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RESEARCH ARTICLE

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The impact of autonomy at work on dementia family carers' ability to manage care-related emergencies, and use technology to that end: semi-structured interviews in Scotland

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ABSTRACT

Most people with dementia (PwD) are cared for by unpaid family carers, many of whom must balance caring with paid work. This regularly entails dealing with care-related emergencies (CRE). This study aims to explore the impact of carers' autonomy at work regarding breaks, schedule, and place on their ability to manage CRE, and use technology to that end. We conducted interviews with 16 working carers of PwD in Scotland. Data were analysed thematically to identify key themes. Autonomy at work appeared on a spectrum from *no* to *complete* autonomy. Carers' position on this spectrum was often dynamic and determined by the nature of their work, their workplace culture and regulations, and their line managers' support – or clients in the case of self-employed carers. Break autonomy allowed carers to use technology to be notified of and delegate the CRE response. Schedule autonomy allowed for an in-person response to CRE. Place autonomy allowed carers to work and care simultaneously, which enabled them to manage CRE immediately but presented them with additional challenges. Distance between workplace and PwD's residence impacted carers' ability to manage CRE, despite having complete autonomy. Implications for healthcare professionals, service providers, employers, policymakers, and technology developers are presented.

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KEYWORDS
Working carers; autonomy at work; care-related emergencies; dementia; technology; interviews

1. Background

People who work full-time while also providing unpaid care to sick, frail, or disabled family members[1] are most likely to care for people with dementia (PwD) (Carers UK, 2013b). The

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experiences and related challenges PwD live through are well-documented, can affect their ability to continue living independently, and include affective and cognitive issues commonly referred to as behavioural and psychological symptoms of dementia (BPSD) (World Health Organization, 2017). Most PwD are primarily cared for in their communities by unpaid carers – family, friends, or neighbours (Alzheimer's Research UK, 2015; Prince et al., 2014). There are approximately 700,000 unpaid dementia carers in the UK (Lewis et al., 2014). Although their exact number is unknown, current societal trends are likely to increase the number of working dementia carers: retirement ages – especially women's – are extending, the prevalence of dementia in the UK will double by 2050, and public funding constraints limit availability and accessibility of care services (Broese van Groenou & De Boer, 2016; Buckner & Yeandle, 2015; Prince et al., 2014; Prince et al., 2016; Round, 2017; World Health Organization, 2017; Yeandle & Buckner, 2007). Already, the Covid-19 pandemic has led to a sharp increase of working carers (Carers UK, 2020; Phillips et al., 2020) which is likely due to the intensified precariousness of the UK health and social care sectors (Charles & Ewbank, 2021).

Both work and caring can positively and negatively impact carers (Carers UK & Age UK, 2016; Yeandle & Buckner, 2007). However, if not sufficiently supported, combining care and work can create significant demands on carers – specifically their time – which can negatively affect their employment, health, and relationships (Carers UK, 2014; Koyama et al., 2017; Kuo et al., 2014; Wang et al., 2011, 2013, 2020; Wittenberg et al., 2019). Caring for PwD is very challenging due to the unpredictable and complex nature of the condition (Matsumoto et al., 2007; Newbronner et al., 2013). PwD's care needs can fluctuate, increase with the progression of their condition, and include everything from care management, assistance with (instrumental) activities of daily living, social or emotional support, and monitoring their safety (Gallagher-Thompson et al., 2020).

Role theory has long been an important theoretical framework to explore the underlying dynamics between work and family life and the strain resulting from role conflict (Edwards et al., 2002; Goode, 1960; Greenhaus & Beutell, 1985; Lavassani & Movahedi, 2014; Rozario et al., 2004). Time-based role conflict arises when the demands of one role (e.g. work) make it physically impossible to address the demands of another (e.g. caring), or through being too preoccupied with one role to meet the demands of the other, even while attempting to do so (Greenhaus & Beutell, 1985). Examples of working carers' time-based role conflict include care management; coordinating and attending medical or similar appointments; and worrying about and managing care-related emergencies (CRE, e.g. falls, accidents and injuries; home environment hazards like fires, floods, electricity or heating blackouts; BPSD-related issues) (Spann et al., 2020). Hereafter, we focus on CRE as their unplannable nature is particularly problematic to reconcile with carers' work.

Technology, herein defined as any electronic and/or digital device, can play an integral part in managing CRE. Spann et al. (2022) found that working carers used monitoring technologies to ensure the cared-for person's safety, and technologies for direct communication and task-sharing tools to coordinate and communicate with their care network, healthcare professionals, and the cared-for person. Technology thus can be an important tool for notifying carers of and managing CRE when at work. This, however, requires carers to have autonomy, i.e. the ability to self-directedly use technologies at

work. There is an evidence gap on the impact of autonomy at work on carers' ability to use technology for care-related reasons (Spann et al., 2022).

Autonomy is a long-debated concept in the work context, especially regarding workers' wellbeing and empowerment, and organisational management (see Gagné & Bhave, 2011 for a brief overview). Broadly speaking, autonomy at work is 'the control workers have over decisions within their job' (Wheatley, 2017, p. 297) and can be separated into job control, i.e. autonomy over work tasks and conduct, and schedule control, i.e. autonomy over work schedule and place (Wheatley, 2017). Autonomy at work hereafter explicitly refers to schedule control. Flexible working is often used synonymously and encompasses 'a wide range of arrangements that allow workers to work more flexibly' (Chung, 2017, p. 4) like compressed hours or working from home. Flexible working is one of the most discussed and sought-after solutions for working carers' time-based role conflict (Carers UK, 2014, 2019a; Spann et al., 2020). However, whereas *schedule control* implies workers' power to self-direct, *flexible working* is a neutral term, revealing no information on underlying power dynamics. Yet it is this power to self-direct that is likely to have a big impact on how carers can deal with CRE at work. While UK employees have the statutory right to request flexible working, it is their responsibility to demonstrate the effect on their employer, and employee requests can be rejected on that basis (Carers UK, 2019b). Similarly, employees have the right to time-off for CRE (GOV.UK, n.d.) but duration, frequency, and pay are left to employers' discretion. This does not apply to self-employed people, who may have more autonomy but also do not have the same employment rights.

In this paper, we aim to address the evidence gap identified by Spann et al. (2022) and explore how working dementia carers experience the impact their autonomy at work has on their ability to manage CRE and use technology to this end. This study is part of a research project investigating how technologies can support working carers of PwD. The interviews conducted for this study (Spann et al., 2021) also addressed work-care reconciliation challenges carers wanted solutions for (e.g. care management, safety concerns, providing entertainment and companionship for PwD, etc.) and their experience with technology. These findings will be published elsewhere.

2. Methods

Interviews allow researchers to gain an understanding of people's lived experiences (Barbour, 2014; Bunniss & Kelly, 2010). We conducted interviews following Witzel's (2000) problem-centred approach, which centres on a specific topic and uses a topic guide to prompt respondents' narration. This enables the in-depth exploration of the topic while ensuring that required themes are addressed. A brief questionnaire captured participants' contextual demographic data.

We conceptualise autonomy at work as break ('Do you have control over your break times?'), schedule ('Do you have control over when you work?'), and place autonomy ('Do you have control over where you work?'). Participants were asked how these concepts affected their ability to combine work and care and use technology (see Table 1).

Table 1. Relevant questions and prompts from the interview schedule.

Can you tell me about your current work situation?	
Prompts	• You indicated that you ○ Have high/low control over your work schedule ○ Can/can't work from home ○ Can/can't take breaks whenever you need to … how does this affect your ability to combine work and care?
Does technology play a part in your support?	
Prompts	• If yes, which technology? • How? What do you use it for? • Are you able to use the technology at work? ○ What is your line-manager's attitude? ○ How does your level of autonomy at work (see above) impact on your ability to use the technology?

A pilot interview confirmed the topic guide's suitability. Interviews took place in Scotland between March and July 2019 at a place most convenient for interviewees: nine chose their home, five neutral places like pubs, cafés, or meeting rooms, and one requested a phone interview. Interviews lasted between 35 and 120 minutes (mean: 90 minutes). All interviews were audio-recorded and observational notes were taken during and after.

2.1. Ethical approval

Full ethical approval was granted by the ScHARR Research Ethics Committee at the University of Sheffield (Reference 022994). All participants were fully informed about the study, including their right to withdraw at any point without consequence, and gave their explicit consent before the interview started. Confidentiality was ensured throughout the study and data stored securely.

2.2. Participants

We used a purposive sampling strategy (Barbour, 2014) to ensure participants had varying levels of autonomy, and that both sexes and a broad age range were represented. To ensure participants had enough experience being both in paid work and unpaid care, carers were eligible if they: (i) were in paid work at least 20 hours/week; and (ii) cared at least 5 hours/week. To ensure carers had had enough time to come to terms with being a working carer and set up their support system, they also (iii) had to have been working carers for at least six months. As caring for PwD living in residential care settings can look vastly different, carers were eligible if they (iv) cared for a PwD outside of residential care settings in Scotland.

2.3. Recruitment

Working carers are difficult to recruit due to generally being very short on time, (see e.g. Arksey & Glendinning, 2008; Barnett et al., 2009; Boezeman et al., 2018; Bourke et al., 2010; Eldh & Carlsson, 2011). Hence, we used a multipronged recruitment approach. Carer organisations, the chamber of commerce, trade unions, the researchers' professional network, and a random selection of businesses operating in Scotland were asked to

distribute our recruitment flyers among their employees, clients, and contacts, and to post an advertisement for the study on their social media channels. Flyers were pinned to several community notice boards, handed out at dementia support groups, and placed at dementia day-care centres. Carers were invited to contact the research team if they fit the eligibility criteria and wanted to get involved. One carer organisation forwarded the contact details of interested clients with their consent, who were then contacted by the research team. We also asked participants to forward our recruitment flyer to other carers they knew who fit the inclusion criteria.

2.4. Analysis

Interviews were transcribed and read multiple times to ensure familiarity with the texts. The data was analysed using thematic analysis (Braun & Clarke, 2006). The question 'How does break, schedule, and place autonomy at work impact on dementia family carers' ability to manage care-related emergencies and use technology to that end?' was used to guide the analysis. Relevant text passages were coded in an inductive, iterative process. Codes were then organised into clusters of meaning that formed the themes and subthemes and the relationships between them (see Figure 1). An overview of the codes, themes and subthemes, and example quotes, are provided in Appendix 1. Emerging themes were discussed within the research team. To confirm the soundness of our analysis, we sent each interviewee a summary of the analysis of their interview, to which six participants (37.5%) responded. Their clarifications and added details helped to improve the interpretation of the data.

3. Findings

Table 2 presents an overview of participants' characteristics. A total of 16 carers participated (ten women and six men). The mean age was 50.6 years (27–70). Seven were in

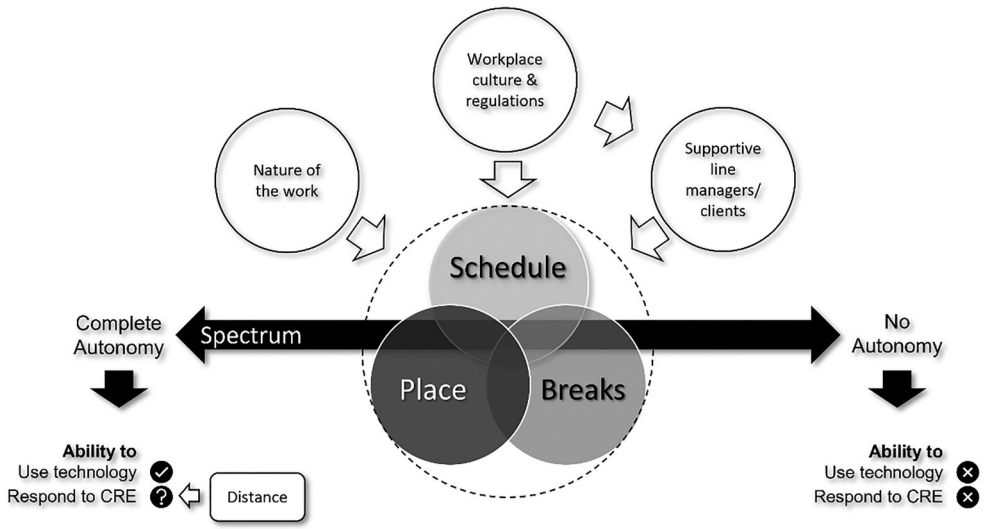

Figure 1. Illustration of the autonomy-at-work spectrum.

full-time employment (>35 hours/week), six self-employed, one partially retired, and two full-time employed while also having a small business on the side. Three carers' situation had changed drastically shortly before the interview: two had resigned their full-time employment for care-related reasons and now worked significantly less than 20 hours/week on a self-employed basis, and for one carer, caring had just ended due to the PwD's passing and they just started to transition into retirement. Per the study's inclusion criteria, only their situation before these events was included in the analysis. Care hours varied between five and, in one extreme case, 75+ hours/week. Most carers could only estimate the number of weekly hours they cared as most was not plannable and

Table 2. Participant characteristics.

Carer		Female (N = 10)	Male (N = 6)	Total n (N = 16)
Age	<40	1	3	4
	40–60	7	1	8
	>60	2	2	4
Employment status	Employed	6	3	9
	Self-employed	2	2	4
	Employed & self-employed	1	1	2
	Partially retired, employed	1	0	1
Weekly workhours	<35 hours	1	1	2
	35–40 hours	7	2	9
	>40 hours	2	3	5
Caring for years	0.5–2 years	3	2	5
	3–6 years	2	3	5
	>6 years	5	1	6
Weekly care hours	<10 hours	2	2	4
	10–20 hours	4	1	5
	21–40 hours	3	2	5
	>40 hours	1	1	2
Work sector	Public	4	3	7
	Private	6	2	8
	Public & private	0	1	1
Industry sector[a]	K: Financial and insurance activities	4	0	4
	L: Real estate activities	1	1	2
	M: Professional, scientific and technical activities	0	1	1
	O: Public administration and defence; compulsory social security	2	3	5
	Q: Human health and social work activities	3	1	4
	R: Arts, entertainment and recreation	1	0	1
PwD				Total n (N = 17)
Relationship to carer	Parent			13
	Parent in-law			1
	Other parental generation			1
	(Ex-) Spouse			2
Age	<70 years			4
	70–80 years			3
	>80 years			10
Dementia Diagnosis	Alzheimer's			5
	Vascular			3
	Fronto-temporal			2
	No official diagnosis			1
	N/A			6
Dementia stage (CDR)[b]	Moderate			5
	Moderate-severe			4
	Severe			8

[a]UK Standard Industrial Classification (ONS, n.d.).
[b]CDR = Clinical Dementia Rating Scale, staging based on participants' descriptions (Waite et al., 1999).

sometimes did not even register as caring (e.g. shopping and home maintenance). Of the PwD, 13 were carers' parents (one cared for both parents), one in-law, one uncle, and two (ex-) spouses.

3.1. Autonomy at work – a spectrum

All carers had experience with CRE at work, ranging from accidents in the home (e.g. falls, leaving the stove on, taking the wrong medication), to the PwD getting into trouble when out and about (e.g. getting lost or picked up by police for shoplifting), to having to manage issues with the care network (e.g. network members needing help to manage BPSD or a breakdown of the care arrangement).

> You are always firefighting; you can't plan anything (Maggie)

Carers' break, schedule, and place autonomy appeared as a spectrum with 'complete' and 'no autonomy' at the extremes (see Figure 1). Complete autonomy allowed carers to generally manage CRE well and use technology. However, the distance between carers' workplace and the PwD's residence could make it physically impossible to manage CRE in person, even if their autonomy would have allowed it. No autonomy, on the other hand, meant that carers were generally unable to manage CRE or use personal technology.

Where carers landed on this spectrum seemed to be impacted by the nature of their work, workplace culture and regulations regarding flexible work or technology-use for private reasons, and the support of line managers or clients. In turn, workplace culture could affect line managers' attitudes, and workplace regulations their ability to offer carers support.

Three interviewees were at the no-autonomy and six at the complete-autonomy end of the spectrum. The remaining seven were somewhere in between. Carers did not necessarily experience their position on the spectrum as static. Hannah, for example, transferred to a different department in her company and got a new line manager who was much more understanding and supportive:

> My previous role I was finding it a real challenge. They weren't that understanding. My current manager couldn't be more understanding. We're two weeks in but I, I just get the feeling that she, she is much more understanding in general. Much more compassionate, empathetic, and much less a micro-manager. So, I think it will work better in every respect. (Hannah)

Similarly, Theresa became very unsure about her autonomy when she got a new boss:

> I feel, rightly or wrongly, to ring this new boss in [location] who doesn't know me and say 'Listen, my mum's not very well. I need to go and spend the afternoon with her', I feel as though I would get a black mark for that. (Theresa)

Carers who normally experienced high autonomy could find their position on the spectrum change temporarily, e.g. when they needed to attend business meetings or go on business trips.

> The only way I wouldn't, I wouldn't do that [leave work for a CRE] is if I was sort of in a video conference and I didn't have my phone with me for instance and I was in the middle of a discussion with someone. (Max)

3.1.1. Break autonomy

Autonomy over when, how often, and how long they could take breaks was essential for carers' ability to use technology for care-related reasons. Complete break autonomy allowed carers to use technology when needed.

> We've all got our mobiles so I mean I can go out for a cigarette break. As long as I take the time off my flexi-time, it's my own time. (Flora)

At work, carers' most important technology was their (smart-)phone. They used it to communicate with their care network and the PwD's healthcare professionals via phone calls, texts, emails, or messenger apps, and to check in with the PwD to see how they were doing or remind them of upcoming appointments, or to take their medication. Some carers also used their phone to manage other technologies like cameras or sensors installed in the PwD's home for their safety.

Some carers needed only a few seconds to periodically check on messages or monitoring technologies. Break autonomy meant that carers could be notified of CRE – by the PwD, care network or emergency services – manage some of them immediately or delegate the response to their care network. However, some carers had to find enough privacy to take a call.

> This open plan environment, you can't just sit there and pick up the phone. I have to find a meeting room, make the call privately. (Theresa)

No break autonomy meant that using phones was limited to fixed break times.

> So apart from being able to make the odd phone call in a break period, that was about it (Gavin).

Not being able to use their phone when needed meant that these carers could not even be notified of CRE, let alone manage them, making them highly dependent on their care network. This was problematic as some carers had to rely on people who had considerable care needs themselves while many others had to get by without professional help due to long waiting lists for care services. Some carers arranged to be called via their workplace in case of CRE.

> [Workplace] has my [department] phone number. So, if that rang then I would be able to answer that, yes. (Rose)

However, technology could still help carers with no break autonomy and no care network to have peace of mind. Some PwD had personal alarm wristbands connecting them to a call centre to coordinate the emergency response. Gavin expressed the wish for automated solutions:

> Maybe if there was something that was more automated, that could provide a kind of a robotic approach, that could in some way, in a compassionate- you know it could even replay my voice perhaps to her. Just giving her the message, you know 'Are you still up, mum? It might be time to go to bed. I'm working at the moment, but I will speak to you in the morning'. (Gavin)

3.1.2. Schedule autonomy

Schedule autonomy meant that carers could manage their work time, taking time off or rearranging their work hours. This enabled them to manage CRE in person. Carers who

had some levels of schedule autonomy generally had complete break autonomy and thus no problems using technology. Conversely, carers with no schedule autonomy did not automatically also have no break autonomy, i.e. having fixed start and end times could still allow them to take breaks when needed. The only option available to carers with no schedule autonomy to still manage CRE *in person* was co-workers taking over their shift and responsibilities.

> My colleagues I work with on my rota, they all know about my home situation. And they wouldn't hesitate if we were fully staffed and probably even if we weren't. They would muck in and take over. (Rose)

One carer changed her work pattern to nightshifts because her care network could look after the PwD at night and the likelihood of CRE coinciding with her work was reduced. This, however, meant that she had to manage daytime care when she needed to catch up on sleep.

> No dayshifts anymore. I used to do the odd dayshift. But I can't leave [PwD] for that length of time anymore. (Rose)

Carers somewhere in the middle of the schedule autonomy spectrum had varying levels of control over their start and finish times. Some could take time off and make it up another day, allowing them to leave work when needed to manage CRE.

> With the nature of the role there is, there is flexibility […] other than the meetings, the work doesn't necessarily need to be done at a specific time of day. (Hannah)

Complete schedule autonomy meant that carers had no restrictions on how they arranged their work hours. These carers could usually integrate work and care more easily.

> My work situation lends itself very well to the situation with my mom. So, I haven't had any problems really. If I need to go out, I just go out. (Max)

However, business trips or meetings could be fixed points in their schedule even they had limited control over. Upcoming deadlines and stressful, performance-driven work environments could make it difficult to prioritise caring.

> Even if work said, 'Yeah, you can have all the time off you want, actually', that's fine, but my workload doesn't go anywhere from having all that time off. (Theresa)

Some carers thus described trying to figure out whether they needed to deal with a CRE themselves and leave their workplace.

> Last week she'd overmedicated. So, you know, some other call to take when you're in a meeting or whatever just to say, you know, and then there's that - is she okay? Do I need to go? Do I need to stay? (Theresa)

3.1.3. Place autonomy

Place autonomy meant that carers could control where they wanted to work. Complete place autonomy meant also having complete break and schedule autonomy and the ability to use technology freely. Some carers' place autonomy was limited by needing to get permission every time they wanted to work remotely or having fixed days at the office. It could also be temporarily limited by business meetings or trips. Working

remotely could make it easier to manage CRE. It also had the additional benefit of freeing up time otherwise spent on commuting. Technology was an essential tool to stay connected to work.

> It [working from home] means that I can stop work and I could pick up the phone and speak, whereas if that was at work, I'd have to find somewhere to do it or if I was in a meeting or whatever. (Betty)

> If I haven't slept until really late during the night because I've been worrying, trying to figure out what the next thing is, I could be really tired. If I'd had to travel in the next day … But if I start, if I log on later, I just know that I'll just finish later and it just helps even in that subtle way, you know. (Betty)

> As long as I can get my, those two days in [city] it is just enough. Everything else can be done off Skype, email, phone and I could be anywhere. (Ian)

Place autonomy did not automatically mean that carers worked where they cared. While some lived too far away from the PwD, others did not see the need as they worked close to the PwD's residence.

> I would work from home if need be, but it makes no sense to me whether to work from home. I work from here because I'm so close anyway. (Max)

> I would prefer to be up here [with PwD] more often but I don't want to take the micky [i.e., to mock/make fun of the workplace], you know. This isn't where I'm based. So, and I have meetings in [town] and things like that and I really should be in the city that my job is located in. (Iona)

Carers who worked and cared at the same place were generally able to ensure the PwD's safety.

> If she wondered around during the day when I was there, I would be able to look out for her. (Maggie)

> In that time with mum just sitting there sleeping, not doing anything, I would do some work but obviously every five, ten minutes I get up and check she's all right and come back, do a bit more work. (Ian)

Some carers co-habited with the PwD, sometimes just briefly before returning to their own home. Others only spent their workday together and returned home in the evening. While these carers could often prevent CRE or manage them promptly, they were faced with unique work-care reconciliation challenges. They often provided high levels of personal care, despite some receiving help from care services. Work interruptions occurred frequently, and some carers felt they had to be constantly vigilant to keep the PwD safe. This required them to be very organised, yet flexible.

> It's absolutely understanding what's needed. Not just what you want to do, what's actually best for you, your mum, and your customers. Yeah. So, there's, there's no way you can structure it. (Ian)

Self-employed carers could face financial pressure if caring took up too much time.

> I might have an eight-hour working day and I might get two hours work done in that time. But I have to live on the money that I make in my job. And if I'm only working two hours a day, I can't live on that. (Maggie)

Working and caring from the same place required boundary management. Some carers felt pressure to keep the PwD company and provide entertainment and expressed feeling guilty if they prioritised work over care and vice-versa.

> I often felt guilty getting on with work when I felt I should be with my wife and also felt guilty when I was with my wife, and I knew that I needed to be doing something for work. (George)

> I would see her walking past the studio door towards her bedroom and I'd say to her, 'Oh, are you away to bed mum?' and she'd just look at me and she'd say, 'What else is there to do', you know. And she's, I know she didn't mean it to come across like that, but there was an element of, not blame but well, you know, 'You're ignoring me, you're working, what am I going to do, there's nothing for me to do', it wasn't just you know, it was, there was a resentment in her voice about it, that she had nothing to do and she was bored and she was just going to go to sleep. (Maggie)

One carer found the constant rapid role-switching between business and providing intense personal care very difficult.

> You're sort of having that [business] conversation to going and wiping poo off the floor or whatever it is, you know. A complete role-switch. And you're going from being a nanny, to being a bloke in a pin-striped suit in the city, to almost, not quite almost, to being a nurse. It's the constant switching between the two that is quite bizarre. (Ian)

3.2. Factors influencing carers' position on the autonomy spectrum

3.2.1. Nature of the work

The nature of their work, i.e. characteristics inherent to some or all activities associated with a specific job, was a very important determining factor. All interviewees on the no-autonomy end of the spectrum worked in client-facing roles in the public sector (i.e. as telephone mental health advisor, airport security officer, and care home assistant). The nature of their work required them to be at a certain place at a certain time and always focused on their work. Technology could only be used during official break times:

> I have to say that the nature of the work I was doing required pretty much 100% concentration. So, whilst deployed it would not have been, it wouldn't have been appropriate, and it probably wouldn't have been supported, to know that somebody could potentially be distracted in that way. (Gavin)

Carers who had some schedule autonomy but were required to work at a specific place were employed in the public or private sector – one was a self-employed childminder. Some had client-facing roles (support worker, childminder, fire safety advisor). This determined their place of work which could vary depending on their client. Others had a desk job with no or limited client contact (civil servant, customer support, privacy officer at a bank) who needed to handle sensitive data or infrastructure only provided at their desk.

> If my job allowed me, I could physically work from home no hassle, but my actual job, my role just now isn't a work-from-home role. (Sue)

Bigger teams, less specialised work, and non-client facing roles seemed to make it easier to take time off for CRE.

> There's enough people that if I go it doesn't have an impact, right? Me disappearing and nearly 200 people in the bit that I'm in, it doesn't kill the business. That's where working for the bank has been my saving grace. (Sue)

> For a huge number of people that are working in office-based roles, I can see that that would work. But yeah, no, equally I can see that there are kind of customer-facing type roles where people go 'No sorry, you're not doing that'. (Hannah)

Carers on the complete-autonomy end of the spectrum were predominately employed in the private sector (project manager, bank clerk), or self-employed (art restorer, property manager, consultant). Their work was often project-based and not client-facing, apart from business meetings. As long as they got their work done on time, there was little scrutiny.

> I've got a lot of flexibility, as long as I get it finished for whenever people need it. But it means that if I need to talk to a doctor on a morning, I can do that and just build my time up later in the day. (Betty)

Business trips or meetings could temporarily change the nature of these carers' work and their position on the spectrum.

> If I were in a meeting, I wouldn't obviously get my phone out and check the [care] camera, or I wouldn't get my phone out and go on the [care network] WhatsApp group. (Iona)

3.2.2. Workplace culture and regulations

For some, it appeared that the nature of carers' work would have allowed for more autonomy than they ended up having. For example, some carers explicitly stated that they were not allowed to use or have their phones on them, even when using them would have been possible without impacting their work. It is unclear whether that was due to their workplace's culture, i.e. the emotional and social environment created by explicit or implicit values, traditions, management style, etc., or explicit regulation.

> I have got time but it [using phones] is, it's not, you can feel it's not looked upon kindly. (Jasmin)

> We're not allowed mobiles. It would be in my bag (Rose).

Some organisations did have explicit flexible working regulations. While some of these regulations had a positive effect on carers' autonomy, others appeared needlessly restricting.

> We can please ourselves any time between seven in the morning 'til nine at night. So that's the sort of space. And in that time, we have to work [at least] three hours. (Flora)

> There were some shift-swap options so, but they were pretty limited because you could only swap with people on the same sort of pattern as such. (Gavin)

Hannah acknowledged the difficulty for large organisations to draft regulations fit for everyone, while Theresa pointed out that regulations could be good in theory, but a workplace's culture – a high-stress and productivity-oriented culture in her case – could make it difficult to benefit from them in practice.

> Because we're an organisation where that policy fits across everybody from people in back-office roles to people that are standing in a branch, they're never going to be able to introduce a policy that is that broad and that flexible. (Hannah)

> On paper, we have a very good flexible and agile working policy. In reality, it's just not always possible. It just depends. Again, it depends on the deadlines I've got, it depends on the meetings I've got. Next week I'll be able to work from home a couple of days, so that's fine. This week I just can't at all cos I've got too much on. (Theresa)

Some carers found that their workplace culture was not understanding, unsupportive, or too performance-oriented for them to disclose their carer status for fear of unfavourable treatment or being seen as unreliable. This could prevent them from seeking more autonomy or disclosing the full extent caring impacted their work, and vice-versa.

> Now, have I gone and asked my employer if I can go do that? No, I haven't. Why not? I don't know. You know, because I'm thinking they're either going to say no, or they're gonna think I'm slacking, you know, shirking my responsibilities at work. (Theresa)

> There maybe was a fear they could question 'What are you doing' you know, 'You can't be going up [to PwD]'. I don't know, I just thought what they don't know won't harm. (Liam)

> I wouldn't want any special dispensation or to be, you know, looked at, not looked upon as a charity case but kind of in that sense, if you know what I mean. To be, maybe not be considered for certain things like trips away or things like that. (Iona)

Workplace culture and regulations did not impact the autonomy of the self-employed carers we interviewed.

3.2.3. Supportive line managers/clients

While often bound or shaped by workplace culture and regulations, line managers were a decisive factor for carers' autonomy, clearly demonstrated by getting a new line manager.

> Unfortunately, my previous manager didn't interpret it [flexible work regulations] that broadly. My current one does. (Hannah)

Supportive line managers could mitigate restrictive regulations, for example by allowing carers to use their phones despite official guidelines.

> I would say to my boss 'I'm gonna have my phone, there's something going on' and that would be fine, because we're not supposed to have our- data protection and all that, we're not supposed to have our phones out. (Sue)

Hence, some carers felt it was essential for line managers to know of their carer status.

> You have to let your employers know what's going on, you have to be honest and say, 'This is the situation, and I am the carer, I'm responsible for these people'. (Sue)

Others seemed to feel they had to earn their autonomy by proving their reliability.

> I guess if you've worked here for years and have proven yourself to be a reliable and committed employee, they're gonna give you a bit more leeway, aren't they? (Theresa)

Some self-employed carers depended on the understanding and support of their clients.

> But they understood because they've got fathers that are now failing themselves. And so, they were actually very, very understanding when last week, for example, when I said, it was the first time ever, 'I'm not gonna be able to come down, mum's gone into hospital'. (Ian)

3.3. Distance

For some carers, having complete autonomy was not enough to effectively manage CRE, due to the distances between their workplace and the PwD's residence.

> The phone would go saying, you know, 'Your mum's double-dosed her medication' or 'She's fallen' and I'm thinking 'I've just arrived in [office]', you know. I cannot physically, you know, I can jump on a train and come back, but by the time I do … (Theresa)

If the distance was too great, their caring role was reduced to managerial tasks, and they could only delegate the CRE response to their care network or emergency services. In the case of business trips, distance could be a temporary issue. Some carers permanently worked at a great distance which they experienced as practically, financially, and emotionally difficult.

> I am close to 400 miles away. So, a journey here is not something I can make in a week and back. Apart from the expense, it's the time. (Gavin)

> I've got this unbelievable rack of guilt that I'm not here and all that is on my brothers and sisters. So, I try and come home at least once, one week every month. (Iona)

Conversely, having no autonomy at work, Gavin found that the great distance helped him let go of some of the responsibility.

> One of the advantages of being so far away is that I found it easier to compartmentalise, that I knew there was nothing I could do. I couldn't just jump in my car to render help. I had to rely on local services. (Gavin)

Place autonomy allowed carers to travel to the PwD, and resume work there. Those with no place autonomy either had to get creative with their schedule or take extended leave.

> They were long shifts, and it was only generally about a four-day week. It did enable me to add quality breaks to long weekends to make five, six or seven days so I could use effectively a week to make a trip up. So that's what I did. Or I took holiday onto it, I took a couple of weeks. (Gavin)

Some carers went to considerable lengths and made personal sacrifices to reduce the distance. Ian, for example, moved cross country and in with his parents. Theresa moved her mother from a different town into sheltered housing near her home. And Maggie had to maintain a long-distance relationship with her partner and keep postponing their life together.

4. Discussion

This study aimed to explore how working dementia carers experience the impact of their autonomy at work on their ability to manage CRE and use technology to that end, thus addressing an evidence gap identified by Spann et al. (2022). Where the neutral term *flexible working* is often employed in the work-care reconciliation discourse, we suggest

using *autonomy at work* as this better describes the underlying power dynamics, i.e. whether the worker has the power to self-direct. Autonomy at work, conceptualised as break, schedule, and place autonomy, can be viewed on a spectrum with 'complete' and 'no autonomy' at the extremes.

Break autonomy, the ability to take breaks when, for how long, and as often as needed, seemed to be the deciding factor in whether carers could be notified of and manage CRE, at least from afar, e.g. by delegating the response to their care network or emergency services. For this, carers mostly used their (smart-)phones: to coordinate and communicate with their care network and the PwD's healthcare professionals, and to check in with the PwD by calling or checking on monitoring technologies in their home. Break autonomy allowed carers to do that freely. Still, technology could play a part in helping carers with no break autonomy to manage CRE, e.g. by connecting the PwD via a personal alarm system to an emergency response call centre. However, carers need to be sure that PwD are able and comfortable to actively use these technologies (Spann et al., 2022). Many carers are not aware of technological solutions to their work-care reconciliation challenges (Carers UK, 2013a; Spann et al., 2022) and would benefit from employers, support organisations, healthcare professionals, etc. raising awareness and providing advice and guidance on technologies carers could use.

Schedule autonomy enabled carers to manage CRE in person by coming in late, leaving early, or rearranging their schedules. Yet, carers working in a stressful or productivity-driven environment, or self-employed carers paid by the hour, might feel pressured to work, and thus not be able to benefit from their theoretical schedule autonomy.

Place autonomy allowed carers to work and care from the same place, meaning they could prevent or manage CRE instantly. However, these carers were faced with additional work-care reconciliation challenges: they provided a substantial amount of personal care, felt they needed to be constantly vigilant to prevent CRE, and experienced many work disruptions. While much of the personal care they provided could be planned around work, they needed to be highly organised yet flexible to accommodate any CRE. Kossek et al. (2006) found that working from home could decrease role conflict if adequate boundary management was employed. Our carers found boundary management very difficult as they felt guilty when they needed to prioritise work over caring and could not keep the PwD company, and vice versa. One carer also described the rapid and frequent role-switching as very challenging.

Break autonomy seemed to only exist in its extremes (either complete or no autonomy), whereas schedule autonomy seemed to have many in-betweens, e.g. flexible start and finish times, banking overtime hours, compressed hours (e.g. working longer days to have a shorter workweek), etc. At first glance, place autonomy appears more in line with break autonomy – either carers can work remotely or not. However, their autonomy could be limited by regulations on remote work or having to ask permission every time they wanted to work remotely.

Carers' position on the spectrum was not always static. Business meetings or trips could temporarily reduce their autonomy whereas a new line manager could change it permanently. A carer passport, i.e. a record that allows carers to carry over negotiated flexibility and support to new roles or line managers, can help preserve carers' autonomy (Carers UK, 2017). Line managers' compassion for carers' situations and trusting them to manage could be just as helpful as bending or generously interpreting official regulations

about flexible working or using technology. This finding is echoed in the literature where line managers have been identified as main gatekeepers for carers' ability to access support and resources (Carers UK, 2019a; Spann et al., 2020) and use technology for care-related reasons (Arksey, 2002; Mahoney, 2004; Mahoney et al., 2008). According to Milasi et al. (2020), workers' access to place autonomy specifically depends on line managers' trust. Ireson et al. (2018) found that workplace culture also determines availability and accessibility of support for carers. Some of our interviewees did not want to tell their employers about their caring responsibilities or ask for more autonomy for fear of career consequences and being viewed as unreliable. Chung (2017) concurs that this flexibility stigma hinders employees from requesting more flexibility, especially in highly competitive workplaces. This is despite evidence that flexibly working employees are more productive, not least because they often feel the need to reciprocate their employers for accommodating their situation. Previous studies have also found that carers made changes to their careers or passed on job advancement opportunities if it awarded them less flexibility (Bernard & Phillips, 2007; Edwards, 2014).

The nature of their work seemed to have a decisive impact on carers' autonomy. Client-facing roles and jobs requiring carers to work highly focused and at specified times and places seemed to offer the least autonomy. Milasi et al. (2020) concurred that some occupations do not allow much autonomy. However, there appears to be a strong cultural aspect to how much autonomy is afforded in specific sectors, highlighted by varying autonomy levels in the same occupations in different European countries (Milasi et al., 2020). It appears that culture, in general, can influence workplace culture which in turn impacts on carers' autonomy. Our interviews further suggest a gender aspect to autonomy in certain work sectors. All but one of our interviewees who had very little to no autonomy, both male and female, worked in traditionally female sectors (child, social, and health care – the exception being airport security). Although inconclusive due to our small sample size, this finding is consistent with previous research on autonomy at work and gender. A Europe-wide study by Chung (2019) concluded that traditionally female sectors have worse working conditions and less schedule flexibility. Larger studies should seek to quantify which work sectors afford which levels of autonomy to carers, based on the nature of the work. Self-employment did not automatically afford complete autonomy as some self-employed carers had to work at a specific time and place. However, none of them had any limitations using technology to be notified of and manage CRE. If caring took up too much of their time, self-employed carers' income could be at risk, especially for those who did project-based work. Despite considerable efforts, we have not been able to recruit carers in 'insecure' work like agency or gig work or zero-hours contracts. Many of these casual workers have no access to employment rights or paid leave which might force them to prioritise work over caring even if they have schedule autonomy.

Distance between the carer and the cared-for person is a well-documented challenge (e.g. see Bernard & Phillips, 2007; Koerin & Harrigan, 2003; Manthorpe, 2001; Spann et al., 2020). Maintaining a close distance was a priority for many of our interviewees, even at a personal cost in terms of relocating themselves or the PwD, putting their romantic relationships on hold, or frequently travelling for hundreds of miles. Distance carers generally value flexible work arrangements and are known to often have to take leave to travel long distances for care-related reasons (Bernard & Phillips, 2007; Edwards, 2014;

White et al., 2020). However, little is yet known about the specific interaction of autonomy at work with distance caring. Our findings show that place autonomy can allow carers to overcome distance and manage their work and care responsibilities from the PwD's home. In contrast, regarding CRE response, distance could make even high levels of schedule autonomy meaningless. Larger investigations should seek to confirm and expand upon our findings.

Future studies should also explore the impact of financial issues on carers' autonomy, which were not part of our investigation. Milasi et al. (2020), for example, found that well-paid employees had greater access to jobs with high place autonomy. Having less financial pressure may mean that carers have greater choice on the job market and can prioritise high-autonomy jobs even if they offer lower pay. It may also enable them to reduce their work hours or take leave to dedicate more time to caring. Having more financial resources may make it easier to afford private care providers or monitoring technologies for peace of mind.

Milasi et al. (2020) found that around 40% of workers who had worked remotely during the Covid-19 pandemic did so because of the pandemic. Before that, remote workers had primarily been high-skilled workers with high autonomy levels who mostly worked on computers. The pandemic has suddenly made working from home possible – necessary – for many workers where this has previously been unthinkable. It has also led to a sharp increase in working carers in the UK (Carers UK, 2020; Phillips et al., 2020). These carers had to deal with a suddenly drastically different work-life while providing even higher levels of care with very little support or guidance, many of them while also home-schooling their children and supporting other vulnerable relatives (Milasi et al., 2020; Phillips et al., 2020). The effects of reconciling work and care for PwD during the pandemic should be further explored, particularly regarding how many carers' newfound autonomy affected their ability to combine work and care under these very difficult circumstances.

4.1. Implications for practice

Our findings have implications for employers, policymakers, and technology developers. Employers should be mindful of their employees' caring responsibilities and recognise the importance of using technology such as their phones for managing CRE. They should revise their regulations to ensure that their employees can have a maximum of autonomy and create a workplace culture where carers feel supported to request more autonomy. Enabling carers to manage CRE could prevent their exit from the labour market which could save employers a lot of money otherwise spent on recruitment and training of replacements for carers. Many carers seem unaware of existing technologies like monitoring technologies which could make it easier for them to reconcile work and care and manage CRE. Employers are ideally positioned to signpost carers to these technologies. Line managers should be encouraged to support carers and use carer passports. Currently, when requesting more flexibility at work, UK employees must prove to their employer that granting this flexibility won't negatively impact their business (Carers UK, 2019b). Policymakers in the UK should learn from the push towards working from home during the Covid-19 pandemic and take this burden of proof off employees. They should also ensure that social care services are available, accessible, and affordable,

particularly for carers who have no autonomy at work to respond to CRE and have no care network to fall back on. Provisions should also be made for self-employed carers whose work is impacted by caring. Healthcare professionals and service providers working with PwD and/or their carers should consider carers' autonomy at work when scheduling appointments and accommodate them where possible (e.g. adjusting their own business hours, providing asynchronous and remote channels of communication like email or video consultations, scheduling appointments well in advance and with carers' prior consultation, etc.). Further, they are well suited to raise awareness and advise carers on potential technological solutions to their work-care reconciliation challenges. Smartphones are todays' Swiss army knives, offering carers many functionalities including messenger apps to coordinate their care network and to manage monitoring technologies in the PwD's home. Technology developers seeking to innovate for working carers need to consider whether and how carers can use their phones when at work. Technology is often the last resort for carers seeking to reconcile caring with work, particularly considering severe accessibility challenges to social care services. Innovative technologies that can autonomously ensure the PwD's safety and wellbeing, provided that they are able and comfortable to use these technologies or have them in their home, can help carers with no autonomy at work to have peace of mind.

4.2. Strengths and limitations

We have employed a purposive sampling strategy to recruit carers with a broad range of characteristics in terms of their age, gender, and autonomy at work, both employed and self-employed. However, our sample size is relatively small and despite considerable efforts, we have not been able to recruit carers working in 'insecure' work such as the gig economy. Future research should address this gap. Future research should also seek the views of employers who might have some ideas about additional changes that could improve the situation of working carers, and of their organisations. We used member checking to increase the trustworthiness of our analysis. Our findings are specific to the context of carers of PwD living in Scotland and may not be transferrable to other countries.

5. Conclusion

Autonomy at work appeared as a spectrum where carers with no autonomy were generally not able to manage CRE and use technology to that end, and carers with complete autonomy were generally able to do so well. Break autonomy seemed to be most influential for carers' ability to use technology, primarily their (smart-)phone at work and manage CRE by delegating the response to their care network. Schedule autonomy enabled them to manage CRE in person. Place autonomy meant that carers could work and care at the same time. While this allowed them to prevent or manage CRE instantly, it also presented them with unique challenges such as problems with boundary management and frequent work interruptions. The nature of carers' work, their workplace culture and regulations, and the support of their line managers or self-employed carers' clients influenced carers' position on the autonomy spectrum. While distance could make high schedule autonomy meaningless for in-person CRE response, place autonomy could

allow carers to overcome distance and work and care from the PwD's home. The findings have implications for employers, policymakers, and technology developers.

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Note

1. Care in this context does not refer to childcare if the child in question has no special healthcare needs.

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References

Alzheimer's Research UK. (2015). *Women and dementia: A marginalised majority*. https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/women-dementia/.

Arksey, H. (2002). Combining informal care and work: Supporting carers in the workplace. *Health & Social Care in the Community*, *10*(3), 151–161. https://doi.org/10.1046/j.1365-2524.2002.00353.x

Arksey, H., & Glendinning, C. (2008). Combining work and care: Carers' decision-making in the context of competing policy pressures. *Social Policy and Administration*, *42*(1), 1–18. https://doi.org/10.1111/j.1467-9515.2007.00587.x

Barbour, R. (2014). *Introducing qualitative research: A student's guide* (2nd ed.). Sage Publications.

Barnett, R., Gareis, K., Gordon, J., & Brennan, R. (2009). Usable flexibility, employees' concerns about elders, gender, and job withdrawal. *The Psychologist-Manager Journal*, *12*(1), 50–71. https://doi.org/10.1080/10887150802665356

Bernard, M., & Phillips, J. (2007). Working carers of older adults: What helps and what hinders in juggling work and care? *Community, Work and Family*, *10*(2), 139–160. https://doi.org/10.1080/13668800701270075

Boezeman, E., Nieuwenhuijsen, K., & Sluiter, J. (2018). An intervention that reduces stress in people who combine work with informal care: Randomized controlled trial results. *European Journal of Public Health*, *28*(3), 485–489. https://doi.org/10.1093/eurpub/cky052

Bourke, J., Pajo, K., & Lewis, K. (2010). Elder care and work-life balance: Exploring the experiences of female small business owners. *New Zealand Journal of Employment Relations*, *35*(1), 17. http://hdl.handle.net/11072/318.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://www.tandfonline.com/doi/abs/10.11911478088706qp063oa. https://doi.org/10.1191/1478088706qp063oa

Broese van Groenou, M., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing*, *13*(3), 271–279. https://doi.org/10.1007/s10433-016-0370-7

Buckner, L., & Yeandle, S. (2015). *Valuing carers 2015: The rising value of carers' support*. Carers UK. https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf.

Bunniss, S., & Kelly, D. (2010). Research paradigms in medical education research. *Medical Education*, *44*(4), 358–366. https://doi.org/10.1111/j.1365-2923.2009.03611.x

Carers UK. (2013a). *Potential for change: Transforming public awareness and demand for health and care technology*. https://www.carersuk.org/for-professionals/policy/policy-library/potential-for-change-transforming-public-awareness-and-demand-for-health-and-care-technology.

Carers UK. (2013b). *State of caring survey* 2013. https://www.carersuk.org/for-professionals/policy/policy-library/the-state-of-caring-2013.

Carers UK. (2014). *Supporting employees who are caring for someone with dementia*. https://www.carersuk.org/for-professionals/policy/policy-library/supporting-employees-who-are-caring-for-someone-with-dementia.

Carers UK. (2017). *Carer passport - employment*. https://www.carerpassport.uk/employment.

Carers UK. (2019a). *Juggling work and unpaid care: A growing issue*. http://www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf.

Carers UK. (2019b). *Your rights in work - Factsheet*. https://www.carersuk.org/images/Help__Advice/work/Your_rights_in_work_UK1031_JUNE_2019.pdf.

Carers UK. (2020). *Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak*. https://www.carersweek.org/images/CW20202020Research20Report20WEB.pdf.

Carers UK, & Age UK. (2016). *Walking the tightrope: The challenges of combining work and care in later life*. https://www.carersuk.org/for-professionals/policy/policy-library/walking-the-tightrope-the-challenges-of-combining-work-and-care-in-later-life.

Charles, A., & Ewbank, L. (2021). *The road to renewal: Five priorities for health and care*. https://www.kingsfund.org.uk/publications/covid-19-road-renewal-health-and-care#now.

Chung, H. (2017). *Work autonomy, flexibility and work-life balance. Final report*. https://kar.kent.ac.uk/65922/.

Chung, H. (2019). 'Women's work penalty' in access to flexible working arrangements across Europe. *European Journal of Industrial Relations*, *25*(1), 23–40. https://doi.org/10.1177/0959680117752829

Edwards, A., Zarit, S., Stephens, M., & Townsend, A. (2002). Employed family caregivers of cognitively impaired elderly: An examination of role strain and depressive symptoms. *Aging & Mental Health*, *6*(1), 55–61. https://www.tandfonline.com/doi/abs/10.10801360786012010114 9. https://doi.org/10.1080/13607860120101149

Edwards, M. (2014). Distance caregivers of people with Alzheimer's disease and related dementia: A phenomenological study. *British Journal of Occupational Therapy*, *77*(4), 174–180. https://doi.org/10.4276/030802214×13968769798719

Eldh, A., & Carlsson, E. (2011). Seeking a balance between employment and the care of an ageing parent. *Scandinavian Journal of Caring Sciences*, *25*(2), 285–293. https://doi.org/10.1111/j.1471-6712.2010.00824.x

Gagné, M., & Bhave, D. (2011). Autonomy in the workplace: An essential ingredient to employee engagement and well-being in every culture. In V. Chirkov, R. Ryan, & K. Sheldon (Eds.), *Human autonomy in cross-cultural context. Cross-cultural advancements in positive psychology, Vol 1* (pp. 163–187). Springer. https://doi.org/10.1007/978-90-481-9667-8_8

Gallagher-Thompson, D., Choryan Bilbrey, A., Apesoa-Varano, E., Ghatak, R., Kim, K., & Cothran, F. (2020). Conceptual framework to guide intervention research across the trajectory of dementia caregiving. *The Gerontologist*, *60*(Supplement_1), S29–S40. https://doi.org/10.1093/geront/gnz157

Goode, W. J. (1960). A theory of role strain. *American Sociological Review*, *25*(4), 483–496. https://doi.org/10.2307/2092933

GOV.UK. (n.d.). *Time off for family and dependants*. https://www.gov.uk/time-off-for-dependants.

Greenhaus, J., & Beutell, N. (1985). Sources of conflict between work and family roles. *Academy of Management Review*, *10*(1), 76–88. https://doi.org/10.5465/amr.1985.4277352

Ireson, R., Sethi, B., & Williams, A. (2018). Availability of caregiver-friendly workplace policies (CFWPs): An international scoping review. *Health & Social Care in the Community*, *26*(1), e1–e14. https://doi.org/10.1111/hsc.12347

Koerin, B., & Harrigan, M. (2003). PS I love you: Long-distance caregiving. *Journal of Gerontological Social Work*, *40*(1-2), 63–81. https://www.tandfonline.com/doi/abs/10.1300J083v40n01_05. https://doi.org/10.1300/J083v40n01_05

Kossek, E., Lautsch, B., & Eaton, S. (2006). Telecommuting, control, and boundary management: Correlates of policy use and practice, job control, and work-family effectiveness. *Journal of Vocational Behavior*, *68*(2), 347–367. https://doi.org/10.1016/j.jvb.2005.07.002

Koyama, A., Matsushita, M., Hashimoto, M., Fujise, N., Ishikawa, T., Tanaka, H., Hatada, Y., Miyagawa, Y., Hotta, M., & Ikeda, M. (2017). Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics*, *17*(2), 108–114. https://doi.org/10.1111/psyg.12200

Kuo, L., Huang, H., Hsu, W., & Shyu, Y. (2014). Health-related quality of life and self-efficacy of managing behavior problems for family caregivers of vascular dementia and Alzheimer's disease patients. *Dementia and Geriatric Cognitive Disorders*, *38*(5-6), 310–320. https://doi.org/10.1159/000360414

Lavassani, K., & Movahedi, B. (2014). Developments in theories and measures of work-family relationships: From conflict to balance. *Contemporary Research on Organization Management and Administration*, *2*(1), 6–19.

Lewis, F., Karlsberg Schaffer, S., Sussex, J., O'Neill, P., & Cockcroft, L. (2014). *The trajectory of dementia in the UK: Making a difference*. https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf.

Mahoney, D. (2004). Linking home care and the workplace through innovative wireless technology: The Worker Interactive Networking (WIN) project. *Home Health Care Management & Practice*, *16*(5), 417–428. https://doi.org/10.1177/1084822304264616

Mahoney, D., Mutschler, P., Tarlow, B., & Liss, E. (2008). Real world implementation lessons and outcomes from the Worker Interactive Networking (WIN) project: Workplace-based online caregiver support and remote monitoring of elders at home. *Telemedicine and E-Health*, *14*(3), 224–234. https://doi.org/10.1089/tmj.2007.0046

Manthorpe, J. (2001). Caring at a distance: Learning and practice issues. *Social Work Education*, *20*(5), 593–602. https://doi.org/10.1080/02615470120075109

Matsumoto, N., Ikeda, M., Fukuhara, R., Shinagawa, S., Ishikawa, T., Mori, T., Toyota, Y., Matsumoto, T., Adachi, H., & Hirono, N. (2007). Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community. *Dementia and Geriatric Cognitive Disorders*, *23*(4), 219–224. https://doi.org/10.1159/000099472

Milasi, S., González-Vázquez, I., & Fernández-Macías, E. (2020). *Telework in the EU before and after the COVID-19: Where we were, where we head to*. https://ec.europa.eu/jrc/sites/default/files/jrc120945_policy_brief_-_covid_and_telework_final.pdf.

Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M., & Glendinning, C. (2013). *A road less rocky: Supporting carers of people with dementia*. https://carers.org/resources/all-resources/84-a-road-less-rocky-a-supporting-carers-of-people-with-dementia.

ONS (Office of National Statistics). (n.d.). *UK Standard Industrial Classification (SIC)*. https://onsdigital.github.io/dp-classification-tools/standard-industrial-classification/ONS_SIC_hierarchy_view.html.

Phillips, D., Paul, G., Fahy, M., Dowling-Hetherington, L., Kroll, T., Moloney, B., Duffy, C., Fealy, G., & Lafferty, A. (2020). The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. *HRB Open Research*, *3*(24). https://doi.org/10.12688/hrbopenres.13059.1

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer report 2016: Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future*. https://www.alzint.org/resource/world-alzheimer-report-2016/.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A., & Salimkumar, D. (2014). *Dementia UK: Update*. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf?fileID=2323.

Round, A. (2017). *Extending working lives: A devolved, lifecourse approach to enabling work beyond state pension age*. https://www.ippr.org/publications/extending-working-lives.

Rozario, P., Morrow-Howell, N., & Hinterlong, J. (2004). Role enhancement or role strain: Assessing the impact of multiple productive roles on older caregiver well-being. *Research on Aging*, *26* (4), 413–428. https://doi.org/10.1177/0164027504264437

Spann, A., de Witte, L., Hawley, M., & Spreeuwenberg, M. (2021). Interviews with working carers of people living with dementia in Scotland. The University of Sheffield. Dataset. https://doi.org/10.15131/shef.data.16826212.v1.

Spann, A., Vicente, J., Abdi, S., Hawley, M., Spreeuwenberg, M., & de Witte, L. (2022). Benefits and barriers of technologies supporting working carers: A scoping review. *Health & Social Care in the Community*, *30*(1), e1–e1500. https://doi.org/10.1111/hsc.13421

Spann, A., Vicente, J., Allard, C., Hawley, M., Spreeuwenberg, M., & de Witte, L. (2020). Challenges of combining work and unpaid care, and solutions: A scoping review. *Health & Social Care in the Community*, *28*(3), 699–715. https://doi.org/10.1111/hsc.12912

Waite, L., Grayson, D., Jorm, A., Creasey, H., Cullen, J., Bennett, H., Casey, B., & Broe, G. (1999). Informant-based staging of dementia using the clinical dementia rating. *Alzheimer Disease & Associated Disorders*, *13*(1), 34–37. https://doi.org/10.1097/00002093-199903000-00005

Wang, Y., Hsu, W., & Shyu, Y. (2020). Job demands and the effects on quality of life of employed family caregivers of older adults with dementia: A cross-sectional study. *Journal of Nursing Research*, *28*(4), e99. https://doi.org/10.1097/jnr.0000000000000383

Wang, Y., Shyu, Y., Chen, M., & Yang, P. (2011). Reconciling work and family caregiving among adult-child family caregivers of older people with dementia: Effects on role strain and depressive symptoms. *Journal of Advanced Nursing*, *67*(4), 829–840. https://doi.org/10.1111/j.1365-2648.2010.05505.x

Wang, Y., Shyu, Y., Tsai, W., Yang, P., & Yao, G. (2013). Exploring conflict between caregiving and work for caregivers of elders with dementia: A cross-sectional, correlational study. *Journal of Advanced Nursing*, *69*(5), 1051–1062. https://doi.org/10.1111/j.1365-2648.2012.06092.x

Wheatley, D. (2017). Autonomy in paid work and employee subjective well-being. *Work and Occupations*, *44*(3), 296–328. https://doi.org/10.1177/0730888417697232

White, C., Wray, J., & Whitfield, C. (2020). 'A fifty-mile round trip to change a lightbulb': An exploratory study of carers' experiences of providing help, care and support to families and friends from a distance. *Health & Social Care in the Community*, *28*(5), 1632–1642. https://doi.org/10.1111/hsc.12988

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom 2019*-2040. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf.

Witzel, A. (2000). The problem-centered interview. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *1*(1). https://doi.org/10.17169/fqs-1.1.1132

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017*–2025. https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf.

Yeandle, S., & Buckner, L. (2007). *Carers, employment and services: Time for a new social contract?* http://circle.group.shef.ac.uk/wp-content/uploads/2018/04/CES-6-EWS4031Time-for-a-new-social-contract.pdf.