



This is a repository copy of *The experience of working informal carers of older people: a qualitative diary study*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/195710/>

Version: Published Version

Article:

Lam, W.W.Y., Nielsen, K. orcid.org/0000-0001-9685-9570 and Kelly, C.M. (2024) The experience of working informal carers of older people: a qualitative diary study. *International Journal of Care and Caring*, 8 (1). pp. 82-97. ISSN 2397-8821

<https://doi.org/10.1332/239788221X16745596718955>

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>



This article is distributed under the terms of the Creative Commons

Attribution-NonCommercial 4.0 International license

(<http://creativecommons.org/licenses/by-nc/4.0/>).

research article

The experience of working informal carers of older people: a qualitative diary study

Winnie Wing Yee Lam, wylam1@sheffield.ac.uk
Karina Nielsen, k.m.nielsen@sheffield.ac.uk
Ciara M. Kelly, ciara.m.kelly@sheffield.ac.uk
University of Sheffield, UK

This article expands understanding of the experiences of working carers by analysing their care activities and applying cognitive appraisal theory to explore how different resources affect carers' appraisal processes. A total of 18 carers from the UK and Hong Kong took part in a qualitative daily diary study. The contributions of the article include providing a broader conceptualisation of care activities and considering the implications of cognitive appraisals and resources in the experience of combining work and care. The findings provide insights into future research design and support development.

Key words informal care • cognitive appraisal theory • qualitative research • working carers

To cite this article: Lam, W.W.Y., Nielsen, K. and Kelly, C.M. (2024) The experience of working informal carers of older people: a qualitative diary study, *International Journal of Care and Caring*, 8(1): 82–97, DOI: 10.1332/239788221X16745596718955

Introduction

An ageing population has increased the demand for eldercare (Carers UK, 2019). With inadequacies in formal support (Yeandle and Buckner, 2017), eldercare responsibilities have increasingly fallen on the shoulders of 'informal carers' (hereafter, 'carers'), namely, the family and friends of care-receivers. Due to an increase in dual-income households and later retirement ages, informal care is increasingly provided by individuals who are also in paid employment (Colombo et al, 2011; Carers UK, 2019). It is thus important to understand both what care activities they perform and their subjective experience of caring. As Pearlin et al's (1990) caregiver stress model suggests, eldercare demands cause strains in family, employment, financial and social life, creating psychological strain and a likelihood of deterioration in health and well-being.

Informal eldercare

Past debates refer to care as the ability to care about the right things in the right way, with the sensitivity and skills to nurture and protect (Allmark, 1995), while caring activity involves being continuously attentive, responsible, competent and responsive to others (Tronto, 1998). Whitmore et al (2015) found that caring had three features: responsibility (personal and family ties that implied care should be provided); vulnerability (facing stress-inducing incidents and environments, including financial challenges); and mutuality (carers and care-receivers sharing feelings about changes in a care-receiver's health condition and experiences). Eldercare provision can be complex and unpredictable, depending on the health condition of the care-receiver (Burch et al, 2019). A carer engaged in eldercare usually has a close relationship with the care-receiver, who is often a family member or friend (Lam et al, 2022). The way in which working carers engage in eldercare requires independent study, as they provide care arising from personal ties, not to earn income, while their paid employment often prevents them from providing round-the-clock care (Williams et al, 2016).

Studies conducted before 2010 often measured eldercare using a dichotomous measure of the number of hours spent on care (Bramble et al, 2020). Recent studies have explored the operationalisation of eldercare as diversified and tend to involve multiple questions about eldercare, such as the health condition(s) of the care-receiver, their proximity, the number and range of care tasks, and the relationship with the care-receiver (Trukeschitz et al, 2013; Rofcanin et al, 2019; Bramble et al, 2020). Some studies also include subjective measures of eldercare 'burden' or stress (Trukeschitz et al, 2013).

Care activities commonly considered in previous research include: assisting with activities of daily living (ADLs) (for example, feeding, showering and changing); assisting with instrumental activities of daily living (IADLs) (for example, grocery shopping, housekeeping and cooking); and providing emotional support and organising care (Katz et al, 1963; Lawton and Brody, 1969; James, 1992; Hoff et al, 2014). However, working carers who have close ties to care-receivers may go 'above and beyond' ADLs and IADLs, and recent studies have considered a wider range of activities. Bramble and colleagues (2020) measured eldercare activities in terms of personal care, mobility help, errands/chores and finance/medical management in latent eldercare profiles. Research has also identified care activities using a 'course of care' trajectory (Schulz et al, 2020) and as fulfilling the social, financial, medical and emotional needs of care-receivers (Rofcanin et al, 2019). As these examples indicate, care activities can be interactive, supportive and supervisory (Folbre and Wright, 2012), and care provision can be physically and emotionally taxing (Williams et al, 2016). Thus, care is not only about hands-on physical tasks; rather, it may also require cognitive judgement and emotional content (James, 1992; Allmark, 1995; Fine, 2015).

There seems to be no consensus on what counts as care regarding the activities carers engage in to support older people, and (to the best of our knowledge) there are no systematic categorisations of the emotional support and managerial aspects of care. Some activities may not have been considered as care, such as visiting the theatre or going on holiday with the care-receiver to enhance their well-being and enrich their life. Furthermore, patterns of caring and carers' decision making are affected by welfare systems and cultural phenomena (Fine, 2015). For example, some cultures place a strong emphasis on family and taking care of older family members (Laidlaw et al, 2010), while the level of support offered to older people differs between countries (Starr and Szebehely, 2017).

Societal and cultural factors may thus add to the lack of consensus on how to define informal eldercare activities. These inconsistencies may also help to explain why many individuals providing care do not self-identify as carers. Further ambiguity comes from the potential for some people to self-identify as carers even though they do not carry out care activities as per narrow definitions of a carer used in the literature (AARP, 2001). This ambiguity hinders carers' ability to seek help and to deliver care (O'Connor, 2007), and may cause the misallocation of support and public resources.

It is therefore important to understand what day-to-day eldercare entails for this growing group of carers and to build a foundation for a more inclusive measurement of eldercare. To address this, we identified three research questions. The first such question is: 'What eldercare activities do carers report performing over a two-week period?'

The experience and meaning of eldercare provision are different for each carer, especially considering the variety of care activities carers perform. In the context of care, carers' well-being is somewhat dependent on care-receivers' health and well-being (Kittay, 2011). Despite the pressures of juggling care and employment (Calvano, 2013; Yeandle et al, 2017), carers of older people have reported both positive and negative emotions regarding their care experiences (Bourke et al, 2010). Caring for loved ones, for example, also means spending time with them and engaging in positive social interactions. This resonates with the mutuality in care mentioned by Whitmore and colleagues (2015). Eldercare provision may thus not always involve stress or strain for carers, and for many carers, it has positive aspects. In the present study, we explore the reasons behind positive and negative appraisals of care experience.

The extent to which carers experience caring activities as positive or negative is influenced by both context and by individuals' own appraisal of the situation. According to cognitive appraisal theory (Folkman et al, 1986), when individuals are confronted with an event, they may appraise it as a threat, as positive or as irrelevant. Similarly, when working carers confront eldercare activities (and have experienced these), whether they perceive these as negative, positive or neutral (their subjective experience) may vary, both between individuals and at different times for the same individual. We formulated our second research question to explore the cognitive processes of working carers: 'How do carers appraise their experiences in eldercare provision?'

Individuals reappraise potentially stressful situations by considering how well they can manage them, for example, by considering what resources are available to help them. Resources are anything perceived by individuals as helping them to attain their goals (Halbesleben et al, 2014). Thus, carers may consider both the situation(s) they face and the resources available to them when appraising if they can take on eldercare tasks. Resources identified in past reviews have included: public or community resources (for example, support services and financial compensation); family-friendly work policies; friends and family (Burch et al, 2019); and individual resources, such as their own good health and well-being (Lam et al, 2022). If carers perceive that they are unable to cope, stress is the likely outcome, leading to our third research question: 'What factors may have contributed to carers' appraisal of the situation?'

We wanted to investigate the daily life of working carers of older people by documenting the actions and processes of eldercare without relying on participants' retrospective memories. A daily diary study offers a unique opportunity to capture previously undocumented care activities, particularly those undertaken within the context of carers balancing caring with paid employment, and carers' thoughts on their caring experiences during the study period. We chose to include carers from the

UK and Hong Kong because these countries have a similar (somewhat limited) level of public support for eldercare, which creates expectations that carers will undertake caring responsibilities (Starr and Szebehely, 2017). These contexts are similar enough to be studied together. Hong Kong was a British colony until 1997, and both regions have liberal residual welfare states that provide limited state support for care (Esping-Andersen, 1990; Sawada, 2004; Flynn and Schröder, 2021). The two countries differ in terms of their culture. Hong Kong is a mainly Chinese society with an emphasis on care for elders that originates in Confucianism (Yeh et al, 2013), and Chinese immigrants (76 per cent from Hong Kong) living in the UK have been found to emphasise filial piety more than their British counterparts (Laidlaw et al, 2010). Rather than comparing the experiences of the UK and Hong Kong carers, we hope to add depth to our understanding of carer experiences within the context of a liberal/residual welfare state by including data from both the UK and Hong Kong. This study aims to explore the experience of working carers through the lens of cognitive appraisal theory. We aim to provide insights into the experiences and appraisals of carers, and suggest a rethink of the current definition of informal care in various support systems and fields of research.

Methods

The present study used a qualitative diary study design. The sample consisted of 18 working carers of older people in Hong Kong ($n = 11$) and the UK ($n = 7$). The data collection mainly took place in 2019 (one participant, HK_L [see Table 1], participated in March 2020, when Hong Kong was still unscathed by COVID-19). Inclusion criteria for participation in the study were: (1) being a carer providing care for at least one older person aged 55 or older who is experiencing problems related to old age; and (2) being in paid employment, either part-time or full-time.

Study participants were invited to write, or to provide audio recordings of, their daily diary describing their experiences of work and care for two consecutive weeks. They were provided with prompts for their diary entries, for example: 'Please describe how long you have spent on caring today'; 'What type of caring tasks did you do today?'; 'How did you juggle the tasks of work and family care (especially eldercare) today?'; and 'What do you think has helped, or could have helped, you to handle both work and care responsibilities?' These prompts and a diary were provided; answers were not required for any prompt, as there may have been nothing to record that day or other things participants thought important to mention. We wanted participants to have complete freedom in deciding what to record.

Participants were recruited via social media posts, posters and personal and extended contacts. Multiple recruitment methods were used, as the study required a substantial time commitment and thus a broad range of potential participants needed to be reached during recruitment. A small financial reward was offered for participation (GBP10/HKD100). Participants returned their completed diaries directly to the researcher, either in hand-written format or as soft copies.

Demographic information on study participants and their care-receivers is shown in Table 1. English entries were transcribed and Chinese entries translated into English. Two participants provided diary entries that did not follow the standard daily diary format. HK_I provided a diary for weekends and a summary of workdays, as he felt workdays followed a routine amenable to such a summarised format. Participant

Table 1: Characteristics of the participants and the person(s) they cared for

Code (no. of completed daily diary entries)	Carers' gender, age	Family and occupational information	Care-receivers' relationship to the carer, age	Health conditions of care-receivers and care context
UK (94)				
UK_A (14)	F, 57	N/A, with two adult children, full-time nurse	Mother, 82	Had falls and moved in with the carer for a period
UK_B (13)	F, 56	Married with two children in 20s, working in non-governmental organisation	Father, 85 Mother, 76	Had two knee replacements, takes medication for blood pressure Takes medication for blood pressure
UK_C (14)	F, 52	Single,* with three children aged 17–22, one has disabilities, school lab technician	Mother, 85	Mobility issues, diabetes and high blood pressure
UK_D (10)	M, 31	N/A, lecturer	Grandfather, 96	Has dementia
UK_E (15)	F, 55	Single,* charity shop manager	Father, 78	Has problems with dizziness, vision, hearing and shoulders
UK_F (14)	F, 69,	Married, with two adult children, part-time school cleaner	Mother, 94	Has diabetes
UK_G (14)	F, 51	Married with two children aged 17 and 20, part-time podiatrist	Mother, 76	Recent knee-replacement surgery
Hong Kong (130)				
HK_A (28)	F, 29	Single,* nurse	Mother, 65	N/A
HK_B (14)	F, 30	Single,* office worker	Mother, 64 Father, 68	N/A Has chronic intestinal illness
HK_C (13)	F, 39	Single,* one son, administration	Mother, 70	N/A
HK_D (14)	F, 57	Married, with two adult children, paediatrician	Father, 80+	N/A
HK_E (14)	F, 41	N/A, merchandiser	Mother, N/A	Has chronic intestinal illness
HK_F (13)	M, 47	N/A, accountant	Father, N/A	Has mobility issues
HK_G (17)	F, 46	Single,* with two adult children, tunnel toll collector and part-time waitress	Mother, 70	Has dementia
HK_H (14)	F, 54	Married, two adult children and one teenage child, civil servant	Mother, 92	Needs to do regular dialysis
HK_I (3)	M, 31	Single,* property management	Girlfriend's grandma, 80+	N/A
HK_J (14)	F, 57	Married with two adult children, finance manager	Mother, 82	Daughter moved in temporarily while the full-time paid carer was on holiday
HK_K (13)	F, 30	Single,* assistant retail project manager	Grandma, 90	Has dementia
HK_L (13)	F, 29	Single,* assistant retail store manager	Aunt, 56	Has dementia, temporarily moved in with participant's family

Notes: * Divorced and widowed are included in single; N/A = not applicable/not stated.

UK_D provided summaries of specific periods within the four months prior to the data collection, as these periods were characterised by high levels of caring duties and could be recalled with detail, assisted by digital records like calendars and text messages. As the data provided in the two retrospective diaries were helpful in addressing the research aim, they were included in the analysis.

Data organisation and analysis were conducted using NVivo 12. We conducted thematic analysis following the six steps outlined in Braun and Clarke (2006). We familiarised ourselves with the data and generated initial codes from the data before searching for themes. Each care activity was coded according to its action, such as ‘preparing food’. These activities were then mapped against existing caring categories (ADLs and IADLs), and those remaining were grouped into new themes based on their similarities. We reviewed, defined and discussed the new themes before naming them, agreeing on ‘social and emotional support activities’ (SESAs) and ‘life administration activities’ (LAAs). We discussed the naming options of ‘life enrichment activities’ (LEAs) and ‘quality of life activities’ and decided on LEAs, which we believed was less open to multiple interpretations and better represented the activities we grouped under that theme.

Findings

Care activities

The first research question aimed to explore what eldercare activities carers reported performing. The diaries revealed that eldercare involved a wide range of tasks, including, but not limited to, assisting with ADLs and IADLs. Carers also performed LAAs, SESAs and LEAs. The following sections describe each type of activity (the numbers in brackets after each activity indicate how many participants reported performing the activity).

ADLs

Participants (especially those caring for someone with high dependence due to old age or health conditions, such as dementia) reported assisting their care-receivers with ADLs (for instance, assisting with toilet visits [1], helping with personal hygiene [5], assisting with movement [4] and dressing [1]). Most participants reported assisting care-receivers to perform ADLs, rather than performing these fully for them. HK_E reported that she “prepared tooth brushing and face washing things, then tidied up clothes and medicines”, but said that she did not have to brush her mother’s teeth. In examples where the carer carried out ADLs for the care-receiver, it was unusual for them to do so. For example, on one day, HK_F assisted his father to have a bath – “[I] prepared hot water, soap and [a] support-chair for him [dad]. After that, I needed to dry him using the towel” – but indicated that there was usually a paid foreign domestic helper to take care of his father.

IADLs

Help with IADLs (for example, shopping [13], food preparation [11], preparation of and assistance with taking medications [3], housework [9], transport [3], assisting in making phone calls or with other technology [3], and managing bills and finances [4]), was frequently provided by the participants. For example, UK_F checked her mother’s insulin levels and administered insulin injections. Carers saw helping with IADLs as necessary due to the older care-receivers’ health, which meant that they could not perform certain activities unaided.

Carers also reported providing support beyond the basic requirements needed to complete IADLs. When shopping, for example, carers described investing additional effort and thought into the older person's preferences and needs. HK_I described food shopping for his girlfriend's grandmother: "Every Saturday morning, I will purchase bread for Grandma ... the bread is bought from a specific bread shop nearby, since the size of the bread is bigger, softer and looser. ... And it is very good for elderly people to eat."

LAAAs

Carers also performed LAAAs to maintain a smooth life operation for care-receivers. The main difference between LAAAs and assisting with IADLs was that LAAAs were typically performed 'in the background' (similar to the 'back office' function within a business), whereas assisting with IADLs was more like working on the shop floor. LAAAs involve cognitive skills, such as coordination, negotiation, communication, identifying needs, monitoring and researching. Examples include private or public care management (2), coordination and communication with other family members about care arrangements (3), research for information (1), applications for welfare payments (1), arranging medical appointments (2), negotiations with care-receivers (2) and the supervision or surveillance of care-receivers (5).

UK_E provided an example of coordination and communication with family members during the care of his grandfather and the National Health Service (NHS): "Phone calls, emails with family – Grandad moved hospital, had to keep getting update checking progress"; and "Phone conversation with other family members, trying to chase up [the] setting up [of] NHS in-house visits." HK_J was involved in the management of a paid care worker, which involved deciding what the worker should do and how certain tasks should be carried out: "I bought some tools for the helper to work more efficiently. I also told her about how to clean the foot of the chair, how to clean CDs and the CD player." HK_H provided an example of a negotiation with the care-receiver:

'I rang my mum to check how she felt, she said she is a lot better and does not need to see a doctor. But I [tried to] convince her to check up. She refused. She said she has an appointment with the kidney department Dr T, so she does not have to go today. I said I will pay for her dim-sum but she still refused. So, up to her then.'

Other examples of LAAAs included: supervision, surveillance and monitoring of care-receivers (4) (including reminding care-receivers of things to be done, such as attending a medical appointment, and activities to be avoided [not going out alone]); monitoring care-receivers' health and behaviour (2) (for example, diet management); and identifying safety needs (2) (such as setting up the railing on a medical bed and checking if a safety alarm should be installed). Since HK_E needed to attend her work despite her mother's dementia, she set up CCTV at home to be able to monitor her mother's activities remotely. Future-focused monitoring (2), where a carer proactively anticipates and scans the environment for potential problems for the care-receiver, frequently occurs in the background. This was reflected in participants' thoughts, rather than described as actions in their diaries, such as when HK_J wrote about what constitutes good care: "Pay attention to the health of the elderly. ... Sometimes when people get old, they

can't be bothered to move, don't think that it is a huge problem, or even are not aware that they can get vaccinations. Carers need to be proactive in bringing them to doctors."

SESAs

Carers also reported providing social and emotional support to care-receivers. Carers often have a close personal relationship with the care-receiver, making SESAs important, as they help maintain the quality of interpersonal interactions and the mental well-being of care-receivers. These activities, which included providing company, having a chat and checking how the care-receiver was doing remotely by text message or phone calls, were performed by almost every participant; the emotional side of these activities included providing comfort and reassurance (3). HK_L reported that her aunt with dementia sobbed in the morning, so emotional labour (James, 1992) was involved as she managed her own emotions while comforting her aunt: "I smiled because I knew she did not intend to annoy anyone. She just can't control it. So, all I had to do is to ask her to remember that soon she can meet her family, she has to be patient." There were times when the SESAs comprised a two-way engagement that benefited both parties, whereby the carer also enjoyed socialising with the care-receiver: "After work, I rushed back to have afternoon tea with mum, my friend joined us as well. Today I am happy and contented. Mum knows my friend too, so we can eat and share what happened together" (HK_A).

LEAs

Carers organised activities to improve care-receivers' enjoyment of life and to provide what they believed was important for them, including holidays (3), family gatherings (9), leisure activities (2) and wellness or beauty activities (2) (for example, hair styling or massage). These were grouped within the theme of LEAs. We distinguished LEAs from SESAs and LAAs because these were activities organised mostly to create good times and memories for the care-receivers, and were not directly related to, or essential for, maintaining their everyday physical and mental well-being. As HK_E mentioned: "I arranged a holiday 3–4 times each year ... hoping that she [mum] can go to more places while she can still walk." UK_A quite often planned activities with her mother. Together, they watched a dance rehearsal, went to a film club and attended a film festival, in addition to some smaller outdoor times when she went with her mother during two weeks, saying that she "felt it's important to take my mum out for a little while most days".

Carers took many issues into consideration when planning and conducting these activities, for example, assessing the adequacy or wheelchair-friendly facilities of the venue or destination (UK_A) and being aware of the needs of the care-receivers, such as visiting toilets or taking medication (HK_E). Although the carer and care-receiver enjoyed the activities together, the carer had to make additional effort to ensure the needs of the care-receiver were met when organising or engaging in these activities.

How carers appraise their care and situations

The second research question aimed to investigate how carers appraised their experiences. The findings revealed differences in how study participants appraised providing eldercare and related events.

One participant perceived it positively, referring to it as a type of “mutual support” (UK_E) with her father; this involved social and emotional support for her at work, as well as instrumental support, when her father helped her out at work to cover her toilet break. The mutuality between carer and care-receiver was also echoed by HK_E, who said: “Mum was happy, so I was happy too.”

Some participants expressed more neutral feelings about providing eldercare, for example, referring to it as “the responsibility of children!” that should not be viewed as a burden (HK_E), or as a stage in life: “We needed to study hard when we were little, we worked hard when we were young, then had children and cared for children. When children are grown up, we then need to care for the elderly. When the elderly die, I am old already” (HK_J). There were no set patterns in the participants’ daily interactions with care-receivers regarding how they appraised their experiences. It is unsurprising that participants wrote that they spent enjoyable and relaxing moments with care-receivers, while other interactions were appraised quite differently by different carers. UK_C, speaking about checking the boiler for her mother, reported feeling “emotionally burdened”, as she had “so many other things to deal with alone, job, bills, disabled son, etc., and I often feel stressed when I have to deal with things like this situation, as it often feels like ‘learned incompetence’ on her part”. Other participants did not appraise similar activities negatively, however.

Participants also perceived differently potentially stressful moments, such as conflicts related to care provision. HK_H interpreted her mother shouting at her on the phone as an indicator that her mother was healthy, and she felt relaxed and happy about it. However, HK_J mentioned growing angry when her grandmother made multiple requests when she really wanted to watch the news. How carers appraise and react to their situations or experiences seems to be affected by personal factors (for example, optimism) and contextual factors (for example, the carer’s priority at that moment). This leads us to the next research question regarding what may explain different reactions in similar situations.

Factors affecting appraisals

The third research question asked what factors may contribute to carers’ appraisal of their situation. The following example illustrates how carers’ care-related knowledge influenced how they appraised their situation and thus changed their response. When interacting with her aunt with dementia, HK_L reported frustrations but often managed to control her emotions, remaining patient towards her aunt, in addition to addressing and easing any tensions between her aunt and other family members because she knew that this was how someone with memory issues would behave. Her family members, on the other hand, seemed to have inadequate understanding and argued with her aunt over matters, as if she could follow conversations. Her ability to remain compassionate and patient was not sustainable every day, however. In one diary entry, she reported being bad-tempered and less compassionate towards her aunt, and attributed this to a lack of sleep. She described the situation as “insane” (negative appraisal) because she had to repeatedly do and say the same thing to her aunt, while the day before, when she had had plenty of sleep, in a similar situation, she had managed to make light of it. Here, the well-being of the carer affected both her appraisal of, and her response to, the situation.

The circumstances of carers and care-receivers affected how the former appraised their care experiences. For example, UK_C cared for both her son with disabilities and her mother, with limited financial resources, even though her mother was “financially comfortable”: “Mum refuses to buy in ready meals ... as they are ‘too expensive’ – she gets her meals free from me instead, which also places financial pressure on me.” This also suggests that the carer felt burdened (negative appraisal) when facing requests from her mother because of her own limited resources to provide care, in terms of both finances and personal capacity.

Participants tended to appraise their care experiences as less negative (for example, less as a burden or less worrisome) when other support was available. In some cases, neighbours performed certain IADLs, such as ironing or shopping, and SESAs (UK_G and HK_C), as they lived near the care-receiver. In other cases, friends of care-receivers living at a distance were able to perform SESAs by telephone to keep the care-receiver socially connected (UK_A). UK_A also found that her son’s dog helped by providing company for her mother while she was at work, enabling her to worry less about her. The presence of others was not always experienced as a support, and working with others to provide care was not always experienced as pleasant. HK_H, for example, reported a minor conflict over a Mother’s Day celebration when her brother arrived much earlier than expected and made her rush to the place of the celebration with her mother.

Paid help relieved some carers from performing hands-on tasks and allowed them to focus on the SESAs, LAAs and LEAs, affecting how they appraised the remaining hands-on tasks they performed. HK_F, whose father had paid help, took his father out for exercise (LEA), had a chat (SESA), anticipated or promptly responded to other health and safety needs (LAAs), and was able to enjoy (positive appraisal) helping his father with personal hygiene (ADL). HK_H also mentioned that her brother had hired a full-time paid carer for their mother, and she seemed to do food shopping and cooking (IADLs) for her mother’s happiness, rather than out of necessity (saying that although she did not enjoy visiting the wet market, the resulting happiness of her mother justified the inconvenience).

Participants in the UK mentioned a lack of reliable paid care providers and the limitations of care services (UK_A and UK_G); participants in Hong Kong were more likely to have full-time paid help at home, as the policy there allowed people to obtain low-cost foreign paid help. HK_K, for example, said that she did not need to assist with ADLs and IADLs during workdays because her relative had assistance from paid carers.

Discussion

This study aimed to enhance understanding of the caring experiences of working carers of older people. First, we explored the care activities they performed. Our findings demonstrate the variety of activities working carers undertake to support care-receivers and to ensure their lives function well, with well-being maintained and enhanced life experiences. The study has highlighted and illuminated care activities beyond assisting with ADLs and IADLs, and provides further understanding of the wide range of activities working carers perform, including SESAs, LAAs and LEAs, which were categorised (and echoed with) those identified in previous studies (James, 1992; Hoff et al, 2014; Bramble et al, 2020).

Folbre and Wright (2012) found that care activities could be interactive, supportive or supervisory; our findings support that and provide further categorisations for such activities.

Carers performed activities that required particular mental and cognitive effort due to their personal ties with the care-receivers. Our analysis reveals that carers paid careful attention to the preferences and needs of those they supported, and shows that identifying and meeting these needs required cognitive effort. SESAs, LAAs and LEAs (in particular) represent the mental and cognitive side of care, which includes comforting, researching, using management skills, identifying needs and planning for the future. Importantly, carers also engaged in emotional labour by controlling their own emotions and providing emotional support (James, 1992). Some of these activities are easily observed (for example, negotiating with different parties); others occurred in the background (for example, future-focused monitoring and anticipating needs). Such attentive, sometimes round-the-clock, monitoring shows the role played by personal relationships in caring. These findings highlight the need for recognition of the mental work involved in family care (Robertson et al, 2019) and contribute to better understanding of the emotional complexity of eldercare. This ongoing observable and background mental and cognitive load on carers in performing care activities needs to be acknowledged by practitioners, policymakers and researchers.

Often, past studies have not taken into account the established relationships (often as family members) that carers have with care-receivers. These ties are likely to affect the personalisation of the care that carers invest in; how they perform their caring activities also reflects the level of concern they feel for the well-being of the care-receiver (Folbre and Wright, 2012) and the expectations of care-receivers and other family members. Carers are also likely to have long-term and in-depth knowledge of care-receivers' preferences, which paid carer workers may lack the opportunity to acquire. These close personal ties may create a sense of obligation or reasons to provide good care, and lead to additional investment in activities designed to meet the socio-emotional needs of care-receivers (SESAs) and provide richness and enjoyment in their lives (LEAs). In most situations, family members are the only carers able to perform LAAs, such as legally representing the care-receiver and maintaining communication among their network of carers, potentially stressful tasks linked to the vulnerabilities inherent in care (Whitmore et al, 2015).

Given the variety and depth of care that carers provide, knowing how they appraise their care experiences is important, as what one appraises as negative may be viewed differently by others. Our data suggest that study participants appraised their care experiences differently. These findings are in line with previous research which suggested that carers have positive and negative care experiences (Bourke et al, 2010; Hoff et al, 2014), and with Zarit et al's (1980) work, which found that the extent to which carers feel burdened depends on their feelings about aspects of care, such as their health, psychological well-being, finances, social life and relationship with the care-receiver. In this study, we chose not only to explore care as a burden, but also to consider carers' positive experiences in providing care, hoping to offer a holistic picture of the support carers provide. Future studies should also consider both the positive and negative aspects of eldercare experience as antecedents to various outcomes.

Cognitive appraisal theory suggests that carers' appraisals of their experience vary and may be influenced by individual and contextual factors. Our findings suggest that caring circumstances (for example, being a 'sandwich carer'), financial situations, the

availability of other help, caregiving knowledge and the carer's situation and well-being can influence how they appraise their caring experiences. We have contributed to the literature by bringing a focus on carers' appraisals of their experiences into the research realm, extending our analysis beyond a focus on caring burden/stress. While we do not propose a new model in this article, we hope to contribute to further development of theories and models, such as the caregivers' stress process model proposed by Pearlin et al (1990), by adding a focus on how carers appraise their experiences and considering what may influence this and how it affects carers' well-being. We also suggest that resources may buffer the relationship between care and well-being by affecting appraisals in ways that previous models may not have considered.

Our data offer perspectives from the UK and Hong Kong. Participants in Hong Kong were more likely to hire paid help than those in the UK due to the availability of low-cost migrant labour in Hong Kong. This illustrates how, under such a labour policy, carers with financial resources may cope with caring responsibilities. When 'hands-on' activities were mainly outsourced and carried out as an option or performed less frequently by carers, they may be viewed less as a burden and more as an enjoyable activity. This also allowed them to focus more on LAAs, SESAs and LEAs, which are not easily performed by paid care workers. This finding highlights the variety of the profile of activities that carers engage in, depending on their financial status, government policy or service availability, and further highlights the importance of a comprehensive view of care activities.

Practical implications

We demonstrate that the range of activities required for eldercare is broader than previously acknowledged and provide a categorisation of these activities according to their function. The categorisation may help to produce policy and direct support towards carers by more accurately identifying who is providing care and by helping carers to identify as carers, enabling them to reach out for support before their responsibilities negatively affect their paid work, care quality or personal well-being. Future policy and interventions should consider supporting carers with different aspects (for example, availability of help, financial support, caregiving knowledge and training, and supporting their well-being) to make care more likely to be appraised positively and thus to improve carers' well-being, as well as potentially the experience of care-receivers.

Strengths and limitations

Our study unveils aspects of the everyday lives of working carers of older people and their thoughts about caring by obtaining detailed qualitative data from the participants. To the best of our knowledge, this is the first study to adopt a qualitative diary method to gather insights into the daily care activities carers engage in. The diary study design provided in-depth and invaluable insights into carers' care activities in their daily lives. Our findings contribute to understanding of what it is to provide care by highlighting activities performed in the context of informal care. While the care outlined by our participants displays some overlaps with previous classifications of care, using the diary method, we were able to tease out important additions and nuances in the delivery of care provided by working carers.

For each type of care activity, we provide a definition and examples, moving the comprehensiveness of the definition of eldercare activities forward beyond current operative definitions and measurement. To date, research studies have focused on identifying carers by asking if they provide personal and household care to older people (Griggs et al, 2020), despite the recent movement to measure eldercare in a more multidimensional way (Burch et al, 2019). We collected data from two countries, capturing care activities not limited to one cultural context. This provides a better foundation for developing criteria to identify carers and for measuring eldercare demand in future studies. We also apply cognitive appraisal theory, which is grounded in psychology, to explain our data, provide explanations relevant to current knowledge and make suggestions for future research.

This study is not without limitations. First, the small sample means that our findings should not be interpreted as an attempt to develop an exhaustive list of activities performed by working carers of older people. However, it enables the development of a broader understanding of the types of activities carers engage in, which have been under-researched in the literature, and deepens understanding of the experience of working carers. We acknowledge that our participants reported few examples of physically demanding care (such as lifting someone unable to move). Moreover, there could be a self-selection bias in the study, in that the working carers providing the most intensive care may have lacked time to participate. Carers caring for older people with very low independence, and who had no one else sharing their responsibilities, may have left the labour market to meet their care demands, and were thus not part of the target sample for this study, even though they had to manage both paid work and eldercare at some point in their lives. Other aspects of care, such as conflict resolution, making judgements and the power relations between carers and care-receivers (for example, how to prioritise and resolve multiple conflicting needs of the care-receiver, and changes in the caring role at different stages of life that change power relations) (Tronto, 1998), may also induce stress and consume emotional and cognitive resources. These were beyond the scope of this article, but we encourage future research in these areas.

Future directions

To offer the most appropriate support to working carers, society first has to be more inclusive in its definition of care by acknowledging the multidimensional work that carers perform. Further work is required to reconsider current ways of identifying carers and to be more inclusive and comprehensive in identifying and measuring eldercare. Future research should also consider how appraisals of caring experience vary among individuals, depending on various personal and contextual factors. Thus, subjective measurements of eldercare provision, alongside objective ones, may be needed to capture eldercare demands effectively.

Conclusions

This study provides detailed information on the multidimensional nature of observable and non-observable care activities that working carers of older people undertake daily. Their experience of caring was also analysed using the cognitive appraisal framework. The study's contributions are threefold. First, we provide categorisations, definitions and examples of care activities that may have been overlooked in previous studies.

Second, our findings highlight the mental and cognitive load of care activities, some of which may be implicit and difficult to observe, laying a foundation for further work and the reconsideration of the inclusivity of the current measurement and definition of care activities. Finally, we provide evidence that individual and contextual factors can change how carers appraise their care experiences, and propose possible aspects for theoretical and intervention developments.

Conflict of interest

The authors declare that there is no conflict of interest.

References

- AARP (2001) AARP caregiver identification study, February: 1–36, <http://assets.aarp.org/rgcenter/post-import/caregiver.pdf>.
- Allmark, P. (1995) Can there be an ethics of care?, *Journal of Medical Ethics*, 21(1): 19–24, doi: [10.1136/jme.21.1.19](https://doi.org/10.1136/jme.21.1.19).
- Bourke, J., Pajo, K. and Lewis, K. (2010) Elder care and work–life balance: exploring the experiences of female small business owners' elder care and Self-employment, *New Zealand Journal of Employment Relations*, 35(1): 17–34.
- Bramble, R.J., Duerk, E.K. and Baltes, B.B. (2020) Finding the nuance in eldercare measurement: latent profiles of eldercare characteristics, *Journal of Business and Psychology*, 35(1): 29–43, doi: [10.1007/s10869-019-09616-z](https://doi.org/10.1007/s10869-019-09616-z).
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2): 77–101, doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa).
- Burch, K.A., Dugan, A.G. and Barnes–Farrell, J.L. (2019) Understanding what eldercare means for employees and organizations: a review and recommendations for future research, *Work, Aging and Retirement*, 5(1): 44–72, doi: [10.1093/workar/way011](https://doi.org/10.1093/workar/way011).
- Calvano, L. (2013) Tug of war: caring for our elders while remaining productive at work, *Academy of Management Perspectives*, 27(3): 204–18, doi: [10.5465/amp.2012.0095](https://doi.org/10.5465/amp.2012.0095).
- Carers UK (2019) *Juggling Work and Unpaid Care*, London: Carers UK, https://www.employersforcarers.org/resources/research/item/download/295_3561d87e6087f030a00bfb2ea24cbe73.
- Colombo, F., Llena–Nozal, A., Mercier, J. and Tjadens, F. (2011) *Help Wanted? Providing and Paying for Long-Term Care*, *OECD Health Policy Studies*, Paris: OECD Publishing.
- Esping-Andersen, G. (1990) *The Three Worlds of Welfare Capitalism*, Cambridge: Polity Press.
- Fine, M. (2015) Cultures of care, *Routledge Handbook of Cultural Gerontology*, December: 269–76, doi: [10.1002/9780470774694.ch21](https://doi.org/10.1002/9780470774694.ch21).
- Flynn, M. and Schröder, H. (2021) Age, work and pensions in the United Kingdom and Hong Kong: an institutional perspective, *Economic and Industrial Democracy*, 42(2): 248–68, doi: [10.1177/0143831X18763542](https://doi.org/10.1177/0143831X18763542).
- Folbre, N. and Wright, E.O. (2012) Defining care, in N. Folbre (ed) *For Love or Money: Care Provision in the United States*, New York: Russell Sage Foundation, pp 1–20.
- Folkman, S., Lazarus, R., Dunkel-Schetter, C., DeLongis, A. and Gruen, R.J. (1986) Dynamics of a stressful encounter: cognitive appraisal, coping and encounter outcomes, *Journal of Personality and Social Psychology*, 50(5): 992–1003, doi: [10.2135/cropsci1977.0011183x001700060012x](https://doi.org/10.2135/cropsci1977.0011183x001700060012x).

- Griggs, T.L., Lance, C., Thrasher, G., Barnes-Farrell, J. and Baltes, B. (2020) Eldercare and the psychology of work behavior in the twenty-first century, *Journal of Business and Psychology*, 35(1): 1–8, doi: [10.1007/s10869-019-09630-1](https://doi.org/10.1007/s10869-019-09630-1).
- Halbesleben, J.R.B., Neveu, J., Paustian-Underdahl, S.C. and Westman, M. (2014) Getting to the ‘COR’: understanding the role of resources in conservation of resources theory, *Journal of Management*, 40(5): 1334–64, doi: [10.1177/0149206314527130](https://doi.org/10.1177/0149206314527130).
- Hoff, A., Reichert, M., Hamblin, K.A., Perek-Bialas, J. and Principi, A. (2014) Informal and formal reconciliation strategies of older people’s working carers: the European carers @ work project, *Vulnerable Groups & Inclusion*, 5(1): 24264, doi: [10.3402/vgi.v5.24264](https://doi.org/10.3402/vgi.v5.24264).
- James, N. (1992) Care = organisation + physical labour + emotional labour, *Sociology of Health & Illness*, 14(4): 488–509, doi: [10.1111/1467-9566.ep10493127](https://doi.org/10.1111/1467-9566.ep10493127).
- Katz, S., Ford, A.B., Moskowitz, R. W., Jackson, B.A. and Jaffe, M. W. (1963) The index of ADL: a standardized measure of biological and psychosocial function, *Journal of the American Medical Association*, 185: 914–8, doi: [10.1001/jama.1963.03060120024016](https://doi.org/10.1001/jama.1963.03060120024016)
- Kittay, E. (2011) The ethics of care, dependence and disability, *Ratio Juris*, 24(1): 49–58. doi: [10.1111/j.1467-9337.2010.00473.x](https://doi.org/10.1111/j.1467-9337.2010.00473.x)
- Laidlaw, K., Wang, D., Coelho, C. and Power, M. (2010) Attitudes to ageing and expectations for filial piety across Chinese and British cultures: a pilot exploratory evaluation, *Ageing and Mental Health*, 4(3): 283–92, doi: [10.1080/13607860903483060](https://doi.org/10.1080/13607860903483060).
- Lam, W.W.Y., Nielsen, K., Sprigg, C.A. and Kelly, C.A. (2022) The demands and resources of working informal caregivers of older people: a systematic review, *Work and Stress*, 36(1): 105–27, doi: [10.1080/02678373.2022.2028317](https://doi.org/10.1080/02678373.2022.2028317).
- Lawton, M.P. and Brody, E.M. (1969) Assessment of older people: self-maintaining and instrumental activities of daily living, *Gerontologist*, 9(3P1): 179–86, doi: [10.1093/geront/9.3_Part_1.179](https://doi.org/10.1093/geront/9.3_Part_1.179).
- O’Connor, D.L. (2007) Self-identifying as a caregiver: exploring the positioning process, *Journal of Aging Studies*, 21(2): 165–74, doi: [10.1016/j.jaging.2006.06.002](https://doi.org/10.1016/j.jaging.2006.06.002).
- Pearlin, L.I., Mullan, J.T., Semple, S.J. and Skaff, N.M. (1990) Caregiving and the stress process: an overview of concepts and their measures, *The Gerontologist*, 30(5): 583–94, doi: [0.1093/geront/30.5.583](https://doi.org/10.1093/geront/30.5.583).
- Robertson, L.G., Anderson, T.L., Hall, M.E.L. and Kim, C.L. (2019) Mothers and mental labor: a phenomenological focus group study of family-related thinking work, *Psychology of Women Quarterly*, 43(2): 184–200, doi: [10.1177/0361684319825581](https://doi.org/10.1177/0361684319825581).
- Rofcanin, Y., Heras, M.L., Escribano, P.I. and Stanko, T. (2019) FSSBs and elderly care: exploring the role of organizational context on employees’ overall health and work–family balance satisfaction, *Journal of Business and Psychology*, 35: 403–19, doi: [10.1007/s10869-019-09629-8](https://doi.org/10.1007/s10869-019-09629-8).
- Sawada, Y. (2004) The social security system in Hong Kong: establishment and readjustment of the liberal welfare model, *The Developing Economics*, 42(2): 198–216, doi: [10.1111/j.1746-1049.2004.tb01063.x](https://doi.org/10.1111/j.1746-1049.2004.tb01063.x).
- Schulz, R., Beach, S.R., Czaja, S.J., Martire, L.M. and Monin, J.K. (2020) Family caregiving for older adults, *Annual Review of Psychology*, 71: 635–59, doi: [10.1146/annurev-psych-010419-050754](https://doi.org/10.1146/annurev-psych-010419-050754).
- Starr, M. and Szebehely, M. (2017) Working longer, caring harder – the impact of ‘Ageing-in-Place’ policies on working carers in the UK and Sweden, *International Journal of Care and Caring*, 1(1): 115–9, doi: [10.1332/239788217X14866307026424](https://doi.org/10.1332/239788217X14866307026424).
- Tronto, J.C. (1998) An ethic of care, *Generations: Journal of the American Society on Aging*, 22(3): 15–20, www.jstor.org/stable/44875693.

- Trukeschitz, B., Schneider, U., Mühlmann, R. and Ponocny, I. (2013) Informal eldercare and work-related strain, *Journals of Gerontology – Series B: Psychological Sciences and Social Sciences*, 68(2): 257–67, doi: [10.1093/geronb/gbs101](https://doi.org/10.1093/geronb/gbs101).
- Whitmore, R., Crooks, V.A. and Snyder, J. (2015) Ethics of care in medical tourism: informal caregivers' narratives of responsibility, vulnerability and mutuality, *Health and Place*, 35: 113–8, doi: [10.1016/j.healthplace.2015.08.004](https://doi.org/10.1016/j.healthplace.2015.08.004).
- Williams, A., Sethi, B., Duggleby, W., Ploeg, J., Markle-Reid, M., Peacock, S. and Ghosh, S. (2016) A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective, *International Journal for Equity in Health*, 15(1): 1–16, doi: [10.1186/s12939-016-0328-6](https://doi.org/10.1186/s12939-016-0328-6).
- Yeandle, S. and Buckner, L. (2017) Older workers and care-giving in England: the policy context for older workers' employment patterns, *Journal of Cross-Cultural Gerontology*, 32(3): 303–21, doi: [10.1007/s10823-017-9332-6](https://doi.org/10.1007/s10823-017-9332-6).
- Yeandle, S., Chou, Y.C., Fine, M., Larkin, M. and Milne, A. (2017) Care and caring: interdisciplinary perspectives on a societal issue of global significance, *International Journal of Care and Caring*, 1(1): 3–25, doi: [10.1332/239788217X14866278171183](https://doi.org/10.1332/239788217X14866278171183).
- Yeh, K.H., Yi, C.C., Tsao, W.C. and Wan, P.S. (2013) Filial piety in contemporary Chinese societies: a comparative study of Taiwan, Hong Kong, and China, *International Sociology*, 28(3): 277–96, doi: [10.1177/0268580913484345](https://doi.org/10.1177/0268580913484345).
- Zarit, S.H., Reever, K.E. and Bach-Peterson, J. (1980) Relatives of the impaired elderly: correlates of feelings of burden, *The Gerontologist*, 20(6): 649–55, doi: [10.1093/geront/20.6.649](https://doi.org/10.1093/geront/20.6.649).