-home care frequently resulted in elevated stress.

> *"So there are lots of things that are good about the services here, but a lot of things that also need tweaking, and part of the problem is lack of resources, you know, the eternal problem"* (ID17C1a)

Some participants identified that they did not access supports that might be helpful for managing stress due to being consumed with their caregiving role and deprioritising the monitoring of their own needs.

> *"They did offer like you know, psychological help for me, they did offer therapy and everything but I think at the time, I was just so focused on my mum, that I kind of didn't really take them up on that"* (ID18A3b)

Participants identified that they did not want to risk being seen as not coping by asking for help, with anticipated consequences such as intervention from social services.

> *"So, I couldn't ask for help because then the social services would have come in because it was said that my daughter had adequate support"* (ID20A4b)

Other participants described actively reaching out for help, such as requesting medication prescribed by their GP to manage their stress and mood.

> *"So eventually, I did phone my GP and I explained what was going on ... I went onto antidepressants and that sorted it out"* (ID3C1a)

3.2 | Domain 2A: Primary Stressors

In the Pearlin's model, primary stressors directly result from the caregiving situation, whereas secondary stressors arise from roles and activities outside of caregiving. Secondary stressors can cause intrapsychic strain with altered self-concept and loss of self.

3.2.1 | 2Aa. Subdomain: Cognitive Status and Problematic Behaviours

Participants described the stressful effect of witnessing cognitive changes including memory loss, communication difficulties and recognition failures in their care recipient. They described this as draining, upsetting and a loss of the person they cared for and of their relationship with that person. Participants reported reducing their stress arising from these behaviours by reminding themselves as they are not the fault of the care recipient, rather the condition they are living with.

> *"When she talks, she talks a lot and it's repeated sentences and so on so, I've heard the same story for like, five years over and over and sometimes it's draining but it's not her fault, it's the disease"* (ID13B5b)

Problematic behaviours such as not accepting support, not adhering to medical advice or being physically and/or verbally aggressive increased stress. These behaviours created relational conflict as well as worry for the care recipient's wellbeing and prolonged suffering.

> *"People with MND do get cognitive changes, do get behavioural changes, do get emotional mobility and they can be angry, they can be self-centred, they can be difficult to care for"* (ID14B3a)

Care recipient resistance to caregiving resulted in increased surveillance (often covert). This surveillance was often near constant, ensuring that the care recipient was safe but with a resultant increase in participant stress levels and fatigue.

> *"I installed cameras in the house, so as I can watch her movements and see what she's doing. But no matter where I am, and if I was on holiday... I'd still be watching the camera to see what she's doing or not doing"* (ID25B2b)

3.2.2 | 2Ab. Subdomain: Activities of Daily Living (ADLs) Dependencies

Dependence of care recipients for ADLs created stress. For some, this was compounded by the need to provide care during the night, including managing healthcare technologies supporting breathing, which interfered with sleep.

> *"It got to the point where he was waking me up sort of three or four times a night every night. So that was getting really stressful and difficult to cope with then the next day"* (ID10C1a)

Another source of stress was care recipient loss of communication function.

> *"He can only mouth things, and I find it stressful when I don't understand him. He finds it stressful when I don't understand him, and then that affects me"* (ID15C1b)

In contrast, some participants spoke about developing a daily routine that provided them an effective coping strategy that relieved the stress of providing daily support for the ADLs.

> "*The day-to-day stuff isn't stressful anymore, really. We wish it wasn't happening to us, but it is. So, getting up and either showering him or get his equipment ready so that he can wash*

> *himself, we've got that off to a tee and I don't find that stressful at all."* (ID24C1b)

3.2.3 | 2Ac. Subdomain: Hardships of Caregiving

Stress, overload, fatigue, anxiety and burnout were common experiences expressed by our participants, particularly those who had provided caregiving for prolonged periods. Caregivers described constant worry, feeling a huge weight of responsibility and sadness watching their relative decline whilst, at the same time, having to deliver practical care and continue their daily lives.

> *"You're in a situation where you're so exhausted with the physical side of it, with the mental side of it of watching this person in such a terrible situation. And every other thing that comes up that you have to do, even though it might be a small thing, seems like a mountain to try to climb"* (ID17C1a)

Relational deprivation was experienced as loss and feelings of loneliness.

> *"The stresses of it were amazing ... the loneliness really was the biggest thing, and the lack of adults' company. Because as I said to the staff all the time, she's not just my wife, she's my best friend"* (ID6B1b)

Losses included loss of their normal life, or of the life and future plans they had expected.

> *"We've not been able to do what we wanted to do for retirement. We can't go on holiday, like we used to go on holiday. It's such kind of things that I find the hardest to cope with really"* (ID10C1a)

Some participants still in a caregiving role expressed anticipated loss of their family member.

> *"I'm grieving somebody who's alive so, it worries me what my reactions going to be when she does pass."* (ID13B5b)

3.3 | Domain 2B: Secondary Stressors

Findings in this domain reveal the pressures caregivers experience that are outside of the direct caregiving role.

3.3.1 | 2Ba. Subdomain: Family Conflict

Participants described the stress of having to 'step-up' to the caregiving role whilst other family members were not doing the same, or to the same level. This created resentment and often added to existing family grievances or conflicts (often unrelated to the caregiving situation) causing stress. This family conflict caused participants to feel unappreciated in their role.

> *"It's kind of awkward we're both in the kitchen and I don't talk to him, then I have to tell him like, you have to grow up, it's like having an extra baby with my dad and it's like well, you should be really helping me, why is it on me and then I kind of get upset"* (ID13B5b)

3.3.2 | 2Bb. Subdomain: Occupation/Economic Strains

Participants referred to the enormity and overwhelming level of responsibility of their role, needing to do 'everything'. This included looking after other dependants, maintaining home upkeep, managing finances, organising care packages and acting as the point of communication about and for the 'patient', all whilst delivering physical and emotional caring tasks.

> *"I think the stress comes from trying to cope with looking after [NAME] and what he needs, and then having to do everything else as well"* (ID10C1a)

The physical and mental exhaustion of trying to maintain a normal life alongside their caregiving role resulted in a constant high stress level that meant dealing with anything new felt like a 'mountain to climb'.

> *"As the carer you've got your person that you're looking after, keeping all of this administration up together and then you're running a house as well, because the house don't run itself"* (ID1C1a)

Participants who had to work to maintain income for themselves and the family expressed the enormous stress that juggling work, caregiving and other commitments created.

> "*I'm very concerned because my mother is getting worse and her ailments are no longer limited to Parkinson's only and at the same time I have a full-time job and I'm not able to compromise much on that because this is my sole source of income"* (ID4B3b)

Many participants found it challenging to set boundaries and to balance their conflicting priorities relating to caregiving and work. Participants described not wanting either role to suffer but finding this impossible to achieve, resulting in feelings of guilt that further contributed to their stress. Working from home was seen as a facilitator to performing both roles but also added to stress as participants did not want the quality of either role to be compromised.

> *"I'd set a boundary from the beginning anyway, that no laptops when she's in the room so that she has me totally, and I'm not ... it's important she doesn't feel as though work is getting in the way. So, that's the tension that I find is difficult to manage"* (ID22B3b)

Having a supportive employer helped to alleviate some of this stress, whereas a less accommodating employer could add to stress.

> *"The company that she did work for ... actually gave us enough money as a gift so that I could stay off work, so I didn't have to worry about paying bills, et cetera"* (ID6B1b)
>
> *"So even though I know there is something in the law that enables me to accommodate caring towards my mom, that's not*

> *being utilised just because I have such [unsupportive] managers"* (ID4B3b)

Some participants described having to give up work completely to care for their family member. In some cases, participants had to take extreme measures to ensure financial stability.

> *"I sold my house, so that was the money worry away, I think money is a desperate worry"* (ID20A4b)

3.3.3 | 2Bc. Subdomain: Social Life/Recreational Constraint

Some participants spoke about the physical restrictions imposed on them or that they imposed on themselves. This included not being able to leave the house (and their care recipient) for even short periods due to the level of care demands and concerns about safety.

> *"I stopped going to the gym because I didn't want to leave them. I went out twice in those months with my friends, and it was just so much of a stress to get somebody to take my place, it was just easier not to go"* (ID9B3a)

Participants described how even when physically able to leave their family member, they could never mentally switch off from their caregiving role as well as the large amount of preparation it entailed.

> "*I have a few hours out with a friend or go to a spa or something, the amount of things you have to think about before you go ... that's the bit I think probably carries the most stress for me, that you just can't stop thinking about someone else the whole time"* (ID24C1b)

Other participants spoke about modifying their social activities such as giving up drinking alcohol so they could always be available in case of caregiving emergencies.

> *"I made the decision I am not drinking now because I cannot afford to have any kind of, if I need to get her somewhere I need to be in a condition to drive her"* (ID1C1a)

Participants described their sense of duty as a caregiver forced putting themselves 'on hold' and giving priority to their care recipient resulting in feeling socially isolated from friends and family. Some participants accepted this willingly, while for others, this created resentment and stress.

> *"I lost contact with a lot of friends ... I hardly saw anybody, and next thing we're in COVID, back to back. So, for about five years I was disconnected, that had a negative impact"* (ID8B3b)

3.4 | Domain 2C: Secondary Stressors—Intrapsychic Strain

Findings in this domain describe the complexity of emotions our caregiver participants commonly experience. Optimal stress monitoring tools should recognise nuances in caregiver stress and provide appropriate feedback.

3.4.1 | 2Ca. Subdomain: Low Self-Esteem/Loss of Self

Participants often felt inadequate in their caregiving role and expressed doubt that they were doing enough for their care recipient. Such negative feelings reduced their self-esteem and how much satisfaction they gained from the role.

> *"I was kind of scared in a way that I wouldn't be up to par... I had no self-esteem and no confidence ... I kind of feel like my self-worth at the time, relied on how well I was doing with my mum and how well I was handling the stress and pressures"* (ID18A3b)

Participants reported neglecting themselves because of their caregiving demands and that the caregiver role became their identity resulting in a lack of self-care. This experience was perceived as stressful, taking an emotional and physical toll on their well-being.

> *"You just keep going and keep going because that's your person and sometimes you don't notice that you've not eaten all day or you know, that you've forgotten stuff that you need to do for yourself so, you fall behind and you end up eating up yourself or not doing what you're supposed to do"* (ID13B5b)

Feeling guilty for not coping played a role in the reasons participants did not seek support from paid caregivers. Those participants who did accept paid caregiving continued to feel guilty despite gaining relief from the support.

> *"If you put her in* [a] *care home, you still have to live with the guilt of that, your brain just doesn't switch off"* (ID13B5b)

Participants described feeling guilty because their relative was suffering, yet it was themselves who was not coping, or conversely, they felt guilty because they were OK, and their relative was not. Participants also felt guilty when at times resenting their caregiving role.

> *"I feel guilty that I'm okay and my brother's not, and I feel guilty if I feel stressed because I'm okay, and he's not, and I just think about how he feels"* (ID11B2b)
>
> *"There are mornings when I don't want to get up and then I feel guilty for not wanting to get up and go down there"* (ID13B5b)

Guilt eroded satisfaction with their caregiving role and their sense of well-being.

> *"Lots of feelings of guilt, even though I know I shouldn't feel guilty because I know I did the absolute best I could do for him"* (ID17C1a)

3.4.2 | 2Cb. Subdomain: Role Captivity

Participants felt a huge weight of responsibility so much so that they feared any absence from their duties would be detrimental to their care recipient.

> *"If I'm not in a good space, then everything falls apart and I can't rely on anybody else to do what needs to be done ... I can't afford to get sick"* (ID13B5b)

How participants approached their caregiving role (whether they embraced it, resented it or were equivocal) influenced their stress levels. For some, this role captivity was overwhelming.

> *"It is just relentless ... Some days you just want to escape for a day"* (ID24C1b)

Participants who embraced the role tended to have lower stress levels.

> *"It's not so bad doing something that you want to do. It's stressful, but it's not nearly as stressful as something you don't want to be doing"* (ID1C1a)

For some, undertaking caregiving roles also helped to relieve stress despite role captivity.

> *"I got fed up of the healthcare professionals bringing up care ... They couldn't quite get their head around the fact that I would be more stressed if I was apart from* [NAME] *than if we're together"* (ID3C1a)

3.4.3 | 2Cc. Subdomain: Competence, Mastery and Gain

Some participants expressed that they gained a lot from caregiving, taking joy from providing care and the experience of being with their family member.

> *"I'm really grateful, it's a blessing and I'm honoured to have her ... She says the most amazing things sometimes which are really funny, we have a good laugh together ... and I kind of feel that this is my chance to give back"* (ID16B3b)

Key to having a sense of competency, mastery and gain was having a well-developed routine and support systems for providing care. This helped participants to feel in control thereby reducing stress.

> *"I would set the whole day's food and drugs along a shelf and I would start at one end and I'd work through to the other and then I knew that I delivered everything during the course of the day because you get tired, you forget, you make mistakes"* (ID1C1a)

3.5 | Domain 3: Mediators

In the Pearlin's model, stress mediators are elements such as social support or coping skills that can mediate the effects of stress. Findings in this domain help us to understand the different stress management strategies caregivers' use. Stress monitoring tools should recognise the stress that may lead caregivers to engage in certain 'coping' behaviours and the effect these have on their recovery/stress levels.

3.5.1 | 3a. Subdomain: Coping

Participants described positive strategies to reduce stress such as exerting control over how care from healthcare professionals and paid caregivers was delivered, e.g., timing of when they were present in the home.

> *"We were going to manage it around our needs and not their operational needs. So nobody was allowed to visit before noon, and nobody was allowed to visit after four o'clock"* (ID3C1a)

Other coping strategies included finding humour in their situation and using problem-solving approaches to avert stress.

> *"You have to have a sense of humour because anyways you would definitely go off your head"* (ID6B1b)

A frequently mentioned coping strategy was taking a brief respite. This took many forms including physical break and emotional breaks. Emotional breaks included actively stepping away for a short period of time.

> *"If I got frustrated, we either had a little discussion or I went for a walk around the garden for two minutes and came back in and calmed down"* (ID12C1a)

Physically getting outside for fresh air with the care recipient helped to reduce participant stress.

> *"The walk out was our fresh air and for me that was the only way to maintain my wellbeing and I didn't have time for anything else, that was it"* (ID1C1a)

Participants spoke about giving themselves permission to participate in activities that promoted their wellbeing such as counselling or social activities. This enabled them to feel refreshed and revitalised to return to their caregiving role.

> *"I also gained counselling, and the main thing that I got is about self-care and creating boundaries so that I didn't get into burnout. I will build in time on the weekend or after work, to do something nice for me"* (ID22B3b)

3.5.2 | 3b. Subdomain: Social Support

Participants reported reduced need for external support to manage stress when they had a good family/friend network that provided trusted and practical support to do other activities and have a break. These family/friend networks reduced stress as they provided the opportunity and emotional support to sound-off when feeling stressed.

> *"I've got some really good friends. And down to one of them even just say, 'For goodness sake, put a pair of big girl pants on and get on with it!' Yeah, okay. I needed that today"* (ID24C1b)

The composition of these networks also differed with life stage with those that were in early retirement having a wider network of friends with time to provide support.

> *"We've only got very small family, and our son did what he could, but of course he was working full-time whereas a lot of our friends were retired. I don't think either of us would've survived without their help"* (ID17C1a)

However, participants identified that support dwindled following the initial diagnosis/illness as well as described limitations as to the type and how much support family/friends could or would provide. If family was not living locally, this also limited opportunities for support.

> *"Although I would speak to people on a daily basis, there was sometimes where you'd try and ring people and they wouldn't answer, or they'd be busy, they'd got their own lives and I didn't want to disturb people. And you felt really alone and really isolated that you couldn't do anything"* (ID6B1b)

Those participants accessing peer support from other caregivers (either formally or informally) found it gave them opportunity to reflect on their experiences, gave encouragement, reduced feelings of isolation and loneliness and helped to normalise the caregiving situation enhancing their ability to cope and reducing stress.

> *"It saved me ... Simple as that. It saved me ... You'd have an adult conversation with other adults who had been through the same thing that you'd been through. Unless you've experienced it, it's really difficult to put it into words"* (ID6B1b)

Participants perceived that interacting with other caregivers who had experienced a similar situation provided better support than that provided by family members or healthcare professionals.

> *"It's not someone saying from a book that this is what you should do ... I'm more likely to take the advice of someone who has been through it than someone that hasn't"* (ID7B3b)

Peer support also provided very practical support in terms of accessing relevant information and advice.

> *"It has been really useful with someone else say "oh did you know you can get bereavement support if you're under this age", and "did you know you can get this from your MND nurses" so they share a lot of information that they've been through"* (ID9B3a)

Participants also provided examples of a lack of social support despite their ongoing and in many cases increasing needs for social, physical and emotional support.

> *"When anything like this first happened, everybody would be there for you... now I need people and it's not, it's more human being behaviour. But people's lives move on."* (ID11B2b)

3.6 | Domain 4: Outcomes—Manifestations of Stress

In the Pearlin's model, stress manifestations are the mental, physical and cognitive health outcomes of stress. Findings in this domain highlight the variety of physical, cognitive and mental symptoms of caregiver stress and their fluctuations. Dynamic monitoring incorporating each domain may lead to personalised, timely and therefore more effective interventions.

3.6.1 | 4a. Subdomain: Physical

Participants spoke of fatigue and exhaustion as well as physical illness associated with unrelenting stress and injuries caused by caregiving.

> *"Oh, I'm exhausted. I would say I have aged tremendously"* (ID21B3b)
>
> *"I took a couple of minor strokes, that's what it was ... So they checked on my medical history and stress was the only thing we could put it down to"* (ID25B2b)

Participants acknowledged the physically demanding nature of caregiving including challenging tasks such as lifting and mobilising that had a direct impact on their physical well-being.

> *"I've got a sore wrist. I've got a sore hip and I pulled a muscle in my chest ... I feel like I've been in a boxing ring with somebody ... I'm just busy all the time and it's heavy lifting. He's a heavy guy"* (ID4B3b)

Weight loss was recognised as an outward sign of stress, either due to low appetite or not taking time for themselves because of an overwhelming focus on their care recipient instead of themselves.

> *"[I] lost nearly a stone in weight, partly because of the stress and partly because I just didn't feel like eating ... That's a good physical indication [of stress]"* (ID17C1a)

3.6.2 | 4b. Subdomain: Cognitive

Decreased cognitive wellbeing as the result of constant caregiving demands resulted in being unable to concentrate or sleep. Heightened stress inhibited how participants functioned during routine tasks. Disturbed sleep was attributed to their constant hyperalert state due to concerns regarding their care recipient's safety.

> *"No, like I say, awake from 3 o'clock this morning so no, I was expecting you know, you're always listening in case you get called"* (ID19B3a)

3.6.3 | 4c. Subdomain: Mental

Participants described symptoms of depression such as feeling tearful, life feeling monotone and losing their sense of humour.

> *"It's difficult balancing my emotions on days, there's some days when I'm there and I just sit there in tears"* (ID13B5b)

Feelings of anxiety and panic were described frequently, particularly when participants felt overwhelmed with their caregiving situation. Some participants described a state of chronic anxiety throughout their daily lives as a caregiver.

> *"It's like a constant feeling of being in a heightened state of anxiety, it is. It's all, there's no escape from it. You wake up in the night and you feel anxious"* (ID23B1b)

Other participants experienced anxiety in heightened bursts with some having panic attacks.

> *"For me, I had a panic attack. I thought it was a heart attack actually"* (ID3C1a)

Stress, anxiety and heightened emotions resulted in irascibility with participants speaking about expressing their feelings of frustration by shouting directed towards their care recipient or towards healthcare professionals. Participants spoke about reaching a tipping point when they felt overwhelmed by stress and unable to cope leading to an outward and verbal demonstration of their stress.

> *"Because I'm shouting and you get to this stage where you're nearly like screaming … You realise that it's got to this stage where the stress is too much now, and it has to come out some way"* (ID26B1b)

4 | Discussion

In this descriptive qualitative study, we used Pearlin's stress process model as the theoretical framework to understand key issues and circumstances that contribute to stress among informal caregivers with diverse caregiving experiences. We identified examples reflective of the subjective, personalised and dynamic nature of stress, as well as important mediators, that are informative for the use or design of stress monitoring tools or intervention that aims to reduce caregiver stress.

For the domain 'Background and context of stress', we found that stress was increased with rapidly changing care recipient needs or those on a palliative trajectory, as well as when caregivers were experiencing health issues of their own, offering a more dynamic picture of the context of stress than previously reported. Relationship to the care recipient and caregiver age had a variable influence on caregiver stress, whereas prior employment in a health or social care field, and access to trusted resources reduced caregiver stress. Important primary stressors were the care recipient's declining and unpredictable cognitive status particularly that resulted in problematic behaviours and communication challenges, high dependency and coexisting caregiving hardships such as loneliness and sense of loss. Important secondary stressors were family conflict, occupation/economic strains and social life/recreational life constraints. Intrapsychic strain was evidenced through low self-esteem, frequently the result of guilt. All participants expressed elements of role captivity with fewer reflecting on the positive elements of caregiving through mastery, as has been reported previously. Mediators comprised coping strategies such as taking control, finding humour, taking brief respite and social activities. Outcomes of stress included extreme exhaustion, physical injuries, weight loss, difficulty sleeping, depression and anxiety. These insights deepen understanding of how stress fluctuates, how support from trusted sources mediates stress and how contemporary caregiving contexts align with Pearlin's domains, offering important implications to inform stress monitoring tools—such as when and how frequently to measure stress as well as the design of interventions to alleviate stress.

We found multiple aspects within the domain 'background and context of stress' that had variable influence on caregiving stress. Caregivers with access to trusted support described feeling less stressed and more able to share their caregiving responsibilities to take respite, serving as an important stress mediator. Conversely, inability to trust offered support increased stress due to the burden of care handover with ongoing, heightened stress while separated from the care recipient, and feelings of guilt (intrapsychic strain) for accessing untrusted support. Mistrust of support services is a well-recognised barrier to uptake of support [20, 21]; this often originates from previous bad experiences with support services [21]. We also found that while caregiver–care recipient relationship was an influential factor on stress, similar to other studies [22], it was, however, less influential than caregiver willingness or perception of choice in taking on the caregiver role. Previous studies have also found that lack of choice was associated with high stress, while intrinsic motivation to care was a protective factor [23, 24]. Cultural norms may influence whether individuals see their caregiving role as a normal process or as a burden [25]. The need for trusted support should be considered as an important element in the design and implementation of interventions to alleviate caregiver stress.

Our participants experienced multiple primary and secondary stressors resulting in them feeling overwhelmed as they often perceived they were expected to 'do everything' with feelings of guilt (intrapsychic strain) exacerbated when they were unable to do so. The UK Office for National Statistics census 2021 in England and Wales identified nearly 2.5 million employed caregivers, with many providing high levels of care (e.g., over 50 h of care per week) [1]. To manage caregiving and occupational responsibilities, many caregivers choose to work from home. Working from home can be viewed as a privilege, as it allows caregivers to care for their relatives while maintaining their employment [26]. This arrangement helps to avoid the logistical and emotional burden of leaving a care recipient unattended or receiving external caregiving support. However, managing both work and caregiving responsibilities often harms caregiver health and well-being [27], resulting in burnout caused by challenges balancing competing priorities. In addition to employer responsibilities set out in the Carers Leave Act 2023 [28], employers and healthcare providers should support working caregivers to establish and maintain healthy boundaries and offer complementary supports, such as psychological counselling and opportunities for work and caregiving respite. Design considerations for stress monitoring tools and supportive interventions, digital or otherwise, must strive to minimise burden, integrate easily into caregivers' daily routines and ultimately reduce, rather than contribute to, stress.

Caregiver strategies that acted as stress mediators included exerting control over their caregiving situations through creating routines and therefore knowing what to expect and via a sense of control over external supports. Those caregivers who experienced less stress and took more joy from the role were less likely to employ this strategy. Other strategies included exercise, going outdoors, taking a brief break by removing themselves from the immediate caregiving situation, and prioritising their own wellbeing. Other research has identified variation in caregiver coping strategies, suggesting there is no one size fits all intervention that relieves stress for caregivers [29]. This may have been especially pertinent in our study population that cared for care recipients with a range of health concerns. For example, caregivers for people with MND have different support needs compared to those caring for people recovering from critical illness. Caregiver stress mediators may need to be tailored to account for these differences [30]. Identifying the specific needs, preferences and challenges faced by caregivers across diverse settings and conditions is crucial in developing effective, flexible and inclusive interventions that accommodate a broad range of caregiving experiences.

Our participants reported similar outcomes of stress experiences reported in research for upwards of 30 years [31, 32]. These include negative physical outcomes such as musculoskeletal injuries from manual handling and weight-loss exacerbated by stress. Caregiver anxiety, depression and irascibility were common as were feelings of guilt, difficulties sleeping and problems with concentration that impact on their ability to deliver care. Several initiatives to support caregivers have been introduced. In the United Kingdom, the Government has prioritised funding for informal caregivers [33, 34], UK charities provide informational, practical and emotional support [35] and the NHS provides avenues for respite care and support [36]. However, several barriers exist to caregivers accessing these services. These include not identifying as a caregiver, not perceiving need for support, not being aware of available resources, negative attitudes towards seeking help, low capacity to seek help and not meeting eligibility criteria for services [37]. Our findings suggest that these barriers remain significant, resulting in unmet needs and challenges for caregivers. Using digital technologies to track personalised manifestations of stress (e.g., physical difficulties and sleep disturbances) may lead to more personalised and responsive supportive interventions.

Our findings highlight the need for trusted, flexible and low-burden interventions that can be integrated into caregivers' already demanding lives to reduce stress. However, to be able to ascertain if such interventions are effective in reducing stress, monitoring tools must reflect the dynamic and fluctuating nature of caregiving stress reflected in our findings. Traditional self-report measures (e.g., Zarit Burden Interview [38] or the Caregiver Strain Index [39]) used to determine caregiver outcomes may not capture incremental or transitory increases in stress associated with certain caregiving situations. Alternatively, these measures may not identify short-term but meaningful reductions in stress relating to interventions such as peer support. Digital forms of stress monitoring include vital sign and stress indices available with wearable technologies or use of digitalised ecological momentary assessment (EMA). EMA captures emotions in real time in the real world through brief and repeated question prompts sent to a smart device. Through repeated and brief measurement, EMA can capture how stress fluctuates as well as stress triggers or mediators. This approach may be better suited to identify changes and triggers of stress to flag early recognition of the need for intervention [40]. This would improve the identification of caregivers who need support, allow efficient targeting of limited resources and reduce unnecessary interventions for well-supported caregivers.

4.1 | Strengths and Limitations of Our Study

The use of the Pearlin's stress process model as our conceptual underpinning meant that our research is robust, with informed connections and meaningful results that are comparable to other evidence in this field. We were able to map data onto our Pearlin-informed analysis framework without the need for framework modification and did not identify new themes outside the framework. However, there was some overlap across Pearlin's subdomains, particularly in terms of stressors and stress mediators. We enhanced trustworthiness through multiple line-by-line readings and coding of transcripts, independent coding and with iterative discussion and sense-making across the wider research team. Our multimodal recruitment strategy resulted in a diverse participant group that enabled us to establish commonalities and differences in factors contributing to or relieving caregiver stress which may be transferable to a wider family caregiver population.

Our data have limitations. Younger caregivers, those from low socioeconomic backgrounds, from ethnically diverse backgrounds and parent caregivers were under-represented limiting transferability of our findings. These groups may experience different stressors such as financial insecurity, needing to balance caregiving with education or employment, or caregiving while parenting children. Alternatively, stress mediators and moderators may be influenced by ethnicity and values in relation to family. Future research should target caregivers with these characteristics to understand any similarities or differences in caregivers and their experiences. We did not perform member checking for credibility to avoid further participant burden and time commitment. Use of video or telephone interviews, as opposed to in-person, enabled informal caregivers to participate with minimal inconvenience; however, it may have affected the level of participant engagement in the interview. The framework method enabled a systematic, transparent and flexible approach to our data. However, this method has been criticised for constraining deeper interpretive analysis and requiring careful reflexivity to avoid forcing data into predefined categories [19].

5 | Conclusion

In summary, our descriptive qualitative study offers a contemporary understanding of the lived experiences of informal caregivers and the complex nature of stress they encounter. Using Pearlin's stress process model, we identified key stressors, including care recipients' high care needs and cognitive and behavioural challenges, role captivity and lack of trusted support, as well as stress mediators such as coping strategies, peer networks and a sense of control.

Our findings highlight that caregiver stress is not static but dynamic, influenced by personal, relational and contextual factors. Digital and nondigital stress monitoring strategies, if designed with consideration of the nature of caregiver stress, offer potential to identify high-stress periods, enable timely and targeted supportive interventions thus guiding more efficient resource allocation. Such supportive interventions must be grounded in trust, adaptable to individual needs and responsive to fluctuations in caregiver stress.

Author Contributions

Sian Saha contributed to study investigation, project administration, data curation and analysis and manuscript writing–original draft. Emily Flowers contributed to project administration, data analysis and writing–original draft. John Rooksby contributed to conceptualisation, data analysis and writing–review and editing. Joan Condell, Faith Matcham, Chee Siang Ang and Alexander J. Casson contributed to conceptulisaton, funding acquisition, data analysis and writing–review and editing. Tony Robinson contributed to data analysis and manuscript writing–review and editing. Louise Rose contributed to conceptualisation, methodology, funding acquisition, data analysis, supervision and writing–review and editing.

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Disclosure

All authors reviewed and approved the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

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

References

1. Office for National Statistics, *Unpaid Care, England and Wales: Census 2021* (London: ONS, 2022).

2. M. Stephanou, “Caregiver Burden: Support Needed for Those Who Support Others and the National Health Service,” *Patient Experience Journal* 10, no. 3 (2023): 23–33, https://doi.org/10.35680/2372-0247.1796.

3. L. Christian, S. Wilson, A. Madison, et al., “Understanding the Health Effects of Caregiving Stress: New Directions in Molecular Aging,” *Ageing Research Reviews* 92 (2023): https://doi.org/10.1016/j.arr.2023.102096.

4. C. Riffin, P. Van Ness, J. Wolff, and T. Fried, “Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers,” *Journal of the American Geriatrics Society* 67, no. 2 (2019): 277–283, https://doi.org/10.1111/jgs.15664.

5. L. Pearlin, J. Mullan, S. Semple, and M. Skaff, “Caregiving and the Stress Process: an Overview of Concepts and Their Measures,” *The Gerontologist* 30, no. 5 (1990): 583–594, https://doi.org/10.1093/geront/30.5.583.

6. Committee on Family Caregiving for Older Adults, *Board on Health Care Services, Health and Medicine Division, National Academies of Sciences, Engineering, and Medicine* (National Academies Press (US), 2016).

7. G. Tatangelo, M. McCabe, A. Macleod, and E. You, “I Just Don’T fFcus on my nNeds Tte uUmet hHalth nNeds of pPrtner and oOfspring cCregivers of pPople with dDmentia: AaqQalitative study,” *International Journal of Nursing Studies* 77 (2018): 8–14, https://doi.org/10.1016/j.ijnurstu.2017.09.011.

8. K. Yaffe, P. Fox, R. Newcomer, et al., “Patient and Caregiver Characteristics and Nursing Home Placement in Patients with Dementia,” *JAMA* 287, no. 16 (2002): 2090–2097, https://doi.org/10.1001/jama.287.16.2090.

9. H. Liu, V. Lou, and S. Xu, “Randomized Controlled Trials on Promoting self-care Behaviors Among Informal Caregivers of Older Patients: a Systematic Review and meta-analysis,” *BMC Geriatrics* 24, no. 1 (2024): 86, https://doi.org/10.1186/s12877-023-04614-6.

10. B. Neale, “Unpaid Carers Are Not Unsung Heroes. We Are Forgotten, Neglected and burnt-out,” *Carers Trust: Inside Rugby* (2023): 1–48.

11. L. Weckesser, F. Dietz, K. Schmidt, J. Grass, C. Kirschbaum, and R. Miller, “The Psychometric Properties and Temporal Dynamics of Subjective Stress, Retrospectively Assessed by Different Informants and Questionnaires, and Hair Cortisol Concentrations,” *Scientific Reports* 9, no. 1 (2019): 098, https://doi.org/10.1038/s41598-018-37526-2.

12. M. Barrero-Mejias, S. Gomez-Martinez, J. Gonzalez-Moreno, M. Rueda-Extremera, E. Izquierdo-Sotorrio, and M. Cantero Garcia, “Effectiveness of Psychological Interventions for Reducing Depressive Symptomatology and Overload and Improving Quality of Life in Informal Caregivers of Non-institutionalized Dependent Elderly: a Systematic Review,” *Frontiers of Medicine* 11 (2024): 1394640, https://doi.org/10.3389/fmed.2024.1394640.

13. A. Schreiner, T. Morimoto, Y. Arai, and S. Zarit, “Assessing Family Caregiver’s Mental Health Using a Statistically Derived cut-off Score for the Zarit Burden Interview,” *Aging & Mental Health* 10, no. 2 (2006): 107–111, https://doi.org/10.1080/13607860500312142.

14. S. Sanghera and J. Coast, “Measuring Quality-Adjusted Life-Years when Health Fluctuates,” *Value in Health* 23, no. 3 (2020): 343–350, https://doi.org/10.1016/j.jval.2019.09.2753.

15. L. Rose, S. Saha, E. Flowers, et al., “Family Caregiver Perspectives on Digital Methods to Measure Stress: Qualitative Descriptive Study,” *Journal of Medical Internet Research* 27 (2025): e66034, https://doi.org/10.2196/66034.

16. A. Tong, P. Sainsbury, and J. Craig, “Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item Checklist for Interviews and Focus Groups,” *International Journal for Quality in Health Care* 19, no. 6 (2007): 349–357, https://doi.org/10.1093/intqhc/mzm042.

17. L. Rose, T. Thaventhiran, and E. Hobson, “Digital peer-to-peer Support Programme for Informal Caregivers of People Living with Motor Neuron Disease: Study Protocol for a multi-centre Parallel Group, single-blinded (Outcome Assessor) Randomised Controlled Superiority Trial,” *Trials* 24, no. 1 (2023): 119, https://doi.org/10.1186/s13063-023-07124-3.

18. K. Malterud, V. Siersma, and A. Guassora, “Sample Size in Qualitative Interview Studies: Guided by Information Power,” *Qualitative Health Research* 26, no. 13 (2016): 1753–1760, https://doi.org/10.1177/1049732315617444.

19. N. Gale, G. Heath, E. Cameron, S. Rashid, and S. Redwood, “Using the Framework Method for the Analysis of Qualitative Data in multidisciplinary Health Research,” *BMC Medical Research Methodology* 13, no. 1 (2013): 117, https://doi.org/10.1186/1471-2288-13-117.

20. V. Richardson, N. Fields, S. Won, et al., “At the Intersection of Culture: Ethnically Diverse Dementia Caregivers’ Service Use,” *Dementia* 18, no. 5 (2019): 1790–1809, https://doi.org/10.1177/1471301217721304.

21. E. Miller and N. Canada, “Linking Employed Caregivers’ Perceptions of Long-Term Community Services with Health Care Legislation,” *Family & Community Health* 35, no. 4 (2012): 345–357, https://doi.org/10.1097/fch.0b013e3182666793.

22. M. I. Broese van Groenou, A. de Boer, and J. Iedema, “Positive and Negative Evaluation of Caregiving Among Three Different Types of Informal Care Relationships,” *European Journal of Ageing* 10, no. 4 (2013): 301–311, https://doi.org/10.1007/s10433-013-0276-6.

23. R. Adelman, L. Tmanova, D. Delgado, S. Dion, and M. Lachs, “Caregiver Burden: a Clinical Review,” *JAMA* 311, no. 10 (2014): 1052–1060, https://doi.org/10.1001/jama.2014.304.

24. S. Kindt, M. Vansteenkiste, T. Loeys, et al., “When is Helping Your Partner with Chronic Pain a Burden? the Relation Between Helping Motivation and Personal and Relational Functioning,” *Pain Medicine* 16, no. 9 (2015): 1732–1744, https://doi.org/10.1111/pme.12766.

25. P. Gérain and E. Zech, “Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving,” *Frontiers in Psychology* 10 (2019): 1748.

26. California Employers Association, “The Remote Work & Caregiving Dilemma” (2023).

27. K. Palmer, K. Walker-Bone, E. Harris, et al., “Health and Employment After Fifty (HEAF): a New Prospective Cohort Study,” *BMC Public Health* 15, no. 1 (2015): 1071, https://doi.org/10.1186/s12889-015-2396-8.

28. Carer’s Leave Act, *UK Public General Acts* (2023).

29. S. Thomas, J. Dalton, M. Harden, A. Eastwood, and G. Parker, “Updated meta-review of Evidence on Support for Carers,” *Health Services and Delivery Research* 5, no. 12 (2017): 1–132, https://doi.org/10.3310/hsdr05120.

30. M. Wasilewski, K. Kokorelias, M. Nonoyama, et al., “The Experience of Family Caregivers of ventilator-assisted Individuals Who Participated in a Pilot Web-based Peer Support Program: a Qualitative Study,” *Digital Health* 8 (2022): 205520762211349, https://doi.org/10.1177/20552076221134964.

31. W. Aamodt, B. Kluger, M. Mirham, et al., “Caregiver Burden in Parkinson Disease: a Scoping Review of the Literature from 2017-2022,” *Journal of Geriatric Psychiatry and Neurology* 37, no. 2 (2024): 96–113, https://doi.org/10.1177/08919887231195219.

32. B. D’Amen, M. Socci, and S. Santini, “Intergenerational Caring: a Systematic Literature Review on Young and Young Adult Caregivers of Older People,” *BMC Geriatrics* 21, no. 1 (2021): 105.

33. Gov.uk, “Benefits and Financial Support if You’Re Caring for Someone” (2024).

34. Gov.uk, “Next Steps to Put People at the Heart of Care” (2023).

35. Carers Uk, “Caring for a Family Member or Someone Else Close to You? 2024” (2024).

36. University Hospital Southampton Nhs Foundation Trust, “Carers Support Service” (2024).

37. H. Choi, M. Reblin, and K. Litzelman, “Conceptualizing Family Caregivers’ Use of Community Support Services: a Scoping Review,” *The Gerontologist* 64, no. 5 (2024): https://doi.org/10.1093/geront/gnad039.

38. S. H. Zarit, K. E. Reever, and J. Bach-Peterson, “Relatives of the Impaired Elderly: Correlates of Feelings of Burden,” *The Gerontologist* 20, no. 6 (1980): 649–655, https://doi.org/10.1093/geront/20.6.649.

39. B. C. Robinson, “Validation of a Caregiver Strain Index,” *Journal of Gerontology* 38, no. 3 (1983): 344–348, https://doi.org/10.1093/geronj/38.3.344.

40. J. Tamm, K. Takano, L. Just, T. Ehring, T. Rosenkranz, and J. Kopf-Beck, “Ecological Momentary Assessment Versus Weekly Questionnaire Assessment of Change in Depression,” *Depression and Anxiety* 2024, no. 1 (2024): https://doi.org/10.1155/2024/9191823.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. *(Supporting Information)*

Supporting Information—Interview guide: Our study interview guide contains all questions asked in each participant interview. The findings from questions 1–4 are reported on this paper and explore participant experiences of being an informal caregiver and the support they receive in this role.