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“The grief exists in a bubble that the rest of the world doesn’t see”: Exploring biographical disruption and meaning-making amongst people bereaved during the Covid-19 pandemic

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ABSTRACT

People bereaved during the Covid-19 pandemic experienced profoundly altered death, mourning and grieving practices. Worsened grief outcomes have been widely reported but less is known about how people coped during these unprecedented times. Using reflexive thematic analysis critically informed by theories of biographical disruption and meaning-making, we analysed 39 interview transcripts from 24 people bereaved during the pandemic in the UK. We describe five core domains of disruption and associated meaning making: difficult and traumatic death experiences; disrupted mourning practices; loss of relationship and sense of self; social relationships, isolation and support; and developing understandings of grief. While the multi-dimensionality and severity of the disruption experienced was striking, so too were the ways in which people reappraised and reconstructed more positive and coherent accounts, often in relational ways, helping to explain their varied grief and coping experiences. Findings demonstrate the utility of critically combining these theoretical frameworks for conceptualising and contextualising grieving during ‘extraordinary’, as well as more ‘ordinary’ times. Implications are identified for minimising the disruption inherent in stressful bereavement circumstances, whilst also supporting people to reconcile and make meaning in their experiences.

1. Background

The Covid-19 pandemic was a devastating global mass-bereavement event with significant short and long term consequences for grief and bereavement experiences. Qualitative studies have described the unprecedented disruptions to healthcare, end-of-life, death and mourning practices, as well as the impact of acute social isolation in bereavement and disruption to informal and formal support (Hanna et al., 2021; Harrop et al., 2021; Torrens-Burton et al., 2022). Quantitative studies have indicated elevated levels of prolonged grief disorder and impaired psychological functioning (Breen et al., 2022; Harrop et al., 2023), associated with the unexpectedness of deaths, social isolation and lack of support (Harrop et al., 2023). The mediating effects of disrupted meaning have also been demonstrated quantitatively (Breen et al.,

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2022), and described qualitatively in our study survey findings, which noted anger and unanswered questions surrounding the death, experiences of grief feeling "unreal" without recourse to collective ritual, and lack of support from family, community and services (Harrop et al., 2021; Torrens-Burton et al., 2022). Reflecting on these findings, we argued for research which goes beyond examining outcomes, focusing instead on how people make sense of and give meaning to their loss and grief experiences (Harrop et al., 2023).

Neimeyer (2001) theorises the process of grieving as one in which the bereaved individual is tasked with reconstructing a meaningful and coherent life-story which can resolve the incongruence that follows the death of a significant other. This involves working to assimilate or accommodate their loss experience as they renegotiate self-narratives which are sufficiently consistent, coherent and meaningful (Neimeyer et al., 2010). Whereas 'assimilation' describes a person's efforts to reconcile their loss experiences with pre-loss beliefs and self-narratives, thereby maintaining continuity with their former self, 'accommodation' describes a person's efforts to adjust or expand their beliefs and self-narrative to embrace the reality of the loss, within the context of new social roles and a changed identity. Problematic grief arises where the individual is unable to make meaning in their experiences of loss and develop a coherent self-narrative which is either consistent with past beliefs and identities or transitional.

Neimeyer's model aligns well with the Dual Process Model (DPM) and Continuing Bonds Theory, both popular in contemporary bereavement research and practice. In the DPM, the bereaved individual is posited as oscillating between two types of coping, both of which feature meaning-making (Schut, 1999). 'Loss-oriented coping' focuses on processing the difficult aspects of the loss, in particular loss of relationship, while the parallel concept of 'restoration-oriented coping' relates to finding new meaning and adapting one's identity. Endeavours to renegotiate a meaningful, continued relationship with the deceased similarly speaks to Continuing Bonds Theory (Klass et al., 1996), which focuses on the importance of maintaining an ongoing relationship with the deceased, and the different ways in which this is experienced and achieved. However, such models have also been criticised for their cultural bias, individualism and corresponding lack of regard to the historical, cultural, social and relational contexts of bereavement (Ribbens McCarthy et al., 2023), with recent sociological perspectives favouring more relational approaches focused on how bereavement is experienced in everyday lives and interactions (Macarthur et al., 2023; Pearce, 2019; Ribbens McCarthy et al., 2023).

Similar sociological theorising is evident in studies of biographical disruption and narrative reconstruction (Bury, 1982; Williams, 1984). This body of work is rooted in chronic illness research, with limited application to studies of terminal illness (e.g. Aoun et al., 2016; Locock et al., 2009; Harrop et al., 2017) and bereavement. Bury (1982) developed the concept to explain how individuals experience and respond to disruptive life events and experiences associated with chronic illness. He proposes two related but distinct types of disruption: experiences and events which disrupt assumptions and behaviours, or which threaten one's biography and self-concept (Bury, 1982; Williams, 1984). While the latter resembles the identity disruption described in current bereavement theory (e.g. Neimeyer, 2001; Schut, 1999), the former also strongly resonates with the observed disruption to death and grieving practices during the pandemic (Torrens-Burton et al., 2022).

The related concept of 'narrative reconstruction' describes responses to the disruption caused by serious illness, including the role of 'talk' in processes of normalisation, moral accounting and the reconstruction of social identities and life narratives (Bury, 1991, 2001; Williams, 1984). As in Neimeyer's model, normalisation can involve both the minimisation and denial of symptoms in efforts to maintain the 'old' normal, as well as processes whereby the illness is incorporated into adapted lifestyles and discussed openly to construct a 'new' normal (Bury, 2001; Harrop et al., 2017). In addition to these normalisation processes, the comprehensive but arguably individualistic meaning-making model developed by Park (2010) to describe adjustment following stressful life events, also distinguishes searching for comprehensibility/significance and cognitive/emotional processing. The described outcomes of these processes include 'sense-made', acceptance, reattributions/causal understanding, perceptions of growth, changed identity and a reappraised meaning of the stressor.

When applied critically, with due regard to social and relational contexts, these theories of biographical disruption and meaning-making hold particular promise for conceptualising and exploring the different types of disruptions faced by people bereaved during the extraordinary circumstances of the pandemic, and their related narrative responses. By applying this framework to an in depth, longitudinal analysis of the lived experiences of people bereaved at this time, we aim to contribute new insights into pandemic grief and bereavement, as well as grief and bereavement experience and theory more broadly.

2. Methodology

This was a mixed-methods study comprising a longitudinal online survey (see Harrop et al., 2021, 2023; Torrens-Burton et al., 2022), with semi-structured interviews with a sub-group of survey participants. Here we describe the nested interview study which was informed by our phenomenological interest in how people make sense of their lives and their experiences. Reflecting this interest we followed the principles and practices of reflexive thematic analysis and corresponding reporting guidelines (Braun & Clarke, 2019, 2024).

Survey participants who consented to be contacted about an interview were purposively selected to reflect variation in key characteristics, including cause of death, relationship to deceased, gender, ethnicity, sexual orientation and grief severity (measured in each survey with the Adult Attitude to Grief Scale, Sim et al., 2014). Participants were sent a copy of the participant information sheet and consent form, and gave informed consent before the interviews took place. We aimed to interview each participant twice, with an approximate four month interval between interviews. First interviews were conducted between April and October 2021, and second interviews between October 2021 and February 2022. Topic guides were developed by members of the research team and advisory group, including our public representative. First interviews focused on exploring in-depth people's experiences at the end of life and in early bereavement, and experiences of grieving, coping and support to date, with each participant's most recent survey responses used as probes for further discussion. Follow up interviews focused on how such experiences had changed (or not) since the previous interview. Interviews were conducted by four female healthcare researchers (KB, ES, EG, DW), including two clinicians. A distress protocol was followed which covered interview conduct, debriefing and follow-up support for participants and interviewers (see Burton et al., 2024, Suppl File 1: topic guides).

Interviews took place via telephone or Zoom and were audio-recorded, professionally transcribed, and anonymised prior to analysis. First interviews lasted between 34 and 98 min (mean 57 min) and second interviews between 23 and 70 min (mean 40 min). The interview data were organised in NVivo12, with separate files created for first and second interviews. After initial reading of a selection of first interview transcripts, EH, FM, ATB independently coded three transcripts each, generating inductive codes which closely described individual participant experiences or perspectives. They then created broader codes which meaningfully described shared or similar experiences, and organised and connected these under higher-level analytical categories, before meeting to discuss the initial themes and agree a preliminary version of the framework with other members of the team. This was an iterative process in which the researchers moved back and forth between the data and analytical concepts, meeting regularly to discuss themes and iterations of the coding framework. The framework developed for the first interviews was applied to the second interview-transcripts, with new codes added as needed. Throughout this process, team members' knowledge and backgrounds informed our discussions of the meaning and significance of the data.

A secondary analysis exploring the data through the lens of biographical disruption and meaning-making was then conducted by EH. Following the same methods of coding and comparison, the researcher selectively coded transcript extracts where 'disruptive' experiences were discussed, and where participants were reflecting on and assigning meaning to these experiences. Whilst coding the transcripts, the researcher wrote detailed case notes for each participant describing individual narratives and themes. This helped to ensure that the nuances and peculiarities of individual stories were not lost in the process of creating and describing group themes. Final themes were fully described and inter-connected in the analytical narrative which was drafted by EH and critically reviewed by all authors.

Ethical approval was granted by Cardiff University School of Medicine Research Ethics Committee (SMREC 20/59).

3. Participants

Twenty four people took part in a first interview; 15 completed a second interview. Participants were bereaved between March and October 2020, and were between seven and 17 months bereaved at their first interview (median = 14 months), ranging in age from in their 20s to their 60s. In terms of relationship to the deceased, our participants comprised nine female partners/spouses, two male partners/spouses, seven daughters, three sons, two sisters and one mother. Six participants identified with a minority ethnic background, and five as LGBTQ+. Most deaths were from Covid-19 (n = 12), followed by cancer (n = 10). Median grief-vulnerability score was 20 (range 12–27) at the second survey (c.7 months post-bereavement) and 19 (range 12–26) at the third survey (c.13 month post-bereavement). Nine participants met the cut-off for high (≥21) or severe vulnerability (≥24) at the 7-month survey and six at the 13-month survey. Pseudonyms have been used as participant-identifiers (Table 1. Participant Characteristics; Table 2. Timeline of UK pandemic restrictions, Suppl file 2).

4. Analysis

Five themes describe core domains of biographical disruption and meaning-making. These include: difficult and traumatic death experiences; disrupted mourning practices; loss of relationship and sense of self; social relationships, isolation and support; and developing understandings of grief. Within each domain we consider the different ways in which norms, behaviours and identities were disrupted, and the negative reactions and more positive responses constructed within participant accounts (Table 3, Suppl file 2).

4.1. Difficult and traumatic death experiences

Many participants were deeply affected by their experiences around the time of death, and some were still struggling to make sense of these experiences at the time of first and sometimes second interviews. They described lasting feelings of guilt and anger in response to perceived poor quality care and their relatives' related suffering. Experiences which disrupted their socio-culturally informed expectations of health and end-of-life care included misdiagnosis of particular conditions, inappropriate treatment responses such as inadequate pain control or missed infections, denial and termination of cancer treatments, and being given terminal prognoses alone or over the phone. Some also described their shock and difficulty accepting that their relatives had died from Covid-19, particularly when they were younger and in reasonable health-as with partners/spouses Marta, Hannah, Jo and Sarah. Such feelings were often compounded by regrets over decisions or actions that may have caused their relatives to catch Covid-19, including supposedly short-stay admissions to care-homes. Many reported that they had experienced significant trauma as a result of these experiences, which for partners/spouses Marta, Jo, Tom and Sarah included suspected post-traumatic stress.

> So that's what I can't come to terms with is losing her the way, the way she died. It was a horrible, horrible death. It wasn't peaceful. It was so unexpected … It wasn't her time to go. So feelings just fester inside you continuously …. And again it's 18 months down the line but those are the feelings I had when she died, and they're still exactly the same … (Sarah,int2)

Participants also described the enduring emotional impacts of being unable to visit or spend more time with their relative, which disrupted their self-expectations for caring, being present and spending quality time together. People described feeling guilty that they were not there to provide emotional support and reassurance, and a general sadness over what terminally ill family-members missed out on due to pandemic restrictions. Some spoke of their powerlessness and ongoing worries regarding the care that was provided without their expected level of involvement and advocacy, as well as missed opportunities for earlier detection of health issues due to shielding guidance. People with relatives in care-homes reflected on how hard it was not knowing how their relative was at the end of their life. Some expressed strong feelings of injustice at being unable to visit when this was allowed in other settings, and again upon later learning of politicians attending prohibited 'lockdown parties'. A persisting need for answers was also evident, with Marta and Susie seeking access to medical records to try to ease their niggling concerns.

> They don't want to release any information, any medical notes. Because I'm the partner … And I even went to my MP to ask for the medical notes, because I don't understand what happened and I would like to understand … (Marta,int1)

However, although these very difficult experiences weighed heavily, at both interviews there were examples of more accepting perspectives as participants reappraised and reconstructed more positive accounts of this stressful period. By acknowledging the full extent of the crisis, they recognised that they could not blame themselves or healthcare professionals for circumstances outside of their control. Rashid described how his anger, sense of injustice and voicelessness relating to his father's care had intensified until the coroner's inquest which helped him to feel more at ease and hopeful that similar future failings could be prevented. Some also recalled others' worse experience, helping them to view their own situation more favourably, and/or looked back on the positive care role that they had performed and the enhanced time together that they shared when isolating at home. Participants also remembered the compassion that they had witnessed from individual staff members, which gave reassurance that their relative was well cared for, or referenced later constructive conversations with care providers about their relative's condition and the care provided to them.

> She (the nurse) said that me mum was treated with dignity and you know, that she was never on her own, um, in the last few days. If anybody had got any paperwork to do, they went and sat with her and did it in her room … I've got to believe that … I would hate to think that she would have died on her own. (Susie,int1)

4.2. Disrupted mourning practices

Restrictions to funeral practices similarly breached moral and normative expectations for saying goodbye to, and celebrating the lives of, those who died. These communal acts of remembrance were seen as important for enabling grieving, and their absence as prolonging the grief process. Perceived inability to fulfil family duties and expectations commonly caused feelings of guilt, not only in relation to the person who died but also other family members who were excluded from planning and sometimes attending the funeral. Attending funerals alone was experienced as surreal and intensely lonely, whilst the small numbers permitted at funerals made it harder to “lighten the mood” (Alison,int1). Rashid described the stress of trying to quickly arrange a religiously appropriate Muslim funeral, while Salma was deeply troubled by her father’s funeral which felt rushed and “like a conveyor belt”- her distress made worse by her Muslim family’s expectations that she (as a woman) stand at the back, having been unable to visit her father in hospital. At first interviews some participants dreaded dealing with their relative’s ashes, or organising delayed memorial events, feeling that they had lost momentum and that too much time had passed. Dealing with other ‘broken’ and insensitive aspects of the death system, such as check-in calls from the government’s ‘track and trace’ service following Covid deaths, and difficulties with practical administrative matters, was a further source of frustration and upset.

> I do feel that it’s been prolonged because somehow, having a celebration with lots of other people, which is a hard thing but somehow if you have that then you start again, I think, whereas I don’t think we ever quite felt like that. (Jane,int1)

However, some participants also gave more positive and meaningful accounts of their commemorative experiences in their first interviews. Innovative examples were given of ceremonies held in gardens, and recordings of readings and songs being sent to non-attendees. Others reflected on how they had ‘made the most’ of the options available and in some cases valued the control that they had over funeral planning. People bereaved later in the pandemic appreciated the ‘little wins’ such as pubs being open to host wakes and good weather. Connections with vicars, celebrants and undertakers enabled a more personal experience and some appreciated the intimacy of small funerals, with more public memorials planned for the future. Tom spoke of the symbolism and privilege of being alone with his wife at the funeral, as they had been on their wedding day. People also reappraised their initially very difficult experiences by again acknowledging how the circumstances had been outside of their control, attaching hope to upcoming memorial events and the opportunity to find closure, reconnect, share stories, and properly celebrate their relatives’ lives. At follow up interviews, many participants looked back on these memorial-events with feelings of relief and accomplishment, while some drew comfort and closure from having finally laid ashes to rest. Although most would not have chosen to hold such delayed commemorations and found their trauma hard to revisit, some reflected on how the forced delay also had its benefits.

> Because we had longer, because we had that enforced break … I wasn’t as numb, I was able to think about it more … there were some advantages, weirdly. (Kate,int2)

4.3. Loss of significant other and disrupted sense of self

While the disruption described above was very specific to the circumstances of the pandemic, participants also navigated more typical forms of biographical disruption caused by the loss itself. All participants gave examples of meaning-making strategies and practices which helped them emotionally process the loss of their relative, whose living presence in their lives was deeply missed. At both interviews, they described actions taken to remember and maintain an emotional connection with them, with some noting the catharsis of feeling their pain when confronting grief in this way. Examples of such activities-conducted communally or sometimes alone-included sharing memories with friends and family, looking through old photos, attending gravesides, creating memorials, and visiting childhood places with siblings. In both interviews Tom described walking to his wife’s grave each morning, appreciating the routine, countryside and exercise, as well as the time spent processing his feelings. Peter explained how he had been building shared histories with his friends by talking through his husband’s life and death with them, while Jane also purposefully talked about her son to help keep his memory alive for his young daughter. People took comfort from symbolic, meaningful associations that they had made, such as the bright moon that appeared on the night of the death, as well as visits to special places on birthdays and anniversaries, including the Covid memorial wall. Recognising their relative’s continued presence in themselves and their family members helped people to make sense of and begin to accept their loss. Partners also commonly expressed gratitude for their happy times and continuing love for one another, while Rosa, Anne, Jess, David and John acknowledged and appreciated the accomplished lives and relatively ‘timely’ deaths of their elderly parents.

> We just walked through the hospital doors and there was the fullest, lowest most gorgeous bright orange moon … and I just felt so close to [Wife] then. And stood looking up at it and this lovely nurse just turned to me and says it is a sign, you know. And I’ve clung onto that moment ever since. Every time … there’s a moon there it’s just [Wife]. (Sarah,int1)

While all participants needed to emotionally process the death, the loss-related disruption to daily routines, behaviours and identities appeared to be felt most acutely by bereaved partners/spouses, particularly given their relatively young ages. In both interviews, partners commonly articulated their intense sense of being alone and the disruption to their self-identity associated with this “loss of literal other half” (Cara,int1). Those who had been caring described the impact of two difficult transitions, first the changed dynamic in their relationship and way of life during illness, and second bereavement and being on their own. Being alone in the house and fulfilling daily tasks and routines provided constant reminders of their partner’s absence. Although some appreciated the familiarity and continued presence of their partners in their homes, in his second interview Tom reflected on how his reluctance to change anything was proving a challenge as well as a comfort, as he described his continuing struggles with working out how to adapt.

> If you think about home, that I’ve surrounded myself with the comfort of it’s exactly as it was as [wife] walked down the path … I’m thinking that’s not helpful to me, but it is … The home that I live in is the home that [wife] created and it’s my comfort blanket. (Tom, int2)

Partners reflected on how there could be no return to normal without the person who had defined their old normal, with some acknowledging a need to reinvent their world. Others, however, spoke of their difficulties imagining a new life or making important decisions, and at both interviews Peter and Sarah spoke of suffering with waves of depression and lack of motivation. Peter described his growing realisation of how central their relationship had been to his identity, and his related struggle with this loss of sense of self, disruption to future plans and certainties he had taken for granted. Sarah described her intense yearning for her wife, feeling that she was merely existing, on ‘autopilot’, waiting for each day to end in the hope that tomorrow will be better. A different kind of disruption to self-narrative was articulated by mother Jane, who, while recognising her own resilience, reflected on the unnaturalness of outliving your children, and her sadness over her son missing out on his daughter growing up. Although accepting of his father’s timely death, John also articulated feelings of biographical rupture, noting the changes to his own daily routine of visiting the care home, and reflecting on how this ‘transitional moment’ was perhaps more acutely felt due to not having family of his own.

> Because if I had a family of my own, it’d be like ‘okay, this is just like a transitional moment’, whereas it feels more, or can feel more like a chapter or something, a book closing, which is really, really odd. (John,int1)

Despite this acutely felt disruption to their daily lives and identities, most partners/spouses described getting used to their ‘new normal’ in first and/or second interviews, and many gave examples indicative of efforts to both ‘assimilate’ and ‘accommodate’ their losses into new and meaningful life-narratives. These included activities which helped them to manage their day-to-day living, but which also fostered a sense of continuity and connection with their partner and their pasts. Alison and Sarah found it comforting to imagine their spouses' reactions to their daily activities and new ventures, if also sometimes upsetting. Kate, who overall was feeling positive at her second interview, felt reassured knowing that her recent career change had been planned with her wife. In a similar vein, Jane cherished her enhanced caring role for her granddaughter, knowing how much it would please her son, while Kate and Cara described the comfort of continuing to care for their partners' pets. Although struggling at both interviews, Peter spoke of the happy memories and therapeutic benefits that he found in his husband's hobby of baking, complementing his more communal efforts focused on maintaining connection by building shared histories with friends.

> I always used to cook with [husband] … but I have started to do things like bake bread and make meals … and that process is quite therapeutic. I enjoy it, it brings back happy memories rather than memories that are painful and it also kind of feels productive.(Peter, int2)

4.4. Social relationships, isolation and support

Fractured and difficult relationships with living family members was another significant source of biographical disruption, particularly earlier on in bereavements. Kate described the tension that emerged with her wife's sister over possessions, and a developing sense that her marriage and relationship was not taken seriously because of their same-sex relationship. Susie described the additional stress that she experienced dealing with her estranged brother, whilst Salma experienced upsetting and enduring tensions relating to her identity as a non-practising Muslim, feeling pressure to conform to her family's beliefs, which strained their relationships, and the extent to which she felt able to grieve with them. There were also examples of perceived inadequacies in the emotional support that people received from family, friends and colleagues, again suggestive of breached moral assumptions. Participants commonly perceived a lack of understanding of their situation, including expectations that they should "snap out of it" (Marta, int1), whilst the perceived trivialities of others' 'everyday' worries made them feel that their grief was not recognised. Some were also reluctant to burden or worry friends or family by speaking honestly about how hard they were finding it, especially when feeling so emotionally drained. The pain of other close family members also made it difficult to maintain a close relationship, even though in the case of in-laws this was seen as important for maintaining an ongoing connection to their spouse.

> My mother, when she's talking about the death … it's difficult if you're not … somebody who's been practicing those beliefs … some part of you feels a bit lost … it's a huge conflict within me, so, you know, I find that hard because I, I sometimes feel, even now my mum will use religion, um, er, against me (Salma,int1).

Pandemic-restrictions further limited the emotional support that people received from their networks. Participants commonly described their need for physical closeness with their families and how hard it had been not being able to fulfil expected customs and rituals together, or reminisce with those close to their deceased relative. Jess described the tension that developed with her siblings when sorting out her father's affairs without face-to-face conversations. At the same time, close confinement with other household members during lockdowns put strain on those relationships, denying people the space they needed to process their emotions.

> We haven't had a chance to meet, because we haven't seen each other. Um, so, it may be that when we're able to meet face to face that we're able to talk through. Um, we'll just you know, reminisce together about our father and I think that that will help (Jess,int1).

With the easing of restrictions participants commonly felt anxious at the prospect of further disruption and changes to daily life. Some found it difficult to reengage with their friends, realising that it was not possible to resume where they had left off, encountering awkward conversations and upset all over again. These relationships were perceived as false in some way, compounding feelings of loneliness and disconnection. Socialising and returning to in-person work was triggering for some and posed a perceived health risk, especially if there were vulnerabilities relating to their own ethnic background or health status. Some participants reflected on how they had been helped by the world stopping, appreciating the time available for coping activities like walking and running, or simply hiding away. Facing up to it again, however, could prove difficult. Sarah explained how she had become used to her solitude and felt reluctant to share the memories of her wife which she had been privately cherishing. She also felt guilty when socialising again knowing that her wife was missing out. Although appreciative of the routine and company offered by his new volunteering role, Tom explained how he found the normality and mundane nature of his colleagues' conversations and the fact that they had never known his wife a challenge. Like Peter and Sarah, he was also confronting the emotional struggles associated with the prospect of resuming shared activities, such as holidays, visiting the theatre and football matches.

> So, it's just having to deal with grief, prolonged grief in two very different ways, one in a hibernated world and then secondly, when the world opens where the world doesn't open for me. (Tom,int2)

Political and societal responses to the pandemic presented further challenges to participants, and were a source of anger and upset at both interviews. Many felt angry at politicians for their perceived failures to protect lives, feeling that the deaths were accepted as inevitable, and questioned whether their relatives would have survived with earlier government intervention. Continued examples of inappropriate behaviour by officials such as lying and breaking lockdown rules compounded these sentiments. People described their anger at seeing the rest of the world carrying on as normal; media coverage and social media comments were triggering, whilst the sharing of conspiracy theories and anti-vaccine rhetoric was deeply offensive and upsetting. John felt the injustice of the stark ethnic/health inequalities manifesting in Covid death-rates, while people bereaved by non-Covid deaths felt that their grief and trauma was less seen than Covid bereavements. While some participants learned to manage these 'threats' by ignoring others' behaviours and selectively watching the news, these experiences also contributed to disenfranchised grief, and feelings of alienation and separation, making it harder to reengage with society.

> I think all the pandemic restrictions just make it feel like the grief exists in a bubble that the rest of the world doesn't see. And particularly because it wasn't Covid death, it feels … it felt a bit like it didn't really matter. (Rashid,int1)

Despite the difficulties that people faced in their social relationships, all participants had some close friends and family members who gave valued emotional and practical support, helping them to navigate the insensitivities of others and create more positive and meaningful life-narratives. At both interviews, examples of this support included friends checking in, providing distraction, sharing memories of the deceased, and "just knowing that people are thinking of you" (Jo,int1). Continued caring for grandchildren provided comfort to Jane and Susie, while Rashid valued his family coming together at the end of his father's life, appreciating how this closeness had continued after the death. Participants also took comfort from the kindness of people less known to them, such as neighbours reaching out and bringing gifts, and the enhanced community spirit and weekly 'clap for carers' during the first lockdown. The benefits of connecting with people with shared experiences, through online bereavement communities or peer support groups were also described, including Covid-19 and (young) widow(er) groups. Kate and Cara described their particular relief at finding LGBTQ +

widow(er) groups, and the deeper connections that they enabled.

> Because I have that group then that compensates, you don't need it from everybody, they've helped me feel more robust and therefore I can cope with other people's insensitivities. And also, I think my kids, my kids are also glorious and their partners … so you don't need support across the board … if you've got enough of it in some places. (Kate,int2)

Although some found re-engaging with life challenging once restrictions eased, many participants described finding meaning through socialising and reconnecting or 'assimilating' with the familiar people, places, activities and hobbies that had constituted their 'old normal', particularly at follow up interviews. Upon returning to work some appreciated the compassionate and flexible approaches of their employers and colleagues, as well as the distraction and routine that old or new roles provided. Many had also focused on making positive changes to their lives as they 'accommodated' their loss experience into a new and purposeful self-narrative, sometimes centred around a greater appreciation of life. These changes included making new friends, and wellbeing practices such as exercise, losing weight, worrying less and acknowledging personal achievements (e.g. going on holiday, holding memorials, sorting out affairs). Some focused on helping others, describing a renewed passion for work in the health and education sectors and sense of purpose from doing something worthwhile, including volunteering and training.

> I'm quite passionate because ….part of my job is to look at admission avoidance to try and keep frail elderly people out of hospital and I'm more passionate about doing that now because of what I've gone through with my own dad … (Rosa,int1)

4.5. Developing understandings of grief and grieving

People used different frames of reference to try to understand their feelings and cognitively process and make meaning in their grief experience. Some used familiar cultural metaphors such as "stiff upper lip" (David,int1) and "sink or swim" (Susie, ints1&2) to explain and make sense of their more controlled responses and disinclination to seek help; an attitude perceived by older participants as more common amongst older generations.

> My sort of make-up rightly or wrongly is more sort of try to be a bit more resilient, a bit more stiff upper lip type approach to it. I know that's not always the best approach to things …..I'm sounding as though I'm feeling sorry for myself now so we'll shut up on that. (David,int1)

Others, however, felt an uncomfortable mismatch between their own lived experiences of grief and cultural/societal expectations and norms, evident in others' attitudes and behaviours. To manage this participants commonly looked to other sources for more realistic explanations and means of understanding. Although Sarah explained how reading about grief had left her feeling confused, others described how self-help resources such as books, websites, online grief events and podcasts enabled them to relate to and learn from others' stories. Verbalising their feelings with sympathetic friends and those who had gone through similar bereavements helped people to feel understood and develop their own shared understandings of their grief and loss experiences. Several participants reported that taking part in this research study had also helped them to process their experiences. Around half of participants had taken up counselling or therapy; viewed by Kate as an "anchor in the week"(int1), therapeutic sessions enabled people to release negative feelings and understand their grief as 'normal', whilst also learning coping techniques such as self-compassion. People valued feeling understood and being able to talk freely with someone unconnected to them or their family, especially when these relationships were strained.

> I just needed somebody to offload to ….Some of the thoughts I were having … would've upset other people. And, that's why I felt I could share that with a counsellor as well, as in somebody that had that attachment to me. (Jo,int1)

At follow up interviews most participants described finding their lives and grief easier to manage. Although they could still be hit hard by their emotions, this was happening less frequently, with descriptions of "grief easier to live alongside" (Cara), "steadier" (Kate) and less painful and raw (Rosa). Exceptions were Tom, who found the "reality check" of the second year harder as his initial numbness had faded, Peter who felt stuck and was suffering with anxiety and depression, and Sarah who felt unable to move forwards due to her intense yearning for her wife. Many participants described how over time they had come to accept their feelings as a natural part of grief and love for the person who died, recognising death as an inevitable part of life. The importance of allowing time and space to process thoughts, learn to live with and understand grief was recognised, as was the need for distraction, self-care, keeping going and maintaining a sense of purpose. For some this motivation was felt to be part of honouring the person who died, but people also recognised that it was "ok not to be ok" (Hannah) and that they could make their own paths and rules. This included being open about when they were struggling, recognising and accepting that grief "comes in waves" (Anne, Alison, Hannah) and understanding the normality of their responses to grief, including swinging between feelings of calm and hysteria. Rosa and Tom drew explicitly on Tonkin's 'ball in bottle' metaphor to help them understand how they could grow their lives around their grief, although Tom still viewed this to be very challenging given the intensity of his grief.

> Yes, um, it's still there, but like I think somebody showed me a diagram recently where there was kind of a ball in a jar ….. You know, you live with it, but you don't get over it, sort of things move around it … the void around it, becomes less, but the feeling's still there. (Rosa,int2)

5. Discussion

Findings from this in-depth qualitative study provide a rich description of the many ways in which people bereaved during the pandemic experienced significant biographical disruption, as well as the different means through which they made meaning in their experiences. Our analysis of participant accounts, explored through a critical lens of biographical disruption (Bury, 1982) and meaning-making (Neimeyer, 2001; Neimeyer et al., 2010; Park, 2010), has described five core domains of disruption and related responses which help to explain the varied grief and coping experiences of study participants, within the historical, cultural, social and relational contexts of their bereavements (Ribbens McCarthy et al., 2023). We distinguish disruptions caused by pandemic circumstances and/or the loss itself, describing disruptions which were normative/behavioural and those which impacted more directly on self-narratives and identity. We also distinguish between participants' breached assumptions regarding their own feelings and behaviours, as well as those of others', recognising the influence of social discourse on these disruptive processes (Turner and Almack, 2019). These findings demonstrate the value of critically combining these theoretical perspectives for conceptualising, contextualising and progressing understandings of grief and bereavement in both 'ordinary' and 'extraordinary' times.

The two domains of disruption most impacted by pandemic restrictions and the immense strain felt by health and death systems at this time were those concerned with end-of-life and commemoration practices. Sub-optimal patient care and communication, being unable to visit and care for family members as expected, perceived suffering, and shock at sudden deaths meant that assumptions for participants' own and others' conduct at this time were significantly violated, in turn impacting their self-concepts and identities. This ‘moral code’ (Stroebe and Schut, 2021) was further challenged by unmet expectations for culturally appropriate mourning rituals, denying people ‘closure’ and the social stability which helps manage the liminality that follows a death (Pearce, 2019). As a result of this dissonance between experience and socio-culturally informed expectations (Turner and Almack, 2019), people suffered feelings of powerlessness, guilt, anger and injustice, finding it hard to grieve and begin to accept the death. This disruption and associated emotional responses closely resemble the loss-oriented stressors and reactions described elsewhere in the context of pandemic bereavement (Stroebe and Schut, 2021; Torrens-Burton et al., 2022) and evident in other pandemic (Hanna et al., 2021) and non-pandemic studies of end-of-life experiences (Harrop et al., 2016).

Despite these difficulties and the acute nature of this disruption, over time many participants found ways of reappraising and making sense of what had happened, providing bereavement-specific evidence for many of the processes described in Park’s broader meaning-making model (2010), while also demonstrating their relational features and contexts. Explaining and acknowledging circumstances which were outside of their control supported comprehensibility and helped reattribute responsibility, while accounts focusing on the more positive aspects of these unusual experiences were also constructed. Here, people described reassuring conversations and the compassion of healthcare staff, their own caring roles and intimate, alternative and postponed memorial events. By acknowledging the worse experiences of others and appreciating their ‘little wins’, participants were also able to view their circumstances more favourably. As observed in the literature on chronic illness and narrative reconstruction (Bury, 1991, 2001; Williams, 1984), through ‘talk’ and processes of moral accounting people reestablished the personal and social acceptability of their disrupted experiences, producing more comprehensible and coherent narratives concerning their relative’s death and commemoration.

While this disruption relating to end-of-life and memorialisation was specific to the pandemic, participants were also challenged by the more typical bereavement disruption caused by the loss of relationship and missing the living presence of their relative (Klass, 1996; Schut, 1999). Consistent with research showing poorer grief outcomes for bereaved partners/spouses (Aoun et al., 2015; Harrop et al., 2023), these participants experienced the most acutely felt disruption to their daily routines and behaviours, as they reflected on the abnormality of being alone and in some cases the significant transitions in and out of caregiving roles and routines (Harrop et al., 2016). Many partners spoke of how these losses disrupted their sense of self and the future they had envisioned together. Some described intense yearning, anxiety, and depression, including feeling on autopilot, struggling to find motivation or make decisions. Such reactions are well documented in the partner-grief literature (Bristowe et al., 2024; Klass, 1996; Schut, 1999), with Bristowe et al. (2024) proposing a ‘liminal’ state in which partners struggling with lack of purpose become trapped between loss and restoration-oriented coping, unable to engage with either. However, in our study, the same partners who described this purposelessness, also described intense yearning alongside efforts to construct meaningful and connected lives, suggesting that their experiences were not fully defined by this ‘liminality’ and that there may be more fluidity and flux between these states than Bristowe et al.’s (2024) model suggests.

Study participants described how they processed their loss by immersing themselves in their grief and feelings (Park, 2010) and, in some cases, acknowledging the long and fulfilled lives of older relatives and the timeliness of their deaths. Participants actively remembered and cherished their lives together, and, alone and with others, visited special places, looked through photos, discussed memories and built shared histories (Park, 2010; Klass et al., 1996; Walter, 1996), demonstrating the strong relational, as well as personal nature of many of these meaning-making activities. Although some partners/spouses were struggling to adjust to their ‘new normal’ of being alone, many gave examples of efforts to normalise by ‘assimilating’ and/or ‘accommodating’ their losses into new life-narratives and identities (Neimeyer et al., 2010). Engaging with old and new activities helped them to manage and, in some cases, move forwards with their lives, whilst also enabling a sense of continuity and connection with their partner and the life they had shared together. This duality illustrates how bereaved individuals sustain ongoing bonds with the deceased in every aspect of life, reconstructing their biographies in ways that allow them to move forwards alongside and apart from those they have lost (Klass et al., 1996; Walter, 1996). Building on Bristowe et al.’s (2024) model, which illustrates how continuing bonds intersect with features of loss and restoration coping, the duality in the function and meaning ascribed to these life-activities demonstrates how seemingly restoration-focused tasks can also be loss-oriented, helping the bereaved to navigate a changed relationship with the deceased whilst also managing daily life.

The disruption to social life and relationships, reflected circumstances and experiences specific to the pandemic as well as experiences common to any bereavement. Changing infection control guidelines significantly impacted social behaviours, limiting opportunities to access support and engage in usual grieving and coping practices, while the dismissive behaviors and attitudes of the public and officials also breached social norms and expectations (Stroebe and Schut, 2021; Torrens-Burton et al., 2022). However, the social worlds and relationships of participants were also disrupted by more ‘ordinary’ examples of family strain and/or perceived lack of understanding within social networks (Breen et al., 2017) and the related incongruence that they perceived between societal/cultural expectations and their lived experiences of grieving (Macarthur et al., 2023; Pearce 2019)- again suggestive of breached assumptions for their own and others’ conduct. This incongruence, intensified by the peculiarities of pandemic bereavement, left people struggling with how they communicated and made sense of their grief, further limiting the support available to them and contributing to a disconnected social identity and sense of self in relation to friends, family, and wider society (Macarthur et al., 2023; Pearce, 2019). A range of documented loss and restoration-oriented reactions to the different aspects of this isolation were described (Stroebe and Schut, 2021; Torrens-Burton et al., 2022). Physical and emotional distance from others intensified feelings of loneliness and disconnection, while the prospect of reintegration and ‘return to normal’ when restrictions eased caused further feelings of anxiety and upset. Lasting anger was felt in response to the insensitive and ill-considered political and public responses to the pandemic and pandemic bereavements (Torrens-Burton et al., 2022), which also contributed to disenfranchisement and a sense that their grief was not recognised (Doka, 1999).

To varying degrees, participants managed this disruption to their social worlds and identities by focusing on and integrating more positive activities, relationships and self-reflection into their lives and self-narratives. As in Neimeyer’s model (2001; 2010), with the easing of restrictions some sought to ‘assimilate’ with their pre-loss, pre-pandemic selves-reengaging in familiar activities and social networks and finding comfort in the continuity of the relationships and roles that defined their old normal. Many participants also engaged in ‘accommodation’, reshaping their identities around new relationships, activities, and life goals. In some cases, this process led to a renewed appreciation for life—a response that has been well documented in grief and coping research (Neimeyer et al., 2010; Park, 2010; Schut, 1999). By connecting and conversing with those with shared bereavement experiences, engaging with self-help resources on grief and in many cases taking up counselling/therapy, participants developed more personal, relatable understandings of grief and bereavement. These interactions helped them to cognitively process and make sense of their feelings (Park, 2010), and repair the disruption caused by the incongruity of cultural norms and lived experiences, developing what Macarthur has termed ‘bereavement affinities’ (Macarthur et al., 2023). This demonstrates how even the more cognitive aspects of grieving are deeply rooted within social relationships (Macarthur et al., 2023; Ribbens McCarthy et al., 2023), reaffirming the importance of social support during bereavement (Cacciatore et al., 2021; Harrop et al., 2023).

5.1. *Strengths, limitations and implications*

Longitudinal interviews, combined with our idiographic, theory-driven analysis, yielded rich insights into the diverse ways that people grieve and cope—and how those patterns evolve or persist over time. In exploring coping 'experience' in an interview setting, however, participants were engaging in a particular form of coping and the accounts produced should be interpreted in the context of those researcher-participant interactions (Bury, 2001; Williams, 1984). We also most likely heard from people more open to reflecting on and discussing their experiences in this way. While we purposively sampled to maximise the inclusion of voices less heard in our survey and bereavement research more widely, including men, LGBTQ + individuals and people from minoritised ethnic groups, further in-depth research involving people from these groups is recommended, as well as other types of death or loss e.g. suicide, child and baby-loss.

Study findings strongly demonstrate the need for policy makers, care providers and communities to reduce the disruption inherent in stressful bereavement circumstances, and to actively support people to make meaning in their experiences. During non-pandemic times this means ensuring compassionate and supportive communication from healthcare professionals at the end of life, including "follow-up" contact which creates space for meaningful discussion of troubling experiences. Informal support such as self-help resources and peer-support groups, as well as grief education and compassionate community initiatives should be made available to improve grief literacy and strengthen support from existing social networks (Breen et al., 2017; Harrop et al., 2023). Enabling timely access to formal support such as grief counselling and in some cases mental health services is essential for the minority of people needing such interventions (Aoun et al., 2015). Interventions which strengthen the observed capabilities of bereaved people to make meaning by connecting with others, normalising, reappraising, reattributing, and developing their own literacies and understandings, seem likely to hold promise.

In preparation for future pandemics, guidance should be developed for health-care settings regarding balancing infection-risk with the need to facilitate patient-family contact and enabling effective, compassionate communication with family members. ldentifying different options for meaningful and alternative commemorative practices, and managing social contact in ways which make allowances for the recently bereaved is also important. Finally, plans are needed for the rapid mobilization of appropriate bereavement support, including proactive sign-posting and processes for identifying and reaching those requiring more intensive support (Harrop et al., 2023).

6. Conclusions

Across participant accounts the multi-dimensionality and severity of the biographical disruption caused by pandemic bereavement was striking. Equally remarkable, however, were the ways in which participants reappraised and reconstructed more positive and coherent narratives, helping them to cope and adapt. These findings demonstrate the utility of bringing together and critically applying theories of biographical disruption and meaning-making for conceptualising, contextualising and progressing understandings of grief and bereavement in 'extraordinary' and 'ordinary' times, providing rich empirical examples which support, challenge and extend existing grief and bereavement theory. Policy makers, care providers and communities must work to minimise the disruption inherent in stressful bereavement circumstances, whilst also supporting people to reconcile and make meaning in their experiences.

CRediT authorship contribution statement

Emily Harrop: Writing – original draft, Validation, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Kali Barawi:** Writing – review & editing, Validation, Investigation, Formal analysis. **Francesca Mazzaschi:** Writing – review & editing, Validation, Project administration, Formal analysis, Data curation. **Anna Torrens-Burton:** Writing – review & editing, Validation, Formal analysis, Data curation. **Eileen Sutton:** Writing – review & editing, Validation, Investigation. **Emma Gilbert:** Writing – review & editing, Validation, Investigation. **Donna Wakefield:** Writing – review & editing, Validation, Investigation. **Silvia Goss:** Writing – review & editing, Project administration, Investigation. **Kathy Seddon:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization. **Mirella Longo:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization. **Lucy E. Selman:** Writing – review & editing, Validation, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Ethics statement

Ethical approval was granted by Cardiff University School of Medicine Research Ethics Committee (SMREC 20/59). Informed consent was obtained from all study participants.

Declaration of interest

All authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2025.118518.

Data availability

The dataset can be found in online repositories. The names of the repository/repositories and accession number(s) can be found at: UK Data Service via https://reshare.ukdataservice.ac.uk/855751.

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