Title: Caring precariously: An interpretive description of palliative care and welfare worker perspectives on end of life carers navigating social welfare needs

Abstract:

Background: Caring at end-of-life is associated with financial burden, economic disadvantage, and psychosocial sequelae. Health and social welfare systems play a significant role in coordinating practical resources and support in this context. However, little is known about social policy and interactions with public institutions that shape experiences of informal carers with social welfare needs at end-of-life.

Aim: To explore ways in which palliative care and welfare sector workers perceive and approach experiences and needs of carers of people with life-limiting illnesses who receive government income support or housing assistance, in an area of recognised socioeconomic disadvantage.

Design: An interpretive descriptive study employed in-depth, qualitative interviews to explore participants' reflections on working with carers of someone with a life-limiting illness. Data were analysed using the framework approach.

Setting/participants: Twenty-one workers employed within three public services in [region] were recruited.

Results: Workers articulated understandings of welfare policy and its consequences for carers at end-of-life, including precariousness in relation to financial and housing circumstances. Identified resources and barriers to the navigation of social welfare needs by carers were categorised as personal, interpersonal and structural.

Conclusions: Caring at end-of-life while navigating welfare needs was seen to be associated with precariousness by participants, particularly for carers positioned in vulnerable social locations. Findings highlighted experiences of burdensome system navigation, inconsistent processes and inequity. Further exploration of structural determinants of experience is needed, including aspects

of palliative care and welfare practice and investment in inter-agency infrastructure for supporting carers at end-of-life.

Key statements

What is already known about the topic?

- Significant financial burden and economic disadvantage are associated with caring at end-of-life

- Government income support benefits may be difficult to access and associated with financial hardship.

- Social policy and liberal welfare states possess potential to contribute to social and health inequalities, yet are underexplored in the context of caring at end-of-life.

What this paper adds

- Participants highlighted experiences of heightened precariousness and structural burden associated with welfare system navigation at end-of-life

- Vulnerable social locations, alongside features and consequences of social welfare policy and administration, were associated with carer precariousness

Implications for practice, theory or policy

- Further practice and research attention regarding structural determinants of experience for vulnerably positioned carers at end-of-life is warranted.

- Structural approaches that facilitate connection between palliative care and welfare sectors, and greater differentiation of welfare policy and processes for end of life carers are needed.

Background

Informal caring at end-of-life is associated with challenging psychological, physical and social implications.[1,2,3] The associated cascading "host" of issues often leads to involvement with services beyond specialist palliative care,[4,5] especially where there are complex socio-economic concerns. Social welfare needs related to income support and housing, alongside related interactions with government agencies in countries with public welfare systems, have the potential to shape carer experience at end-of-life.

The economic impact of caring at end-of-life is known to be significant, with "financial pain" related to varied economic changes and hardships associated with dying and bereavement.[6] A systematic review established that financial costs of caring at end-of-life are substantial and can contribute to multidimensional carer burden.[7] Consequences are heightened for low socioeconomic groups, with income and net worth expended in end of life caring proportionally higher in low-income groups,[8] and potential to exacerbate health inequalities.[9] Yet, interactions between end of life carers and social welfare systems have received limited attention. A UK-based investigation of the use of health and social services in the year before death reported a low uptake of income support benefits.[10] Further, findings from a study of financial costs incurred by family caregivers within palliative care in New Zealand suggested entitlements needed to be easier to understand and utilise.[11] A comparison of sources of financial support for family carers at end-of-life across six countries established that government financial support was characterised by complex application processes and eligibility criteria and barriers to receiving benefits.[12] Within an Australian study, all participants receiving government assistance reported economic hardship, and government welfare programs were found to lack flexibility to accommodate the changing and complex needs of dying patients and their carers.[13] Housing insecurity and policies have also been identified as contributing to distress for Canadian carers at end-of-life.[5]

Social policy is known to potentially increase inequality,[14] with liberal welfare states (such as Australia, Canada, New Zealand, UK and USA) understood to contribute to social and health inequalities.[15] The provision of modest, means-tested benefits are a central feature of these welfare states.[15] Welfare systems constitute structural determinants of carer experience that may perpetuate disadvantage, or "institutional inequity."[16] Patients and carers positioned as "structurally vulnerable," due to intersecting social and structural forces that constrain decision-making, frame choices, and limit life options,[16,17] may be exposed to experiences of layered disadvantages at end-of-life,[18,19] and in bereavement.[20] Further exploration of structural conditions such as welfare policy and public organisations is warranted,[15] specifically in relation to vulnerably positioned carers.

Aim

This study sought to explore ways in which specialist palliative care and welfare sector workers understand and approach experiences of informal carers of people with life-limiting illnesses, receiving government income support or housing assistance in [region]; This region includes areas of relatively high socioeconomic disadvantage[21] with lower household incomes, higher unemployment rates than metropolitan averages, and intergenerational poverty.[22] The engagement of workers was anticipated to offer novel insights on systemic issues with potential to inform practice and policy. Subsequent to the current study, bereaved carers from the same community were interviewed and findings are yet to be reported.

Methods

A social constructionist perspective shaped the research design and analysis, viewing meaning as subjective; created through interaction rather than discovered.[23,24] This methodological approach underpinned the use of interpretive description,[25,26,27] which values exploration of contextualised meanings " that may yield application implications"[26] within specific fields.[27] Stakeholders within

public palliative care and welfare services in [region] were identified and consulted by one researcher with twelve years clinical experience in this region (XX). Ethics approval was obtained from [anonymised for review]. Stakeholders were invited to share study information with potential participants identified within the palliative care service, and local offices of two government welfare organisations responsible for administering income support and public housing through face to face, phone and online processes. This purposive approach was adopted to target workers who met inclusion criteria (i.e. occupying roles involving policy administration and/or support of carers of people with life-limiting illnesses). Upon expressions of interest, one researcher (XX) confirmed eligibility and scheduled interviews in private rooms within respective organisations. Recruitment and interviewing was undertaken over five months from November 2018.

In-depth interviews were guided by a framework with open-ended question prompts; to facilitate co-creation of meaning within the practice context.[27,28] One researcher with a background in social work conducted interviews (XX), supervised by three researchers with backgrounds in nursing, social work and psychology (XX, XX & XX). This collective experience supported capacity to anticipate and manage challenging issues that may arise during interviewing. Written informed consent was obtained from all participants, with consent explained as an "open" process.[29] Interviews were audio-recorded and transcribed verbatim excepting one interview where detailed notes were taken, as the participant expressed discomfort with audio-recording. Transcripts were entered into NVIVO 12 for analysis.

The framework approach[30,31] provided "analytic guidance"[27] in concurrent analysis and data collection. Analysis was undertaken in iterative stages,[30] to develop a coherent conceptual description of thematic patterns.[26,31,32] One researcher (XX) led analysis and engaged in ongoing discussion with the other researchers to enhance analytic rigour. A preliminary thematic index was developed[30] through in-depth review of a sub-set of five randomly selected transcripts. All

transcripts were reviewed against this index, which was refined as analysis progressed. Subject matrices on identified themes were created and synthesised in a summary framework. Participants were invited to provide commentary on this framework before further refinement in an attempt to return purposefully to sources;[27,33] and reflect meaning creation as a "collective" endeavor." [34] Through discussion between researchers, it was determined that a level of saturation of themes was reached given themes began to be repeated as analysis progressed.[35] It was anticipated that further recruitment would not necessarily yield significantly richer understandings.[36]

Results

Palliative care workers (n=7) from three health service sites and welfare workers (n=14) from two welfare organisations were interviewed. One interview was undertaken via telephone. Interviews lasted between 34 and 75 minutes (mean, 55.81). Participant characteristics are summarised in Table 1.

Features and perceived consequences of relevant welfare policy

Participants identified welfare policy of relevance to carers of people with life-limiting illness, administered by two organisations (Table 2). Carers Payment and Allowance were the primary income support benefits discussed. Commentary from several welfare workers related to the inability to necessarily back-pay these payments to the point at which carers first initiate a claim. This change was reportedly implemented two years prior to the period of interviewing, and was described as potentially contributing to financial disadvantage. Regarding housing, understandings of policy governing the transfer of public housing tenancies from a dying person to another family member or carer were varied. Welfare workers confirmed that applications to transfer a tenancy to a carer or family member from a tenant with life-limiting illness could not be made prior to the tenant's death, contrary to the apparently incorrect understanding of several health workers who indicated they still encourage carers to seek to be "added" to tenancies pre-death.

Perceived consequences of welfare policy for end of life carers were explored (Table 3). Participant observations were of "precariousness," or a sense of insecurity and instability for carers at end-of-life that stems from "vanishing" (lacking or difficult to access) resources, from multiple angles.[37] Workers associated financial precariousness with aspects of policy, where the amount of income support payments did not adequately meet living costs, or where carers weren't eligible for payments despite already experiencing financial strain and significant illness-related costs;

> *"I find usually, the amount of (income) support they get, it doesn't even help cover, especially with their medical costs and stuff... I've even had patients and carers sometimes say it's almost worth staying at work somehow if possible to be able to survive." Palliative Care Worker, P7*

Welfare processes, such as lengthy and sometimes delayed determinations of income support claims (e.g. at one time, carer benefits were taking more than 16 weeks to process), were seen to be related to persistent financial strain and uncertainty; undermining management of ongoing living costs. Online processes were seen as difficult and financially disadvantageous for older carers or those with lower literacy, who may delay or avoid applications. Many participants noted uncertainty related to housing, with some carers reportedly ruminating about the possibility to be relocated from public housing following the death, fearing dislocation from informal supports and their home in bereavement. Several workers commented on the reduced affordability of private rental at end-of-life for carers and patients, due to limited or pending income support;

> *"...a lot of people are in a private rental, and their income has dropped dramatically and they're either both on income support or they've both got no income and are waiting for income support. So we've got that crisis of, someone working, (then) not working; primary income earner, they're now the carer of that person and then they're technically not going to*

be able to sustain, even with the income support benefits, the income that's needed to

sustain their private rental." Palliative Care Worker, P5

Participants associated the nature of income support processing with significant backwash for

carers, including distress, distrust and anger arising from lengthy wait times and delays, and at

times, death of the unwell person prior to approval. Inconsistent information provision about

payments and varied approaches to discretion and expediting claims were also identified as sources

of mutual frustration for carers and workers;

> *"And you feel like you're the meat in the sandwich where you're trying to follow the policy*
>
> *but you're also feeling for the customer… they are like, you know, dire straits, no money,*
>
> *they've had to give up work and things like that to look after this person…" Welfare Worker,*
>
> *W11*

The provision of incorrect advice due to workers lacking understanding of welfare processes was

related to carers not applying for benefits, or being unaware claims can be expedited. The work of

"system navigation", arising from accessing and coordinating health and social support aside from

formal system navigators[38] was seen to be necessitated by welfare system features, including

burdensome bureaucratic requirements, difficulties contacting agencies, and challenges related to

gathering sufficient medical evidence to substantiate the life-limiting nature of illnesses. Certain

(sometimes intersecting) social locations were repeatedly identified by participants as more likely

to struggle with this system navigation, and thus more likely to experience disadvantage (see

findings regarding barriers, below).

Perceived resources and barriers in navigation of welfare needs

Participants viewed certain personal, interpersonal and structural conditions as resources that

promoted effective navigation of welfare needs at end-of-life (Table 4). Carers with sufficient

"system literacy" (possessing skills and attributes in system navigation) and a willingness to

Commented [A1]: Is there a different word you can use (implications?)

practically prepare for death (e.g. completion of will, funeral planning) were seen as possessing qualities that contributed to proactive system navigation and follow up of issues. Strong connections with informal support networks were seen to facilitate access to practical assistance (e.g. transport to attend organisations) and advocates to whom tasks of system navigation could be delegated. Identified structural resources which supported carers' navigation of welfare needs included policy literate health and welfare workers with sound policy knowledge and the capacity to clearly communicate relevant information, and welfare workers who practiced discretion, particularly in response to financial strain at end-of-life. The engagement of "system mentors" (e.g. hospital social workers) was seen to be protective; improving the capacity of carers to navigate systems, and facilitating access to advocacy and information at end-of-life;

> *"They support their clients and they give supporting letters which actually help us because we need everything documented in the file… We don't know their medical condition or... their history of life, right?" Welfare Worker, W2*

Responsive welfare agency culture was characterised as involving flexible engagement with carers (e.g. home visits to follow up rental arrears at end-of-life), and tailored processes, (e.g. expediting income support claims). Strategies which cultivated connection between health and welfare sectors were described as supporting relationships of care and an empathic understanding of other practice contexts that contributed to positive outcomes for carers – including interagency meetings and collaborative approaches to complex areas of need. An example shared by one palliative care worker highlighted an enhanced practice relationship arising from the profound impact of a joint assessment undertaken with a welfare worker;

> *"She (welfare worker) rang me the next day, she goes, "I don't know how you guys do what you do because that has shaken me." I said, "That's the coalface of our work, but I need to understand the coalface of your work." And then from there, we've, mutual respect… she*

said meeting (the patient and carer) changed the whole way she thinks about the referrals that we're sending. Because what does cancer mean to people? What does metastatic disease mean? What does homelessness mean? They deal with homelessness all the time, but what does it mean?" Palliative Care Worker, P5

Several workers also discussed the way in which senior welfare leadership with power to influence culture (e.g. around applying discretion) shaped in-office welfare agency culture, and positive outcomes for carers.

Specific barriers were viewed to hinder navigation of welfare needs at end-of-life. Workers associated certain social locations related to education, ethnicity and class with precariousness. Carers with lower levels of literacy or from non-English speaking backgrounds were seen to experience more difficulties completing claims, managing online processes, and comprehending their rights. Lower levels of systems literacy, characterised by a lack of policy and process knowledge, and sometimes the erosion of personal agency arising from cumulative and negative experiences of welfare agencies due to intergenerational poverty, were viewed as leading to a sense of resignation to poor outcomes;

"The people won't do anything about it (following up problems with claims and income support) because they don't know how to agitate. But if you did it over in (another, more affluent region), there'd be a demonstration and decisions would be reversed. But it doesn't happen in places like this, you know. Because people just don't do it, they just accept, which is awful." Palliative Care Worker, P4

Additionally, the context of caring for a deteriorating family member was seen to contribute to emotional overwhelm and diminished capacity to attend to welfare concerns;

"…they've got other priorities. They don't want to come and sit here. I mean, like if you look outside (into front of welfare office), if you were to walk in and you've got someone that's

> *dying at home, you're not going to stand in that queue. You just got to walk straight back out." Welfare Worker, W11*

Isolation from informal networks (e.g. due to geographical distance, estrangement) was viewed as undermining support with system navigation. Structural barriers included health workers lacking policy literacy and clarity about eligibility for benefits; relying on incorrect information or avoiding proactively providing information;

> *"Sometimes the information you get… is unclear… what's printed out there and accessible to the everyday person, in the past to me hasn't been very penetrable. It hasn't made a lot of sense. It's been a little unclear about what (the) entitlements would be. That's why I'm often saying to people, "Yeah, go in (to the welfare agency in person), you have to talk about what's particular to your circumstances."" Palliative Care Worker, P1*

Participants identified aspects of transactional welfare agency cultures that hindered system navigation at end-of-life, including lengthy wait times on the phone and in-office. A number of workers commented on payment delays due to doctors submitting incomplete or insufficient evidence to successfully "prove" an illness is life-limiting. Other noted system limitations included limited psychosocial professionals within health services, to facilitate needed advocacy at end-of-life. The fragmentation of services through reduced inter-agency connections was described as contributing to the erosion of working inter-agency relationships, with good outcomes for carers at times reliant upon connections between particular workers that were not consistent, nor equitable;

> *"You don't want it, I suppose, to be relational in that way, just depending on one person being very helpful. You want a system that works where health employees can liaise with other government agencies in the best interests of our people." Palliative Care Worker, P1*

The processing of income support claims at external sites (rather than in local offices) was also described as a barrier to enabling frontline workers to accurately update carers on the progress of their claims;

> *"Sometimes you do sound like a broken down record and it sounds really, really bad because you don't want to sound like you're fobbing off a customer for any purpose. But I think that's how government's made it. Like you know, at one point in time, every office, any claims that came in, (the local office) was responsible for the processing and they were accountable to get those things done on time. Whereas now… someone in (other cities around country) could be processing anything from anywhere around Australia… It just makes us feel that, "Are we giving the customer the right message? Are we giving them those correct timeframes?" Welfare Worker, W11*

Participants also highlighted diminished infrastructure between different agencies, with lacking direct telephone connections between workers and reduced networking opportunities undermining support coordination.

Discussion

Main findings and implications for policy and practice

This study presents nuanced understandings of the navigation of social welfare needs while providing informal end of life care, in an area of relative socioeconomic disadvantage. To our knowledge, perspectives of palliative care and welfare workers have not been explored in this domain. Synthesis of their reflections offers insights regarding structural factors that may shape experiences of system navigation and caring at end-of-life. Welfare policy and processes were associated with a constellation of concerns, with potential to contribute to "structural burden" for carers, or stress arising from negotiating complicated and fragmented systems,[38] and psychosocial precariousness.

Observations regarding the consequences of financial difficulties and employment-related strain encountered by end of life carers are consistent with previous studies.[13,39,40] Identified structural barriers such as complex and burdensome application systems and delayed benefits reflect findings that government financial support processes related to end of life caring in developed countries are time consuming, repetitive,[13] and obstructive.[12] Findings provide further support for differentiating benefits for carers from existing "generic" payments, given the unique, dynamic and complex circumstances associated with end of life.[12,13] Findings also suggest end of life caring may constitute another critical period of the life course[41,42] in which the effects of public policy are heightened, especially for those occupying vulnerable social locations. Further investigation of approaches to providing more responsive income support for end of life carers is needed.

The concept of precariousness has been utilised in the study of employment[43] and isolation,[37] and resonates with our findings regarding welfare needs and caring at end-of-life. Diminishing or difficult to access resources, alongside welfare policy and processes, appeared to contribute to multifaceted uncertainty and unpredictability[37] in relation to income, housing and psycho-social wellbeing. Formal health systems have also been found to amplify the vulnerability of carers by failing to acknowledge burdens associated with meeting basic needs at end-of-life.[5] Recognition of this precariousness identifies the role of structural determinants and challenges the rhetoric of individual responsibility that typically pervades health and social care within liberal welfare states, imposing a sense of "moral judgement" on carers[17] who may struggle to successfully navigate forces beyond their influence. In a climate of shrinking welfare states and "economic tightening,"[3] greater attention to consequences of public policy and institutional processes is essential. This necessitates a holistic, "upstream" focus,[44] beyond interventions focused on equipping or educating individual carers to navigate end-of-life. Research exploring longer term socio-economic consequences of structural factors associated with caring at end-of-life is required, as these may be

hidden from the focus of specialist palliative care services and possess implications for bereavement.

Findings point to repercussions of welfare processes for structurally vulnerable carers. Certain social locations related to age, literacy, language and pre-existing poverty appeared to be more likely to be associated with difficulties navigating welfare systems; potentially at greater risk of disadvantage. At end-of-life, poor outcomes related to complex care systems and relationships for the structurally vulnerable[5,19] and considerable inequity in financial support[12] have been identified. Palliative care workers must therefore perceive social needs related to income support and housing as an "essential component(s) of palliative care"[5] and develop current social policy literacy to support timely access to assistance. Additionally, further understanding of the exercising of discretion in the administration of welfare policy is needed, given it appears to benefit carers on an ad hoc basis, cultivating inequity. Access to needed resources should not be facilitated by chance interactions, contingent upon a worker's level of policy knowledge or approach to discretion.

Findings also underscored problematic fragmentation between organisations, with difficulties establishing relationships of care and diminished opportunities for collaboration. There were exceptional examples of working relationships, personally carved out between particular individuals. Yet this again perpetuates inequitable meeting of needs, given "silo-ed" systems have been related to poor continuity of care; and are particularly detrimental for structurally vulnerable populations.[5] Our findings signify the need for systemic investment in cultivating local connections between palliative care and welfare sector workers, such as inter-agency practice groups or forums, and professional development regarding the social determinants of caring and life-limiting illness. Such strategies may not only better serve vulnerably positioned carers, but may provide supportive infrastructure for palliative care and welfare workers in negotiating the personal and professional challenges of working with people in the context of life-limiting illness, welfare needs and grief.

Limitations

As welfare policy is subject to change and varies across socio-political contexts, and given the lack of male participants, findings need to be carefully interpreted. Since this study was undertaken, COVID-19 has also already led to changed welfare administration and policy in Australia, although these changes may be temporary. Regardless, findings affirm and extend the limited existing knowledge in this domain, with implications for other liberal welfare states.

Conclusion

Given the expected increase in demand for palliative care[45,46] with significant consequences for health and welfare sectors, exploration and evaluation of approaches for addressing structural determinants of caring experiences is crucial, particularly in relation to those positioned as structurally vulnerable. Organisational leadership across both sectors is vital to this end, reflective of recognition that "top down" political commitment and policy action across agencies is essential for creating supportive and equitable environments,[47] in contrast to those that perpetuate precariousness for end of life carers.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Ethical approval

Ethical approval was granted from [anonymised for review].

Data management and sharing

Data are stored within [Region] Local Health District, data are not shared. The interview framework can be obtained from the authors on request.

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