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Parental bereavement – impact of death of neonates and children under 12 years on personhood of parents: a systematic scoping review

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Abstract

Background: Losing a child tragically impacts the well-being and functioning of parents. With these effects extending beyond emotional, physical morbidity and compromising self-perceptions, appropriate, longitudinal, timely and personalised support is key to effective care of bereaved parents. However, in the absence of a comprehensive understanding of parental bereavement, effective support of bereaved parents remains suboptimal. To address this gap, we scrutinise prevailing data on the effects of a child's death, aged 0–12 years, through the lens of the Ring Theory of Personhood (RToP).

Methods: To study prevailing accounts of bereaved parents following the death of a child, we adopt Krishna's Systematic Evidence Based Approach (SEBA) to structure our Systematic Scoping Review (SSR in SEBA).

Results: Three thousand seventy-four abstracts were reviewed, 160 full text articles were evaluated, and 111 articles were included and analysed using thematic and content analysis. Four themes/categories were identified relating to the four rings of the RToP. Findings reveal that static concepts of protective and risk factors for grief are misplaced and that the support of healthcare professionals is key to assisting bereaved parents.

Conclusion: In the absence of consistent support of bereaved parents, this study highlights the need for effective training of healthcare professionals, beginning with an appreciation that every aspect of an individual parent's personhood is impacted by the loss of their child. Acknowledging grief as a complex, evolving and personalised process subjected to parental characteristics, settings, context and available support, this SSR in SEBA calls attention to effective nurturing of the relationship between parents and healthcare professionals, and suggests use of the RToP to assess and direct personalised, timely, specific support of parents in evolving conditions. We believe the findings of this review also call for further studies to support healthcare professionals as they journey with bereaved parents.

Keywords: End of life, Palliative care, Death, Neonate, Infant, Paediatrics, Parents, Ring theory of personhood, Personhood, Bereavement

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Background

The loss of a child has tragic implications upon a parent's wellbeing [1, 2] and social function [3]. Evidence of protracted emotional distress [4], higher divorce rates

[5], increased psychiatric [6] and medical admissions [7, 8], greater physical [9] and emotional [10] morbidity and higher mortality [11] also suggests impact upon the bereaved parent's beliefs, values, principles [12], spiritual concepts [13], their existential, spiritual, individual, relational, medical and societal roles, needs and goals [8, 14–17], and their relationships with family members, close friends, and members of society [18]. Some authors have suggested that such deep and diverse change may be framed as a change in the bereaved parent's sense of self [19–23]. Such a posit finds support from Bartel [24]'s account of grieving families, Mahat-Shamir [25]'s report on parental experiences following the loss of their child and Einarsdóttir [26]'s article on maternal grief.

It is to this sense of disruption of a parent's concept of personhood or "what makes 'you' you" [27–35] that we turn our attention to in order to better understand the impact of such loss, and to better direct timely, personalised, appropriate, holistic and longitudinal support to bereaved parents. Thus, a review of current data on the effects of a child's death on a parent through the lens of the Ring Theory of Personhood (henceforth RToP) [27, 35] was carried out.

Krishna's Ring Theory of Personhood

The employ of the RToP to capture the impact of bereavement is not new [24–32]. The RToP has been used within other Palliative Medicine settings to study changes in thinking, values, beliefs, roles and relationships amongst terminally ill patients [24–32]. Here extrapolating its use to bereaved parents finds support from Kuek, Ngiam [32]'s study of the impact of caring for dying patients upon physicians in the intensive care.

Here, the RToP's unique ability to capture change in the parent's perspective of themselves and their relationships [36], roles in the family and in society [26] also leaves it best placed to capture liminality which Turner [37] defines as "entities ... neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony" [25]. The insights provided will greatly enhance support of bereaved parents. Here, a better understanding of the RToP's four domains depicted as four interconnected rings – the Innate, Individual, Relational and Societal rings is required (Fig. 1).

The Innate Ring is the innermost ring of the RToP and may be seen to derive itself from the genes that define oneas human and the individual's religious beliefs, such as their ties with a Higher Power. The Innate Ring is

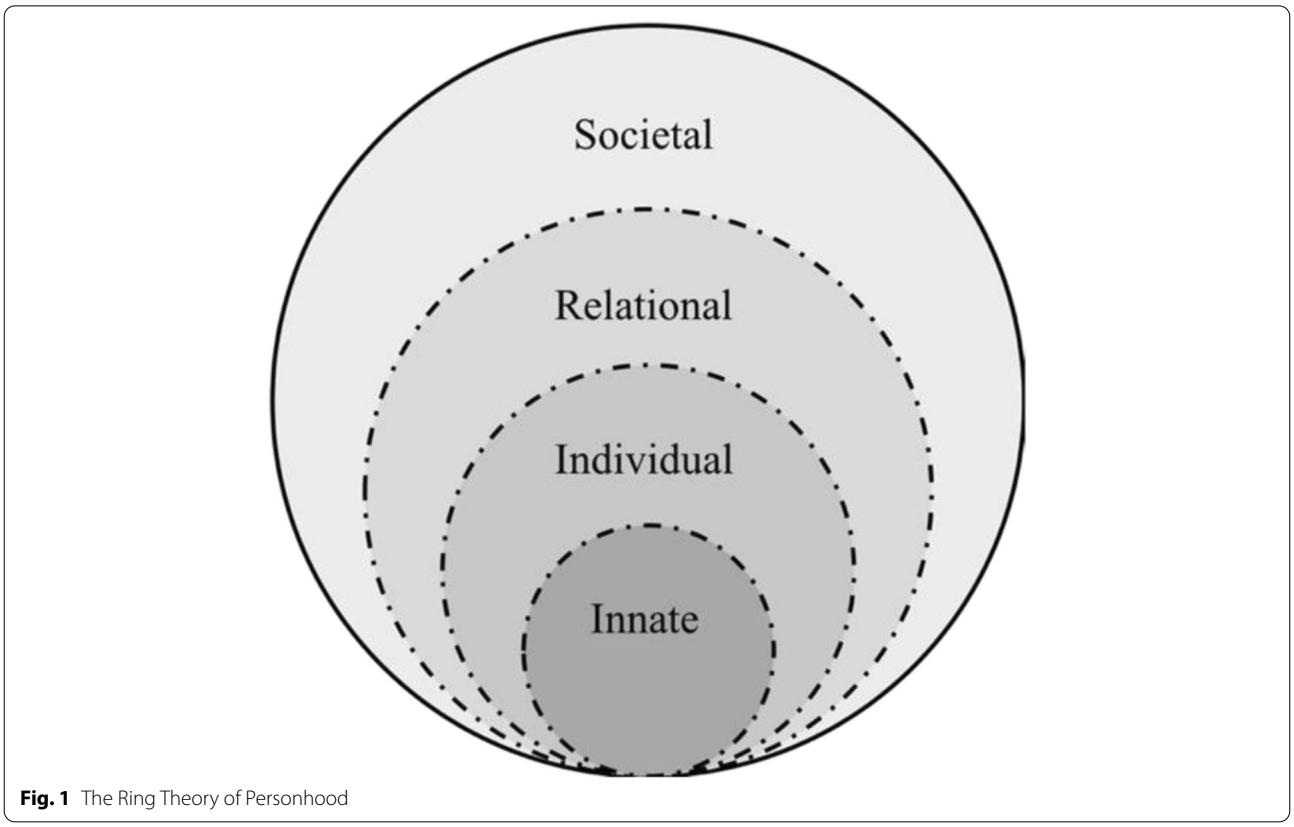

Fig. 1 The Ring Theory of Personhood

also shaped by historical factors such as the person's gender, race, culture, religion and heritage that they are born into. The combination of all these considerations confers the individual with respect and rights reserved for all human beings until their death. Here, the RToP's dynamic nature may be used to capture change in the bereaved parent's [38] spiritual beliefs and existential coping.

The Individual Ring builds upon the Innate Ring and relates to the person's conscious function, ability to think, feel, communicate, act and maintain his or her own personhood. The loss of conscious function eliminates the Individual Ring. The Individual Ring guides the motivations, inclinations, thoughts, traits and actions behind their individual identity. The RToP's ability to detect change in the Individual Ring will help healthcare professionals better understand the bereaved parent's thought process, emotions and coping mechanisms [39, 40].

The Relational Ring contains relationships that the individual determines to be important to them. These relationships may be with family members or friends. For bereaved parents, it is members of the Relational Ring that often provide comfort and support. Changes within the Relational Ring will highlight support and stressors upon the bereaved parent [41].

The Societal Ring, which is the outermost ring, contains relationships with colleagues, acquaintances, contacts and members of networks that the individual does not have significant personal ties with. The Societal Ring also houses cultural norms, professional standards, and societal obligations such as familial, professional, and societal expectations prescribed to the individual within their role in the community. The Societal Ring will also capture society's support and consideration for the bereaved parent as well as the parent's perception of their cultural and social roles and responsibilities [42, 43].

Perhaps more significantly, each ring contains specific values, beliefs, principles, and expectations that come together within the Individual Ring and influence preferences, motivations, decisions and biases, thoughts, and actions. This highlights the interrelatedness of the rings and the central role of the Individual Ring. Concurrently, changing conditions [44], evolving contextual [45], existential, personal, relational, and societal considerations also impact the individual's thoughts and actions. This underlines the importance of the RToP's ability to capture changes in thinking, coping mechanisms[39, 40], needs, motivations in the parent and explain their decisions [46] and actions [47] which will then guide their timely, personalised and targeted support [48].

Methodology

A systematic scoping review (SSR) has been undertaken to study the scope and depth of current data on the complex multidimensional aspects of grief [49, 50] and 'meaning-making' [51–53] upon the personhood of bereaved parents. The SSR's flexible approach facilitates identification of patterns, relationships, and disagreements within regnant quantitative and qualitative data drawn from a wide range of study formats and settings.

However, the reproducibility and transparency of current forms of SSRs are subject to concern due to a lack a consistent approach to structuring, reporting and analysis of the included data. To counter these issues, Krishna's Systematic Evidence Based Approach (SEBA) guided SSR (henceforth SSR in SEBA) is adopted. Built on a constructivist perspective and a relativist lens, SSRs in SEBA are able to effectively contend with the notion of psychological constructivism [54] used to describe 'meaning construction' in grief [55] and provide a longitudinal, context dependent [56, 57], socioculturally and ideologically appropriate understanding [58, 59] of the grieving process and its sequalae [60, 61]. A holistic approach also helps address ethical concerns [62] surrounding research on bereaved parents.

In keeping with the SEBA methodology, a team of experts was engaged to oversee and advise the research team at all stages of the research process. This expert team included a medical librarian from the Yong Loo Lin School of Medicine (YLLSoM) at the National University of Singapore (NUS) and local educational experts and clinicians at the National Cancer Centre Singapore (NCCS), Palliative Care Institute Liverpool, YLLSoM and Duke-NUS Medical School. They served to enhance the accountability of the SSR in SEBA findings.

Conforming to the SEBA methodology, the research and expert teams adopted the principles of interpretivist analysis and immersed themselves in the data through repeated reading, analysis and reflexive discussions so as to piece the qualitative data together in a meaningful manner [63–66]. The SEBA process comprises of the following six stages: 1) Systematic Approach, 2) Split Approach, 3) Jigsaw Perspective, 4) Funnelling Process 5) Analysis of themes from data and non-data driven literature, and 6) Discussion: Synthesis of SSR in SEBA (Fig. 2). These are applied and elaborated upon below.

STAGE 1 of SEBA: Systematic Approach

i.Determining the title and background of the review

In order to ensure a systematic, reproducible and transparent approach to the review, the expert

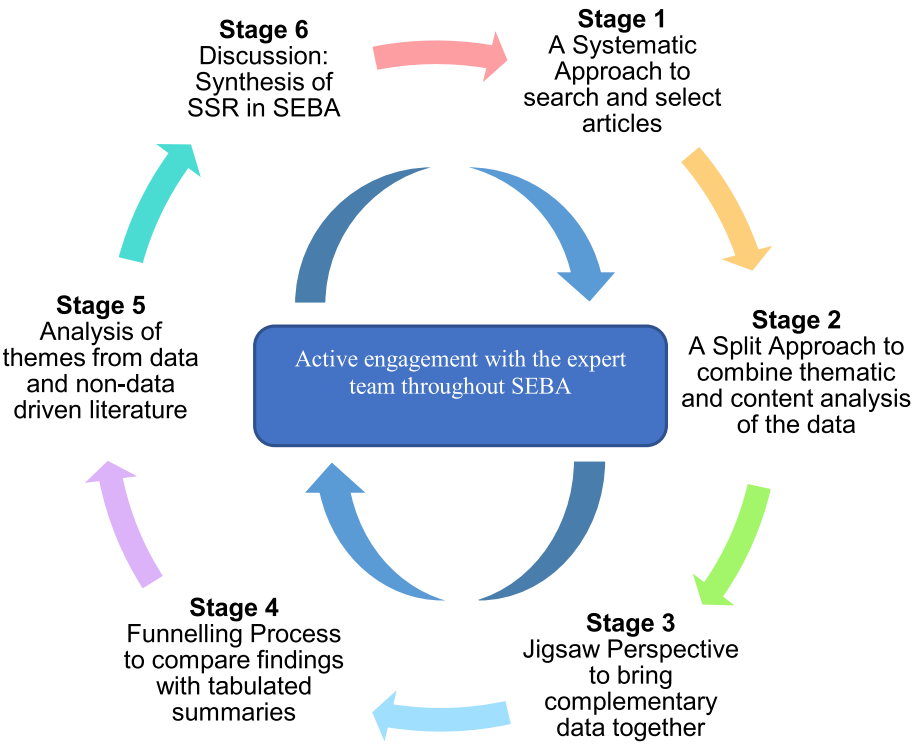

Fig. 2 The SEBA Process

and research team discussed and agreed upon the overall goals, study population, context and concept to be evaluated.

ii.Identifying the research question

The four members of the research team discussed the research question with a medical librarian from the expert team. Guided by the Population Concept, Context (PCC) elements of the inclusion criteria, the research question was determined to be: "How is the personhood of parents affected by the death of their child (aged 0 to 12 years)?" The secondary research questions were determined to be: "What are the key characteristics of the bereavement process for parents?" and "How do their relationships with others change following the death of their child?" To help focus attention upon the loss of a child we adopted the World Health Organisation's classification of a child and a young child [67].

iii.Inclusion criteria

All grey literature, peer reviewed articles, narrative reviews, systematic, scoping and systematic scoping reviews published between 1st January 2000 and 31st December 2020 were included in the PICOs [68, 69] outlined in Table 1.

iv.Searching

Four members of the research team carried out independent searches of four bibliographic databases (Pubmed, EMbase, Psychinfo, CINAHL) and a grey literature database (Google Scholar). In keeping with Pham, Rajić [70]'s recommendations on ensuring a viable and sustainable research process, the research team confined the searches to articles published between 1st January 2000 and 31st December 2020. The searches were carried out between 18th October 2020 and 17th January 2021 using the following search terms: "personhood", "selfhood" AND "end of life", "palliative care" AND "death", "sudden death", "neonate" AND "infant", "paediatrics"' and their combinations. The search strategies are presented in Additional file 1.

v.Extracting and charting

Using an abstract screening tool, the research team independently reviewed the titles and abstracts to identify a list of relevant articles believed to be of relevance that met the inclusion criteria that were set out in Table 1. Next, they individually evaluated full text articles within this filtered list in a second sieving process, resulting in a final list of included articles. These individual lists were discussed amongst the researchers at online meetings and Sandelowski and Barroso [71]'s 'negotiated con-

Table 1 PICOs inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population	● Biological parents and/or legal guardians of deceased neonates and/or children up to the age of 12 years of life [67]	● Parents who are not related by the law or by blood ● Non-1st degree relatives ● Patients who are adolescents above the age of 12
Intervention	● Intervention programmes for parents of deceased neonates up to the age of 12 between 1st January 2000 and 31st December 2020	NA
Comparison Outcome	● Outcomes of intervention programmes ● Changes in parents' personhood ● Programme evaluation results, from forms and questionnaires done by bereaved parents ● Gaps and improvements to current intervention programmes ● Views of bereaved parents on healthcare and intervention programmes	● Observations and recounts of parental behaviour by healthcare staff
Study design	● All study designs and article types were included (observational studies, randomised controlled trials, cohort studies, cross-sectional studies, longitudinal studies and case studies, ancestry approach/review) in the English language	● Non-English language articles

sensual validation' was used to achieve consensus on the final list of articles to be included. Here, negotiated validity sees "*research team members articulate, defend, and persuade others of the "cogency" or "incisiveness" of their points of view or show their willingness to abandon views that are no longer tenable. The essence of negotiated validity is consensus.*" (p.229) This final list was then reviewed by the last author.

STAGE 2 of SEBA: Split Approach

The research team was divided into two teams to concurrently analyse the included articles using Braun and Clarke [72]'s approach to thematic analysis and Hsieh and Shannon [73]'s approach to directed content analysis. Also known as the Split Approach, this method allows focus on key aspects of the "*entire experience of anticipating a death, the death itself and the subsequent adjust to living*" [12]. All 111 articles were read and reviewed by both research teams independently.

Thematic analysis

In Phase 1 of Braun and Clarke approach, an iterative step-by-step thematic analysis was carried out by a team of three researchers who who independently and actively read the included articles to identify meaning and patterns. In Phase 2, 'codes' were constructed from the 'surface' meaning and collated into a code book to code and analyse the rest of the articles using an iterative step-by-step process. As new codes emerged, these were associated with previous codes and concepts. In Phase 3, codes were organised into themes that *"represent some level of patterned response or meaning within the data set*" [74]. In Phase 4, each member of the research team refined their themes to ensure they were coherent and representative of the whole data set. After completing the first 4 phases, the team came together in Phase 5. In this phase, the team discussed the results of their independent analysis online and at reviewer meetings. 'Negotiated consensual validation' was used to determine the final list of themes.

Directed content analysis

Hsieh and Shannon's approach to directed content analysis was employed to enhance the validity of the findings, add 'consistency' to the delineation of themes by drawing upon prevailing codes and categories, and address the relative failure of thematic analysis to address contradictory data [73].

The first stage saw three reviewers draw codes and categories from Krishna [35]'s article entitled "*Accounting for personhood in palliative sedation: the Ring Theory of Personhood*" which was chosen due to its holistic study of various aspects of personhood amongst terminally ill patients. Each code was defined in the code book and used in the second stage to independently extract and code relevant data from the included articles. In keeping with deductive category application, any relevant data not captured by these codes were assigned a new code. "Negotiated consensual validation*"* was used to achieve consensus on the codes, and this code book was then used to code the rest of the articles [75].

STAGE 3 of SEBA: Jigsaw Perspective

Here, the Jigsaw Perspective saw the themes and categories viewed as pieces of a jigsaw puzzle where areas of overlap allowed for these pieces to be combined to create a bigger picture of the overlying data. The combined themes and categories are referred to as themes/categories. The Jigsaw Perspective employs Phases 4 to 6 of

France, Wells [76]'s adaptation of Noblit and Hare [77]'s seven phases of meta-ethnography.

As per France, Wells adaptation, the themes and categories identified in the Split Approach were grouped according to their focus. Each theme and category within the group were contextualised by reviewing the articles from which they were drawn. Reciprocal translation determined if the new data provided by the respective themes and categories could be used interchangeably

STAGE 4 of SEBA: Funnelling Process

The funnelling process sees the themes/categories identified in the Jigsaw Perspective compared with the tabulated summaries created, in keeping with recommendations set out by Wong, Greenhalgh [55]'s RAMESES publication standards: meta-narrative reviews and Popay, Roberts [78]'s "Guidance on the conduct of narrative synthesis in systematic reviews". The tabulated summaries ensured that the themes/categories identified provided an accurate representation of existing data (see Additional file 2). They also included quality appraisals using the Medical Education Research Study Quality Instrument (MERSQI) [79] and the Consolidated Criteria for Reporting Qualitative Studies (COREQ) [80].

The Funnelling Process employed Phases 3 to 5 from France, Wells adaptation where the themes/categories identified in the Jigsaw Perspective were juxtaposed with key messages identified in the tabulated summaries. The funnelled themes/categories formed the basis for the discussion narrative's 'line of argument' in Stage 6 of SEBA.

Results

A total of 3074 abstracts were reviewed, 160 full text articles evaluated, and 111 articles included as outlined in Fig. 3 below. Of the included articles, 14 were quantitative studies, 52 were qualitative studies and 20 were mixed studies.

In the interest of space and ease of review, the themes and categories identified are summarised in Table 2.

The Funnelled themes/categories were as follows.

1) Innate Ring
   - Spirituality/Religion
2) Individual Ring
   - Attitude to Life and Death
   - Positive thinking
   - Setting and timing of child's death
   - Coping Mechanism
   - Positive coping
   - Development of psychosocial morbidities
3) Relational Ring
4) Societal Ring

Funnelled Themes/ Categories 1: The Innate Ring

Spirituality/ Religion

Whilst spiritual support is generally seen to help a parent's coping and grieving process [81–85], attenuate shock, disbelief, and yearning [86], reduce parental grief (despair, detachment, and disorganisation), improve mental health (depression, post-traumatic stress), enhance personal growth [85], remain connected to their deceased child [28] and find meaning in their loss [84, 87–90], being aware of how the individual parent is addressing his or her grief is critical.

Falkenburg, van Dijk [91] found that many parents had their faith profoundly shaken [91–94]. Frei-Landau, Hasson-Ohayon [59] suggest that there are three manifestations of existential or divine struggles. They are: absence of divine struggle, an explicit divine struggle where the parent seeks explanations, and an implicit divine struggle where the parent does not discuss religiosity [61]. Understanding these states is critical to the provision of effective support, since there is no consistency as to how religious affiliations across cultures impact grief in parents. For instance, South American families reported that their spirituality [95] was compromised by evangelical family and/or friends [96] whilst self-reported non-religious participants in Beijing found religious mores a source of support that enhanced spirituality [97]. Similarly, whilst Hedayat [98] suggested that in Muslim societies the death of a child a reinforced their religious faith [92], some bereaved parents believed that their child's death was a punishment from a Higher Power [89, 99, 100] and turned their disappointment inward and or towards the Higher Power [99].

van der Geest, van den Heuvel-Eibrink [100] found that religious beliefs were less affected in some societies like the Netherlands where religion appears to play a less significant role in the society as compared to the United States where religion is seen as a significant source of support.

Funnelled Themes/ Categories 2: The Individual Ring

Bereavement is influenced by personality traits [59], culture, demographics [101], attitudes, values, and beliefs as well as previous stressful encounters and one's physical and emotional health [102–104].

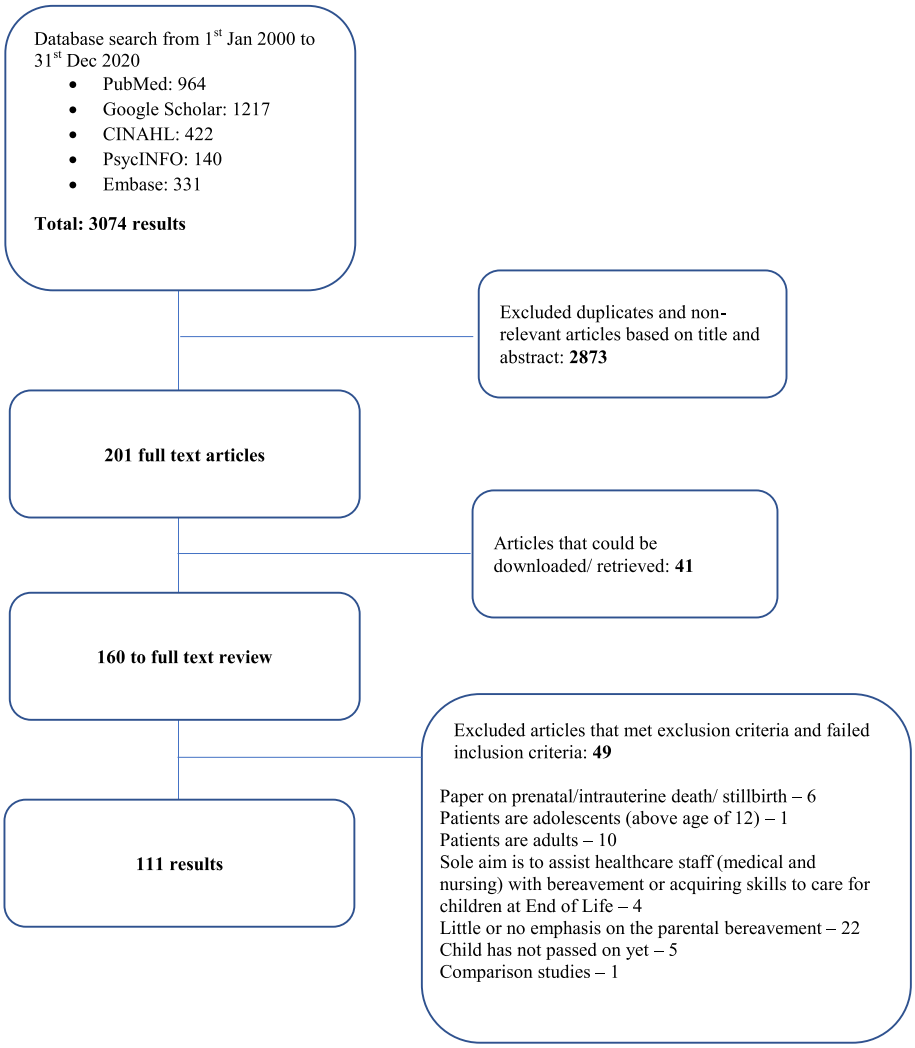

Fig. 3 PRISMA flow chart

Attitude to Life and Death

i.Positive thinking towards death

Some parents viewed their child's death as relief from pain and suffering [92, 105], an inevitable part of life [106] or a 'greater plan' [107], thus reducing fears of their own mortality [108, 109]. These provided them with a source of courage [106, 109], a newfound appreciation for life [92] and even hope and solace [86, 93].

ii.Setting and timing of child's death

The setting and timing of a child's death greatly impacts the parent's bereavement. A death following a protracted illness predisposed them to complicated grief [110] and desensitisation [111]. On the other hand, being aware of the child's prognosis helped prepare some parents [110, 112]. Direct, timely, and personalised communications [113], effective end of life care [111, 114–124], respect for advance care planning (ACP) [111] and parental involvement in care determinations also assuaged parental grief [84, 125, 126].

Coping

i.Positive Coping

Parents who could share their feelings [127, 128], and received guidance [116, 117, 119, 127, 129, 130] and frequent updates on their child's prognosis and health status [131, 132] in an honest [120], under-

Table 2 Themes and categories identified

Themes identified through Thematic Analysis	Categories identified through Directed Content Analysis
1) Honour memory oPreserving deceased child's presence in family life o Living in a way that honours their deceased child o Remembering their child/keeping memory of child alive o Forgetting memory of child 2) Spirituality/ Religious mores/ practices 3) Personality 4) Attitude to Life and Death o Grief-alleviating factors o Grief worsening factors o Anticipatory Grief o Behavioural Manifestations o Coping Mechanism 5) Strengthening relationship ■ between parents and children, other family members, ■ and healthcare staff o Weakening relationship ■ between parents and children, other family members, and healthcare staff o Familial duties o Changing membership (promotion/ severing of ties)/ new memberships 6) Societal relationships o Professional relationships o Interaction with healthcare professionals o Acquaintances o Societal expectations	1) Innate Ring 2) Individual Ring 3) Relational Ring 4) Societal Ring

standable [133], consistent [114, 117, 128], compassionate [90, 111, 115, 118, 119, 134] and culturally sensitive manner [87, 117, 128, 135, 136] coped better and suffered less grief [88, 90, 120, 127, 129, 131, 133, 136–142]. Parents found that being present at their child's death [140, 143] ameliorated the grieving process [134, 140] as "*seeing and holding or being allowed to touch and hold helps the bereaved person adapt to the loss and say goodbye*" [98, 126, 144, 145].

Also helpful were healthcare professionals who maintained contact with the parents after the child's demise [81, 83, 88, 108, 114, 135, 138, 140, 146, 147]. These relationships created a social space that kept the child's identity alive [139] and facilitated personalised home-based bereavement services [10, 87, 143, 146, 148, 149] both for the individual [82] and for the couple [82, 112, 149, 150].

Positive coping facilitated personal growth [109], resilience [90, 106, 132], better self-understanding [89, 109], meaning making [87, 90] and motivation to invest in self-care [132]. Parents with positive coping mechanisms were also more appreciative of non-material values such as their health and family [90, 92, 95, 108]. Parents also recovered faster [87, 108, 148, 151] through personal and societal undertakings such as by giving back to society in their deceased child's name [106, 109, 134, 149, 152], donating their child's organs [153], creating a trust fund or foundation [109, 142, 154], and/or organising support groups for other parents in similar situations [87, 90, 92, 109, 127, 138, 155]. On a personal level, parents coped better by commemorating their deceased child on their birthday or death anniversary [82, 89, 96, 138, 156], visiting their child's grave, holding on to their child's possessions or keeping photographs, footprints, locks of hair, quilts or toys [89, 95, 115, 116, 127, 156–158] and creating "memory boxes" [92, 115, 127] that serve to reaffirm the deceased child's place within the family [140].

ii.Development of psychosocial morbidities

Psychosocial morbidities were precipitated by anticipatory grief [159], loss of parental role [113, 160], and a sudden death [161]. Exacerbation of parental grief [10, 146] was also noted when the child experienced poor symptom management [10, 108, 143, 146, 151, 152], prolonged illness [120], and a hospital death [162], particularly when the parent was separated from the child [131, 148], insufficiently prepared for the loss [92, 100, 113, 116, 131, 150, 163], and faced a lack of conducive environment to say goodbye [148, 164]. Psychosocial morbidities were exacerbated by poor transition of care [114, 127, 129, 140, 143, 148], poor communication [10, 82, 116, 117, 129, 131, 132, 135, 143, 148, 165–167], unrealistic prognostication [10, 113, 129, 132, 135, 138, 165, 166], role conflict between parents

and healthcare providers during end of life decision making [167–169] and the healthcare providers' lack of cultural sensitivity [170]. Anger, fear and guilt [96, 106, 117, 118, 134, 163, 171], anxiety, depression, post-traumatic stress symptoms [89, 158, 163, 168, 172, 173], insomnia [89], permanently damaged parental self-concept [168], role confusion [171], poor social function [10, 89, 99], functional impairment such as phobias or somatic problems [81, 92, 155, 163, 174], suicidal ideation and prolonged grief [10, 89] were also exacerbated by inadequate social [82, 88, 120, 148, 154, 161, 165, 175], spiritual [82, 88, 98, 176, 177] and bereavement support [82, 83, 89, 92, 108, 109, 127, 141, 143, 148, 150, 152, 154, 163, 178].

Inadequate gender and personalised bereavement support also raised concerns [179]. Fathers were found to refrain from expressing their grief openly [95, 99], isolate themselves from family and friends, shun spiritual services [99], exhibit a greater need for respite from their child's care [179] and succumb to delayed grief reactions [161]. Mothers were found to be more likely to become depressed [95], experience more physical ailments and social ill-health [174] and require longer recovery [116, 177].

Funnelled Themes/ Categories 3: The Relational Ring

Scocco, Idotta [101] suggest that coping with bereavement is also influenced by the relationship shared with the child, the circumstances of the death and the consequences of the death. Bartel [24] noted that the death of the child brings about "*relational grieving*" for the individual, family unit and the larger community.

Whilst such loss can strengthen marital relationships [106, 155, 158] and provide distinct mutual spousal support [89, 90], spousal ties may be frayed by disagreements, stress and grief [39, 92, 112, 134]. Here, involvement of the parents' other children in the grief-sharing process may help the family come closer together [92, 109] and give life meaning [106]. Support from friends and extended family may also help to strengthen these ties [88, 137, 140, 154, 155, 176].

Conversely, neglect of the other children jeopardised nuclear and extended familial ties and dynamics [82, 83, 95, 143, 148, 150, 155]. Ties between parents, friends and family may also be weakened when life-and-death decisions are not mutually supported [180] or misunderstood [90]. Relationships also suffer as a result of insensitive communications [85, 89, 90, 167] and when bereaved parents subconsciously isolate themselves from others [89].

Funnelled Themes/ Categories 4: The Societal Ring

Honest, timely, personalised, empathetic, kind, culturally sensitive and respectful support enable healthcare professionals to provide more effective 'external' and longitudinal assistance to parents [115, 118, 120, 129, 130, 133, 137, 139, 146, 149, 150, 167, 181]. It also helps to affirm parents of their place in society [81, 82, 133, 136–139, 148, 163, 176]. Other bereaved parents may also serve as a further source of advice and guidance [89, 130, 182].

However, poor bereavement support may leave parents feeling 'abandoned' [82, 85, 114, 120, 127, 176, 183], resulting in the feeling of having suffered a 'double loss' [109] or 'multiple losses' [111, 184].

STAGE 5 of SEBA: Analysis of themes from data and non-data driven literature

Acknowledging the potential impact of poor quality appraisal scores amongst the largely non-evidence based grey literature and opinions, perspectives, editorials, letters and non-primary data-based articles underlined the need to assess the impact of such data on the synthesis of the discussion portion of this SSR in SEBA. The research team found that the themes identified from separate thematic analysis of evidence-based and non-evidence-based data were similar, suggesting that the latter included in this review did not bias the analysis untowardly.

Stage 6 of SEBA: Synthesis of SSR in SEBA

In keeping with SEBA, the discussion portion of this SSR in SEBA was guided by the Best Evidence Medical Education (BEME) Collaboration guide [185] and the STORIES (Structured apprOach to the Reporting In healthcare education of Evidence Synthesis) statement [186].

Discussion

In answering its primary research question, this SSR in SEBA highlights three key findings in viewing *the impact of death of a child between 0 to 12 years on the personhood of a parent* through the lens of the RToP. To begin, this review highlights evidence that the loss of a child will impact every aspect of a parent's life. These changes to their spiritual beliefs, psychoemotional state , relationships, roles and expectations are captured within the Innate, Individual, Relational and Societal domains of the RToP. Secondly, perhaps more significantly, this SSR in SEBA highlights the dynamic nature of the bereavement process and the influence of a variety of factors within each of the four rings of the RToP. These findings undergird the notion of a personalised grief experience that requires an individualised, holistic, and longitudinal support mechanism. Overall, this data underscores the significant role that healthcare professionals play in supporting bereaved

parents and in assessing and engaging with different elements of the parent's life to better support them [187].

However, this review also highlights a number of consistent factors that attenuate and exacerbate the acute effects of loss (Table 3) that may help to guide healthcare professionals in their assessment and support of bereaved parents. Reiterating the importance of forming personalised relationships with them, this data underlines the critical need to support healthcare professionals in meeting their various roles and responsibilities [188–192].

Relationships with healthcare professionals

Whilst this SSR in SEBA brings to the fore several considerations, perhaps the most significant and thus the focus of our discussion is the role of the relationship between bereaved parents and the healthcare professional journeying with them. Built upon trust, individualised relationships allow for the provision of appropriate, specific,

Table 3 Protective and risk factors

	Protective factors	Risk factors
Innate Ring	Presence of spiritual support, guidance and counsel [81–85]	Perceptions of guilt, anger, desperation and Divine punishment [89, 99, 100]
	Strong spiritual beliefs [151]	
	Belief in reunion with child in the afterlife [86, 93]	
Individual Ring	Viewing death as positive outcome Relief from suffering [92, 105] Greater purpose [107] Reduced fear of death [106] Appreciation of own mortality [108, 109]	Anger, fear and guilt to changes in the child's condition [96, 106, 117, 118, 134, 163, 171]
	Well symptomatically cared for [114–120]	Protracted dying process [111, 120] Poor symptom management [10, 108, 143, 146, 151, 152]
	Frequent personalised and timely updates on child's prognosis and condition [131, 132]	Being unaware of prognosis [112] Ineffectual preparation by healthcare professionals [92, 100, 113, 116, 131, 150, 163] Unrealistic prognostication [10, 113, 129, 132, 135, 138, 165, 166],
	Personalised communication [113]	poor communication [10, 82, 116, 117, 129, 131, 132, 135, 143, 148, 165–167]
	Being present at the death [98, 126, 140, 143–145]	Not involved in end-of-life decision [84] Separated from the child [131, 148] Lack of a conducive environment to say goodbye [148, 164]
	Respect for advanced care plan [111] Effective end of life care [121–124]	Inadequate social [82, 88, 120, 148, 154, 161, 165, 175] Inadequate spiritual [82, 88, 98, 176, 177] Inadequate bereavement support [82, 83, 89, 92, 108, 109, 127, 141, 143, 148, 150, 152, 154, 163, 178]
	Positive means of coping including: Remembering the child [87, 89, 90, 106, 109, 132] (memory boxes, commemorating anniversaries) [82, 89, 92, 95, 96, 115, 116, 127, 138, 156–158] Greater self-care [152, 155] Giving back to society [106, 109, 134, 149, 152] Donating organs [87, 90, 92, 109, 127, 138, 155] Re-dedicating their lives [107, 109, 134]	Anxiety, depression, post-traumatic stress symptoms [89, 158, 163, 168, 172, 173] Insomnia [89] Permanently damaged parental self-concept [168] Role confusion [171] Poor social function [10, 89, 99] Functional impairment such as phobias, or somatic problems [81, 92, 155, 163, 174] Suicidal ideation and prolonged grief [10, 89]
Relational Ring	Spousal support [89, 90]	Spousal disagreements, stress, grief [39, 92, 112, 134]
	Support from family and friends [88, 137, 140, 154, 155, 176]	No family/friends to support [83] Insensitivity from family/friends [85, 90, 167]
	Support from remaining children [92, 109]	Previous neglect of other children [82, 83, 95, 143, 148, 150, 155]
Societal Ring	Continued support from healthcare professionals who knew family and the child [81, 83, 88, 108, 114, 135, 138, 140, 146, 147]	Feeling 'abandoned' by the hospital staff [82, 85, 114, 120, 127, 176, 183] Reporting feeling of having suffered a 'double loss'[109] or 'multiple losses' [111] following poor bereavement support [184]
	Trusting relationship with healthcare professionals [114–119, 147]	
	Able to share feelings [127, 128] Receive guidance [116, 117, 119, 127, 129, 130] Receive culturally appropriate care [87, 117, 128, 135, 136] Receive compassionate care [90, 111, 115, 118, 119, 134]	Lack of professional support [84, 125] Poor transition of care [114, 127, 129, 140, 143, 148] Role conflict [167–169] Loss of parental role [113, 160] Lack of cultural sensitivity [170]

timely, accessible, holistic, and longitudinal support [114–119, 147, 188, 193]. This is cultivated by attending to the parents' needs, preparing them for anticipated loss, providing them with a 'locus of control' [17] and opportunities to say goodbye and grieve in a manner that best reflects their particular beliefs and contextual considerations. Journeying [191] with the parents through their child's terminal stages of life is important, but equally critical is sharing in their loss and providing support in their bereavement. Jensen, Weng [194] found that such support was not always available. Here, this SSR in SEBA not only highlights the need for such consistent longitudinal support for families, but underscores the importance of sustained training, debriefs and holistic guidance for the healthcare professionals who journey with them.

Change

To meet their longitudinal roles and responsibilities, healthcare professionals should be equipped with longitudinal support and training. This is underlined by the knowledge that factors previously deemed supportive to coping and meaning-making may turn into risk factors and vice versa. With Knapp and Contro [95], Jonas, Scanlon [96], van der Geest, van den Heuvel-Eibrink [151] and Cai, Guo [97] highlighting the interchangeability of factors listed in either column in Table 3, data here suggests that the RToP's ability to capture such change ought to be used in the training of healthcare professionals so that they are better able to respond appropriately to each individual parent's bereavement needs [27–30, 33, 34, 195]. Addressing change in the rings of the RToP foregrounds the import of timely [57] and context sensitive [7] assessments of parental coping [25, 89, 196, 197] and careful involvement of various members of the bereaved parents' friends, relatives and community.

Training

With present accounts suggesting grief support training to be inadequate [198] and thus limiting one's ability to identify and provide bereaved parents with individualised [191] and responsive support [25, 197], this SSR in SEBA underscores the importance of healthcare professionals being well-trained to discern when and how to support them and which family members, friends, and communities may help to supplement their support system. Important, too, is training in developing open, mindful, personalised, empathetic, kind, and culturally sensitive communications skills. Particularly on how and when parents are consulted on care determinations and offered honest, consistent, understandable, and compassionate guidance, clinical updates and prognostications. Such skills should be complemented with training in the appreciation of the parents' religious beliefs [84, 86, 88–90], individual meaning-making proceses [86, 93, 106, 108, 109], and support provided or desired from their spouse, close friends, families [106, 155, 158] and-community [89, 130, 140, 143].

Operationalising the RToP

To aid these endeavours, we believe that it is possible to adapt the RToP's four domains into a framework to assess each parent's state and needs (Table 4). Critically, the tool will allow transparency and accountability in bereavement risk assessments, convey critical information within the multi-disciplinary healthcare team [165, 191, 193, 199], and provide a robust structure for documentations and follow-up. Additionally, it will also help determine the intensity of support provided to prevent parents from feeling 'abandoned' [191, 200] by healthcare providers.

Limitations

This SSR in SEBA was limited by use of the RToP which remains unproven in this context despite it being utilised in other populations in palliative care. There is also an array of methodological weaknesses amongst

Table 4 Using RToP's four domains to assess parent's state and needs

Innate ring: Spiritual needs and importance placed on it Sources of spiritual support	Individual Ring: Self-support Couple's therapy Family support Other available support mechanisms Stressors and changing situations in their life Provide avenues to seek help Determine the role that family and friends have in supporting the particular parent and their own coping mechanisms
Relational ring: The support from those near and dear to parents The importance placed on this	Societal Ring: Determine support within the parent's work environment and the larger social circle determine support of the remaining children in their own school environment Engagement with the parent's general practitioner, district nurses and counselling teams

the included articles including failure to detail sample populations, information on care settings, place of death, duration of illness, available support, research methodologies, validity of findings as well as a lack of longitudinal data. There could also be differences in individual approaches during data analysis, though this was minimised as much as possible through corroboration with the team at each stage of the analysis. This raises questions as to the veracity of conclusions drawn and applicability of recommendations made beyond North America and Europe as most of the included articles were from these English-speaking Western countries.

Conclusion

This SSR in SEBA has important implications for neonate, paediatric and bereavement units highlighting the longitudinal and personalised expectations upon healthcare professionals in this field. It also emphasises the need for training and support of these healthcare professionals, forwarding the idea of the RToP as a training tool and as an assessment tool to evaluate change in the individual parent's coping abilities. We envision that this tool will help to guide the provision of timely, personalised, appropriate, holistic and longitudinal support for both the healthcare professional and the bereaved parent. As we look forward to engaging in future discussions in this critical area of study, we believe it is vital for further research to be conducted to better elucidate ways in which healthcare professionals may be more comprehensively trained and supported as they journey with these parents. In addition, it is crucial to further determine the viability of the RToP as an education and assessment tool.

Abbreviations

SSR: Systematic Scoping Review; NUS: National University of Singapore; YLLSoM: Yong Loo Lin School of Medicine; NCCS: National Cancer Centre Singapore; PCC: Population, Concept and Context; PICOS: Population, Intervention, Comparison, Outcomes, Study Design; RToP: Ring Theory of Personhood; SEBA: Systematic Evidence Based Approach.

Supplementary Information

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Additional file 1. Search Strategy.

Additional file 2. Tabulated Summaries.

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Authors' contributions

PSV, JYL, RWLL, HH, XHT, WQL, MBXYL, ASIL, MC, CL, VRB and LKRK were involved in data curation, formal analysis, investigation, preparing the original draft of the manuscript as well as reviewing and editing the manuscript. All authors have read and approved the manuscript.

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