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Review article

Disadvantaged and disenfranchised in bereavement: A scoping review of social and structural inequity following expected death

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ABSTRACT

An emphasis on individual intervention and psychological complexity has characterised research on bereavement following an experience of life-limiting illness. Exploration of "structural vulnerability" as a positionality produced by social and structural inequity could provide insights into areas of practice and policy in need of development. This scoping review sought to summarise published research on experiences of social and structural inequities in the context of bereavement due to life-limiting illness. Underpinned by recognised methodological frameworks, systematic searches were conducted of four electronic databases. Eligible studies attended to bereavement experience following the death of an adult due to life-limiting illness, included consideration of social and structural inequities, and were undertaken in high income countries between 1990 and 2018. Following thematic analysis, a conceptual framework was developed. Of 322 records, 62 full text articles were retrieved and 15 papers met inclusion criteria. Studies highlighted unequal social status in bereavement related to gender, class, sexuality, ethnicity and age, with structural inequity experienced in interactions with institutions and social networks. Studies also identified that the experience of bereavement itself may be accompanied by exposure to disenfranchising systems and processes. Structural vulnerability appeared to be associated with outcomes including psychological distress, social disenfranchisement and practical concerns such as financial strain, housing insecurity and employment issues. Social and structural inequities potentially contribute to layered and patterned experiences of disadvantage and disenfranchisement following expected death, with implications for individual agency. Findings point to the need for consideration of socio-ecological approaches within and beyond specialist palliative care, involving development of more responsive social policy, coordinated advocacy, and systemic capacity building regarding experiences of grief, to better support populations positioned as structurally vulnerable in bereavement.

1. Introduction

Palliative care practice and research has historically esteemed a rhetoric that conceptualises families and informal networks as the 'unit of care', with the identification of psychosocial needs and provision of appropriate support in bereavement considered an integral feature of care provision (Palliative Care Australia, 2018a,b; Hall et al., 2012; Relf et al., 2008). Bereavement following caring for someone with a life-limiting illness is accompanied by the potential for varied and complex psychological, social and physical outcomes (Stroebe et al., 2007, Hall et al., 2012). In particular, the understanding and treatment of prolonged grief disorder has received significant ongoing consideration, with sustained interest in the capacity of palliative care services to undertake screening that may identify potential for complex outcomes in bereavement (Sealey et al., 2015; Garrido and Prigerson, 2014; Neimeyer and Burke, 2012; Ghesquiere et al., 2011). Much emphasis has therefore been placed on individual experience (Allan and Harms, 2010) and evaluating the extent of the risk of poor psychological outcomes experienced by family members. In a critical reflection on the grief literature, Breen and O'Connor (2007) recognised the persistent focus upon intrapsychic experience, "symptoms" and "risk factors," neglecting in-depth consideration of contextual variables in bereavement of a social and systemic nature (Breen and O'Connor, 2007: 209). Allan and Harms (2010) acknowledged that "prevailing" theoretical perspectives have potentially negated the broader complexity of lived experience (Allan and Harms, 2010). This emphasis has endured, as it appears there continues to be limited attention to the "distal determinants of health" (Keleher, 2007b: 54) in the context of bereavement

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following expected death, including the exploration of social and structural inequities that may shape bereavement experience.

The concepts of inequality and inequity have received increasing attention beyond this context. Health inequalities have been defined as the systematic differences in the experiences of individuals and groups that relate to the social conditions in which a person is born, lives, works and dies (Commission on the Social Determinants of Health, 2008), while inequalities that are avoidable by reasonable means are considered to be inequities (CSDH, 2008); or differences that are unnecessary and avoidable, as well as unfair and unjust (Whitehead, 1992: 431). Structural vulnerability is a location created by social and structural inequity, with social inequity characterised as arising from "unequal social status" on account of experiences such as racism, classism and sexism (Reimer Kirkham et al., 2016: 295), and structural inequity related to the bias embedded in "structures of government, institutions or social networks" that leads to "extreme social disadvantages" such as poor housing and poverty (Reimer-Kirkham et al., 2016: 295). Quesada et al. (2011) conceptualise structural vulnerability as a "positionality" that is a function of social and structural inequity; related to one's situation in hierarchical social order and networks of power relationships, with the potential to impose emotional and physical suffering on specific populations in a patterned manner (Quesada et al., 2011) and "disproportionate burdens" related to poor health and social suffering (Reimer Kirkham et al., 2016: 295). Individuals are positioned as structurally vulnerable due to the intersection of personal characteristics, cultural values, and institutional structures (Quesada et al., 2011), with the potential for structural vulnerability to be exacerbated by government policy and resource allocation (Reimer-Kirkham et al., 2016). The language of vulnerability appears to be more conceptually appropriate than the rhetoric of 'risk', given that vulnerability is viewed as an indicator of inequity and inequality and necessitates consideration of social and political structures (Quesada et al., 2011). The concept of structural vulnerability therefore constitutes a useful vehicle for an exploration of the way in which social and structural inequities shape engagement with material and non-material resources, including decision making capacity and scope for participation (McNeil et al., 2015: 169). Attention to material resources such as income and housing remains essential, however it has been asserted that the non-material determinants of health, which may "restrict the ability of some individuals and groups to voice concerns," have been underexplored (Reimer-Kirkham et al., 2016: 297).

Although the association between structural forces and poor health outcomes has been articulated, it has been argued that "the conventional biomedical paradigm largely fails to translate the documentation of social forces into everyday practice and epistemology", with clinicians continuing to treat individuals in a "psychological, cultural and class vacuum," (Quesada et al., 2011: 344). There appears to be limited attention to vulnerability and disadvantage within palliative and end-of-life literature, with a "paucity" of research critically considering the way death and care at end of life are influenced by inequity (Reimer-Kirkham et al., 2016: 294). Stienstra and Chochinov (2012) described the notion of being "created vulnerable." In addition to the vulnerabilities universally experienced when one nears death due to illness, they argued that "hidden assumptions about the circumstances in which people live, including homelessness or poverty, or about specific groups of people, including people with disabilities or recent immigrants, shape care practices and policies," and may "result in differential treatment, or exclusion from what is assumed to be 'normal' or 'standard care practices'" for people in need of palliative care (Stienstra and Chochinov, 2012: 38). Ahmed at al (2004) described a similar phenomenon of "double disadvantage" for individuals with life-limiting illnesses, where "mutually reinforcing," complex and cyclical "patterns of double or more disadvantages" often related to social exclusion, may contribute to barriers to accessing palliative care (Ahmed et al., 2004: 526). Additionally, it has been acknowledged that low socioeconomic populations face greater health needs as well as barriers in accessing end of life care (Lewis et al., 2013) and lack awareness about palliative care and related services (Koffman et al., 2005). Blank and Burstrom (2002) have also asserted that the social consequences of illness (including financial hardship) may actually exacerbate inequalities in health and mortality between different socioeconomic groups. However, while there is limited exploration of the experience of patient populations seeking palliative or end of life care in published work to date, the consequences for the bereaved appear to be less evident.

Literature pertaining to public health approaches to palliative care and bereavement claims that "upstream" actions, involving socio-ecological approaches to public policy, organisational change, and engagement, possess the potential to contend with the social determinants of health, improve well being, develop social capital (Sallnow and Paul, 2015), and build community capacity to manage death, dying and bereavement (Street, 2007: 105). "Downstream" approaches, concerned with "access to primary care, health information and communication," have reportedly not significantly challenged the health status of the most vulnerable populations (Keleher, 2007a: 32). Palliative care services have been challenged to broaden their focus beyond the care of individuals "downstream," and consider "upstream" policy and community service issues (Street, 2007: 105). However, the extent to which current models of palliative care have articulated approaches required to address social and structural inequities that mediate experiences of life-limiting illness, death and bereavement for those positioned as structurally vulnerable remains unclear. Furthermore, there are arguably stressors associated with the post death experience and post caring circumstances following life-limiting illness that are distinct from pre-death experience. Explicit exploration of these concepts and the existing evidence on bereavement experience and structural vulnerability following life-limiting illness is warranted. The purpose of this scoping review was to map the available evidence on experiences of social and structural inequities in bereavement, following the experience of a death due to a life-limiting illness.

1.1. *Theoretical framework*

Critical social theory and an understanding of the concept of disenfranchised grief underpinned the approach to this scoping review. Critical social theory is concerned with integrating individual experience within the broader social and political context, situating an understanding of the "personal" within overarching ideology and material conditions (Allan, 2003). Seeking to interrogate issues related to power, justice and oppression (Fook, 2003), this perspective attempts to understand the ways that the economy, matters of race, class and gender, education, social institutions and cultural dynamics interact to construct a social system (Kincheloe and McLaren, 2003). Cacciatore and Bushfield (2008) identify that the macrosystem or "overarching socio-political system" can shape and legitimise attitudes, values and beliefs through legislation, policy and culture and can therefore function to marginalise particular groups (2008: 378). Thus socially sanctioned norms that "attempt to define who, when, where, how, how long, and for whom people should grieve" (Harris, 2010: 244); may become "prescriptions rather than descriptions" (Allan and Harms, 2010: 72). The integration of a critical social lens provides a framework for the exploration of "social rules" (Doka, 1989, Harris, 2010) about death, dying and bereavement, possibly embedded in social and structural domains, with the potential to contribute to structural vulnerability.

Disenfranchised grief is perceived as occurring where, for varied reasons, the bereaved are not seen to possess the "right to grieve," or where grief is not "openly acknowledged, socially validated, or publicly observed" (Doka, 2002: 5). Disenfranchisement is related to the "individual's experience of deviating from social norms" (Robson and Walter, 2013: 112), which can alienate the griever from external supports, as well as their "own subjective inner experience" (Reynolds, 2002: 356). Shaped by social structures, social policy can be enfranchising in validating and supporting individuals adjusting to loss

(Reynolds, 2002: 351), or disenfranchising to varying degrees - in a hierarchical rather than in a binary fashion (Robson and Walter, 2013). Both critical social theory and the concept of disenfranchised grief provoke contemplation of the way in which capitalistic economic structures and the application of policy and processes that pertain to these structures esteems the pursuit of productivity, consumerism (Harris, 2010: 247) growth, expansion and acquisition (Reynolds, 2002: 354) - in stark contrast to the experience of loss, which is often perceived as signifying vulnerability and weakness (Harris, 2010: 247), and inherently unpredictable and disruptive (Reynolds, 2002).

Informed by critical social perspectives, this review sought to reflexively identify themes pertaining to both social and structural inequities as features of structural vulnerability in published research; considering the consequences for individuals bereaved following life-limiting illness, and situated within systems and networks underpinned by norms and values with the potential to shape experiences of structural vulnerability and disadvantage. Although the primary objective pertained to mapping findings related to a priori notions of social and structural inequity drawn from existing literature and reiterated in the methods below, critical exploration of the findings within the discussion sought to be underpinned by the theoretical lens articulated, attuned to potential implications for the individual agency of the bereaved.

2. Methods

A scoping review of the literature was conducted, guided by Arksey and O'Malley's methodological framework for conducting scoping reviews (Arksey and O'Malley, 2005) and informed by another seminal framework (Levac et al., 2010). Scoping reviews seek to provide a map of key concepts related to an area of research, rather than the best available evidence with regard to a particular question (Arksey and O'Malley, 2005; Levac et al., 2010). This approach is useful in identifying gaps in existing literature where limited work has been undertaken (Arksey and O'Malley, 2005), and in the context of fields where evidence is emerging (Levac et al., 2010). The Arksey and O'Malley (2005) framework consists of the following stages; 1) identification of the research question for the scoping review, 2) identification of relevant studies, 3), selection of relevant studies, 4) charting the data, 5) collating, summarising and reporting results and 6) consultation (described as optional). Quality appraisal of studies was considered to be beyond the scope of this review (Arksey and O'Malley, 2005; The Joanna Briggs Institute, 2015).

2.1. Stage One: identification of research question

Levac et al. (2010) argue that articulation of the purpose of the scoping review and linkage of this purpose with the research question at Stage One promotes clarity regarding the rationale for the review. The objective of this review was to provide a thematic summary of the available literature on structural vulnerability in bereavement following life-limiting illness, identifying potential gaps and possible implications for health professionals, policy makers, and those engaged in service provision, development and research related to palliative and bereavement care. Therefore, the research question was: what is understood of the experience of social and structural inequities in bereavement following an experience of the death of someone with a life-limiting illness? This question was developed in light of recognition that synthesis of the available knowledge related to the experience of structural vulnerability in bereavement following life-limiting illness has not been undertaken. Levac et al. suggest that a “broad question” with a “clearly articulated scope of inquiry” assists with direction, clarity and focus (Levac et al., 2010: 3), defining the concept, target population and health outcomes of interest. Thus previously articulated definitions of social and structural inequity (Reimer Kirkham et al., 2016) and structural vulnerability (Quesada et al., 2011) were essential to guide the search strategy and selection of relevant studies. Again, for the purposes of the review, social inequity was defined as “unequal social status” on account of racism, sexism, classism and similar (Reimer Kirkham et al., 2016: 295), and structural inequity was defined as the bias embedded in “structures of government, institutions or social networks” that leads to “extreme social disadvantages” (Reimer Kirkham et al., 2016 295). Structural vulnerability was therefore conceptualised as a function of both social and structural inequity, recognised as a “positionality” produced by one's location within a “hierarchical social order of diverse networks and power relations” (Reimer-Kirkham et al., 2016: 294) with the potential to impose suffering in a patterned manner (Quesada et al., 2011). For the purposes of this review, “life-limiting illness” was defined as “illnesses where it is expected that death will be a direct consequence of the specified illness,” (Palliative Care Australia, 2018b: 6). In considering which facets of the research question were particularly important, a “series” (Archibald et al., 2016: 4) of sub-questions were developed:

- Which social and structural inequities (as intersecting features of structural vulnerability) have been explored in this literature?
- Which bereavement consequences have been explored?
- Have responses or actions to structural vulnerability been suggested?
- Which areas are identified as gaps in research and practice?

2.2. Stage two: identification of relevant studies

A systematic search of electronic library databases of relevance to the focus of the review (Medline, EBSCO CINAHL, SocINDEX and Social Work Abstracts) was conducted using a search strategy developed from the research question, in consultation with a research librarian. The electronic search was limited to items published in English, from January 1990 to June 2018. Three domains informed the search terms utilised, which included MeSH terms as well as others:

2.2.1. A focus on bereaved populations

Terms included ‘Bereavement’ or ‘Bereaved’ or 'Grief.’

2.2.2. The context of palliative care (ie, life-limiting illness)

Terms included ‘Palliative care’ or ‘Terminal care’ or ‘Hospice care’ or ‘End of life’ or ‘End-of-life’ or ‘Supportive Care.’

2.2.3. Exploration of structural vulnerability as a function of social and structural inequity

Terms included ‘poverty’ or ‘socioeconomic factors’ or ‘inequity’ or ‘inequality’, ‘income’ or ‘income support,’ or ‘unemployment’ or ‘employment,’ or ‘housing’ or ‘public housing’ or ‘homelessness’, or ‘discrimination’ or ‘stigma’ or ‘marginalisation’ or ‘social policy (public policy)’ or ‘social welfare,’ or ‘social determinants of health,’ or ‘structural vulnerability’ or ‘social justice.’

Hand searching was also undertaken to identify any additional studies that appeared to be of significance from the reviewed full text studies and other sources. Following the removal of duplicates, 322 studies were identified.

2.3. Stage three: selection of relevant studies

Authors met to discuss inclusion and exclusion criteria initially, at the commencement of the review. The first author then undertook the screening of abstracts (KB) in consultation with other authors (JL and MD). Consultation was ongoing, in light of the iterative nature of the searching and selection stages (Arksey and O'Malley, 2005). Abstracts were screened and considered for inclusion in the review where studies appeared to meet the following criteria:

2.3.1. *Inclusion criteria*

Population

- Related to the experience of bereaved adult populations (in aims and findings).
- Focused on bereavement following the death of an adult with life-limiting illness as defined above (or including significant attention to post-death/bereavement experience, where studies may also include findings related to pre-death experience).

Concept

- Consideration of social and/or structural inequities, as defined above.

Context

- Experiences within high income countries.
- Published in the English language.

2.3.2. *Exclusion criteria*

- Focused on pediatric care, death of a child or the experience of bereaved children.
- Focused on low and middle income countries, where social welfare programs, policy and structural issues vary from those within high income countries.
- Studies which did not constitute research eg reflections, editorials
- Alternate focus to bereavement arising from life-limiting illness (eg suicide, sudden traumatic deaths), given the different nature and meanings of death and caregiving experience

Refworks (ProQuest) software was used to manage retrieved articles. An excel workbook was developed to account for decision making in relation to each study against the inclusion criteria, with reasons for exclusion.

Full text articles were obtained and review of these was conducted for 62 studies. One researcher undertook the initial full text review (KB), again in regular consultation through face-to-face meetings with other authors (JL and MD) throughout this process, to ensure a consistent approach with regard to determinations about included studies. The full text of 11 articles that were considered to be in question in terms of meeting inclusion criteria were independently scrutinised by two authors (JL and MD) and then resolved through discussion and consensus with the first author (KB), before the studies for inclusion in the review were finalised. Articles were included in the analysis where the focus of the study placed significant weight on the experience of bereavement due to life limiting illness, however the sample may have also included adults bereaved in other circumstances, or where findings also gave some consideration to pre-death experiences, and where other inclusion criteria were met. Such articles were included in the interest of maintaining a broad focus so as not to exclude relevant findings, and given the limited number of articles available. The selection process was summarised in a modified PRISMA flow chart (Fig. 1).

2.4. *Stage four: charting the data*

A 'common analytical framework' was developed to collect a consistent standard of information on each study, employing a 'descriptive-analytical' method to press beyond simply generating a short profile of each article (Arksey and O'Malley, 2005: 26). Key characteristics of included studies were first charted in an excel document, recording title, author/s, year of publication, publication study location, aims, methodology, focus population and participant characteristics (number, mean age and range, gender). A charting template form (in a word document) was also used for each article, in order to extract more detailed information on identified a priori themes related to the research question and sub questions. This form was refined somewhat as extraction progressed, reflective again of the iterative nature of charting (Levac et al., 2010: 6) and ongoing consultation between researchers. For each study, the charting template form prompted reporting on findings related to social inequity, structural inequity, associated experiences of bereavement and post caring, and any responses or actions recommended in relation to addressing structural vulnerability. Research gaps that were noted within study discussions and conclusions were charted, as well as any other data that related to the scope of the review.

2.5. *Stage five: collating, summarising and reporting results*

To enhance rigorous reporting of findings, Levac et al. (2010) recommend three steps in collating, summarising and reporting results; analysing data, reporting results, and applying meaning to results. Descriptive analysis of study characteristics was undertaken, and techniques of thematic analysis were employed (Braun and Clarke, 2006) to identify preliminary themes from charting template forms. Preliminary themes were collated in a conceptual framework that was repeatedly reviewed and refined. Secondly, in reporting and exploring results the intention was to present a rich 'thematic construction' that moved beyond simply summarising selected studies, acknowledging that commentary on the weight of evidence is outside the scope of this review, given that quality appraisal was not undertaken (Arksey and O'Malley, 2005; The Joanna Briggs Institute, 2015). The findings within the conceptual framework were categorised according to the nature of social inequity, or the nature of unequal social status, highlighting associated themes pertaining to structural inequity alongside implications in bereavement. Themes pertaining to recommended responses and research gaps were also tabled separately. Thirdly, the meaning of findings in relation to the study purpose was explored and implications for research and practice considered.

2.6. *Stage six: consultation*

Consultation with stakeholders seeks to enhance the meaning and applicability of the scoping review (Arksey and O'Malley, 2005). Levac et al. (2010) argue that this component should not be considered optional given that it contributes to the rigor of the review. However they acknowledge that clarity is lacking in relation to the timing, nature, purpose of consultation with stakeholders, as well as approaches to integrating into findings (Levac et al., 2010: 7). In this review, brief consultation with stakeholders within palliative care services, bereavement services and other providers of health and social care in the context of bereavement and loss was undertaken regarding the approach to the review, with future consultation for the purposes of validating findings and informing future research (Levac et al., 2010: 7) not undertaken at the time of publication.

3. Results

3.1. *Characteristics of studies*

A total of 15 articles met inclusion criteria (Fig. 1). Characteristics of included studies are summarised in Table 1. Four studies were conducted in the United Kingdom, three in the United States of America (USA), two studies each in Australia, Canada and Ireland, and two further studies included a range of countries.

A total of seven studies were qualitative in nature, involving in-depth interviewing (Blackburn and Bulsara, 2018, Glackin and Higgins, 2008), semi-structured interviews (Fenge, 2014; Spruyt, 1999), and secondary analysis of data drawn from larger studies (Holtslander and Duggleby, 2010; Stajduhar et al., 2010). A further five studies employed quantitative methodology, involving cross-sectional survey

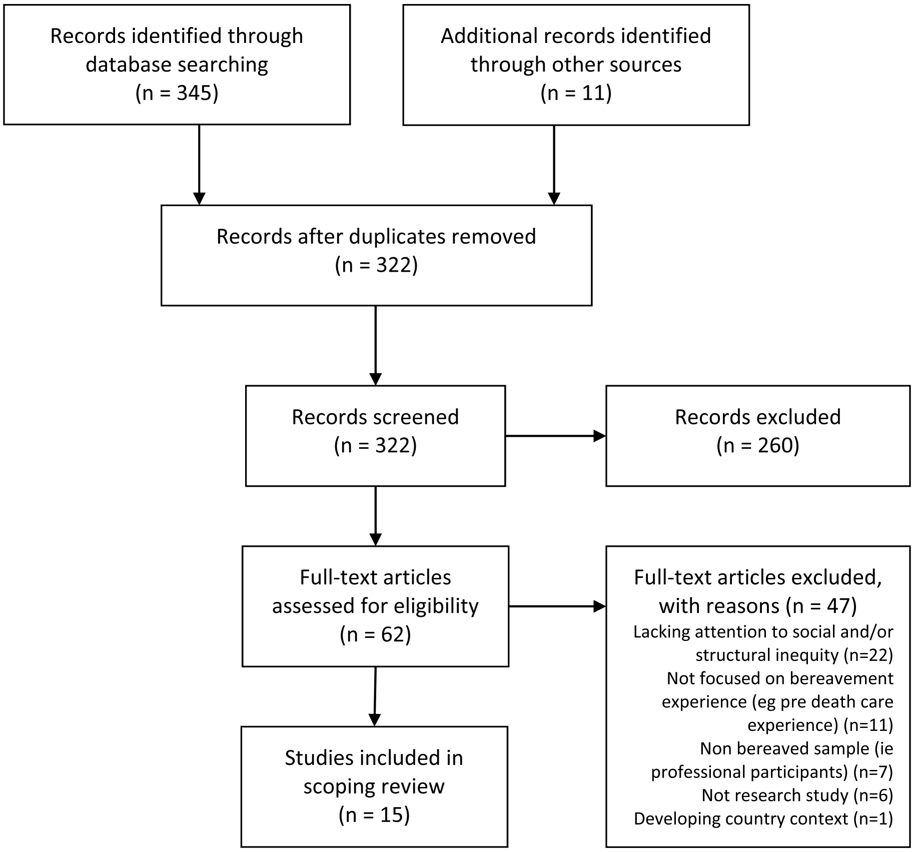

Fig. 1. Flow chart of study selection.

questionnaires (Koffman et al., 2005), structured telephone interviews with close-ended questions and self-administered questionnaires (Wyatt et al., 1999), population-based surveys or structured interview data (Roulston et al., 2017; Williams et al., 2012), or data from an intervention study (Utz et al., 2011). One study employed a mixed-methods approach (Corden et al., 2010), and two studies were systematic reviews (Bristowe et al., 2016; Holtslander et al., 2017). These systematic reviews were included, given that included sources in a scoping review can be "open" or broad to allow for the inclusion of a range of information (The Joanna Briggs Institute, 2015: 13), particularly in domains where evidence is limited. The intention was to map the current landscape, given the emerging nature of the field of study. Elements of findings within the systematic reviews were of relevance to the aims of this review, beyond the findings of individual studies (four) included in these systematic reviews that were also included in this scoping review.

Populations bereaved in the context of palliative care or cancer experiences were the sole focus of eight studies. The remaining studies involved recruitment approaches that either targeted participants bereaved due to life-limiting illness, stated that this was the predominant experience of the sample, or involved community sample groups where the nature of the sample appeared to include individuals bereaved following life-limiting illness (asterisked in Table 1). Six studies focused on partner bereavement, and four studies on bereavement following informal care provision. Key findings identified through analysis are summarised in Table 2 and reported below.

3.2. *Key themes pertaining to structural vulnerability (related to social and structural inequity) and bereavement experience*

3.2.1. *Sexism*

Of the studies reviewed, five presented findings related to social and structural sexism in bereavement (Corden et al., 2010; DiGiacomo et al., 2015; Holtslander and Duggleby, 2010; Holtslander et al., 2017; Williams et al., 2012). The unequal social status of women was evident in findings that described women as experiencing greater financial disadvantage than men post death, and more likely to experience poverty lasting up to three years following the death of their partner in the UK, especially pensioners (Corden et al., 2010). Corden et al. (2010) also found in their quantitative sample that the number of women who were financially worse off actually doubled following partner bereavement (from 24% to 48%), with women experiencing the emotional impact of perceived financial decline more intensely than men (Corden et al., 2010). Structural vulnerability arising in the context of gender was also closely intertwined with age and ethnicity in several studies. Societal expectations were found to contribute to social inequity in bereavement for older women; in being subject to prescriptive expectations (DiGiacomo et al., 2015) and challenges associated with navigating the loss of social identity (Holtslander and Duggleby, 2010). In a study that included women of African American background, women were more likely to be widowed and for a longer duration than men, with the financial strain of longer-term widowhood more pronounced (Williams et al., 2012). Studies considered various manifestations of related structural inequities; or the ways in which systemic characteristics and culture (within institutions, organisations and government structures) and social networks functioned to contribute to experiences of disadvantage. Formal systems were reported to disadvantage older bereaved women and heighten vulnerability through layers of administrative burden, fraught interactions with organisational staff in bereavement and the experience of invasions of privacy (DiGiacomo et al., 2015). A loss of financial security and increased financial strain (DiGiacomo et al., 2015, Holtslander and Duggleby, 2010) were reported, related to pension decreases in bereavement (DiGiacomo et al., 2015) and occurring alongside the consequences of a sense of unpreparedness among older women to manage financial

Table 1

Authors	Year	Location of study	Aim	Design/Methodology	Population (n =)	Gender (n =)	Age range (years), mean (years)
Blackburn and Bulsara[1]	2018	Australia	Report on experiences of the bereaved when dealing with institutions and the impact of attending to practical matters in bereavement.	Qualitative descriptive study, in depth interviewing with thematic analysis.	Bereaved (n = 24), non probability purposive sample, identified through palliative care services.	Female = 19 Male = 5	44–87 years, not reported
Bristowe et al.*[2]	2016	Systematic review of studies from UK (2), USA (17), Canada (2), Ireland (11)	Identify and appraise the evidence of the bereavement experiences of lesbian, gay, bisexual and/or trans people who have lost a partner and develop an explanatory model of lesbian, gay, bisexual and/or trans partner bereavement.	Systematic review in accordance with PRISMA guidelines, thematic synthesis.	Bereaved lesbian, gay, bisexual and/or trans partners (n = 555) from primary studies (23 articles reporting on 13 studies).	Female = 105 (62 lesbian, 42 LGB, 1 trans*) Men = 450 (421 gay or bisexual, 23 GB, 6 heterosexual)	Not reported
Corden et al.*[3]	2010	UK	Explore the financial and economic implications of the death of a life partner.	Mixed methods study; qualitative in depth interviews and quantitative statistical sample drawn from the British Household Panel Survey, interviewed three times before and three times after the death (with no individual appearing in both groups).	Quantitative sample of partners interviewed pre and post death (n = 750 couples), qualitative sample of bereaved partners (n = 44),	*Quantitative sample:* Female = 66.67% Male (X %) *Qualitative sample:* Female = 31 Male = 13	*Quantitative sample:* 18–93 years, approx. 17 years *Qualitative sample*: Not reported
DiGiacomo et al.*[4]	2015	Australia	Elicit contemporaneous descriptions of older women's experiences and needs for information, services, and support upon spousal bereavement.	Qualitative study, three in-depth semi-structured interviews at 6 month intervals; with first interview between 2 and 47 months after husband's death (median 12 months). Interpretive Phenomenological Analysis.	Convenience sample of bereaved female partners aged 65 years and over (n = 21)	Female = 21 Male = 0	63–82 years, 71.43 years
Fenge*[5]	2014	UK	Identify and explore the experience of end of life and bereavement for lesbian and gay elders.	Qualitative exploratory study, qualitative interpretive approach to analysis, with thematic content analysis of semistructured interviews.	Snowball sampling of bereaved older lesbian and gay bereaved people (n = 4) and those supporting them in bereavement (n = 3). *Only experiences of bereaved lesbian and gay participants extracted*	Female = 1 Male = 3	Not reported
Glackin and Higgins*[6]	2008	Ireland	Explore and describe the bereavement experience of lesbian or gay and bisexual people after the death of their partner, within an Irish context.	Qualitative exploratory descriptive design, with face to face, unstructured, in depth interviews that continued until no more participants could be accessed. Time since death of partner to time of interview ranged from six months to 20 years.	Multi-pronged sampling approach to elicit sample of partner bereaved (n = 7), five of whom were in receipt of hospice care with the death due to cancer (two deaths were sudden - MI and suicide)	Female = 4 Male = 3	Not reported
Holtslander and Duggleby[7]	2010	Canada	Explore psychosocial context of bereavement for older women who were caregivers for a spouse with advanced cancer.	Qualitative study - secondary thematic analysis of data collected for constructivist grounded theory study. Analysis of interviews and diaries using constant comparison during data collection, and thematic analysis.	Purposive sampling to select female, bereaved, spousal caregivers of deceased palliative care patients, aged 60 years and over (n = 13).	Female = 13 Male = 0	60–79 years, not reported
Holtslander et al.[8]	2017	Systematic review of studies from USA (14), Canada (11), Australia (7), UK (4), Sweden (4), Japan (2), Hong Kong (2), New Zealand (1), Republic of Korea (1) and Denmark (1)	Conduct a qualitative metasummary to explore the experiences of bereaved family caregivers of people who received palliative care services, regardless of their underlying disease.	Systematic review of qualitative or mixed methods research studies using Sandelowski and Barroso's qualitative metasummary method.	Bereaved participants, after caregiving (n = 1132) from 47 qualitative studies.	Female = 701 Male = 396 Transgender = 3	21–95 years, 62.68 years
Koffman et al.[9]	2005	UK	Compare the outcomes of bereavement among family or close friends of deceased first-generation black Caribbean and white native-born patients living in the UK.	Quantitative study, comparative cross sectional questionnaire survey administered during face to face interviews, 10 months after the patient's death (survey included structured interview to explore deceased's last 12	Family and close friends of 50 deceased first generation black Carribbean and 50 native born white patients with advanced disease (n = 100)	*Black Carribbean sample:* Female = 36 Men = 14 *White sample:* Female = 31 Male = 19	*Black Carribbean sample:* Not reported, 68.5 years *White sample:*

(*continued on next page*)

Table 1 (*continued*)

Authors	Year	Location of study	Aim	Design/Methodology	Population (n =)	Gender (n =)	Age range (years), mean (years)
				months of life, GHQ-28 and Core Bereavement Items Scale)			Not reported, 71.9 years
Roulston et al.[10]	2017	Northern Ireland	Identify which factors significantly affected bereavement outcomes of adults who cared for someone with a cancer diagnosis.	Quantitative study, population based postal survey capturing sociodemographic characteristics, retrospective data about patient care (Client Service Receipt Inventory), patient palliative outcomes in week prior to death (Palliative Outcome Scale) and health related quality of life (EuroQol EQ-5D), and intensity of respondent grief (TRIG).	Bereaved relatives of individuals with cancer where death occurred at home, hospice, nursing home or hospital in Northern Ireland (n = 467)	Female = 282 Male = 185	25–87 years, not reported
Spruyt[11]	1999	UK	Describe the palliative care experience of Bangladeshi bereaved carers and patients in the Tower Hamlets area in the east of London.	Qualitative, ethnographic study, semi structured interviews.	Bereaved carers identified through review of patients known to community palliative care team (n = 18)	Not reported	25–60 years, not reported
Stajduhar et al.[12]	2010	Canada	Describe the perspectives of bereaved family caregivers of advanced cancer patients, on what made their grief difficult.	Qualitative study, secondary analysis of qualitative data drawn from ongoing mixed method study. Secondary analysis involved three focus groups with bereaved family caregivers and two focus groups with health professionals. Interpretive thematic analysis.	Purposive sampling used to select participants for the qualitative portion in original study. Secondary analysis limited to bereaved family caregivers (n = 19) and health care professionals (n = 14) *Only experiences of family caregivers extracted*	Female = 14 Male = 5	42–85 years, 63 years
Utz et al.*[13]	2011	USA	Identify personal resources, features of the marital relationship, and death circumstances that affected perceived self-competency among recently bereaved older adults.	Quantitative study of data from "Living After Loss" (LAL) study, designed to test the effectiveness of an intervention derived from the Dual Process Model of Coping (Stroebe and Schut, 1999). Participants randomly assigned to either an intervention that combined restoration and loss oriented coping activities or to a comparison group focused solely on loss-oriented coping, completion of questionnaires prior to and after the intervention to assess adjustment to widowhood (2–6 months post loss)	Widowed persons (n = 328).	Female = 200 Male = 128	50–93 years, 69.6 years
Williams et al.*[14]	2012	USA	Examine how the passage of time since spousal loss varies by social and demographic characteristics. Examine the variation in an array of key social and demographic constructs by time since spousal loss among African American and White community-dwelling adults age 65 years and older, controlling for physical, emotional, and cognitive status.	Quantitative, using data from the University of Alabama at Birmingham Study of Aging - a population based, prospective, observational study of community-dwelling adults age 65 and older. Baseline assessment interview and second in-home assessment interview 48 months after baseline.	Spousally bereaved community dwelling adults 65 years and over (n = 260) - including African American widowed adults (n = 150) and white widowed adults (n = 110)	Female = 206 Male = 54	Not reported, 75.5 years,
Wyatt et al.[15]	1999	USA	Better understand the needs of terminal caregivers and supply a basis for tailoring interventions to them during caregiving and early bereavement.	Quantitative study, structured telephone interview with bereaved caregivers approximately three months after patients death, collecting data on psycho-spiritual variables, personal-social variables, caregiver health status variables and financial status variables.	Bereaved caregivers (n = 124) drawn from convenience sample of patient/caregiver dyads known to three community cancer centres in Michigan.	Female = 93 Male = 31	26–78 years, 56.8 years

issues, in the context of traditionally defined gender roles (DiGiacomo et al., 2015). Concerns for older women related to housing affordability and concerns about the possibility or reality of having to relocate home (DiGiacomo et al., 2015; Holtslander and Duggleby, 2010) were also noted. These two studies raised additional challenges associated with navigating employment systems, with older women potentially needing to commence work in bereavement (Holtslander and Duggleby, 2010), and confront barriers such as limited employment options due to age (DiGiacomo et al., 2015). Social networks were described as functioning to disenfranchise women through sanctioned norms regarding expressions of grief according to gender; including pressure to “get over” difficulties in grief after providing care (Holtslander and Duggleby, 2010) and a reported societal bias which was seen as placing greater expectations on women than men in widowhood (Williams et al., 2012). Emotional and psychological consequences included distress and uncertainty, a sense of demoralisation following interactions with organisational representatives (DiGiacomo et al., 2015); increased psychological distress for up to two years post-death of a partner related to perceptions of adverse change in financial circumstances following the death (Corden et al., 2010), and the hindering or oppression of the expression of grief (Holtslander et al., 2017).

3.2.2. *Classism*

Evident in four studies, social and structural “classism” related to income, employment and other personal resources such as financial circumstances and education, shaped structural vulnerability in bereavement (Corden et al., 2010; Roulston et al., 2017; Utz et al., 2011; Wyatt et al., 1999). Lower income appeared to contribute to unequal social positioning; identified as related to pre-existing hardship, age and gender (Corden et al., 2010) and illness related financial strain (Corden et al., 2010; Wyatt et al., 1999). Experiences of poverty were evident, with a drop in income meaning that one in five bereaved partners in the Corden et al. study were living below the official poverty line (Corden et al., 2010) and forty percent of the sample in the Roulston et al. study experiencing deprivation (Roulston et al., 2017). Associated structural inequities were experienced, apparent in descriptions of disenfranchising characteristics of formal systems such as burdensome institutional processes, and inadequate support from staff within support services, including poor advice and the neglect of privacy (Corden et al., 2010). Multiple contacts with services in bereavement were associated with a sense of despair, and sometimes a sense of bereaved partners being prevented from attending to their grief (Corden et al., 2010). Elements of encounters with government income support systems were identified, including experiences of inconsistent assistance in relation to income support benefits, a “widespread lack of knowledge” about state bereavement benefits, the compounding of financial problems due to systemic issues (Corden et al., 2010) and financial issues that were largely accounted for by reduced social security benefits following a death (Wyatt et al., 1999). Issues associated with housing benefits, concerns about maintaining mortgage or rental payments and security of tenure in bereavement were also reported, and for some related to lengthy delays and financial strain (Corden et al., 2010). Barriers to maintaining employment pre-death while in a caring role were noted, with a majority of participants in one study who took on employment after the death doing so to cover personal finances (Wyatt et al., 1999). Cessation of employment in bereavement was found to be associated with more intense grief (Roulston et al., 2017); in another study taking employment and caregiver monthly income were negatively associated with depressive symptoms (Wyatt et al., 1999). Structural vulnerability arising in the context of poverty and classism in bereavement appeared to contribute to challenging emotional and psychological experiences. Depressive symptoms related to changes to income (Wyatt et al., 1999), or functioning as a barrier to returning to employment (Roulston et al., 2017) were identified. Heightened grief was associated with higher levels of deprivation and lower socio-economic status (Roulston et al., 2017), and with lower levels of personal resources, such as the individual's level of financial resources and education (Utz et al., 2011). Systemic issues functioned as triggers of grief for bereaved partners (Corden et al., 2010), with a range of practical issues evident that were associated with additional financial strain and distress (Corden et al., 2010; Wyatt et al., 1999).

3.2.3. *Heterosexism*

Four studies pointed to social and structural heterosexism as contributing to structural vulnerability in bereavement (Bristowe et al., 2016; Fenge, 2014, Glackin and Higgins, 2008 and Holtslander et al., 2017). Unequal social status related to the non-heterosexual orientation of the bereaved was found to shape the individual's grieving role and identity, and thus access to and scope for engagement with informal and formal support. This was related to the nature of disclosure and acceptance of non-heterosexual relationships in the context of bereavement (Bristowe et al., 2016), the impact of the way in which non-heterosexual relationships were understood and acknowledged (Glackin and Higgins, 2008), and a heightened risk (or actual experiences) of disenfranchisement (Bristowe et al., 2016; Fenge, 2014 and Glackin and Higgins, 2008). Related structural inequities were evident. Studies highlighted disenfranchising features of formal systems, such as systematic stigma and discrimination (Fenge, 2014, Holtslander et al., 2017), and limited cultural competency of health and social care staff, which in bereavement hindered comprehensive assessment of needs and related to experiences of a heterosexist bias in bereavement counselling services (Fenge, 2014). Bereaved partners concealed the nature of the loss and the relationship when a partner with HIV or AIDS died, in light of concerns about the impact upon their employment and support network (Bristowe et al., 2016). Additional legal stress, financial stress and complexity associated with negotiating financial entitlements, along with additional barriers to other formal support (Bristowe et al., 2016, Glackin and Higgins, 2008) were described. Findings also demonstrated the potential for social networks to function in disenfranchising ways. In contrast to heterosexual bereavement experience, additional barriers to informal support networks and societal rights were perpetuated by families (Bristowe et al., 2016, Glackin and Higgins, 2008; Holtslander et al., 2017) and by faith communities, for example with regard to marginalisation during funeral rituals (Glackin and Higgins, 2008). Non-disclosure of relationships (Bristowe et al., 2016; Fenge, 2014) and stigma related to HIV or AIDS (Holtslander et al., 2017) constituted barriers to informal support networks, with these barriers characterised as persistent, despite legislative changes recognising civil partnerships (Fenge, 2014). Experiences of stigma, homophobia and invalidation due to the heterosexist bias of bereavement support groups were evident (Glackin and Higgins, 2008). Being positioned as structurally vulnerable due to non-heterosexual orientation appeared to be associated in bereavement with heightened grief experiences and emotional distress (Bristowe et al., 2016 and Glackin and Higgins, 2008), as well as practical complexity and social isolation and invalidation (Bristowe et al., 2016; Fenge, 2014, Glackin and Higgins, 2008).

3.2.4. *Ethnocentrism*

A total of three studies explored experiences of social and structural ethnocentrism (Koffman et al., 2005, Spruyt, 1999 and Williams et al., 2012), with findings that suggested ethnicity has the potential to contribute to structural vulnerability in bereavement. In a UK study comparing bereavement outcomes for bereaved family or close friends of Black Caribbean and white native-born backgrounds, Koffman et al. (2005) identified that ethnicity appears to predict psychological distress in bereavement, with higher levels of depression and anxiety for Black Caribbean family members (than for white family members) in bereavement, and with this difference “best” accounted for by post-death legal and housing concerns. Again, in a USA-based study, Williams et al. (2012) found ethnicity and gender to be related to vulnerability, with African American women more likely to be widowed

Table 2
Summary of key findings.

Nature of structural vulnerability	Related studies	Experience of social inequity	Experience of structural inequity	Associated elements of bereavement experience
'Positionality' due to social & structural inequity (Quesada et al., 2011)		Unequal social status on account of … ? (Reimer Kirkham et al., 2016)	How do systems, services, structures of government, institutions and social networks function to contribute to disadvantage and vulnerability? (Reimer Kirkham et al., 2016)	
Social and structural sexism (arising in context of the experience of women)	Corden et al. (2010)[3] DiGiacomo et al. (2015)[4] Holtslander and Duggleby (2010)[7] Holtslander et al. (2017)[8] Williams et al. (2012)[14]	**Unequal social status on account of sexism - due to positioning of women** ● Experience greater financial disadvantage than men[3] ● Related to ***age*** - experiences of disenfranchising societal expectations and loss of social identity[4,7] ● Related to ***ethnicity*** - more likely to be widowed and for longer, financial strain more pronounced[14]	● **Characteristics of formal systems and services** eg. Burdensome administrative processes, challenging interpersonal interactions and barriers to navigating systems such as costly financial advice[4] ● **Encounters with government income support systems and issues** eg. Reduced government income support[4], related financial stress and associated uncertainty[4,7] ● **Encounters with housing systems and issues** eg. Uncertainty associated with affordability issues or fears regarding relocation, impacts of pre existing financial issues or lack of estate planning pre death[4] ● **Experiences of employment issues eg.** Perception of limited employment options due to age as barrier[4], managing the challenge of having to commence employment[7] ● **Characteristics of social networks and societal expectations regarding women, their roles, and grief** eg. Sanctioned norms according to gender regarding expressions of grief and types of support[8], pressure to 'get over' difficulties[7], societal bias perpetuating less defined norms and fewer expectations in widowhood for men than women[14]	● **Emotional/psychological** eg. Distress related to pension reduction, demoralisation and erosion of self concept related to interactions with organisations[4] ● **Practical** eg. Feared or actual relocation of home[4,7], financial strain[3,4], forced to commence work[7], reduced access to transport[3] ● **Social** eg. Imposition of norms and expectations[8,14], loss of social identity of older women[7] ● **Grief experience** eg. Disenfranchised[7], hindering of expression of grief[8]
Social and structural classism (arising in context of poverty related to income, employment, and other personal resources)	Corden et al. (2010)[3] Roulston et al. (2017)[10] Utz et al. (2011)[13] Wyatt et al. (1999)[15]	**Unequal social status on account of classism - due to poverty of income[3,10,15], employment[15] and personal resources[13]** (eg. financial circumstances, education)	● **Characteristics of formal systems and services** eg. Burdensome processes requiring multiple contacts, fraught by errors and delays, inadequate support from staff (communication issues, insensitivity and poor advice, neglect of privacy)[3] ● **Encounters with government income support systems** eg. Assistance derived on inconsistent basis[3], lack of knowledge regarding state bereavement benefits[3], reduction in income due to social security benefits[15], escalation of financial issues[3] ● **Encounters with housing support systems and issues** eg. Fears associated regarding housing benefits and security of tenure[3], financial strain and distress despite issues often being resolved[3] ● **Experiences of employment issues** eg. Commencing employment post death to cover personal finances[15], cessation of employment associated with heightened grief[10]	● Emotional/psychological eg. Depression associated with change of income[15], with lower personal resources[13], as barrier to returning to work (also anxiety, substance abuse)[10]. Loneliness associated with lower personal resources[13] ● Practical eg Increased financial strain, uncertainty and despair associated with systemic issues[3], fear associated with outcomes and future interactions with formal services and systems[3], uncertainty associated with mortgage and rental payments[3] ● Grief experience eg. Heightened grief associated with level of deprivation[10], with lower personal resources and self competence[13], poorer bereavement outcomes related to lower socioeconomic status[10]
Social and structural heterosexism (arising in context of sexual identity)	Bristowe et al. (2016)[2] Fenge (2014)[5] Glackin and Higgins (2008)[6] Holtslander et al. (2017)[8]	**Unequal social status on account of heterosexism - due to non heterosexual orientation** ● Impacts grieving role, identify, recognition of relationship and identity[2,5,6] ● Impacts access to informal and formal support[2,5,6,8]	● Characteristics of formal systems and services eg. Cumulative experiences of stigma and systematic discrimination against same sex partners[5,8], poor cultural competency of social care workers[5], contributed to concealment of relationship status[2], perpetuated barriers to formal support[2,6], associated with additional legal and financial stressors and complexity[2]	● **Emotional/psychological** eg. Heightened distress[2,6], suicidal ideation in context of death due to HIV/AIDS particularly where social support/integration low and caregiving burdensome[2] ● **Practical** eg. Additional legal and financial stress[2,6], concealing nature of identity/relationship due to fears regarding consequences for employment[2]

(*continued on next page*)

Table 2 (*continued*)

Nature of structural vulnerability	Related studies	Experience of social inequity	Experience of structural inequity	Associated elements of bereavement experience
‘Positionality’ due to social & structural inequity (Quesada et al., 2011)		Unequal social status on account of … ? (Reimer Kirkham et al., 2016)	How do systems, services, structures of government, institutions and social networks function to contribute to disadvantage and vulnerability? (Reimer Kirkham et al., 2016)	
		● Experiences mediated by acceptance and disclosure[2,5]	● Characteristics of social networks and societal perspectives eg. Disenfranchisement perpetuated by informal networks due to homophobia[8], discrimination against same sex partners[8], estrangement (with legal and financial consequences)[2], additional barriers to social rights/ rituals (eg funerals)[5,6], lack of societal recognition of relationships[6], and invalidation[6], heterosexist bias[6] or stigmatization[2] in bereavement support groups	● **Social** eg. Persistent experiences of stigma and discrimination[2,5], decreased support networks and isolation[6] ● **Grief experience** eg. Heightened[2], hidden or suppressed[5,8], disenfranchisement mediated by disclosure (identity/relationship) and acceptance[2,5,6]
Ethnicity (social or structural ethnocentrism)	Koffman et al. (2005)[9] Spruyt (1999)[11] Williams et al. (2012)[14]	**Unequal social status on account of ethnocentrism - due to ethnicity ie Black Caribbean,[9] African American,[14] Bangladeshi[11]** ● Related to ***gender*** - associated with increased likelihood of widowhood, duration of widowhood (and more pronounced financial strain)[14]	● **Encounters with income support systems and issues** eg. Lack of awareness regarding income support[11], benefits associated with experiences of financial difficulty[11], potential for increased financial strain (related to being less closely tied to formal economy of pensions/wages)[14],	● **Emotional/psychological** eg. Distress related to financial strain[14], anxiety related to unmet financial assistance needs[9], heightened depression and anxiety (Black Caribbean white participants)[9] ● **Practical issues** eg. Heightened financial concerns[9,11,14], financial difficulties associated with benefits, unemployment, debt and death/funeral costs[11], potentially unmet needs for financial assistance[9,11], persistent hardship/strain[14], post death legal and housing concerns (related to higher levels of depression and anxiety among Black Caribbean participants)[9] ● **Social** eg. Increased vulnerability to social isolation due to long term widowhood[14] ● **Grief experience** eg. Unresolved grief, affected by intergenerational tension[11]
Being bereaved (social and structural ‘bereavism’)	Blackburn and Bulsara (2018)[1] Holtslander et al. (2017)[8] Stajduar et al (2010)[12]	**Unequal social status on account of social and structural disenfranchisement of grief** ● Related to informal caring[8,12]	● **Characteristics of formal systems and services** eg. Burdensome processes[1], multiple contacts, intrusive organisational protocols, mechanistic, formal and rigid processes[1], lacking or unhelpful formal supports[8], lack of mechanisms to support information sharing/coordination pre death with post-death implications[12], inadequate leave entitlements[1] ● **Characteristics of social networks** eg. Imposing pressure to “move on”[8], underestimating significance of loss[8],	● **Emotional/psychological** eg. Demoralisation, shame and fatigue related to interactions with formal systems[1], helplessness, sense of invisibility or alienation related to inadequate/unhelpful experiences of formal support[8] ● **Practical** eg. Financial strain and stress[1,8,12], pressure to return to work[8], fears regarding future interactions with organisations[1], negotiating estate matters alongside employment and limited leave entitlements[1] ● **Grief experience** eg. Grief responses triggered/ heightened by interactions with formal systems[1], delayed due to demands of practical tasks[1], expression hindered by societal context[8], impacted by physical health problems post-death[8,12]

and for longer than white women, and experiencing amplified financial strain in longer term widowhood (Williams et al., 2012). In terms of interactions with income support systems, Spruyt (1999) reported heightened socio-economic issues and financial difficulties post-death among bereaved Bangladeshi carers in the UK, associated with both pre-existing issues and bereavement costs, with fifty per cent of participants in significant debt in bereavement. Financial strain was also recognised as potentially heightened given that African American women, like other groups of ethnic and racial minority status, may be "less closely tied to the formal economy of wages and pensions" (Williams et al., 2012). Thus, some structural factors related to income support systems and financial needs were described as potentially perpetuating disadvantage in bereavement. Structural vulnerability related to ethnicity appeared to be associated with distress in bereavement, related to persistent financial stain (Williams et al., 2012) and a greater prevalence of depression, anxiety and health related problems among Black Caribbean participants (as opposed to white participants) (Koffman et al., 2005). Bereaved Bangladeshi carers characterised their grief as unresolved and persistent (Spruyt, 1999), underpinned by ongoing practical and financial issues. Financial concerns were a feature of bereavement experience for study participants across all three studies, with the impact of increased vulnerability to social isolation due to the exposure to long term widowhood noted for African American women (Williams et al., 2012).

3.2.5. *'Bereavism'*

Finally, the experience of being bereaved in and of itself appeared to contribute to structural vulnerability, apparent in findings that revealed a broad social and structural disenfranchisement of the griever, post death (Blackburn and Bulsara, 2018; Holtslander et al., 2017; Stajduhar et al., 2010). This might be described as 'bereavism,' or a unique and unequal social status on account of bereavement, which seemed to position individuals differently in the social landscape, and appeared to relate to experiences of structural disenfranchisement through interactions with formal systems or institutions, within employment contexts and within social networks. Distinctive practical complexities and stressors that accompanied post death experience and required navigation by the bereaved were evident. In a study attending to experiences of a bereaved sample in specifically dealing with institutions and practical matters in bereavement, Blackburn and Bulsara (2018) reported bereaved individuals negotiating legal and financial issues encountered experiences of burdensome processes and multiple contacts with services, intrusive organisational protocols, and institutions characterised by mechanistic, formal, and rigid cultures that lacked compassion. This "macrosystem of bureaucracies" was described as specifically shaping bereavement experience in detrimental ways (Blackburn and Bulsara, 2018: 6), and associated with inadequate leave entitlements to attend to systemic complexities (Blackburn and Bulsara, 2018). The Holtslander et al. (2017) systematic review echoed experiences of lacking or unhelpful formal supports, identifying a common theme of bereaved caregivers not experiencing recognition of the significance of their losses, alongside "pressure to move on" in the absence of appropriate support (2017: 15). In one situation, Stajduhar et al. (2010) identified a lack of mechanisms to support information sharing and promote cooperation between related systems (eg health and social services) pre death, which contributed to distress post-death. Social networks were also experienced as imposing pressure to return to employment post death (Holtslander et al., 2017). The unequal social positioning of the bereaved alongside the disadvantages arising from these potentially disenfranchising systems and networks, appeared to contribute to a sense of demoralisation and frustration (Blackburn and Bulsara, 2018), and feelings of helplessness and isolation arising from experiences of formal support as inadequate or unhelpful (Holtslander et al., 2017). Grief was triggered by institutional encounters or processes with an apparent "instrumental" focus, or at other times intentionally delayed or deliberately suppressed by individuals due to the weight of practical tasks requiring attention (Blackburn and Bulsara, 2018). Practical consequences in bereavement were varied and included increased financial strain (Blackburn and Bulsara, 2018; Holtslander et al., 2017; Stajduhar et al., 2010), fears about future interactions with organisations (Blackburn and Bulsara, 2018), and difficulty attending to estate matters alongside paid employment and limited leave entitlements (Blackburn and Bulsara, 2018).

3.3. *Recommended responses to addressing structural vulnerability*

Studies made recommendations regarding approaches to addressing structural factors with the potential to perpetuate vulnerability and disadvantage. Several recommendations pertained to broadly improving culture, processes and policy within formal systems and institutions. Improved organisational protocols, informed by further research (Blackburn and Bulsara, 2018), and involving streamlined, cross-sector, policy initiatives (DiGiacomo et al., 2015) with central points of contact (Blackburn and Bulsara, 2018) were suggested, in order to minimise administrative burdens, complexities and delays for the bereaved. Fenge (2014) pointed to the need for further development of capacity and cultural competency within social care providers in order to better attend to the consequences of ageism, homophobia and heterosexism.

In light of frequent recognition of the potential for financial strain and disadvantage in the context of experiences of structural vulnerability, several studies made recommendations regarding the facilitation of access to financial planning, advice and support. For older bereaved women, it was suggested that timely, affordable and ethical financial management and planning services for would be of value (DiGiacomo et al., 2015). In response to ethno-specific and pre-existing socio-economic needs in bereavement, practical financial support was recommended (Spruyt, 1999). The incorporation of the provision of financial advice and support pre and post-death for carers was also highlighted (Roulston et al., 2017; Wyatt et al., 1999).

The need for more inclusive and supportive employment conditions and leave entitlements was acknowledged within a few studies, given related vulnerabilities of an emotional and practical nature in bereavement. Studies called for consolidation and improvement of policy and employment practices related to work and care provision (Stajduhar et al., 2010; Roulston et al., 2017), and review of the nature of government bereavement leave in order to more realistically reflect the volume of time required to attend to estate and other practical matters (Blackburn and Bulsara, 2018). The integration of "support sessions" for carers on finances and employment as a standard feature of care, beginning pre-death, was also recommended (Wyatt et al., 1999).

Some recommendations related to the need to address causes of social isolation and disenfranchising social networks. The importance of shifting societal awareness regarding vulnerable groups in bereavement was identified, including a need for broader sensitivity and consideration of the political, social and historical context for LGBT communities (Bristowe et al., 2016). Considering the recognised structural vulnerability of older bereaved women, there were suggestions regarding the cultivation of public rituals of remembrance to promote community support and understanding (Holtslander and Duggleby, 2010), and a call for investment in development, evaluation and dissemination of multimodal based interventions to reduce isolation in ageing generally, with particular attention to long-term widows (Williams et al., 2012).

A significant number of recommendations were specific to formal health care settings or specialist palliative care contexts. Studies highlighted the importance of confronting educational needs of health professionals, particularly with regard to impact of historical disadvantage encountered by LGBT bereaved and the impact on fears and expectations of services (Bristowe et al., 2016, Fenge, 2014 and Glackin and Higgins, 2008). Interventions that involved individualised, appropriate care (Bristowe et al., 2016) and advocacy on behalf of individual carers in their navigation of systems, welfare agencies and other services (Corden et al., 2010; Stajduhar et al., 2010) were promoted. The importance of strengthening holistic pre-death supports (Stajduhar et al., 2010; Wyatt et al., 1999) was noted, with Wyatt et al. arguing that this should promote a return to "pre-caregiver roles in optimal time" (1999: 24). Recommendations also included models of care that attend to more than simply emotional and psychological support needs (Blackburn and Bulsara, 2018) and that specifically honour the way in which experiences of caregiving impact bereavement (Holtslander et al., 2017).

3.4. Identified gaps in research and evidence

Future research priorities that were identified in relation to the needs of structurally vulnerable populations were varied. With the heterosexist focus of existing research noted (Glackin and Higgins, 2008), suggested areas of further study included participatory projects with older LGBTI populations (Fenge, 2014), research with sexual minority groups such as transgender and intersex populations (Fenge, 2014), and further study of the experience of lesbian women (Glackin and Higgins, 2008). Expanded investment in research exploring cross-cultural considerations in bereavement (Holtslander and Duggleby, 2010; Spruyt, 1999), and the experience of younger bereaved populations (Blackburn and Bulsara, 2018) was supported. The study of remote communities and pre-existing inequity in the context of bereavement was also recognised as an area worthy of increased exploration (Roulston et al., 2017).

The lack of attention in bereavement literature to the experience of administrative burden was noted, alongside a call for further research into local, cross-sectoral strategies of relevance (DiGiacomo et al., 2015). Blackburn and Bulsara (2018) also called for investigation of the psychological consequences of dealing with practical issues in bereavement, in relation to the potential impact upon experiences of prolonged grief disorder. Other suggested domains for further research included attention to the issue of receptivity to support in bereavement (Blackburn and Bulsara, 2018), further examination of practical issues and instrumental coping outcomes (Utz et al., 2011), and additional qualitative research on the impact of long term widowhood on the health and wellbeing of women (Williams et al., 2012).

4. Discussion

The objective of the review was to map current evidence regarding bereavement and structural vulnerability, namely; the positionality that arises from intersecting experiences of social and structural inequity (Reimer Kirkham et al., 2016; Quesada et al., 2011), in bereavement following the death of an adult with a life-limiting illness. Three central issues were identified, with the following discussion to be framed by an exploration of each of these issues.

4.1. Experiences of disadvantage arising from the dimensions of structural vulnerability in bereavement are layered and patterned

This review demonstrated that specific groups of bereaved individuals may be disadvantaged in multiple ways, due to varied dimensions of their structural vulnerability. Studies pointed to overlapping experiences of social and structural inequity, for example in relation to age and gender (DiGiacomo et al., 2015; Holtslander and Duggleby, 2010), in relation to age, gender and ethnicity (Williams et al., 2012), or in relation to age and non-heterosexual identity (Fenge, 2014). Furthermore, findings suggested that bereavement itself may constitute a form of social inequity that broadly exposes grieving individuals to policy, processes, systems and networks that function in bereavement in uniquely disenfranchising ways, with an apparent esteem of processes that promote "productivity" and "stoicism" (Harris, 2010). This finding is reflected In Reynold's recognition of the "bereaved in general, and the disenfranchised griever in particular" as a "vulnerable and oppressed population," (Reynolds, 2002: 352). Thus, overlaid experiences of heterosexism, classism, sexism and ethnocentrism, historical and current, in addition to the experience of bereavement, constitute a positionality that potentially subjects the griever to layers of disadvantage. This concept of 'bereavism' requires further exploration, particularly in relation to structural disadvantage. While Ahmed et al. (2004: 526) articulated the notion of "double disadvantage," this review appears to suggest that multiple layers of disadvantage may contribute to detrimental emotional, psychological, social and practical outcomes in bereavement. While the findings of this review do not suggest that detrimental outcomes in bereavement are purely attributable to the experience of structural vulnerability, this positionality appears to increase the likelihood of certain populations experiencing "disproportionate burdens" (Reimer Kirkham et al., 2016: 295), or additional negative outcomes over and above those experienced by others in bereavement, for instance, women of an ethnic minority background as opposed to women from non-ethnic minority backgrounds (Williams et al., 2012) and female as opposed to male bereaved partners (Corden et al., 2010). Thus, experiences of disadvantage can impose suffering in bereavement in a "patterned" (Quesada et al., 2011) as well as a layered manner and appear to constitute a way in which individuals may be "created vulnerable" (Stienstra and Chochinov, 2012) following a death. More nuanced recognition of vulnerability as an "indicator of inequity and social inequality" (Quesada et al., 2011: 345) is therefore necessary both broadly and in clinical settings, beyond assessing for individual psychological "risk factors" in bereavement.

4.2. Structural vulnerability possesses implications for individual agency in bereavement that must be considered

Given acknowledgement that individuals "internalise" unequal social status in "a complex and poorly understood process of embodiment that shapes their behaviours, practices and self-conceptions," (Quesada et al., 2011: 342), it became evident that consideration of the repercussions for the individual agency of the bereaved would be integral to this discussion. Although the concept of agency was not explicitly examined by the included studies, a number of implications for individual agency are implicit in the summary of findings, and were identified. A critique of the notion of agency is inherent to an exploration of structural vulnerability, given that such an exploration by nature involves the "analysis of forces that constrain decision-making, frame choices, and limit life options" (Quesada et al., 2011: 342). Interrogation of the construct of agency is also central to research underpinned by a critical lens, which seeks to expand human agency by exposing forces that prevent individuals and groups from shaping decisions of importance (Kincheloe and McLaren, 2003: 437). For the bereaved positioned as structurally vulnerable, decision making, choices and life options would foreseeably be mediated by various social and structural "forces", including factors related to disenfranchising networks and systems; formal and informal.

Options in relation to accessing and experiencing social support appeared to be shaped by several forces in the reviewed studies. Persistent societal perspectives about the grieving role or gendered expectations regarding the expression of grief (Holtslander and Duggleby, 2010; Holtslander et al., 2017; Williams et al., 2012) impacted bereavement experience, particularly for older women. Thus, it is foreseeable that these forces may limit the availability and experience of informal support. It seems probable that some bereaved individuals may feel pressured to conform to "implicit social grieving rules" to mitigate the "social pain" of being excluded from desired relationships or support (Harris, 2010). Experiences of support and social capital for non-heterosexual bereaved were also shaped by the degree and nature of disclosure of identity and relationship status (Bristowe et al., 2016), influenced by family and faith communities, and affected by systematic experiences of discrimination (Fenge, 2014). These findings resonate somewhat with the assertion of Neimeyer et al. (2014) that individuals grieve "under the watchful eyes" of family as well as those who "hold religious and political power" (Neimeyer et al., 2014). Recognising disenfranchisement as a "process of alienation" that fractures grievers from not only social support but their own "subjective inner experience," (Reynolds, 2002: 356), disenfranchising societal contexts therefore potentially function to not only limit options for informal support, but to undermine potential for the structurally vulnerable to express support needs and preferences in accordance with the nature of their grief and personality.

Arguably, latitude for decision making and choice with regard to finances and employment in bereavement were shaped by varied and evident factors. For instance, where there is a widespread lack of knowledge about the range of income support benefits available (Corden et al., 2010), the potential for structurally vulnerable individuals to make informed choices regarding the most appropriate options in times of stress and uncertainty will likely be hindered. Preexisting notions of gender roles that contributed to the inheritance of consequences of poor financial decision making of male partners (DiGiacomo et al., 2015) may at least initially influence capacity for informed decision-making, and therefore options in relation to the management of financial matters. Inadequate or inflexible workplace entitlements in bereavement (Blackburn and Bulsara, 2018), or alternatively, potential barriers to employment due to gender and age in bereavement (DiGiacomo et al., 2015) may reduce options to maintain ongoing engagement in paid work following caring, evidently disadvantageous considering recognition that taking a job was in another study negatively associated with depressive symptoms and positively related to positive outlook in bereavement (Wyatt et al., 1999). Broadly, for the structurally vulnerable in bereavement, the cumulative weight and dominance of stressors associated with financial and practical matters appeared to contribute to varied emotional and psychological difficulties, which may limit one's capacity to oscillate between attention to both loss and restoration oriented tasks in bereavement (Stroebe and Schut, 1999; Corden et al., 2010), and may undermine navigation of economic decision-making and choices regarding employment.

For the individual positioned as structurally vulnerable, it appears that future capacity to advocate for oneself and engage with formal support systems may be undermined by some experiences of interactions with these systems in bereavement; theoretically limiting choice and decision making capability. Negative interactions with organisations that contributed to fears related to future contact and outcomes (Blackburn and Bulsara, 2018; Corden et al., 2010), and led to demoralisation (Blackburn and Bulsara, 2018), despair (Corden et al., 2010), and persistent uncertainty (Corden et al., 2010; DiGiacomo et al., 2015; Holtslander and Duggleby, 2010; Holtslander et al., 2017), at a time of already understandably heightened distress, could diminish current and future openness to engagement with agencies and services. This assertion seems especially pertinent when also considering several studies that referred to a pre-existing level of vulnerability coming into bereavement, whether due to factors such as illness related financial strain or income poverty, (Corden et al., 2010), ethnicity (Spruyt, 1999) or lower personal resources (Utz et al., 2011) - which is likely indicative of needs that necessitate ongoing contact with formal services. This combination of factors could perpetuate the embodiment of unequal social status and possibly a sense of 'unworthiness' of assistance and appropriate support, as well as a hesitation or resistance regarding future engagement with formal services. Furthermore, Reynolds (2002: 365) recognises the often "instrumental" nature of organisational practices, and therefore the increased likelihood of policy that reflects the dominant discourse about grief and is therefore restrictive in defining the socially accepted scope of grief and coping styles, potentially perpetuating societal and self judgement according to "dominant cultural prescription" (Breen and O'Connor, 2007: 202).

4.3. Coordinated, socio-ecological approaches to address structural vulnerability require further exploration

The above discussion contextualises the concept of agency socially and structurally, shaped by social norms as well as by interactions with services, systems and organisations. Quesada et al. (2011) argues for the demystification of the concept of agency through lifting "moral judgment" that suggests individuals "understand and control the consequences of their everyday actions" (2011: 342), and may imply that responsibility largely lies with individuals to address experiences of disadvantage and disenfranchisement that accompany structural vulnerability. Interestingly, in some suggested responses to issues related to structural vulnerability, the onus was placed on carers to 'learn,' or to 'be educated' through information or skills development provided by health professionals. Suggestions included the provision of financial advice in the context of socio-economic deprivation (Roulston et al., 2017) and support sessions on financial and employment planning to be provided pre or post-death for carers by health services (Wyatt et al., 1999). It seems that such suggestions may constitute interventions that focus "primarily on changing the micro-behaviours of individuals through knowledge-based education interventions, based on middle class models of rational choice decision-making" (Quesada et al., 2011: 344). As "downstream" approaches, such interventions may be of benefit in some circumstances, but may unfortunately offer "little to change the health status of the poorest and most vulnerable people," (Keleher, 2007a: 32).

As discussed above, several included studies also made recommendations to be applied within the context of specialist palliative care or health care provision. This did not constitute a primary focus of this review given the emphasis upon consideration of "upstream" factors related to socioeconomic, environmental and cultural conditions (Keleher, 2007a), including other services, systems, government structures and institutions. However, across the existing literature base in end of life and palliative care, a leaning towards exploration of individual interventions, applied pre-death or in early bereavement in the context of experiences of specialist palliative care appears to persist, with a neglect of socio-ecological concerns including the concept of health equity or "society's obligation to improve unequal health outcomes," (Reimer Kirkham et al., 2016: 296). The inference that health professionals in palliative care can significantly mitigate issues related to inequity, through clinical interventions, primarily with a psychological focus, and applied in a short, time-limited window at end of life and in early bereavement, is highly problematic. Perhaps it is true that in research and practice, as Reynolds argues, health professionals have "adopted the individual helping encounter as a default position in our advocacy for those we serve," forgoing the "more systemic helping interventions of the political process," (Reynolds, 2002: 384).

Undeniably, individual psychosocial interventions within the context of specialist palliative care at the end of life and in early bereavement warrant ongoing investment and development. However, this represents an incomplete picture of the response that is required, and such an emphasis potentially cultivates blindness to the "many aspects of health beyond those within the mandate of healthcare services," (Sallnow et al., 2016b). If end-of-life care issues should not be viewed as distinct from social issues such as poverty or inequity (Sallnow et al., 2016a: 208), then the experience of structural vulnerability in bereavement also demands specific attention. This is especially warranted given that family members and carers can experience a sense of abandonment post-death (Holtslander et al., 2017; Stajduhar et al., 2010) by formal health services that may have been engaged in palliative care provision, despite the persistent rhetoric of the family as the "unit of care". Increased investment in a truly socio-ecological understanding of and response to the factors that may contribute to structural vulnerability in bereavement necessitates the expansion of strategies beyond the domain of specialist palliative care and formal health care. The "new" public health approach, with a focus on the total population, recognition of non-professional actors in healthcare, and an emphasis on wider social, environmental, physical and economic determinants of health (Sallnow et al., 2016b: 26) must be developed if the complex needs of structurally vulnerable groups are to be addressed and the structural contributors to disadvantage and disenfranhisement challenged.

Reviewed studies incorporated several suggestions relating the development of more flexible, supportive systems, with some potential to mitigate structural inequity. However it appears that pathways to addressing structural vulnerability in bereavement have been under-explored and under-researched, with a recognised neglect of vulnerable populations associated with death, caregiving, bereavement and loss in public health research (Karapliagou and Kellehear, 2016). There is an evident need for public health approaches to be explicitly applied to bereavement care (Breen et al., 2014; Rumbold and Aoun, 2014), with “applications to bereavement trail(ing) well behind applications to dying” (Rumbold and Aoun, 2014: 132). In light of the findings of this review, capacity building “both within and outside the health care sector” (Reimer Kirkham et al., 2016: 297), and in government and non-government agencies positioned at the coalface of supportive work with vulnerable populations in bereavement and in other critical periods of loss and change could mitigate some experiences of demoralisation and distress, sometimes associated with administrative burdens and interactions with agencies in bereavement. Partnerships and strategies enshrined within organisational policies, cultures and practices that seek to increase communication and information sharing between health and social care settings could lessen the need for multiple contacts with services post-death. Coordinated, intersectoral advocacy campaigns around structural issues - such as the need to address limited and inflexible leave entitlements - as well as integrated education and policy that minimises the potential for stigma and discrimination (O'Connor et al., 2010; Tehan and Thompson, 2013) appears to be justified, especially considering the assertion that professional, ‘white collar’ employees are often the recipients of “enlightened, sensitive and flexible” end-of-life policies, with minority and disenfranchised groups additionally disenfranchised in this way (Reynolds, 2002: 394). Participatory projects involving representatives from health and social care settings, as well as bereaved individuals, could inform the development of frameworks that are inclusive of varied approaches to coping in bereavement. Such actions may expand the capacity of communities, organisations and government structures to, as Street (2007: 107) argues, “cope with the inevitability of death and consciously support loss, grief, dying and bereavement, especially in the most vulnerable community members.”

This review also demonstrates the need for focused research into extremely disenfranchised populations who are likely to experience structural vulnerability in bereavement, and may be somewhat ‘hidden’ from the gaze of formal health care and specialist palliative care providers. Further exploration of the experience of structural vulnerability within culturally diverse populations in bereavement is warranted, especially given current and complex needs related to intergenerational loss and trauma sustained by significant refugee and migrant populations re-located in high income countries, as they navigate unfamiliar health and welfare systems. Additional research regarding the experience of sexual minorities may also further develop socio-ecological approaches to attending to social and structural inequity for such populations.

4.4. *Strengths and limitations*

As far as we are aware, this scoping review is the first to explore bereavement experience following life-limiting illness drawing upon the concept of structural vulnerability and related issues. Strengths included the use of broad search terms and the ongoing nature of consultation between authors throughout the review process. There are however, several limitations that require articulation. The number of articles selected for the review may have been limited due to the nature of the electronic databases searched. Only studies published in English were included, which may have excluded relevant research that was only available in other languages. Additionally, one researcher undertook much of the primary analysis, meaning that researcher bias may have impacted the process. Quality appraisal of included studies was considered to be beyond the scope of this review, in light of the small number of identified studies as well as the exclusion of quality appraisal from the Arksey and O'Malley (2005) framework. However, the researchers are aware that omission of quality assessment from scoping reviews has been the subject of continued discussion in terms of the potential implications for the uptake and relevance of scoping reviews (Levac et al., 2010: 8). Findings should therefore be interpreted cautiously, also in view of the methodological and contextual heterogeneity of included studies, which posed some challenges for analysis, summarising findings and discussion.

Several included studies also reported positive findings, for example experiences of individual capacity building in bereavement in relation to practical tasks (Holtslander et al., 2017), a sense of growth or mastery in learning new skills or developing new roles (Corden et al., 2010; Blackburn and Bulsara, 2018) and positive experiences of support (Fenge, 2014; Wyatt et al., 1999). However, these were somewhat overshadowed by findings reporting wide-ranging challenges for varied and vulnerable populations in bereavement. This finding perhaps represents a deficit- (rather than strengths-) focused lens that underpins this area of research as well as western models of health and social care. Perhaps it also reflects the range of serious challenges in need of attention in addressing the complexity of structural vulnerability. Furthermore, the research question sought to map experiences of social and structural inequities as features of structural vulnerability, and thus positive outcomes related to growth and support were not the central focus of this review. The nature of positive experiences and strengths in the context of bereavement following life-limiting illness may be a valuable future focus of research.

5. Conclusion

Being positioned as structurally vulnerable in bereavement following life-limiting illness appears to be associated with layered and patterned experiences of heightened disadvantage, arising from unequal social status as well as exposure to structural inequity. Consequences for individual agency potentially include disenfranchisement from social support and informal networks, hindered scope for decision-making in relation to economic concerns, and implications for one's future engagement with formal support services. Further exploration of structural responses and strategies that might seek to address the socio-ecological determinants of structural vulnerability in bereavement is indicated.

Findings call for contemplation of more nuanced understandings of complexity and vulnerability in the context of bereavement following expected death. This should incorporate attention to indicators of cumulative and systemic oppression, discrimination, disenfranchisement, and issues related to the access to and utilisation of material resources, alongside ongoing efforts to understand indicators of psychological distress and complexity. A wider conceptualisation of vulnerability could potentially draw upon the evolving scholarship on intersectionality, with its consideration of complex relationships and interactions between social locations and structural disadvantage (Hankivsky et al., 2014). Inherently and unavoidably political, given that relationships involving class, gender and ethnicity for instance, are “produced through the apparatus and ideology of the state,” (Navarro, 2011: 313); public health responses to structural vulnerability must address the manner in which institutional culture, government policy and the nature of informal networks and social expectations are shaped by esteemed “western” values such as productivity, independence and stoicism (Harris, 2010), which can perpetuate disadvantage and disenfranchisement, and the erosion of agency. Cognisant of this, future research could contribute to the development of inclusive, equity informed assessment and policy frameworks to be utilised by specialist palliative care services, as well as generalist health care providers and agencies engaged in social welfare provision in times of crisis, loss and change for family members and carers in bereavement following life-limiting illness. Given the universal nature of grief, findings may also inform the development of structural capacity within organisations beyond the purview of formal health care and palliative care, responding to the diversity of bereavement experiences including trauma and sudden natural death, to cultivate more appropriate and responsive support systems for those positioned as structurally vulnerable.

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