(How) Will it end? A qualitative analysis of free-text survey data on informal care endings

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The health and social 'after-effects' of caring are well established, yet the way carers experience pathways out of caring remains under-researched. In this article, we analyse qualitative free-text responses (n = 1,746) from a national survey of Australian carers to explore current and former carers' concerns, opportunities and preferences around care endings. Our thematic analysis derived three key findings: (1) anticipation and fears for the care recipient; (2) prospects for life after caring; and (3) responsibility, recognition and loss. We engage with scholarship on the moralities of caring to discuss carers' precarious relational and social positions, and their uncertainties around how caring ends.

Key words Australia • former carers • informal care • qualitative analysis


Introduction

In Australia, over 2.6 million people are carers, approximately 10 per cent of the population (ABS, 2020). A ‘carer’ is defined as ‘any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness,
drug and/or alcohol dependency, chronic condition, terminal illness or who is frail’ (Carers NSW, 2020; see also the Carer Recognition Act 2010 [Cth], s 5). In Australia, carers most commonly provide care to a spouse or partner, child, or parent, are more likely to be female and middle-aged, and, on average, provide 35 hours of care per week (ABS, 2020). Many carers have significant social, health and economic support needs due to the often physically, mentally and time-demanding nature of caring situations. In Australia, government-funded supports allow carers to access training, peer support, counselling and respite, as well as income supports, depending on individual circumstances (Cresswell, 2017; AIHW, 2019). Since 2020, most services previously delivered through other federal programmes, state agencies or community organisations have been offered through the integrated Carer Gateway service model (DSS, 2021); however, some services are still offered by providers outside this model (for example, in the context of existing aged-care or disability services). Overall availability of and engagement with services and support varies; in particular, those who do not identify as ‘carers’ are less likely to be connected with support (Knowles et al, 2016). Indeed, carers represent diverse and heterogeneous communities, and support tailored to those different social and cultural contexts has been shown to be lacking, including representation and servicing the needs of less visible carer groups, such as those from Aboriginal and Torres Strait Islander, culturally diverse, and Lesbian, Gay, Bisexual, Transgender plus (LGBT+) communities, as well as young carers (for example, Hunter et al, 2016; Leu and Becker, 2017; Martin et al, 2019; Poon and Lee, 2019; Walker et al, 2020).

Across contexts, at some point, caring relationships, duties and roles inevitably conclude, and a considerable proportion of carers become former carers (Larkin, 2009; Cavaye and Watts, 2016b; Corey and McCurry, 2018; Larkin and Milne, 2021). However, how caring ends is not well understood. Despite considerable scholarship that has documented the impacts of caring for the well-being of carers themselves, end-of-care experiences have received relatively little attention (Larkin and Milne, 2021). Care endings are often complicated and fraught with challenges; moreover, perspectives vary in terms of what constitutes the ‘end’ of care, including delineating current from former or ex–carers. How care endings are understood has important implications for practice, including the delivery and provision of support and entitlements, as well as in recognising and making the experiences of current and former carers visible. In this article, we aim to thematically explore and thus better understand carer reflections on how their caring might end, including their preferences and concerns about life beyond caring. In doing so, and informed by an interpretive sociological approach to research design and analysis, we aim to elucidate the normative moralities and subjectivities that circulate around and within care endings.

**Background**

**What makes a care ending?**

Existing research has outlined various care endings, including: the relinquishment of full-time care via admission of the care recipient into supported accommodation; the recovery or improvement (however partial) of the care recipient’s condition; or bereavement (Davies and Nolan, 2004; Cavaye and Watts, 2016b; Watts and Cavaye, 2018; Larkin and Milne, 2021). Importantly, these examples may not a priori constitute an end to care; pathways ‘out’ of caring are not linear or temporally clear, and they often involve prolonged commitment,
duties and ongoing carer identity (Cavaye, 2006; Molyneaux et al, 2011; Larkin and Milne, 2017). Moreover, many carers move in and out of caring roles given fluctuating needs and requirements over the life course; some will care for multiple recipients simultaneously (for example, ‘sandwich’ generation carers looking after children and parents) (Steiner and Fletcher, 2017) or over time (for example, ‘serial carers’) (Larkin, 2009).

Experiences of life beyond caring also rest on how carers identify as current or former, or sometimes not as carers at all (Molyneaux et al, 2011). As such, the affective, private process of making sense of changing relationships and identities in and beyond caring has been shown to be challenging, variously involving experiences of bereavement, as well as loss of identity, selfhood and purpose (Davies and Nolan, 2004; Larkin, 2009; Cronin et al, 2015; Nathanson and Rogers, 2020). The ambiguous position occupied by carers within health and social care systems is also well documented; former carers are vulnerable to marginalisation given the focus of policy, support and entitlements on those currently engaged in caring, rather than those ‘post-caregiving’ (Orzech and Silverman, 2008; Larkin and Milne, 2017). In Australia, the Carer Recognition Act 2010, for example, outlines how carers should be supported, including provisions for well-being, employment and education. While timely, appropriate and accessible support for carers is included in the Act, there is no explicit inclusion of former carers, who receive only incidental attention across formal policy. Bereaved carers, for example, are entitled to a (limited) allowance or payment after the person’s death (Social Security Act 1991 [Cth], s 21). Similarly, although Carer Gateway services include ‘futures planning’ support, the extent to which current carers engage with or receive support in preparing for transitions out of care is not known. As such, the growing scholarship focused on former carers and on futures planning is crucial for conceptualising (and better supporting) pathways out of caring (Larkin, 2009; Cavaye and Watts, 2016b; Larkin and Milne, 2017, 2020; Watts and Cavaye, 2018; Walker and Hutchinson, 2019).

The lived experience of former carers

The majority of studies of former carers focus on a particular context (for example, bereavement), a single condition or illness profile (for example, dementia), or a single group of carers (for example, spouses) (Cavaye and Watts, 2016b; Larkin and Milne, 2017; 2021). This work has been invaluable in informing policymakers and service providers to tailor support to suit the needs of particular carer groups or experiences. For example, a significant scholarship attends to experiences of grief and bereavement, foregrounding carers’ psychological support needs following the death of a loved one, as well as the challenges inherent to (re)constructing life (Aneshensel et al, 2004; Larkin, 2009; Breen, 2012; Cavaye and Watts, 2016a; Kirby et al, 2018; Nathanson and Rogers, 2020). Another prominent area of study has been the relocation of care to hospital or other supported accommodation, revealing the challenges carers experience in transitioning to roles with less control or visibility, and the feelings of guilt related to relinquishing care (Davies and Nolan, 2004; Dahlborg Lyckhage and Lindahl, 2013; see also Walker and Hutchinson, 2019). Research on former carers for people with dementia has similarly illuminated the difficulties carers face in managing uncertainty, obligation, connection and separation (Egdell, 2013; Johansson et al, 2014; Corey and McCurry, 2018).

Across these and other settings, research has demonstrated the considerable ‘after-effects’ experienced by carers, such as poorer health, fatigue and exhaustion, depression, loneliness, and financial precarity, which occur due to taking on a caring
role, continuing or even intensifying after the end of care (McLaughlin and Ritchie, 1994; Larkin, 2009; Cronin et al, 2015; Cavaye and Watts, 2016b; Corey and McCurry, 2018; Watts and Cavaye, 2018). Collectively, this research has highlighted former carers’ unmet needs, including a lack of support in navigating liminal experiences ‘between’ caring and other ‘post-caring’ identities, recognising the effort required to ‘move on’ following care endings (for example, returning to work, retirement or fostering new relationships) (see also Orzeck and Silverman, 2008). A burgeoning literature has also examined carers’ experiences of (re-)entering the labour market, articulating the nexus of health and social characteristics that further marginalise some carers. Importantly, this work reveals how existing structural inequalities that striate workforce participation, in particular, those related to age and gender, can compound or exacerbate the challenges of navigating post-caring employment (Ehrlich et al, 2020; Spijker et al, 2021).

Conceptualising care endings

Care endings are mediated by the sociocultural factors, familial dynamics and moralities that shape understandings and experiences of care more broadly. In the first instance, access and opportunity to organise alternative forms of caring varies, as do opportunities for individuals to extricate themselves from caring roles or re-enter employment (Dahlberg et al, 2007; Egdell, 2013; Spijker et al, 2021). Familial traditions, for example, related to care provision by women in the home, reproduce normative scripts about who ought to provide care and for how long (Keating et al, 2019). Constructs of care as a ‘labour of love’, marital vows that include ‘in sickness and in health’ and ‘till death do us part’, and social norms related to filial piety and intra-family solidarity all (re)produce logics and expectations of/for care (Egdell, 2013; Keating et al, 2019). Notably, these expectations are not universal, varying across cultures and generations (Greenwood et al, 2015; 2019; Chan et al, 2020).

Examining the moralities that underpin day-to-day experiences of caring is particularly pertinent for conceptualising care endings. Scholarship spanning philosophy and sociology has theorised how the virtues of caring (for example, dedication, willingness and the ability to persevere despite increasing care demands) are socioculturally and morally elevated (Pickard, 2010; Kittay, 2011). A ‘good carer’, then, could be one who does not anticipate or desire an end to caring (see also Pickard, 2010). Moreover, (some) care endings are less socially acceptable, or even taboo (for example, leaving a partner who comes to require additional care, or admitting a loved one into supported accommodation) (Davies and Nolan, 2004; Cronin et al, 2015). In other contexts, however, caring can be stigmatised (for example, in relation to leading a self-determined life, supporting someone with a stigmatised condition, living in ‘welfare dependency’ and so on). As such, some carers (for example, young carers) can feel pressure – as ‘good’ citizens – to actively seek a life beyond caring (see also Addo et al, 2021). Conceptualising caring as a moral activity is thus useful in foregrounding the lived experience of the ‘good life’ and ‘good’ caring in practice (Tronto, 1993; Pickard, 2010; Kittay, 2011). Considerations of what constitutes good caring, including forms of obligation, reciprocity and autonomy, are critical for better understanding how moral boundaries shape end-of-care experiences (see also Tronto, 1993; Mol, 2008). Below, we explore carers’ accounts of their experiences and thoughts about the past and future (in and beyond caring). In doing so, we aim
to offer sociologically driven insights into how current and former carers articulate care endings in order to contribute to the growing literature oriented towards making visible the broader inequities and vulnerabilities of (former) carers.

**Method**

Our qualitative, inductive, thematic analysis draws on data from free-text responses to an optional question from a national survey of informal carers (for a summary report, see Carers NSW, 2020). Ethics approval for the survey was obtained via the Human Research Ethics Committee of Macquarie University (Reference Number: 6233). Recruitment of participants for the 2020 National Carer Survey occurred via carer associations’ websites, social media, newsletters, client databases and stakeholder networks, media releases, and paid social media promotion. The survey comprised 73 questions, including: initial screening questions; six sections covering the caring relationship and role, services and support, paid work, and carer health and well-being; and a final ‘about you’ section (Carers NSW, 2020). Survey respondents broadly reflect the geographic distribution of the Australian carer population, though there was a higher response rate in some states (South Australia, New South Wales and Victoria) (Carers NSW, 2020). Within the overall survey sample, 80 per cent of participants were female, the median age was 58 years, 95 per cent identified as ‘Australian’ and spoke only English, 64 per cent were not employed, and 18 per cent had a bachelor degree or higher (Carers NSW, 2020). As such, female carers were over-represented, as were older people, those unemployed or not in the labour force, and those who had lower educational attainment compared to the national carer population, while carers with Indigenous or culturally diverse backgrounds were under-represented (Carers NSW, 2020).

The survey did not specifically focus on care endings, but many respondents explicitly flagged this topic (identified during our initial read-through and related discussion of responses). The research aims and findings addressed in this article are thus inductively derived from our analysis of responses to the final survey question: ‘Optional: Is there anything else you would like to tell us about your experiences as a carer?’ Questions of this nature (for example, ‘Any other comments?’) are frequently included in surveys but rarely analysed (O’Cathain and Thomas, 2004). Here, we sought to ensure that these responses were formally analysed and valued as part of an ethical approach to data and knowledge generation (Decorte et al, 2019). While free-text survey responses – as qualitative data – have been critiqued as potentially lacking richness, such data can yield meaningful insights that are not available via closed questions (LaDonna et al, 2018). Indeed, free-text responses are increasingly recognised for their narrative potential and intrinsic value, and have been shown to be beneficial in allowing participants to expand on an issue by focusing on the ‘why’ and ‘how’, while also offering an outlet to include survey feedback (O’Cathain and Thomas, 2004; Rich et al, 2013).

Our approach to research design and analysis is informed by the interpretive traditions within sociology, focused on exploring the nuances of a range of positions and perspectives amid broader experiences and perceptions. Rather than focus on statistical or comparative analysis, we sought to uncover thematic domains that could help us conceptualise care endings that move across carer ‘groups’ or demographic categorisations. While acknowledging the importance of variation according to
geography, generation and socio-demographic and other characteristics, we aimed to explore and emphasise some of the underlying relations of care and caring in order to develop a better understanding of how moralities and subjectivities might inflect experiences or perspectives on care endings. The analytic process in this article followed a form of ‘informal data sharing’ (Heaton, 2008), as some of the researchers were not involved in the original research study; we were therefore conscious of the importance of robust communication between researchers within the team in order to provide sensitivity around the study context (Hinds et al., 1997). Following the approach to coding development set out by Braun and Clarke (2020), we conducted a thematic analysis via an inductive and iterative process. First, EK and GN familiarised themselves with the responses (divided into two halves) in order to identify broad issues and thematic areas. They then discussed their respective issues and themes, before identifying ‘care endings’ for further analysis. Next, data relating to endings was identified and imported into NVivo 12 qualitative analysis software for systematic coding. These data included responses that described futures/experiences beyond caring, anticipated experiences of life after caring (for both carer and recipient) and reflections on opportunities for paid employment and relationships (or lack thereof). Coding was conducted by EK and GN, then cross-checked; initial themes were developed and refined in order to move towards an overall interpretation of the data. EK and GN were in dialogue throughout the coding process, reflecting on the data and themes in consideration of existing literature. Emphasis was given to the retention of nuances in the participants’ responses, and atypical cases or contradictions were noted (Ezzy, 2002). From here, the themes were further developed, reviewed and refined. Data excerpts were cross-checked with participants’ gender, age, relationship to the care recipient and the characteristics listed for the (up to two) care recipient(s). Unless otherwise specified in the following results, no patterns across the responses were found.

**Results**

The survey was completed by 7,735 carers, 22.6 per cent of whom responded to the final, optional free-text question (n = 1,746). Characteristics of respondents who answered the optional question were compared with those who did not; most characteristics were similar, but differences pointed towards those who responded to the optional question as having more committed or demanding caring roles. Relative to the overall survey sample, these respondents provided more hours of care per week (an average of 78.1 hours compared to 72.8 hours) and provided care to the main recipient for longer (an average of 14.2 years compared to 12.4 years). Independent samples T-tests confirmed the statistical significance of these differences at the p > .005 level. Chi-square tests (with Yates’ continuity correction) on categorical variables revealed that these respondents were also more likely to suffer psychological distress at a higher rate (49.5 per cent compared to 45.7 per cent [p < .01]), as measured through the Kessler five-item psychological distress scale (ABS, 2012), and experience a higher rate of social isolation (35.9 per cent compared to 29.7 per cent [p < .001]), as measured by the Hawthorne friendship scale (Hawthorne, 2006).

Of the 1,746 responses analysed, 32 per cent were from respondents who identified as having a current caring role, 55 per cent were from those who had a current and a former caring role, and 13 per cent were from those who had a caring role in the
past. A quarter (24.3 per cent) were caring for more than one person, 40.5 per cent were caring for a partner, 24.8 per cent were caring for a parent or parent-in-law, and 46.2 per cent were caring for a child (including adult-age children). Almost half (47.9 per cent) cared for someone receiving aged-care services, 62.1 per cent cared for someone receiving disability services and 52.2 per cent cared for someone receiving mental health services. Responses ranged from one word to multiple paragraphs; we identified 498 (28 per cent) related to care endings. In the following, we explore the three key themes derived from our analysis.

‘What if something happens to me?': anticipation and fears for the care recipient

The first theme encompassed responses that articulated carers’ fears for the care recipient’s future. Responses in this theme included anticipations of how the care recipient might manage if the current carer was unable to continue. Comments often described the pressure to persevere with caring amid the compounded challenges of paid work, caring and concern for the care recipient: ‘I need to work to support my family and my dad and constantly feel the pressure to keep going. I worry what will happen to dad if something happens to me?’ (female, aged 43, caring for a parent with frailty, dementia and chronic conditions). This response reveals caring as seemingly highly contingent on the dedication and prolonged commitment of individual carers. This was arguably most pronounced within the expression of fears for the care recipient’s safety and quality of life if such care were to end: ‘I am extremely worried about the future as I realise that her [adult daughter on the autism spectrum] quality of life is totally dependent upon me fulfilling my role as a carer’ (female, aged 59). Similarly, another respondent, caring for a partner with chronic physical and mental health conditions, noted that the onus of care rested on them: ‘I stay because he [partner] wouldn’t survive without me’ (female, aged 55).

While feelings of obligation tied to the well-being and survival of loved ones were common, so too was apprehension around care provision in the eventuality of a cessation of the current care arrangement. As one carer, for her ten-year-old daughter on the autism spectrum, noted: ‘I have no confidence the government would look after my child appropriately if I wasn’t around’ (female, aged 50). The perceived lack of available viable or attractive care alternatives was revealed in responses that foregrounded necessity in/of their care provision: ‘It sucks but it’s necessary, there’s no-one else to do it if I don’t. It tests your commitment, ie: did you REALLY mean it when you said in sickness and in health?’ (male, aged 55, caring for a partner with a neurological condition).

While rarely described as attractive or ideal, informal care was elevated above institutional or other formal care. The excerpts do not necessarily imply substandard or unavailable formal care. They do, however, suggest a link between uncertainty about care endings and perceptions that care by family or known close ties is inherently of a higher quality than that which could be offered by other formal care arrangements: ‘We are Carers because we love our families and know that we will give more to those we care for than paid service providers no matter how well trained and caring they are. We all fear the day when we can no longer carry out our roles’ (female, aged 71, caring for an adult-age child with physical and intellectual disabilities). For parent carers, concerns hinged on how to position children (often at adult age) to ‘best manage’ in
the future (see also Bowey and McGlaughlin, 2007; Walker and Hutchinson, 2019). As one carer to an adult daughter with mental illness and drug and alcohol dependency noted: ‘It is bloody hard work and I worry what will happen to my daughter when my partner and I are gone’ (female, aged 74). In addition, fears related to carer ageing and physical deterioration were common, highlighting the interdependence of older (frail) carers and adults with disabilities: ‘Am healthy and mobile for my age 85. I dread the time I might have to enter care. My chief worry is about my son, now, 42 [with intellectual disability]. How will he cope’ (female, aged 85).

Irrespective of the care relationship (that is, not only carers of adult-age children), responses typically reflected the demands of caring and a lack of hope: ‘Although I love my husband dearly, I feel I am going downhill as fast as him. I can see no hope for the future’ (female, aged 68, caring for a partner with frailty and terminal illness). As these excerpts show, care endings were frequently framed in terms of anticipatory fears for the care recipient and the viability of alternative care arrangements (see also Brennan et al, 2018). Thoughts about when and how care might end played on carers’ minds; many responses included descriptions of feeling anxious or helpless about how recipients would manage in the future. It was clear from our analysis that respondents felt that planning and preparing for the future was challenging, anticipated that feeling well supported was unlikely, and had few opportunities to openly discuss or manage care options. In tandem with such concerns were those related to carer identity within and beyond caring, as we discuss in the next section.

‘I’d love to have my own life again’: prospects for life after caring

Respondents’ worries about their own prospects beyond care formed another key theme within our analysis. Concerns coalesced around experiences of social liminality (Dahlborg et al, 2013; Cronin et al, 2015), including the experience of putting one’s life ‘on hold’, and the consequences therein: ‘Its challenging and sad because we look to a time when she is gone and consider only then will our lives resume, we feel life is on hold until then and there is a lot of guilt in feeling this way. – It sucks’ (female, aged 55, caring for a parent with chronic conditions and dementia). This response reveals the relational and identity-based intersections of long-term care, grief and bereavement (see Breheny et al, 2020). Managing the tensions between obligation, love, guilt and loss was difficult for many carers, particularly where an anticipated care ending marked the death of the care recipient. So too were concerns ever present around post-caring financial and work-related precarity:

I have basically put my life on hold and given up the job I loved to dedicate my life now to care full time for my mother. I no longer have money for even the most basic things in life. I feel incredibly depressed but do my best not to show it. What do I do after my mother passes away, life may also cease for me. (Male, aged 50, caring for a parent with ageing-related frailty and chronic conditions)

Managing prolonged social or professional absence featured heavily in responses, including fears about loneliness, social isolation and financial hardship after caring ended. The limited prospects for employment (or career progression) were highlighted in many responses:
I love being a carer. It’s a role suited to me…. I dislike being so poor, constant financial anxiety…. The fear I’ll give my all to these two now but will have a poor lonely old age myself. No super [pension] to afford a decent facility, no current recognized skills so I can earn a living. (Female, aged 50, caring for a parent with ageing-related frailty and a partner with physical disability and terminal illness)

By the time I am finished with my caring role … who will employ me?? I will be too old to get a job, any job and too young for the pension. I am doomed…. Despite my best efforts, I think I am royally screwed. My reward for all this caring will be living below the poverty line. For the rest of my life…. my savings went ‘poof’. I don’t regret a thing but my future is bleak to say the very least. (Female, aged 55, caring for a parent with ageing-related frailty and physical and neurological conditions)

We saw frequent reference to a perceived lack of tailored government support for former carers. The following response is indicative of many responses that reflected the resentment or despair felt by carers, including limited acknowledgement (on the part of the state and the community/society more broadly) of the skills required for caring, or of the physical and mental toll of such experiences:

There are many carers who dread what will happen to them after the person they care for dies. They are looking at JobSeeker (Newstart) [unemployment benefit] and the financial commitment taken on in consideration of their caree – e.g. rent or mortgage – they could lose their home. For many they have lost contact with career/work and are emotionally and physically long-term exhausted. (Female, aged 64, formerly cared for a partner for 25 years)

Present in accounts of the fears about longer-term financial security were feelings of resentment and hardship relative to discourses of good citizenship and good caring (see also Pickard, 2010). Such responses reflected experiences of injustice and inequity, in that carers did not feel that they received sufficient service support, despite demonstrating their good citizenship by caring. Several carers positioned their financial precarity (and related sacrifices) relative to equivalent savings for the taxpayer or government:

I am most concerned that if I survive my partner, my income will reduce to the point where I will be unable to pay my bills. I have no idea how much I will have to live on. Since I cared for him for 12 years, it seems a shame that I might have to live in poverty after saving the tax payers so much money over so many years. (Female, aged 72)

While many responses pointed to concerns about particular support services and systems, there were also concerns about a lack of help or recognition of carers’ work and effort on the part of individual families, communities and society more broadly. Such reflections were particularly pronounced in women’s responses:

No one ever asked me if I wanted to be a carer, they just assumed I would do it, or, I had to try to pick up the pieces of systems not working, because of the terrible consequences of letting someone fall through the gaps. Carers
are treated abysmally by society and even by their own families. We are truly invisible. We are usually female, we age, and we end up poor…. When I reach retirement age, I am looking at having no-one from my family left, no money, no super, and being homeless. Possibly it won’t get this bad, but that will only be by chance at this point, because I have little power to alter this future. (Female, age not disclosed, caring for a parent with ageing-related frailty and chronic conditions, and a sister)

The gendered division of caring labour is noteworthy here given the prevalence in our analysis of female respondents concerned about future work and relationship prospects. Prolonged absence from the workforce, in part, due to a lack of recognition of caring as ‘work’, leaves women disproportionately vulnerable to financial insecurity after caring ends (*Jenkinson, 2004; Larkin, 2009; Ehrlich et al, 2020*).

‘Care doesn’t stop, it just changes’: responsibility, recognition and loss

The final theme derived from our analysis captures the complexity and blurriness of subjective experiences of care endings, and of what constitutes a ‘carer’. Many respondents resisted being positioned as ‘former carers’ (see also *Davies and Nolan, 2004*), for example, emphasising the considerable ongoing labour required in coordinating care with others, including long after full-time care relinquishment: ‘Even though my son is living in supported accommodation, it does not mean my caring has stopped. I work in conjunction with his service provider to ensure they are carrying out their caring role effectively’ (female, aged 63, who cared for son for 26 years). This response implies distrust of service providers, particularly in the difficulties of resolving the relinquishment of care to institutions (*Caron and Bowers, 2003; Davies and Nolan, 2004; Johansson et al, 2014*). Moreover, the following response and many others highlight the moral imperative for carers to demonstrate their ongoing dedication to ‘good’ care through maintained input/contribution: ‘It doesn’t end once the person lives in a RACF [residential aged care facility]. They vary sometimes especially with people living with dementia. I still visit everyday/check meds etc (comms [communications] are not very efficient)’ (female, aged 57). The ongoing labour and additional stress of moving a recipient into residential care underlined the challenges for carers in retaining control and/or insight around the quality of care provided:

Once the person you care for goes into residential care, you[r] care doesn’t stop, it just changes and you are battling in a system that is understaffed and lowly valued in society. In short you relinquish control over to people who will never be able to care for your loved one as you can. You have more time for yourself but more worry about what happens or doesn’t happen in care. Not quite as challenging as caring at home but still dominates the carers life. (Female, aged 60, former full-time carer for a parent)

Responses like those earlier reveal the ‘battle’ carers felt they must engage in, not only to maintain control around good-quality care, but to retain recognition as a carer with ongoing responsibilities and demands. Carers’ emotional strain in experiences of relinquishment was very clear: ‘Only that when it comes to the end of the caring journey, nothing can prepare you adequately for the emotional upheaval [sic] of
navigating the aged care sector and getting your loved one [wife with dementia] into professional care’ (male, aged 70). Many responses highlighted the struggles carers experience with labels such as ‘former’ or ‘ex-carer’, as well as the related (lack of) support provision. Some respondents addressed the perception that support services were inaccessible for carers after full-time/at-home caring had ceased, describing this time as particularly isolating:

As a now ex-carer, I feel like I have been cut off from many support services as they focus solely on carers who are still actively caring. I’ve spoken with other ex carers and they feel the same. The time that carers have the most pressing need for support is when they are no longer carers. (Male, aged 60, who cared for a partner with dementia)

The isolation experienced by ‘ex-carers’ was articulated by several bereaved carers, who described the challenges that bereavement presented, not only in terms of the loss of the person, but also of carers’ own loss of purpose, self and role/job: ‘When a partner dies, you lose not only this person you love, you lose your job of caring for that person, life becomes meaningless’ (female, aged 58, who cared for a terminally ill partner). These and other responses resonate with what Jenkinson (2004) and Larkin (2009) have termed the ‘post-caring void’:

As a carer that has lost a loved one I felt that after mum passed you lose your identity … you are no longer a carer and seem to be thrown to the wolves of centre link [Centrelink is the Australian government agency responsible for social support payments] to be told you have to now find a job?? I found this very overwhelming whilst trying to organise a funeral and sort out a will which was being contested from a younger sibling, on top of trying to sort out my own health issues. (Female, aged 62, who cared for a parent for more than a decade)

The preceding excerpts point to the difficulty in anticipating or preparing for post-caring life, as well as a lack of guidance or resource allocation oriented towards the periods following care (see also Caron and Bowers, 2003; Orzeck and Silverman, 2008). Moreover, they allude to the complexities in pathways out of caring, eased or impeded by socio-structural and relational factors.

Discussion

In this article, we offer grounded insights into carers’ perspectives and experiences related to the pathway out of care, what we have called ‘care endings’. Reflecting on the breadth and detail provided across these data, we posit that this optional survey question offered an outlet for responses that might be considered private, taboo or hard to talk about. As such, these responses perhaps indicate a lack of opportunity or support for carers to discuss, prepare and plan for endings within and outside their families (see also Brennan et al, 2018; Walker and Hutchinson, 2019). Our analysis elucidates the normative pressures and moral subjectivities that circulate around care endings. Carers must navigate often competing discourses, resolving respective moral imperatives related to duty and obligation with those of autonomy and choice (see also Mol, 2008; Pickard, 2010); as one respondent wrote: ‘I am conflicted by wanting “a life” and being needed as a carer’. Our findings indicate a range of practical concerns
and considerations – financial and employment precarity, as well as social isolation. Put simply, many carers expect their life after care to be profoundly difficult and to feature an entanglement of loss, isolation and precarity. Importantly, our analysis also points to inequalities within and across the experiences of carers, where pathways out of caring might be more straightforward for some than for others. The responses of many women, for example, underline the persistence of traditional moral expectations related to care provision (see also Ehrlich et al, 2020).

Concerns about how caring may end are shaped by constraints that coerce or impose particular conditions under which care will be relinquished. In practice, though, these imagined conditions may not constitute a clear or complete end to caring roles or responsibilities (nor may a complete end to care be desirable). The number of respondents who highlighted the continuation of caring beyond full-time relinquishment, along with those who had experienced multiple caring roles, complicates the very notion of an ending (Larkin, 2009; see also Walker and Hutchinson, 2019). The subjective determination of an ending to a care relationship – by family, by the state and by carers themselves – is thus worthy of careful and ongoing discussion. How carers ‘fit’ such categories or labels, including the various legacies of carer identity, requires consideration in terms of who ought to be able to access support and relevant services. Moreover, our data raise broader questions around whether carers should be labelled as ‘former’ or ‘ex’ based on the conclusion of various duties, roles, responsibilities or identities. In many ways, these ambiguities foreground the precarious positionality occupied by carers, pointing to the importance of sustained research and policy attention on making ‘hidden’ experiences more visible (see also Orzeck and Silverman, 2008; Knowles et al, 2016).

Many of the responses included in our analysis portray a landscape characterised by a perceived lack of alternatives for care and support, whether formal or informal. Given the challenges faced by carers, and the subjective variations in what constitutes an ‘end’ to caring, it is critical that support foregrounds carers’ well-being, agency and autonomy, moving beyond a focus on making caring roles more ‘sustainable’. We note here the distinction (in our analysis as in the wider literature) between care endings and carers’ desires for respite or more assistance; we do not wish to understate the importance of improving health and social support to better support those who wish to continue caring. Here, we argue that much greater improvements are also required to support the transition of carers (and care recipients) out of particular caring scenarios or roles. Moreover, our findings suggest a clear and urgent demand for the support needs of former carers to be more explicitly recognised in policies. Integrating a range of services that can comprehensively support experiences of loss and bereavement, (re)entry into the labour market, (re)development of social support and relationships, and preparation for future transitions is critical. Continuity of support throughout and beyond care endings (however partial) is also crucial for alleviating carers’ fears related to being cut off from services once caring-related tasks or roles conclude. In this way, support services that include resources or guidance for planning and managing the pathway out of caring, we argue, are critical for improving the well-being, autonomy and socio-economic positioning of carers. Development and implementation of tailored policies that reflect the importance of supporting former carers is also needed. This is especially pertinent given our finding that those currently caring broadly anticipate the challenges that have been shown to be experienced by former carers. In this way, our research complements studies focused on former
carers by highlighting the congruence between expected or anticipated worries and the difficulties experienced following a care ending (Cronin et al, 2015; Watts and Cavaye, 2018; Walker and Hutchinson, 2019; Larkin and Milne, 2021).

A strength of our study lies in our inclusion of, and focus across, diverse care relationships and contexts. Our study is also limited in several ways. Although the number of unsolicited responses on care endings suggests its importance as an issue for carers, our analysis is limited to ‘fixed’ free-text responses, and, as such, we cannot unpack these issues or further explore them with individual carers (Harrop et al, 2016). Our analysis also consists only of those carers who voluntarily participated in a survey, in English, and included ‘optional’ insights by way of their free-text responses. Moreover, previous research has suggested that those who choose to answer open questions may be more articulate or more interested in the survey compared to the respondents overall (O’Cathain and Thomas, 2004); as shown earlier, some significant differences were observed for the respondents in this survey. As such, the sample, while national in reach, may not represent the experiences of those less visible, less interested or with less intensive caring roles, and thus may not reflect the experiences of more vulnerable or less accessible carers across Australian communities. Targeted future research aimed towards generating in-depth understanding of the experiences of less visible or accessible carers will offer important additional insights.

Conclusion

Informal care, so often, is variously perceived and experienced as work, as relation, as duty, as caring ‘for’ and as caring ‘about’. These variations, we argue, also shape care endings; such endings thus reflect broader subjectivities that circulate around dignity, justice and dependency, both within and after caring (Tronto, 1993; Kittay, 2011). Attending to carers’ anticipated concerns, hopes and expectations for care endings offers insights that can be used to develop more effective pathways out of caring. Importantly, such a focus can inform how to better support those who wish to continue caring, as well as understand the experiences of carers as they navigate life after caring (Caron and Bowers, 2003; Larkin, 2009; Breen, 2012; Cronin et al, 2015; Nathanson and Rogers, 2020).

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Conflict of interest

The authors declare that there is no conflict of interest.

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