**Title:** Bureaucracy and burden: An Intersectionality-Based Policy Analysis of social welfare policy with consequences for carers of people with life-limiting illness

### Abstract

*Background*: For informal carers of people with life-limiting illness, social welfare policy related to income support and housing has been associated with varied psychosocial issues, yet remains relatively under-explored. An intersectional approach offers potential to illuminate diverse experiences and implications.

Aim: To explore the way in which caring in the context of life-limiting illness is framed within welfare policy, to articulate inequities encountered by carers, and to identify policy and practice recommendations.

*Design*: The Intersectionality-Based Policy Analysis (IBPA) Framework was used to situate findings of a broader qualitative study.

Setting/participants: Data were collected via semi-structured interviews with participants who were bereaved carers (n=12), welfare workers (n=14) and palliative care workers (n=7), between November 2018 and April 2020, in an Australian region associated with socioeconomic disadvantage. Five elements of IBPA were applied to the products of analysis of this data.

Results: Use of the IBPA Framework revealed that representations of carers and causes of their welfare needs in policy were underpinned by several assumptions; including that caring and grieving periods are temporary or brief, and that carers have adequate capacity to navigate complex systems. Policy and processes had differentiated consequences for carers, with those occupying certain social locations prone to accumulating disadvantage.

Conclusions: This intersectional analysis establishes critical exploration of the framing and consequences of welfare policy for carers of people with life-limiting illness, presented in a

novel conceptual model. Implications relate to intersectoral development of structural competency, responsiveness to structurally vulnerable carers in clinical practice, and needed policy changes.

# Keywords

Caregivers; Palliative care; Social welfare; Public policy; Intersectional framework;
Bereavement; Socioeconomic factors

## **Key statements**

What is already known about the topic?

- Income support policy for carers of people with life-limiting illnesses is associated with barriers to access, complex processes, and lacks responsiveness.
- Housing policy may be associated with insecurity and psychological concerns for carers of people with life-limiting illnesses.
- There is limited understanding of the way in which consequences of social policy and structural forces may be differentiated for carers pre- and post-caring.

What this paper adds

- Socio-political forces and assumptions were identified as driving policy framing and producing inequity.
- Social locations associated with material and non-material resources shaped exposure to structural burdens associated with the welfare system.
- Intersectional analysis found disproportionate and differentiated burdens and disadvantages associated with welfare policy and processes for carers, described in a conceptual model.

*Implications for practice, theory or policy* 

- Intersectoral development of structural competency within health and welfare domains is needed.
- Strategies that increase clinician capacity to identify and respond to carers positioned as structurally vulnerable are indicated.
- Findings should inform advocacy for changes to welfare policy within Australia and other liberal welfare states.

# Background

In the context of life-limiting illness, caring is associated with economic strain, social isolation, mental health concerns, and inequality<sup>1,2,3,4,5,6,7,8,9,10</sup>. Liberal welfare states (e.g. Australia, Canada, USA, UK) are associated with lower social expenditures, the centrality of the employment marketplace in promoting socioeconomic security<sup>11</sup>, strict entitlement rules<sup>12</sup> and higher health inequalities than other forms of welfare state<sup>13</sup>. Income support within liberal welfare states for carers of people with a life limiting illness (any illness where it is expected that death will be a direct consequence<sup>14</sup>, and illness trajectories may vary significantly) or at end-of-life (where the death of the care recipient is deemed likely within twelve months<sup>15</sup>) is associated with barriers to access, unclear eligibility conditions, lacking responsiveness, and complex processes<sup>2,5,6,7,16</sup>. Housing policy has also been associated with insecurity, distress and the exacerbation of mental and physical health concerns<sup>17,18</sup>. In Australia, income support for unpaid carers has been available since the 1980's 19; with a government pension or allowance representing the main source of income for 24.1% of primary carers in 2018<sup>20</sup>. However, carers' experiences of welfare policy remains relatively underexplored.

An intersectional approach asserts that policy is not neutral, but experienced differently by populations; thus an emphasis on single factors (e.g. gender) may contribute to a false and exclusionary classification of people that does not reflect lived experience<sup>21,22,23</sup>. Seeking to interrogate power structures including policies and institutional forces<sup>21</sup>, an intersectional lens pursues a holistic understanding of complex systems and marginalisation<sup>21,23,24</sup>. Increasing interest in employing intersectionality in equity-driven policy analysis<sup>25</sup> is evident in calls to explore gender inequalities and other social determinants of health at end-of-life<sup>26</sup>, and to address societal forces that perpetuate

stigmatisation of diverse experiences of grief<sup>27</sup>. An intersectional approach offers potential to illuminate the heterogeneity of carer experiences of welfare policy and guide clinical and social care.

### Aim

The aim of this work was to explore the policy framing of caring in the context of life-limiting illness in Western Sydney, to articulate related inequities, and to identify recommendations that might inform policy and practice. The Intersectionality Based Policy Analysis (IBPA) Framework<sup>23,25</sup> was applied to findings of a broader study, given the potential utility of this lens in developing inclusive theorisations about caring, bereavement and structural vulnerability. The products of this IBPA are the focus of this article.

### Methods

*Design*: A broader qualitative study sought to inform approaches that might improve the experience of informal carers of people with life-limiting illness<sup>14</sup>; where carers encountered social welfare policy during and following care provision. Underpinned by a social constructionist perspective<sup>28,29</sup>, interpretive description<sup>30,31,32</sup> framed design.

Setting: The study was situated in Western Sydney, a region associated with relative socioeconomic disadvantage<sup>33</sup>.

Population: Two cohorts of participants were sought; workers from public services in the region (the palliative care service and two welfare organisations responsible for income support and housing, where workers were employed in roles involving support of carers of people with life limiting illness); and former carers known to the palliative care service (where carers were at least three months bereaved, over 18 years, English-speaking, and past or current recipients of welfare assistance from either or both of the welfare organisations, in the context of the illness and/or death of the care recipient).

Sample: Participants were purposively recruited according to the above criteria.

Within the involved services, information about the study was circulated among workers by stakeholders consulted by one researcher (KB), and expressions of interest were invited.

Formers carers were invited by mail to express interest in participation at least three months following the death.

Recruitment: Upon receiving expressions of interest from workers and carers, one researcher (KB) confirmed eligibility via phone and scheduled in-person and telephone interviews. Consent was discussed and obtained in writing at interviews.

Data collection: In-depth interviews were undertaken by one researcher (XX) with fourteen welfare workers and seven specialist health workers, and twelve bereaved carers between November 2018 and April 2020, guided by two respective interview frameworks.

Data analysis: Interview data were initially analysed using the framework approach<sup>34</sup>, with findings reported elsewhere<sup>35,36,37Error! Bookmark not defined.</sup> The IBPA framework (Table 1)<sup>23,25</sup> is designed to reveal critical information for future policy and practice priorities, and was chosen as an analytic framework to undertake further analysis. Given the majority of social determinants of health are shaped by policies beyond the healthcare sector<sup>38</sup>, this approach is fitting for analysis of findings pertaining to welfare policy. Five elements of the framework were identified to be of greatest relevance to the aim (descriptive questions two, three and four, and transformative questions six and seven) and applied to findings of the broader study, including thematic charts and summaries of interview findings, as well as related government policy information<sup>39,40</sup>. Several IBPA questions were identified as beyond the scope of this analysis, including those pertaining to implementation and evaluation. This IBPA was also informed by a priori conceptualisations of structural vulnerability;<sup>41,42</sup> defined as a positionality<sup>41</sup>, produced by unequal social status

and biases within structures of government, institutions or societal networks that contribute to social disadvantage<sup>42</sup>. One researcher (XX) led the IBPA; professionally situated in the field of study; having coordinated the broader study in ongoing consultation with three other researchers (XX, XX and XX).

Ethical issues: Ethics approval for the broader study was obtained from [Anonymised].

### **Results**

what is the policy 'problem' under consideration? (IBPA Q2)<sup>23</sup>: The liberal welfare state shaped the characterisation of caring and bereavement, where forms of government welfare are needed. Welfare policies which were the focus of this analysis are summarised in Table 2. These modest welfare benefits exist to support 'survival'; where engagement in paid employment is difficult and personal resources are insufficient. Life-limiting illness appears to be construed as a threat to active and continuous labour market participation for carers. Several assumptions underlie this characterisation. Firstly, given the structure of some welfare provisions, policy implies that the 'labour' of caring and bereavement is generally time-limited or brief, and not in need of tailored policy responses. Encounters with low rates of payment inadequate to meet living costs pre- and post-caring reflect this construction of caring as transitory, meaning benefits poorly served carers engaged in lengthy, burdensome periods of caring. Complex application processes and delays disadvantaged carers who had exhausted financial resources, or needed to return to the workforce post-caring.

"They (carers) lose all control of the situation. They have very limited control of what's happening to... their loved ones. They're made to feel that they have absolutely no say in what's going on... And then after going through all of that and

with the physical and mental stress that places on them, at the end of the day, when the person passes away, I think they're just left in this limbo ...you know, they need time for themselves to readjust, and yet they're being asked to jump through hoops for the system." Welfare worker (W6)

Insufficient and delayed reimbursement of carers may suggest that the availability of informal care is 'taken-for-granted.'

"(It) took me three months to get the (carers) payment... besides, yeah, ...those couple of weeks, then getting rejected, then going to fill out all those forms again, and yeah, and then I only got back paid from the second time I lodged the form, not the first time, because it got rejected. So yeah. For a measly not even half of what I was earning working full-time." Bereaved carer (C6)

Secondly, welfare policy appears to assume that carers possess similar and adequate capacity for system navigation; the accessing and coordination of support without formal system navigators<sup>43</sup>. Workers and carers typified welfare application and maintenance processes as administratively burdensome, complex (i.e. requiring reasonable literacy in written and spoken English) and overly virtualised (i.e. reliant on reasonable technological literacy). Multiple barriers to system navigation were identified, more so for those who were structurally vulnerable, yet policy features anticipated that individuals possessed capacity to exercise agency and manage significant navigational tasks during heightened periods of stress.

"People's... literacy and, yeah their comfort in dealing with agencies, that's another factor. Cause if they're not confident, or they've been kind of knocked back by different systems over time... sometimes it's just like 'Yeah, it's the system, that's just the way it is, and what's the point in trying.' So I think people's own personal

experiences with those agencies are a factor. If they have mental health issues, or their own health issues, sometimes they just can't, there's no capability to address this stuff. That can actually leave them quite vulnerable, because they're left without a pension, or they're left without adequate housing." Palliative care worker (P1)

Thirdly, there is an assumption that carers during end-of-life and bereavement benefit from 'productivity.' Findings suggest that 'productivity' operates as an implicit and often uncritically held value within the welfare state, driven by the expectation that workforce engagement is protective and positive. This reflects Australian government rhetoric and approaches that esteem employment over 'hand outs'44; restricting access to support. The most pertinent example related to the transition from a carer payment to the lower rate of unemployment benefit in early bereavement, where carers and workers lamented inflexible policy conditions, and formal advocacy was needed (e.g. by health professionals) where there were barriers to employment post-caring (e.g. physical or mental health issues).

"There isn't that middle ground space for people who you know, have experienced the passing of a loved one, and then transition (to an unemployment benefit). I know that they've been given 14 weeks, but sometimes people need more... because participation requirements are for the general population and that means whether it be you've experienced grief, you've experienced trauma ...I think it's just being a little bit more flexible with that, just having a middle ground, and we don't have any programs at the moment for that. I think that would be very helpful." Welfare worker (W12)

"They've got no recent job skills, because they've been caring for such a long time, so
I think those sorts of supports are really lacking for people, because it's also, it's very
hard to link people in to get ready for that time when there will no longer be a carer,

because they don't have the time to do it beforehand, and then afterwards it's like...

you go for a job anywhere, it's like 'What've you been doing for the last 10 years?'

'Well, I've been caring for my sick mom, and she's now passed away.' You're like

'Well, you haven't even completed your education, because you struggled with it. Or

you've completed it with really bad results, so...'" Welfare Worker (W13)

Not being 'productive' or ready to 'participate' seems to be a systemic justification for

punitive penalties for non-compliance with policy conditions.

"...some people may not be comfortable (sharing about their coping in bereavement) so instead of disclosing that to their job services provider, they then just don't turn up. Because they're not sleeping, for example... It's just too much for them and obviously whether it be depression or they're just dealing with the grief, they're not meeting their requirements with their job services provider. So it's now also very strict as well, so they're not making contact with job services provider. At the end of the day... because there's been no contact, after once or twice, their payments are then suspended" Welfare worker (W12)

How have representations of the 'problem' come about? (IBPA Q3)<sup>23</sup>: IBPA enabled consideration of the way in which findings of the broader study reflected the socio-historical context in which systems have framed welfare policy responses to caring and bereavement. Carers and workers described low rates of payment and strict conditions associated with some benefits, seemingly reflective of the prioritisation of 'social investment discourse' in Australia, which reveres connection between carers and the paid workforce, prioritises paid work over caring, and undermines recognition, support, and equality for carers<sup>19</sup>.

"I just feel like I shouldn't be feeling, I should be ready to go back to work, or I shouldn't be grieving, or, yeah, it just makes me feel like I'm doing something wrong

when I'm trying to do the right thing for once [i.e. attending to her own mental health issues, in context of history of past admissions for mental health care and suicide attempts], but they don't make you feel like you're doing... And they don't understand the impact of caring for someone, watching them slowly die [crying]."

Bereaved carer (C6)

"When people say maybe a job will be better for me, but um, it's not. It's not that I don't want to work, it's the mindset of, 'I've got to go to work, I've got to be good.'

What if I start crying at work? They're not going to keep me there, are they? I'll knock off, but they'll go "There goes [name] again, off going home again because she's all upset." I just don't think I could... I started crying coming here, driving coming here [to research interview]... You don't mean to cry, you think everything's all right and then all of a sudden, I don't know, I just think of something of him, because I cared for him so long." Bereaved carer with pre-existing depression, on unemployment payment in bereavement (C5)

Societal devaluing of caring may also influence policy, given informal care is rarely considered worthy of forms of formal recognition (e.g. wages)<sup>45</sup>. Furthermore, fuelled by poorly resourced systems and pursuits to reduce health service-related costs, the role of discourse about the place of end of life care was noted, where home is often constructed as the preferred place of care<sup>46,47</sup>. The somewhat uncritically idealised notion of home as the site of 'successful' care and death<sup>26,48</sup> is imbued with substantial expectations of informal carers. Yet a narrative that esteems caring and dying at home is incongruent with findings that revealed insufficient, poorly navigable welfare benefits that are centered around workforce participation.

How are groups differentially affected by this representation of the 'problem' (IBPA Q4)<sup>23</sup>: Analysis suggested that this policy framing imposes a heavier burden upon some carers, over others. IBPA highlighted the heterogeneity of informal carers of people with life-limiting illness. Fragmented health and welfare systems generated system navigation and structural burden<sup>43</sup>; with the extent of exposure to policy consequences differentially experienced.

Carers possessing specific forms of legitimised or 'dominant' social capital<sup>49,50</sup> (e.g. membership of networks who support navigational tasks and adjustment in bereavement), economic capital (e.g. capacity to afford legal and financial advice) and cultural capital (e.g. skills in system navigation, high systems literacy), appeared to be able to minimise navigational tasks and thus structural burden. Welfare policy framing positioned these forms of capital as valued and normative. Carers best served and most advantaged in welfare system interactions appeared to be relatively affluent, connected, well-resourced and credentialed.

"If you've got a bit of process knowledge and familiarity to the environment makes a huge difference, doesn't it? ... The ease of navigating or at least you can ask the person a question... But perhaps someone coming in off the street. Do they get the same service? Does every person good customer service, does familiarity make a difference?" Bereaved carer with professional experience of government agencies (C2)

"At the final instance it doesn't make a big difference now (having received income support). (It is)... for the sake of people that are really much more in need than us, partly because of our superannuation." Bereaved carer (C11)

Analysis also identified that differentially validated coping orientations led to disenfranchisement of some carers. Processes appeared to advantage carers engaged in forms of instrumental coping; (i.e. through cognitive or behavioural approaches e.g. problem solving and mastery)<sup>51</sup>; viewed by some welfare workers as 'self-helping' and 'compliant'.

"I knew it was necessary. I knew all of those phone calls were very necessary. You need to hold your head together." Bereaved carer (C4)

However, carers engaged in more intuitive coping<sup>51</sup>, or experiencing 'overwhelm' in bereavement due to a deluge of stressors<sup>52</sup> (e.g. physical/mental health issues, concurrent losses/trauma, financial strain); often found navigational tasks obstructive and detrimental.

"You know, I might get up in the morning and I know I've got to ring so-and-so or I've got to make a call to change something, it takes me all day to actually make that call.

And some days I just don't do it. Some days I know there are things I should do, but I can't do it." Bereaved carer (C3)

"When you're going through an intense period of that you need a human to converse with... Someone who can go, 'I'll do that for you. I can make that phone call for you while still you're with me. Let's get that done now.' Because if you're a) exhausted, b) you're not going to be thinking, you're not thinking clearly, c) you'll be emotional, that's my experience. So it's very hard if you're emotional, you don't have clarity of thought, you don't really know what you need." Bereaved carer (C2)

Viewed by some workers as 'not helping themselves,' these carers were at a heightened risk of structural burden and poor support, particularly when already positioned as vulnerable due to other social locations (e.g. Aboriginal background, low English literacy, older age).

What inequities actually exist in relation to the 'problem'? (IBPA Q6)23: Analysis considered the function of intersecting social locations in interactions with systems, identified from summaries interview findings. Data related to social locations were synthesised and summarised in Figure 1, adapted from and informed by the work of Morgan<sup>53</sup>. Figure 1 highlights intersecting axes of privilege and oppression that differentially situate individuals in the landscape of welfare needs, during and following caring, with antipodes representing maximum privilege or oppression. Carers were viewed as occupying specific points of juxtaposition on each of the axes. Some axes constitute locations already associated with inequity, (e.g. lacking English literacy or forms of capital/resources, diverse or minority background)<sup>54,55</sup>, while other axes relate to novel findings about non-material determinants (e.g. the role of cultural capital and coping orientations) that may limit agency. Carers are subject to policy and processes which incorporate classism, ableism, educationalism, ageism, racism, and 'bereavism'56; systemic biases that may fuel social disadvantage<sup>42</sup>. Several social locations were not clearly evident in findings (e.g. gender, sexuality). Given existing evidence (see Discussion), these locations were included yet 'bracketed'<sup>57</sup> in Figure 1, to signal their known significance.

Figure 2 represents a conceptual model of key findings of this IBPA. Figure 2 highlights the way in which identified social locations position carers differently in relation to the welfare system, and drive structural vulnerability. The welfare system is situated within the neo-liberal social, economic and political milieu and assumptions that underpin framing of the policy response to carers. Tasks of system navigation are generated and maintained within this landscape, with potential for structural burden<sup>43</sup> amplified by burdensome policy processes, disproportionately so for carers with an accumulation of locations proximal to oppression (Figure 1). These carers appeared more likely to encounter

precariousness<sup>58</sup>, defined here as increasing insecurity and uncertainty related to diminishing, difficult to access or disenfranchised resources. Unnecessary, unjust and avoidable outcomes resulted, including additional financial and employment-related strain. However the experience of advantaged carers was associated with less exposure to precariousness, and more likelihood of psychological well-being, financial and housing security; given access to valued material resources and validated non-material resources. Advantages were experienced in patterned ways; more so for those occupying an accumulation of social locations proximal to privilege in Figure 1.

Where and how can interventions be made to improve the problem? (IBPA Q7)<sup>23</sup>:

Strategies and interventions at upstream/macro, midstream/meso and downstream/micro levels<sup>59,60</sup> were identified, according to their relevance to welfare, clinical/health-related, or intersectoral domains (Table 3). Reflective of an intersectional lens, recommendations were not focussed on specific axes or social locations, given the propensity of such strategies to fail to address multiple identities and heterogeneous populations<sup>22</sup>. Recommendations were instead informed by a life course approach, which acknowledges that the impacts of public policies may be pronounced at certain periods or transitions within the life course<sup>13,61</sup>; and in times of heightened vulnerability<sup>44</sup>. An in-depth exploration of recommendations in Table 3 is beyond the scope of this article. However, implications of these and other products of the IBPA will be expounded below.

## Discussion

Main findings and what this study adds: This IBPA suggests that inequities, or inequalities that are avoidable by reasonable means<sup>55</sup> and unnecessary, unfair and unjust<sup>62</sup> were experienced in patterned ways<sup>41</sup> by carers of people with life-limiting illness.

Disproportionate and differentiated burdens of welfare system navigation were associated

with the accumulation of precariousness and disadvantage. Certain social locations (e.g. culture and ethnicity, access to education) are already clearly associated with social and health inequities<sup>54,55</sup>, and burdensome encounters with government (through institutions and policy) are associated with psychological and social costs, more so for people with cognitive or psychological conditions, less education, smaller support networks and other vulnerabilities<sup>63</sup>. This IBPA revealed under-explored consequences of policy framing for carers during and post-caring, and identified some driving forces of inequity, including problematic assumptions that underpin policy. Analysis expands limited knowledge regarding differentiated impacts of structural determinants for some carers in the context of life-limiting illness, caring and bereavement<sup>56</sup>, and illuminates intersectoral, clinical and welfare-related implications.

Enhanced coordination between social security and healthcare systems may reduce administrative burden and improve well-being for those receiving benefits<sup>63</sup>. The cultivation of intersectoral relationships through networking, educational opportunities, and partnerships for care delivery possesses potential to achieve more sustainable health outcomes than palliative care services can achieve alone<sup>64,65</sup>. Furthermore, development of 'structural competency' in palliative care and welfare practice would support capacity to recognise the limits of agency and personal resources in traversing complex systems<sup>66,67</sup>. Training in structural competency would assist providers to respond to policies and systems that produce and maintain inequities<sup>68</sup>, not only in caring and bereavement, but in other critical periods of the life course (e.g.: injury, labour market exit)<sup>13,69</sup>.

Furthermore, this IBPA points to the need for palliative care clinicians across disciplines to more proactively identify and respond to carers positioned as structurally vulnerable to mitigate exposure to disadvantage and maximise support opportunities. In the

clinical encounter, methods of obtaining case histories are often blind to structures that shape patient and carer trajectories, with consideration of alternative strategies indicated (e.g. 'arrow diagrams' as a practical, reflective tool<sup>68</sup>). Assessment of structural vulnerability should be integrated with standard domains of assessment (e.g. physical, psychosocial, spiritual), with scope to refer for specialised psychosocial care and advocacy for those disproportionately exposed to forms of social disadvantage at end-of-life and in bereavement.

This IBPA also resonates with existing calls for welfare policy that is more responsive to stressors associated with caring at end-of-life<sup>5,6,16</sup>. Fragmented social service delivery in Australia<sup>44</sup> has generated structural burden for other populations in periods of illness and upheaval<sup>70</sup>. Strategies to improve coordination of benefits and transition processes during times of change are needed across liberal welfare states. It is also widely recognised that the Australian unemployment benefit, currently the second lowest in the OECD<sup>71</sup>; fails to ensure adequate material living standards<sup>72,73,74</sup>. Carers in general represented one in five recipients on this benefit in 2018, when only one in nine Australians were carers<sup>75</sup>; reporting higher levels of psychological distress than other carers and additional costs<sup>73</sup>. Further investigation is promptly necessitated. Palliative care clinicians are uniquely placed to make practice-informed contributions to political advocacy regarding this and other issues impacting structurally vulnerable carers.

Given findings of this IBPA and 'the survival imperative' for structurally vulnerable populations during end-of-life<sup>18</sup>, it seems basic material needs (secure housing, immediate necessities) would likely be prioritised in bereavement, over help-seeking for psychological concerns exacerbated by inequity. Noted barriers to accessing specialist counselling (e.g. high costs<sup>76</sup>, prohibitive gap payments<sup>77</sup>, issues associated bereavement care for ethnic

minority communities<sup>78</sup>), and narrow conceptualisations of psychosocial complexity<sup>79,80</sup> may hinder access to psychosocial support for structurally vulnerable populations. Further development and evaluation of intersectionality- and equity-informed models of bereavement care within and beyond palliative settings is indicated.

Interestingly, this IBPA did not speak strongly to gender and sexual identity. Yet, informal care provision is understood as gendered<sup>81</sup>, with women disproportionately bearing financial and psychosocial impacts of caring<sup>19</sup>, and prone to social disenfranchisement, housing instability and financial disadvantage in the context of life-limiting illness<sup>82,83,84</sup>. Additionally, non-heterosexual carer identity is associated with experiences of systemic discrimination<sup>85,86</sup>, legal and financial complexity, and barriers to support<sup>87,88</sup>. Female and LGBTQI+ carers may encounter systemic biases. These locations were bracketed in Figure 1, however greater understanding of their intersection with caring is needed.

### **Limitations and strengths:**

This IBPA pertains to experiences of the Australian policy milieu in a particular context. While findings subjected to IBPA were rich and in-depth, analysis may have been further strengthened through representation of culturally and linguistically diverse or Indigenous perspectives in the broader study, given the noted diversity in Western Sydney<sup>89</sup> A key strength relates to the novel application of IBPA within this context, with further potential to employ other IBPA elements to implement and evaluate recommendations.

### Conclusion

IBPA has supported a critical and social contextualisation of the framing and differential consequences of social welfare policy for carers; beyond "one-dimensional" or "additive" approaches to analysis. It is hoped that this form of critical discussion advances a

shift in understandings of and responses to social and structural determinants of caring and grieving for palliative care clinicians, and inspires advocacy and research that transforms policy and intersectoral engagement.

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### **Author contributions**

XX led design, analysis, and writing and revision of the manuscript. XX, XX and XX contributed to analysis and critically revised drafts of the manuscript.

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The authors declare that there is no conflict of interest.

# **Ethical approval**

Ethical approval was granted from [anonymised].

# Data management and sharing

Data are stored within [Region] Local Health District, data are not shared.

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