

Contextual information behaviour analysis of grief and bereavement: temporal and spatial factors, multiplicity of contexts and person-in-progressive situation

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Introduction. Grief and bereavement include cognitive, affective and physical dimensions. Pre- and post-grief manifest at different times of coping with loss and bereavement. Contextualisation of information behaviour studies and comprehension of contextual components e.g. temporal and spatial factors, progression and phenomenal contexts of grief is essential for information interventions. Although agreement on the meaning of context might continue to escape information behaviour researchers, widely cited interpretations of context might be used to analyse a selective body of literature to direct grief and bereavement information behaviour studies.

Method. Interpretations of context and situation by Savolainen (temporal and spatial factors), Fourie (multiplicity) and Dunne (person-in-progressive-situation) are, selectively applied to a thematic content analysis of papers on grief and bereavement. Phenomenal context is analysed in more detail.

Analysis. A thematic content analysis matrix was developed.

Results. The analysis revealed a minimum of ten contextual components to consider in information behaviour studies of grief and bereavement.

Conclusion. Information behaviour studies on grief and bereavement should acknowledge the diversity of contexts and contextual components that impact on information needs, unique requirements for information such as memorabilia, information processing and sharing of information.

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Introduction and rationale

Each year millions of people are affected by the unexpected death of loved-ones and victims of crime, natural disasters, war and terrorism (Addington-Hall and McPherson, 2001; Behnke, *et al.*, 1987; Boelen, *et al.*, 2016; Cohen and Hoffner, 2016; Mason and Toftagen, 2019; Scocco, *et al.*, 2019; World Health Organisation, 2019). Each suicide for instance directly affects at least six significant others, referred to as 'suicide survivors' (Shneiderman and colleagues, 1969, cited in Scocco, *et al.*, 2019, p. 223). Public grieving for celebrities such as Michael Jackson and Aaron Swartz (a hacktivist) and close loved-ones are increasingly shared through Twitter, Facebook and other social media (Lee and Goh, 2013; Martini, 2018; Ruthven, 2012).

Sometimes dying is slow and painstaking, adding to the challenges faced in caregiving. Families are not prepared on how to take care of terminally ill patients, to accept the responsibility of making decisions on behalf of patients or for the deep and painful emotions of pre-grief (Zhou, *et al.*, 2018; McIlvennan, *et al.*, 2016). Often grief escalates to prolonged, complicated or traumatic grief and in extreme cases to psychiatric care, following post-trauma, depression and hypomanic symptoms and even drug and alcohol abuse (Li, *et al.*, 2015). Medical staff such as nurses, doctors and therapists and professional caregivers often also experience intense grief. Although they are expected to offer information, guidelines and support to patients and families – prior to death in preparation, as well as afterwards (Barry, *et al.*, 2012), concern is often expressed about their own ability to cope with grief and bereavement and the need for training (Spencer, 1994). Even serious injuries such as brain injury, strokes and loss of a body part may result in a significant gap between the pre and post-injury person leading to intense grief (Merlevede, *et al.*, 2004; Yehene, *et al.*, 2019). Grief has also been reported for cases of infertility and failed in-vitro fertilisation treatment (Lee, *et al.*, 2010) and premature ovarian failure (Singer, *et al.*, 2011). Although grieving mostly brings to mind the death of a person, it is also associated with many other types of loss such as grieving for the loss of a safe and familiar physical space – a house or country (e.g., in the case of refugees), loss of a job or grieving for loss of trust and innocence such as in cases of abuse and rape. This paper focuses only on grief related to the death and dying of human beings.

Although death and dying are eminent parts of life and the everyday life challenges people face, coping and making sense with the process and effect do not come naturally. People need to learn to *cope* with bereavement (Stroebe and Schut, 1999). Their bodies, minds and brain need to adjust to a new way of being (O'Connor, 2019). They need to redefine themselves and the world in which they live, accept the choices and decisions they made on behalf of patients and navigate discussions about death and the deceased (Basinger, *et al.*, 2016; Yang, *et al.*, 2011). As new information becomes available or as social values change, they sometimes need to struggle with changed perceptions of the identity of the deceased (Doka, 2019). People must be prepared for death and grieving (Barry and Prigerson, 2002; Hales, *et al.*, 2012) through various forms of support (cognitive support, emotional, medical and psychological therapy [in extreme cases]). In order to do this, provision of information and harvesting information from the bereaved, using various instruments and methods are important (Kersting, *et al.*, 2007; Lafarge, *et al.*, 2013; Wheeler and Austin, 2000). Understanding of the information needs and behaviour of the bereaved and especially caregivers can inform clinical care. Their experiences, needs and coping abilities are often affected by perceptions on the quality of dying, lack of information and poor communication (Hales, *et al.*, 2012), and more importantly a diversity of cognitive and affective states of mind (Luecken and Appelhans, 2005; White and Fessler, 2018). Spatial (i.e., place) and especially temporal (i.e., time) factors are significant in understanding information behaviour in the context of grief and bereavement. Their growing importance in information behaviour research *per se* is portrayed in the significant contributions by Savolainen (2006a, 2006b), as well as by the work of Dunne (2002) and others on information behaviour experiences in progressive situations. Understanding such influences on changes in information needs and information behaviour might guide health professionals and others offering support to those who are grieving to develop interventions and support appropriate to time, place and progress. It might also reveal the complexities of information needs, information behaviour and the diversity of intervening variables that require further investigation using an approach of multiplicity of (sub)contexts where information behaviour in such contexts are then studied in their own right (Fourie, 2012).

Problem statement and research question

Information behaviour and information needs literature on grief, bereavement, dealing with loss, death and dying is limited. A substantial body of research has, however, been reported on coping with grief and bereavement, counselling, therapy and other interventions (Aho, *et al.*, 2011; Dias, *et al.*, 2019). Regardless, reports of frustration, loneliness and despair prevail (Laurent, *et al.*, 2016); sometimes the bereaved even turn to dangerous psychic practices (Shepherd, 2009) prying on people with 'lonely hearts and grieving souls' or adopt malfunctioning coping strategies like alcohol and drugs (Valentine, *et al.*, 2018). Timely and appropriate information and support, based on knowledge of information needs and information behaviour can make a difference to quality of life, coping and making sense. There are many contexts where information behaviour is understudied. Grief and bereavement, *albeit not always for human beings*, are experienced by all people, throughout their life with different levels of intensity and on multiple occasions. Grieving is an ongoing process that can benefit from more appropriate information support and understanding. This is one reason why a contextualised analysis of reports on information behaviour in grief and bereavement is essential.

The question that arises: How can a contextual information behaviour analysis of grief and bereavement inform information behaviour studies?

Clarification of concepts

Information behaviour

Information behaviour refers to all information-related activities and encounters, including information seeking, information searching, browsing, recognising and expressing information needs, information encountering, information avoidance, information processing, information sharing and information use (Fourie and Julien, 2014 – acknowledging definitions by well-known information behaviour researchers [Case, Savolainen and Wilson]). Considering the complexity of grief and bereavement, knowledge sharing (Savolainen, 2017) and information processing must be added. In the context of grief and bereavement, information behaviour is marked by anxiety, uncertainty and deeply emotional feelings of loss and fear with both affective and cognitive factors at play (Mystakidou, et al., 2009).

Grief

Grief is a natural multifaceted, multi-occurring response individuals experience throughout their lives to a variety of losses, most notably the death of someone with whom a close bond of affection was shared such as a father grieving the loss of a child or a child grieving the loss of a parent (Aho, et al., 2011; Jones, et al., 2015). Grieving is a pervasive, highly individualised, dynamic process marked by emotional, physical, cognitive, behavioural, social, cultural, spiritual and philosophical dimensions (Blanchard, et al., 1976; Cowles and Rodgers, 1991). It is related to mourning and often used interchangeably with bereavement. There are different types and phases of grief: pre-grief (also known as preparatory or anticipatory grief) and post-grief (Chapman and Pepler, 1998; Holm, et al., 2019; Kobiske, et al., 2019; Mystakidou, et al., 2009). Grief can manifest as complicated, prolonged and disenfranchised grief (Blanchard, et al., 1976; Boelen, et al., 2019; Dell'Osso, et al., 2011; Tang and Chow, 2017) or as traumatic grief where there is a clinical diagnosis of persistent complex bereavement disorder (PCBD) often with comorbid symptoms of posttraumatic stress disorder (PTSD) and/or major depressive disorder (MDD) (Smid, et al., 2015).

Bereavement

Bereavement refers to the state of loss. When a loved one dies, a person in bereavement needs to adapt to the loss, recover and live in a new reality in which the deceased is absent, and where individuals learn to live without what they have lost. The closeness between the bereaved and the deceased and the ongoing relationship between the griever and the deceased is of significant importance (Medlineplus, 2020).

The concepts of *context* and *situation* will be clarified under a separate section, *Perspectives of context and contextualisation*.

Brief background on grief and bereavement

Grief is often marked by stages such as denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1969). It can take different trajectories such as resilience when a person maintains relatively stable, healthy levels of psychological and physical functioning and recovers when normal functioning temporarily gives way to threshold or sub-threshold psychopathology such as symptoms of depression or posttraumatic stress disorder before people return to their state before the loss. In other cases, there is chronic disfunctioning associated with prolonged suffering and inability to function over several years, or delayed grief when adjustment appears normal and distress starts months later (Bonnano, 2019). The ability to understand and process experiences in addition to sense-making is very important in grieving and bereavement. Information can play an important part in appropriate combination with therapy, counselling, medication and psychological and psychiatric interventions. The development of information interventions needs to be based on more than just the recall of experiences and preferences and needs captured in a single interview or focus group where input often focusses on whether experiences of care were positive or negative (Agnew and Duffy, 2009). A deep, contextualised more holistic understanding of the complexities of information behaviour in grief and bereavement is required to fully benefit from information interventions integrated with other support. This would include an understanding of the contexts/components/elements identified in Table 2. By considering the complexities of contextualisation for grief and bereavement, this paper moves toward a means to gain such understanding.

Method

Context and situation have featured in many discussions of information behaviour, most notably the recent work of Agarwal (2018) and older work of Courtright (2007), Dervin (1997), Johnson (2003), Savolainen (2006a,b), Sonnenwald (1999) and Talja in e.g. Talja, et al. (1999) on context and Cool (2001), Allen (1996) and Dunne (2002) on situation. Agarwal (2018) argues for a contextual identity framework accommodating different, valid views of context. He explains

what one concluded to be context depended on the view one was using to envision context. All views were true and co-existed, and were a part of the concept of context. They were just different ways of looking at the same thing. Depending on where you looked at it from, and what you focused on, you would see different things... (p. 82).

Agarwal's framework holds much value; I, however, decided to first explore contextualisations of grief and bereavement from the point of view of Savolainen (Sairanen and Savolainen, 2010) who have reported on both health information behaviour and context and my own work reporting on contextualisation for information behaviour in health contexts (Fourie, 2012). Dunne's (2002) interpretation of person-in-progressive-situations based on Allen's earlier work on person-in-situation will also be considered for its value when studying changing trajectories of grief. The interpretations of these authors are covered in the section on Perspectives of context and contextualisation and will be used as grounds to develop a matrix for the thematic analysis of a selection of research reports on grief and bereavement (see Table 2) that can stimulate information behaviour research.

Exploratory thematic analysis, guided by insight from the work of Savolainen (2006a,b), Dunne (2002) and Fourie (2012) was applied to the selected documents.

Thematic analysis is a data reduction and analysis strategy by which qualitative data are segmented, categorized, summarized, and reconstructed in a way that captures the important concepts within the data set. Thematic analysis is primarily a descriptive strategy that facilitates the search for patterns of experience within a qualitative data set; the product of a thematic analysis is a description of those patterns and the overarching design that unites them (Ayres, 2008, el).

The documents were first scanned, before coding phrases related to aspects of information behaviour as per the accepted definition of information behaviour. These included, information needs, additional needs, information sources and people providing information and support, and comments on frustrations with information provided. I did not only look for issues of progress in situations (related to work by Dunne, 2002), time and space (related to work by Savolainen, 2006a,b on temporal and spatial issues). These, however, stood out as well as the fact that there are many other issues that relate to Fourie's (2012) approach on multiplicity of contexts that need to be understood individually e.g. the nature of diseases and palliative care treatment, and that have a very important impact on information needs and information behaviour of those going through grieving and bereavement. The codes were grouped to identify themes as presented under Discussion of Findings. Many of the themes and sub-themes, however, emerged inductively from the documents. Apart from the explicit themes noted, there might be implicit issues and themes that might be revealed in a second round of analysis. As noted by Given (2016, el), other researchers might add additional or different interpretations: '*As qualitative research design is embedded in a constructionist view of reality, it is expected that different people will interpret data in different ways*'.

The scope of the literature search is presented in Table 1; information behaviour studies on grief and bereavement *per se* are very limited, but a wider body of literature on grief and bereavement that reveals experiences, explicit and implied information needs and information reactions and that can shape further research could be identified.

Table 1: Literature search

Databases	<p><i>Library and Information Science databases:</i> Library and Information Science Abstracts (LISA), Library and Information Science Source, Library and Information Science & Technology Abstracts (LISTA)</p> <p><i>Health Science databases:</i> AIDS and Cancer Research Abstracts, BioMed Central, CINAHL: Cumulative Index to Nursing and Allied Health Literature, Medline, PsycINFO, Social Sciences Citation Index, Web of Science (Clarivate Analytics)</p>
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Search terms	Grief (and variations such as grieves, grieved, grieving) Bereavement (and variations such as bereaved) Information (to retrieve publications on information needs, information behaviour/behavior and the many specific information activities such as information seeking and information sharing)
Fields	Title, keywords and abstract; depending on the number of records retrieved, I used different combinations e.g. grief, bereavement in the title and terms related to information behaviour and information activities in the title, abstract or keyword fields, or all in the title. The intention was to retrieve a representative and manageable body of literature for further consideration. No limits were placed on date and language when searching. When selecting papers for further reading, only full-text papers in English were used.
Additional	Intentionally using only 'information' as search term and not specific information activities meant that highly focused manual selection was required.

Perspectives on context and contextualisation

Many authors have offered interpretations of contexts and situations in context. It is argued that a context is larger than a situation and may consist of a variety of situations; different contexts may encompass different types of situations (Sonnenwald, 1999, p. 3). Courtright (2007) and Sonnenwald (1999) have portrayed contexts as frameworks for meaning and reference including interacting and contextualising elements, components, rules, resources, boundaries, constraints, privileges, individual and social actions and processes. There are changes and movement in context (Courtright, 2007, p. 290) and time and spatial factors are important in demarcating context (Dervin, 1997). Savolainen (2006a,b) added a substantial contribution to work on temporal and spatial issues in contexts and the impact on information behaviour; his arguments are covered in more detail under a sub-heading. According to Johnson (2009, p. 596) there are three *senses* of context: situational approaches where context is seen as equivalent to the situation in which an individual is immersed; contingency approaches that include the active ingredients that have specific, predictable effects on various processes; and context as major frameworks for meaning, systems and interpretation. Multi-contextuality and multi-dimensionality also feature in discussions of context: Johnson (2003, p. 736) refers to multi-contextual approaches to understanding processes, Dervin (1997) to different senses of context and Fourie (2012) to a multi-contextual approach. As noted earlier, Agarwal (2018) also supports different views on context.

Talja, Keso and Pietiläinen (1999, p. 752) distinguish between objectivied versus interpretive approaches. They note limitations of an objectivied *natural* approach naming entities which affect the research object (in the case of this paper, grief and bereavement) and that might imply that language describes reality and facts objectively and seemingly unproblematic and transparent and not acknowledging that such factors and the meaning of entities might constantly change and need to be negotiated. They argue that

'Particular kinds of conceptualizations make it possible for the researcher to approach information needs, seeking and use from a particular angle and limit other ways in which these phenomena could also be viewed'.

Interpretation of contexts are influenced by social and cultural meaning and values that might change. This paper is a first step to move towards a deeper understanding of interpretive approaches.

Fourie's perspectives on context

Fourie (2012) argues for multiplicity of context in healthcare and situations of existentialism. In each healthcare context such as pregnancy, diagnosis with a specific type of cancer, receiving a specific treatment or experiencing a remission stage of a life-threatening disease (sometimes referred to as survival) there are sub-contexts or related contexts that might be studied in their own right such as pain (Fourie and Nettet, 2017), religion and spirituality and culture. If combining findings from studies on these contexts first as a phenomenon in its own (e.g., understanding the complexities of pain and challenges in expressing information needs – [Fourie and Nettet, 2017]) and then secondly in relation to the disease or health situation, insight and understanding might be deepened. This may appear as an objectified approach to context, but the argument, as will be shown in further discussion is actually to apply an interpretive approach to each intervening variable that might be interpreted in its own right as a context forming part of multiple contexts related to a phenomenon such as pain, cancer diagnosis or palliative care. An element of explanatory thematic analysis might thus be added to understand information behaviour in grief and bereavement.

Savolainen's perspectives: spatial and temporal contexts

Everyday life that includes situations where people need to deal with illness and poor health, critical diagnoses, caregiving, grief and bereavement, has many nuances. Savolainen (1995) refers to *way of life* – the context where individuals need to master everyday challenges. Savolainen's interpretation of context allows for spatial qualifiers of context such as conceptual space (Savolainen, 2006b) and time as a context of information seeking (Savolainen, 2006b). His work offers a significant contribution on spatial and temporal factors in contexts. Savolainen also refers to the conceptual space of information-seeking phenomena where small worlds and information grounds can serve as contexts of information seeking and sharing (Savolainen, 2009). He considers spatial factors with regard to information resources where he argues on three viewpoints: (i) realistic-pragmatic approach focusing on the availability of information resources in various places and the influence on information seeking; (ii) the perspectives approach focusing on how people access the significance of various sources by means of spatial constructs such as information horizons; (iii) objectifying approach that views these as discrete and separate entities – without reckoning with subjectively interpreted meaning. A central point of departure in the perspectivist approach is the view that the spatio-temporal context should not be understood as an independent entity, but as an external and entity-like phenomenon that constrains action (Savolainen, 2006b). In this paper, space is extended to the space in which a phenomenon of study manifests and not just the space of information sources. Temporality in contexts can address the trajectory of grief and bereavement, starting with pre-grief.

Dunne's perspective on person-in-progressive-situation

Dunne (2002) developed her model on person-in-progressive-situation from a study with battered women. She builds on earlier work of Allen (1996) on the information needs from a person-in-situation approach. Her model focusses on the changes in information needs, seeking, and use at various stages in the progression of abuse. The experiences and information needs of a battered women is not static – she faces many stages as the battering changes and might become worse. This can be related to temporal factors as argued in the later work of Savolainen (2006b), and can significantly guide understanding of the differences in challenges, information needs and experiences over the trajectory of grief and bereavement, starting with pre-grief.

Findings from thematic analysis

Based on the literature review and thematic analysis of approximately 360 papers, ten themes were identified. There might be more – the intention is not to be comprehensive, but to reflect the unique complexities of information behaviour in contexts of grief and bereavement. For each theme I provide some sub-themes, as well as references. More were, however, consulted, but length constraints must be respected. Only one of the themes, the phenomenal context of death is discussed in more detail to show the value of this approach to context in information behaviour studies, with brief reference to situations in progress (i.e., disease trajectory) and context as space. Very few studies dealt directly with information behaviour and aspects of information behaviour as per the definition accepted. Examples of such articles include Cohen and Hoffner (2016), Lee and Goh (2013), Luecken and Appelhans (2005), Ngo, *et al.* (2019), Okamoto, *et al.* (2017), Ruthven (2012), Thimm

and Nehls (2017) and Verkissen, *et al.* (2019). The wider body of literature on grief and bereavement *per se* was thus analysed to deduct implications for research on information behaviour.

Table 2: Matrix to analyse findings from studies of grief and bereavement information behaviour in context

Context	Supporting references (selective – more were consulted)
Phenomenal context of death – how and when death occurred	
<i>Natural death</i> : caused by diseases and medical conditions; the nature and prognosis of each has an important impact on experiences (Fourie, 2012). Grief and bereavement studies are connected to many diseases – Alzheimer's, cancer, dementia, epilepsy and severe chronic obstructive pulmonary disease (to name but a few).	Alisic, <i>et al.</i> (2017); Bellon, <i>et al.</i> (2015); Garstang, <i>et al.</i> (2016); Holland and Neimeyer (2011); Kersting, <i>et al.</i> (2005); Lafarge, <i>et al.</i> (2013); Pote and Wright (2018); Thomas, <i>et al.</i> (2014); Valentine <i>et al.</i> (2018); Zucker, <i>et al.</i> (2015)
<i>Traumatic death</i> : caused by disasters (e.g., earthquakes), war, homicide, terrorism, abuse, accidents and suicides. Traumatic deaths can be violent or non-violent. Natural death can be peaceful or marked by intensive experiences of pain and suffering.	
<i>Termination of life</i> : e.g., regarding pregnancy (i.e., abortion, discontinuing life-support, euthanasia)	
Phenomenal context of grief – how grief is experienced	
Grief and bereavement according to phases and challenges that are widely accepted as the norm (e.g. Kubler-Ross, 1969) – admittedly not without challenging discourse (DowneWamboldt and Tamlyn, 1997).	Bonnano (2019); DowneWamboldt and Tamlyn (1997); Garstang, <i>et al.</i> (2016); Holland and Neimeyer (2011); Kubler-Ross (1969)
Prolonged, complicated and traumatic grief; grief complicated with post-traumatic disorder	
Grief characterised by serious physical and psychological developments such as psychiatric disorders and addiction.	
Relational contexts – relationship with deceased (primary versus distant or unacquainted [stranger] relationships)	
Spousal/intimate partnership relationships	DeCinque, <i>et al.</i> (2006); Fried and O'Leary (2008); Holland and Neimeyer (2011);
Parental relationships	Johnson, <i>et al.</i> (2015); Jones, <i>et al.</i> (2015);
Child-in-relation-to-parent relationships	Lockton, <i>et al.</i> (2019); Okamoto, <i>et al.</i> (2017);
Sibling relationships	Sanders, <i>et al.</i> (2007); Thomas, <i>et al.</i> (2014);
Grandparent and other relationships	Ussher, <i>et al.</i> (2009); Vamos (1993);
Family in general with different strengths and closeness of relationships	Verkissen, <i>et al.</i> (2019)
Distant, unacquainted and stranger relationships	
· Healthcare professional-patient relationship e.g. therapists, nurses, palliative care teams and social workers	
Carers – family as well as professional carers	
Place / location (where death occurred) as context (i.e., spatial context)	
Specialised healthcare institution (e.g., hospital, hospice, emergency care, intensive care, nursing home)	Choi, <i>et al.</i> (2012); Teno, <i>et al.</i> (2001); Flam (1999); Jacob (1996); Lees, <i>et al.</i> (2014); Newsom, <i>et al.</i> (2019); Ngo, <i>et al.</i> (2019);
Home	Scott (2013); Thompson, <i>et al.</i> (2012)
Other (e.g., workplace)	
Geographic region (e.g., country)	
Socio-economic area (e.g., low socio-economic area/ neighbourhood)	
Time (time of grief in relation to death [i.e., temporal context])	
<i>Time in relation to moment of death:</i>	
<ul style="list-style-type: none"> at time of death, within 1 week, 1 year or 7 years post-mortem (i.e., immediately after death, after an autopsy) time before death (pre- or preparatory grief) end of life/terminal period 	Barr and Cacciatore (2007); Gill and Lowes (2014); Grenklo, <i>et al.</i> (2013); Harper, <i>et al.</i> (2011); Ito, <i>et al.</i> (2010); Lykke, <i>et al.</i> (2019); Malkinson and Bar-Tur (2004); Mayer (2017); Paun and Cothran (2019); Pohlkamp, <i>et al.</i> (2019); Stephen, <i>et al.</i> (2015); Taylor, <i>et al.</i> (2013); Vergo, <i>et al.</i> (2017); Yu, <i>et al.</i> (2017); Zhou, <i>et al.</i> (2018)
<i>Duration of the dying process:</i>	
<ul style="list-style-type: none"> sudden (unexpected) death slow (their might be an expectation of death) 	
<i>Duration of grief:</i>	
<ul style="list-style-type: none"> prolonged grief and long-term bereavement 	
<i>Duration of care:</i>	
<ul style="list-style-type: none"> long-term care 	

Social context – social support during grief and bereavement

Familiar circle of support e.g., family, friends and colleagues, church
 Unacquainted social support e.g., through social media
 Coping in isolation
 Coping under social rejection

Diamond, *et al.* (2012); Perluxo and Francisco (2018); Thimm and Nehls (2017)

Cultural context – values of death and dying, rituals

Values of death and dying
 Rituals for grief and bereavement
 Cultural approaches/norms on care and decision-making at time of death
 Cultural approaches/norms on death and dying

Chow (2010); Li, *et al.* (2018); Smith-Howell, *et al.* (2016); Yang, *et al.* (2011)

Religious and ideological contexts

Beliefs

Choudhury (2017); Kongsuwan, *et al.* (2019); Staley (2017); Whitehead (2015)

Person-in-progressive situation in context (e.g., challenge, problem)

Grief has often been referred to as a journey (McAlearney, *et al.*, 2015) or as manifesting on a continuum (Compton, 1989). According to Rein (2006) 'It's the journey, not the destination' that is important.
 Nature of challenge and problem in the specific context e.g., cognitive, emotional, social
 Progression, movement (e.g., grief trajectories)
 Changes during grieving (e.g., forming a new identity)
 Tasks and responsibility in the situation in context e.g., caregiving at end of life
 Grief and healing trajectory (this may differ from the norm e.g., with experiences of secondary loss and grieving becoming dysfunctional; maladaptive coping)

Arizmendi and O'Connor (2015); Bateman, *et al.* (1992); Compton (1989); Feigelman, *et al.* (2019); McAlearney, *et al.* (2015); Phipps (2018); Rein (2006)

Pathological contexts of grief, bereavement and disease that leads to serious physical, emotional and psychological problems

Complicated grief
 Traumatic grief

Dodd, *et al.* (2019); Garstang, *et al.* (2016)

Only the phenomenal context of death (i.e., how death happened) is explored in more detail with brief reference to spatial and temporal context as well as person in progressive situation as related to the phenomenal context of death.

Phenomenal context – how and when death happened

There are many disease and death/termination variables that have an impact on how grief manifests: poor psychological adjustment, being recently bereaved, previous experiences with death and bereavement, and reactions such as acceptance and positive reframing (Lafarge, *et al.*, 2013). The very nature of how and when people die, i.e., the phenomenal context of death has a definitive impact on the experiences of families and reactions such as anxiety, regret, self-blame, guilt, feelings of being overwhelmed, separation distress and traumatic distress (Holland and Neimeyer, 2011). Apart from signaling a need for support and treatment, these might trigger information needs and a diversity of often unpredictable coping strategies (Lafarge, *et al.*, 2013), also resulting in information needs and portraying a diversity of information behaviour. This is especially true of violent deaths due to intimate partner violence, homicide and abuse (Vatnar, *et al.*, 2017) where the bereaved might face concerns about not seeking or not being successful in seeking help for the deceased. Their thoughts often reflect on 'information' (signs, words, warning) that might not have been noted or interpreted correctly and that might have prevented the death. Suicide notes (with information) does not necessarily relief grief or provide all answers (Feigelman, *et al.*, 2019). Death of addicts are often stigmatised; bereaved people have reported judgement and insensitive treatment and a lack of supportive information on how to cope. Some, especially traumatic deaths, are more prone to complicated and traumatic grieving (Boelen, *et al.*, 2019; Tofthagen, *et al.*, 2017). This also applies to termination of life e.g., termination of pregnancy for foetal abnormality (perinatal grief) (Kersting, *et al.*, 2005; Lafarge, *et al.*, 2013), miscarriage or abortion at an early stage where long term post-traumatic stress and complicated grief were reported. The bereaved need information as reassurance that the right decision was taken and on coping with judgement from others.

Death caused by diseases impact in different ways on grief and bereavement. Studies on a variety of diseases have been reported e.g. cancer (Pritchard, *et al.*, 2009), dementia (Pote and Wright, 2018) and many others. The nature of the disease, the duration and how it was perceived all impact on the bereaved and their information behaviour. Health conditions such as early or late pregnancy loss (Heiman, *et al.*, 1997) and stillbirth (Siassakos, *et al.*, 2018) have dramatic impact on experiences. This paper will not go into detail. Sherwood, *et al.* (2004) found parents of children with a brain tumour must be prepared through information on what to expect as well as how to deal with information on managing cognitive and neuropsychiatric problems at home. In the case of unexpected death, parents need to be informed on the full detail of their child's death (Garstang, *et al.*, 2014). Not receiving such information, creates the perception that they are being avoided. Processing of information on an autopsy is difficult, and they need follow-up appointments to enable them to obtain further information as they may have been too distraught at the time of the death to ask appropriate questions or comprehend the answers. Parents also value the emotional support provided by continuing contact with health-care professionals. Understanding procedures and protocol and the need for saying goodbye to their child are important. Sudden infant death syndrome (SIDS) as cause of death often leave parents with feelings of guilt and the need to know if they could have prevented it (Garstang, *et al.*, 2016). Their research found that bereaved parents want detailed information about their child's death. Parents also want health professionals to explain the role of risk factors.

Death related to medical procedure such as renal transplant failure (Gill and Lowes, 2014) presents many challenges particularly in relation to the provision of information and emotional support post-graft failure and detail on the possibility of failure. In order to provide appropriate information in terms of the timing and nature of information provision and whether factual and informative information versus consoling information and support for distress should be provided, health providers need information from the bereaved parents. It is in particular important to know how they experienced the death as well as their experiences throughout a disease trajectory (i.e., person-in-progressive situation) (Muders, *et al.*, 2015; Nielsen, *et al.*, 2017). Tang and Chow (2017) explain that subjective and objective traumatic death have been observed; subjective traumatic experience especially can lead to complicated grief. Various means and instruments and combinations thus need to be employed to solicit how the death was (subjectively) experienced.

The cause and circumstances of death influence many things, such as the time that was available (and often not used) to provide information and support to families to prepare for death. Good examples are patients in terminal care (e.g., terminal cancer, renal failure). In other phenomenal contexts such as accidents or homicide there is no time to prepare families. When preparatory time is available, it should be used. In a study on elderly patients in terminal care, Costello (2001, p. 59) found that although nurses provide individual care to dying patients, much of this was aimed at meeting patients' physical needs. Although they reported psychosocial

aspects including spiritual and emotional care to be important, there was little evidence of them being orientated towards this in practice. Many studies have noted how experiences of the treatment of patients influence the intensity of grief (Costello, 2001). Information alone is, however, not enough; emotional engagement and consideration of affect and emotion is essential (Costello, 2001), as well as the situation in progress – time before or since death. From an information behaviour perspective, deepening of understanding depends on the ability of people to share experiences and information needs. As a result of cognitive challenges and subjective experiences it might be difficult to express information needs and also to process information when provided (Kosminsky, 2017).

Grief following death by natural causes such as disease is influenced by the nature of the disease. Some cancers are painless and death follows quickly. With others patients suffer a lot of pain. In some cases, bereavement is aggravated because no information was provided that death might be an outcome or on how to support the patient experiencing immense pain. Bellon, *et al.* (2015) found 38% of their participants could have benefitted from immediate and long-term epilepsy information that might improve support to prevent epilepsy-related deaths and improve understanding. Cases of unexplained natural deaths such as Sudden Unexplained Death in Childhood (SUDC) and Sudden Infant Death Syndrome (SIDS) are especially problematic (Rudd and D'Andrea, 2013). Preliminary information on cause of death, follow-up communication referrals and further resources, but also human compassion and support, professional mental health support, and community experience were found important to bereaved parents (Garstang, *et al.*, 2014, 2016; Rudd and D'Andrea, 2013).

The institution of treatment at the time of end-of-life and death and the location of death impact on experiences and thus information behaviour (Grande, *et al.*, 2004; Scott, 2013). Sometimes families have a choice in deciding the location such as for hospice and home hospice care – sufficient information on all available options, communication and discussion to respect patients' wishes can have an important influence on the bereaved and their reflection on whether they made the right decision (Choi, *et al.*, 2012). The different stages or moments in the grieving process where awareness is intensified in the hospice environment relates to the person-in-progress-situation (Jacob, 1996); this must be acknowledged in information and emotional support. Rainsford, *et al.* (2018) report on a safe place to die in rural context. They found that

Rural residency creates both safe and unsafe places. Dying in a safe place was more important than dying at home. Dying in a rural hospital can be appropriate, and at times necessary and planned. The task for all those providing and supporting end-of-life care is to ensure all places for dying can deliver the 'safe death'.

Apart from spatial and temporal contexts and the experiences of the person-in-progressive-situation, there are many other contexts (i.e., multiplicity of contexts), components or elements of context that will influence information needs and information behaviour in contexts of grief and bereavement.

Discussion

A brief glimpse from an exploratory and partially explanatory thematic analysis of different contexts, components and elements of contexts sensitise us to the possibility that in grief and bereavement there are two continuums that are equally important to studies of information behaviour, namely: (i) giving information to the bereaved and (ii) gathering information from them on their experience and needs. Without knowledge of the experiences, perceptions and needs of the bereaved (even if only by inductively deducing these from reports on grief and bereavement *per se*), it is not possible to meet their information needs and support their information behaviour. Grieving can take many turns and trajectories, and is an ongoing effort to cope and make sense. More than in any other context or situation there is never only one predictable time or format for information provision. Apart from preparatory information on death in cases of life-threatening diseases or treatment in intensive care, bereaved people need information on the possibility of death such as with epilepsy patients and at various times after death. They need information in various forms, e.g. grief-focused exposure, memorabilia, writing assignments and farewell rituals (Smid, *et al.*, 2015). Information alone is never sufficient to address the complexity of the needs of those in grieving. Mindfulness of the affective and emotional support is in particular important.

Traditional methods of data collection such as interviews, questionnaires, and focus groups are not sufficient. Various alternative or supplementary methods have been noted. Chow (2010) reported on data mining of recorded interviews, methods of writing through loss and longitudinal studies as well as a spectrum of standardised instruments such as the two-track bereavement questionnaire, the child's information processing speed index; the child behavioral checklist and parental perception of behavioural changes scale (Yehene, *et al.*, 2019).

Although researchers aim for generalisation, participants (i.e., the bereaved) have reported that they do not want to be treated as stereotypes (Valentine, *et al.*, 2018). The complexity of different contexts and causes of death and the finer nuances are enormous. Even the type of information and information sources differ from other contexts reported in information behaviour studies. Information behaviour studies with the bereaved should not work from only a clinical understanding of the context, but also the bereaved's perceptions (Smid, *et al.*, 2015) and the possibility of multi-contexts. Apart from clinical observation, and standardised tests such as the brief COPE and short perinatal grief scales (Lafarge, *et al.*, 2013), researchers need to depend on the information provided by the bereaved. This might be clouded by inadequate integration of the memory of the traumatic loss, negative appraisal of the traumatic loss, sensitivity to matching triggers and new stressors, and attempts to avoid distress (Smid, *et al.*, 2015).

Conclusion

This paper could only give a brief glimpse of the immense complexity of context in grief and bereavement and how different perspectives might sensitise information researchers to contexts, components and elements of contexts and situations in progress to consider. More so, this paper emphasises the fact that none of these could reveal the full complexity of information behaviour if studied in isolation. Hopefully this paper will stimulate further research.

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