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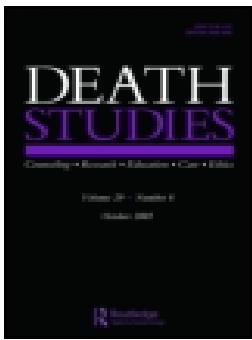
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## Understanding the spirituality of parents following stillbirth: A qualitative meta-synthesis

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### ABSTRACT

This meta-synthesis aims to synthesize qualitative evidence from primary studies to better understand the experience of the spirituality of parents and its relationship to adapting following stillbirth. Five electronic databases were systematically searched and the quality of 21 eligible studies was critically appraised. A thematic synthesis revealed two analytical themes: (1) Spiritual suffering following stillbirth; (2) Moving through spirituality to adapt to the loss, each encompassing four descriptive themes. The findings can inform a more culturally and spiritually sensitive approach to care, taking into account the parents' beliefs, folk customs, religion, values, and spiritual needs.

### Introduction

Despite the 2.6 million stillbirths worldwide each year (Lawn et al., 2016), the parental experience after a stillbirth is frequently unacknowledged by health professionals, family, and society (Burden, Bradley, & Storey, 2016; Mulvihill and Walsh, 2014). Stillbirth is one of the most challenging bereavement experiences and has life-long impacts for parents (Nuzum, Meaney, & O'Donoghue, 2018; Scott, 2011) as well as substantial psychological, social, and financial consequences (Heazell et al., 2016; Pollock et al., 2019). However, parents' spirituality as an aspect of human experience and its relation to coping after a stillbirth remains insufficiently understood, in contrast to other findings from literature reviews.

Spirituality is a dynamic and intrinsic aspect of humanity through which one seeks ultimate meaning, purpose, transcendence, and experiences relationships with the self, family, and others, including community, society, nature, and the significant or sacred (Puchalski, Vitillo, Hull, & Reller, 2014). It consists of three main components: connectedness, transcendence, and meaning of life (Weathers, McCarthy, & Coffey, 2016), as well as multiple distinct dimensions such as spiritual or religious beliefs, rituals and practices, coping, distress, relationship with the

transcendent, sense of meaning, or life purpose (Steinhauser et al., 2017).

Although religion and spirituality are different concepts, they are interlinked, considering that spirituality can be expressed through religious affiliation, religious activities, and religious beliefs (Weathers et al., 2016). Religion is an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent (God, Higher Power(s), or ultimate truth/reality), which is practiced in private or public settings and is derived from established institutions and traditions (Koenig, King, & Carson, 2012).

Deep suffering after the loss of a loved one impacts the spiritual domain as attempts are made to make sense of and to heal from suffering (Wright, 2017). A significant body of research indicates that people use spirituality in different situations of bereavement (Becker et al., 2007; Wortmann and Park, 2008; Zakar, Zakar, Mustafa, Jalil, & Fischer, 2018) and that bereaved individuals suffer profoundly not only in relation to the death of their loved one but also in their relationship with God and their faith community, a condition known as complicated spiritual grief (CSG) (Burke, Neimeyer, Young, Bonin, & Davis, 2014). These studies indicate the influence of religious and spiritual beliefs on bereavement, which have often

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been associated with better outcomes in adapting to loss (Forhan, 2010; Heazell et al., 2016), but which may also be significantly challenged by the loss (Burke and Neimeyer, 2012; Nuzum, Meaney, O'Donoghue, 2017).

While the phenomenon of spirituality is inherent in childbirth experience (Crowther and Hall, 2015) and grief (Steffen and Coyle, 2011), no review has investigated the spirituality of bereaved parents following stillbirth to fully understand it and explore its influence on parents' grieving process. There is still conflicting evidence as to whether spirituality helps in the process of coping or adjusting to bereavement (Christian, Aoun, & Breen, 2018; Wortmann and Park, 2008). We know that support and counseling after a perinatal death can decrease the duration of bereavement (Forrest, Standish, & Baum, 1982) and that a spiritual crisis following loss has been associated with complicated grief (CG) (Burke, Neimeyer, Young, Bonin, & Davis, 2014; Burke and Neimeyer, 2014). Thus, this meta-synthesis will add to the existing body of knowledge, as little is known about parents' spirituality following stillbirth. This review could contribute to the enhancement of the ability of healthcare professionals to support parents during their grief experience. This study may also be useful to policymakers and could aid in the development of strategies and interventions that incorporate the spiritual dimension to assist bereaved parents in softening their suffering.

This research paper aims to synthesize qualitative evidence from primary studies to better understand the experience of the spirituality of bereaved parents and its relationship with adapting following a stillbirth. In so doing, the study seeks to answer the following research questions: (a) How does the experience of stillbirth impact the spirituality of the bereaved parents? and (b) Which aspects of spirituality facilitate parental coping following a stillbirth?

## Methods

Meta-syntheses strive to understand and explain a researched phenomenon to stimulate new knowledge from previous studies (Walsh and Downe, 2005). In this meta-synthesis, we carried out a thematic synthesis (Thomas and Harden, 2008) and followed steps outlined by Sandelowski and Barroso (2007). We used the guidelines of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) for reporting the synthesis of qualitative

research (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

## Search strategy

Five electronic databases – PUBMED, CINAHL, PsycINFO, LILACS and SCOPUS – were searched in December 2017. We formulated a sensitive and comprehensive search strategy according to the SPIDER tool (sample, phenomenon of interest, design, evaluation, research type) (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014), and relevant search terms were adapted to optimize the unique features of each database. No limitations restricting either publication date or country of origin were imposed. The reference lists of publications that fulfilled the inclusion criteria were reviewed manually to identify additional studies not retrieved in the electronic search.

A set of terms (including Emtree, DeCS and Mesh terms) and keywords synonymously relating to family, perinatal death, spirituality, religion, and qualitative research was used to restrict the literature scope (Table A1). The Boolean operators “or” and “and” were used to distinguish synonyms and combine search terms. The search included specific keywords relating to perinatal death and family to capture the available research reports including a sample of several family members who had experienced a perinatal death. When conducting a meta-synthesis research project, having a representative sample is important for ensuring validity (Finfgeld-Connett, 2018). Thus, the topic of this meta-synthesis was reframed by the number of available research reports that broadly related to a sample of parents who had experienced a stillbirth. This iterative process regarding the scope of the review is part of undertaking a meta-synthesis (Walsh and Downe, 2005).

## Eligibility criteria and study selection

Articles included in this meta-synthesis met the following criteria: (i) the sample included parents (mother and/or father) who had experienced a stillbirth (defined as fetal death between 20 weeks of gestation and the time of birth (De Frain et al., 1991)); (ii) the phenomenon of interest was the spirituality experienced and expressed following stillbirth; (iii) primary research that utilized qualitative methods for data collection (e.g. focus group interviews, individual interviews, observation, blogs analysis)<sup>1</sup> and for data analysis (e.g. thematic analysis, framework analysis,

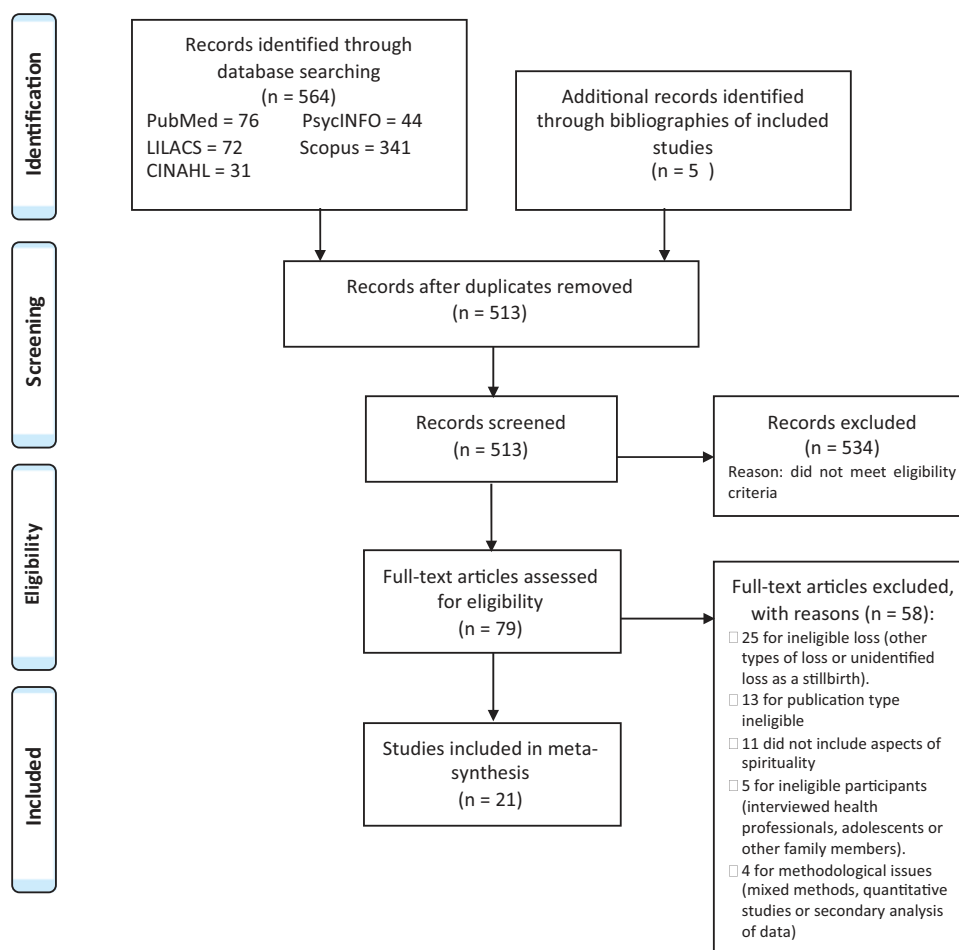


Figure 1. PRISMA Flowchart of studies selection process (Moher et al., 2009).

grounded theory) (Leavy, 2014); (iv) original research published in English, Spanish, Portuguese, and French, languages which were then read and understood by the authors; and (v) journal articles, as the majority of peer-reviewed research studies are published in this format (Stansfield, Brunton, & Rees, 2014).

As mentioned earlier, spirituality encompasses a multiplicity of phenomena. To account for the diversity of spiritual experiences that follow stillbirth, which are embedded within both secular and established institutional contexts, we considered the essential attributes of the concept of spirituality forwarded by Weathers et al. (2016): namely, connectedness (to self, others, God or Superior Being(s), and the world or nature), transcendence, and the meaning of life. These attributes were used to identify the included studies, to extract data related to spirituality (such as, for example, the use of religion), and to support the analysis in accordance with the research questions.

Studies with mixed samples of parents experiencing other perinatal losses (e.g. miscarriage and neonatal

death) were included whenever (a) the data and the findings regarding participants' experience of stillbirth could be distinguished from those of participants who experienced a loss other than stillbirth, or (b) the largest part of the sample referred to participants with a stillbirth experience. Mixed method or case studies, as well as studies carried out with adolescent parents (<17 years) or reporting parents' experience of subsequent pregnancies, were excluded.

The PRISMA flowchart was used to report the selection process of the studies (Moher, Liberati, Tetzlaff, & Altman, 2009) and the search results are shown in Figure 1. The search identified 569 articles including five manually screened from the reference lists. We imported the articles into Endnote X8 software and deleted the duplicates. The remaining 513 studies had their titles and abstracts screened independently by two reviewers (WAA; NBP) based on inclusion and exclusion criteria. Inter-reviewer agreement assessed by Cohen's kappa statistical test found strong agreement ( $\kappa = 0.85$ ) (McHugh, 2012), and disagreements were resolved by a third reviewer (FDM).

After this, 434 articles were rejected for failing to meet the inclusion criteria. A total of 79 full texts was reviewed independently by two reviewers (WAA; LCN), and a further 58 were excluded for failing to meet the inclusion criteria. Therefore, the sample for this meta-synthesis was composed of 21 original articles.

### **Quality appraisal**

Critical Appraisal Skills Program (CASP) (Critical Appraisal Skills Programme, 2018) was used to assess the quality of the included studies. This tool consists of 10 questions which address the research aim statement, the appropriateness of qualitative methodology, sampling method, data collection and analysis, reflexivity, ethical considerations, clarity of statements of findings, and the meaningfulness of the results. Two team members (NBP; SZ) independently appraised each article and provided an assessment for each question (“yes”, “no” or “can’t tell”) with a justification for their response. Disagreements among them were resolved through discussion with a third reviewer (WAA). We did not exclude papers based on the quality assessment, but it provided information on the robustness and rigor of included studies (Table A2).

### **Data extraction and synthesis of findings**

Data extraction was carried out by the first author (WAA) using extraction tables and independently checked for relevance and suitability to our meta-synthesis by a coauthor (NBP). Data extraction included study details such as study setting, research purpose, theoretical and methodological framework, participants, sampling, data collection and analysis methods, and major findings (themes and subthemes). Table 1 shows the characteristics of these studies.

A thematic synthesis approach was adopted to analyze and synthesize the data (Thomas and Harden, 2008). This approach is a three-stage process for the identification and development of themes, and involves the process of coding text, developing descriptive themes, and generating analytical themes. First, one author (WAA) inductively coded data line-by-line according to its meaning and content. Similar codes were then grouped into a hierarchical tree structure. Finally, descriptive themes were developed and then further interpreted to yield analytical themes to answer the review questions. The software QSR International’s NVivo 12 for Mac was used to facilitate the

management and coding of data presented as “results” or “findings” of included studies. To ensure the integrity of the codes, two authors (SZ; NBP) read and re-read the data, double-checking the codes for consistency and validation. They applied the codes independently from the finalized code structure. Discrepancies were negotiated, and the consensus was reached through in-depth discussion, involving the team of researchers (Bradley, Curry, & Devers, 2007). Thus, we refined the coding frameworks until the new themes were sufficiently abstract or analytical for description and explanation of the descriptive themes, and a final version was agreed upon. A diagram was produced to illustrate the dynamic relationships between analytical and descriptive themes of findings (Figure 2).

## **Results**

### **Characteristics of the studies**

The studies included in this meta-synthesis involved 570 parents (91% women and 9% men) from 13 countries: Sweden ( $n=4$ ), Taiwan ( $n=4$ ), Israel ( $n=2$ ), Iran ( $n=1$ ), South Africa ( $n=1$ ), United Kingdom ( $n=1$ ), Australia ( $n=1$ ), Northern Ireland ( $n=1$ ), Ireland ( $n=1$ ), Somaliland ( $n=1$ ), Brazil ( $n=1$ ), Malaysia ( $n=1$ ), and Japan ( $n=1$ ). Most studies adopted the purposeful sampling strategy and in-depth interviews for data collection. There was a range of qualitative approaches used, including content analysis ( $n=6$ ), phenomenology ( $n=5$ ), Grounded theory ( $n=3$ ), ethnography ( $n=2$ ), thematic analysis ( $n=1$ ), narrative ( $n=1$ ) and others ( $n=3$ ). The critical appraisal revealed that most studies provided clear statements of the methods and processes employed for qualitative research rigor and value. However, discussions of the role of the researcher, reflexivity, and ethical considerations involving informed consent or confidentiality were either insufficient or absent in most studies. Detailed information on the included studies is shown in Table 1 and Table A2.

### **Findings from the thematic synthesis**

Analysis of studies was organized and presented around two analytical themes – namely, (i) spiritual suffering following stillbirth, and (ii) moving through spirituality to adapt to the loss – and eight descriptive themes, which are illustrated in Figure 2. The distribution of included studies by analytical and descriptive themes is shown in Table A3.



**Table 1.** Characteristics of primary qualitative studies ( $n = 21$ ).

Location (Author, year)	Purpose	Methods	Sample
Iran (Allahdadian et al., 2015)	Explore social support to aid mothers in adaptation after the experience of stillbirth	Purposive sampling; interview; content analysis	$n = 15$ women; Age range = <30-40; Gestational age = 22-37; Time since loss = >3 months
Blog "Glow in the Woods" (Bakker and Paris, 2013)	Examine the impact of stillbirth and neonatal death on parental religiosity	Purposive sampling; manifest content of blog posts, Susan Herring's web content analysis paradigm	$n = 142$ women + 6 men; Age range = 20-40; Time since loss = 2 weeks to 12 years; Religion = 40% Christians, 16% nonreligious, 5% Jews, 4% atheists, 2% Neo-pagans, 1% Hindus, <1% Buddhist, <1% Mormon, <1% Muslim, <1% Unitarian Universalist
South Africa (Corbet-Owen and Kruger, 2001)	Determine (a) the meaning that pregnancy loss had for them and (b) what their emotional needs were after their loss(es)	Purposive sampling; interviews; constructionist Grounded theory techniques	$n = 8$ women; Age range = 18-33; 75% Religious
United Kingdom (Downe et al., 2013)	Obtain the views of bereaved parents about their interactions with healthcare staff when their baby died just before or during Labor	Purposive sampling; in-depth interview; technique of constant comparative analysis from Grounded theory	$n = 22$ women + 3 men; Age range = 18-42; Gestational age = 24-42 weeks; 68% First pregnancy; Religion = 64% Christian, 23% non religion, 14% other
Israel (Golan and Leichtentritt, 2016)	Examine the meaning itself that women who experienced stillbirth attribute to their loss and to the lost figure	Snowball sampling; in-depth interviews; phenomenological method	$n = 10$ women; Age range = 20-30; Gestational age = >23 weeks; Time since loss = 1-9 years; 50% First pregnancy; Religion = Secular and Jewish
Israel (Hamama-Raz et al., 2014)	Describe and analyze the meaning ascribed to coping with stillbirth among ultraorthodox Jewish women	Purposive sample; semi-structured interview; thematic content analysis, influenced by the phenomenological-hermeneutic tradition	$n = 10$ women; Age range = 26-55; Time since loss = 7 months to 13 years; 100% First pregnancy; Religion = Ultraorthodox denominations
Taiwan (Hsu et al., 2002)	Explore (a) the experiences of Taiwanese mothers of stillborn babies, their coping strategies, and (b) the ways in which their subsequent human interactions are shaped by Taiwanese culture	Field notes, interview, and participant observation; ethnographic analysis: themes identification and analysis of the sociocultural context	$n = 20$ women; Age range = 22-40; Gestational age = 27-42 weeks; Time since loss = 12 months; 30% First pregnancy
Taiwan (Hsu et al., 2004)	Explore the interpretation that Taiwanese mothers commonly attribute to stillbirth	Purposive sample; field notes and interviews; ethnographic analysis: themes identification and analysis of the sociocultural context	$n = 20$ women; Taiwan; Age range = 22-40; Gestational age = 27-42 weeks; Time since loss = 12 months; 30% First pregnancy
Australia (Lee, 2012)	Describe Australian women's experience of late pregnancy loss, with a particular emphasis on their experiences with the health care system	Online open-ended survey; Thematic analysis	$n = 14$ women; Age range = 23-30; Gestational age = 20-37 weeks; Time since loss = 3-4 months
Sweden (Lindgren et al., 2014)	Investigate mothers' experiences of saying farewell to the baby when leaving the hospital	Semi-structured in-depth interviews; Content analysis	$n = 23$ women; Age range = 22-41; Time since loss = 5 weeks to 6 years
Northern Ireland (McCreight, 2008)	Explore how women emotionally responded to loss and the care they received from medical staff	In-depth interviews and field notes; narrative analysis	$n = 23$ women; Age range = 19-60; Time since loss = 2 weeks to 34 years
Sweden (Nordlund et al., 2012)	Explore the lived experiences of mothers following the death of a baby and their interaction with healthcare professionals	Web-based survey; Content analysis	$n = 84$ women; Gestational age = >22 weeks
Ireland (Nuzum, Meaney, O'Donoghue, and Jackson, 2017)	Explore the spiritual and pastoral needs of bereaved parents following stillbirth and what their experiences of care were	Purposive sample; Semi-structured interview; Interpretative phenomenological analysis	$n = 12$ women + 5 men
Somaliland (Osman et al., 2017)	Describe the experiences of Muslim Somali mothers who have lost their babies at birth	Interview; Giorgi's phenomenological approach	$n = 10$ women; Age range = 17-43; Gestational age = $\geq 28$ weeks; Time since loss < 6 months; 50% First Pregnancy; Religion = Muslim
Sweden (Säflund et al., 2004)	Focus on caregivers' support in the event of a stillbirth, as revealed by parents' experiences	Convenience sample; semi-structured interview; content analysis	$n = 31$ women + 24 men; Women age range = 22-42; Gestational age $\geq 28$ weeks; Time since loss = 4-6 years; 58% First Pregnancy

(Continued)

Table 1. Continued.

Location (Author, year)	Purpose	Methods	Sample
Sweden (Samuelsson et al., 2001)	Describe how fathers experienced the intrauterine death of their child	Interview; phenomenological analysis	$n = 11$ men; Age range = 31–46; Gestational age = 32–42 weeks; Time since loss = 5–27 months
Brazil (Santos et al., 2004)	Comprehend the women's perceptions within their real circumstances of having gone through the problem of losing their babies	Interviews; content analysis	$n = 7$ women; Age range = 17–38; Time since loss = 4–13 weeks
Malaysia (Sutan and Miskam, 2012)	Explore the psychosocial experience and support following perinatal loss	Purposive sampling; In-depth interview, field note and focus group; exploratory and descriptive analysis	$n = 16$ women; Age range = 23–37; Time since loss = 1 week to 12 months; Religion = Muslim
Taiwan (Tseng et al., 2014)	Describe the process of Taiwanese women's recovery from stillbirth	Purposive sampling; in-depth interview; inductive analytic, to capture patterns and generate interpretive descriptions	$n = 21$ women; Age range = 23–43; Gestational age = 20–37 weeks; Time since loss = 6 months to 6 years; 48% First pregnancy; Religion = 38% Taiwanese folk beliefs, 19% Buddhism, 14% Taoism, 10% Christianity, 10% I-Kuan Tao
Taiwan (Tseng et al., 2017)	Explore the meaning of rituals that women and their families perform after a stillbirth	Purposive sampling; in-depth interview; content analysis	$n = 17$ women; Age range = 24–41; Gestational age = 20–36 weeks; Time since loss = 7–55 months; 44% First Pregnancy; Religion = 38% Taiwanese folk beliefs, 31% Buddhism, 13% Taoism, 13% I-Kuan Tao beliefs, 6% Christianity
Japan (Yamazaki, 2010)	Describe the meaning of fetal death in the lives of Japanese women in a local community	Theoretical sampling; in-depth semi-structured interviews; technique of constant comparative analysis from Grounded theory	$n = 17$ women; Age range = 28–38; Gestational age $\geq 28$ weeks; Time since loss = 1–6 years; 59% First Pregnancy

### **Analytical theme 1: Spiritual suffering following stillbirth**

Parents' spiritual suffering following stillbirth is characterized by conflicting expressions of hope and lack of hope, attempts to deal with profound questions and lack of meaning, experiences of spiritual struggle, and a sense of disconnect from the self and the surrounding world.

#### **Conflicting expressions of hope and lack of hope.**

Parents struggled with a sense of conflictual hope when they tried to cling on to hopes that the baby was still alive or would survive until birth, even in the face of clinical evidence or the announcement of the diagnosis (Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Samuelsson, Rådestad, & Segesten, 2001). The hope for a miracle until the moment of birth led parents to have greater involvement with religious practices during pregnancy and to seek complementary and alternative practices (Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Sutan and Miskam, 2012).

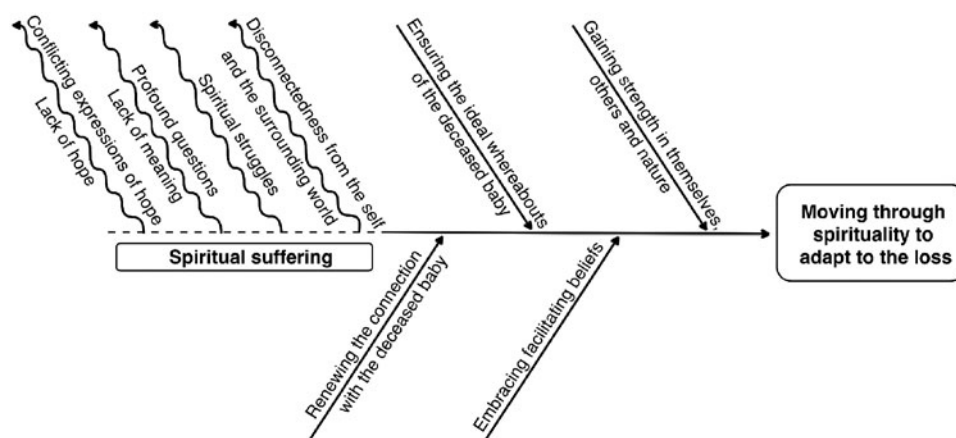
However, the final confirmation of the death at birth resulted in a pronounced feeling of hopelessness and loss of joy, parenthood, future plans and the breaking of the bond built during pregnancy (Bakker

and Paris, 2013; Downe, Schmidt, Kingdon, & Heazell, 2013; Golan and Leichtenritt, 2016; Hsu, Tseng, Banks, & kuo, 2004; Lee, 2012; Lindgren, Malm, & Rådestad, 2014; Samuelsson et al., 2001; Tseng, Hsu, & Hsieh, 2017). Hopelessness was fueled by feelings of guilt and failure (Corbet-Owen and Kruger, 2001; Samuelsson et al., 2001). The loss arose in them feelings of emptiness, grief, devastation, fear, anger, difficulty in accepting the loss, pessimism about subsequent pregnancies, desire to die, and mental vulnerability (Allahdadian, Irajpour, Kazemi, & Kheirabadi, 2015; Osman, Egal, & Kiruja, 2017; Santos, Rosenburg, & Buralli, 2004).

#### **Dealing with profound questions and lack of meaning.**

Parents demonstrated a strong desire to seek to understand why their baby had an anomaly or died. They struggled in many ways with existential and unanswerable questions, such as "Why did this happen to our baby, or to us?" (Corbet-Owen and Kruger, 2001; McCreight, 2008; Nuzum, Meaney, O'Donoghue, and Jackson, 2017). Searching for meaning was an active and distressing pursuit involving belief systems, worldview, and events that occurred during pregnancy for an explanation or cause of loss (Hamama-Raz, Hartman, & Buchbinder, 2014; Hsu,





**Figure 2.** Spirituality and its relation to parental coping following stillbirth.

Tseng, & Kuo, 2002; Hsu et al., 2004; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Osman et al., 2017; Samuelsson et al., 2001). The absence of identifiable reasons contributed to suffering, and the lack of meaning in their lives and the baby's life (Allahdadian et al., 2015; Bakker and Paris, 2013). Furthermore, other questions accompanied by conflict and doubt were related to the meaning attributed to the lost baby and their reaction to the loss (Golan and Leichtentritt, 2016), as well as to what happened to their baby after death, such as the whereabouts and well-being of the deceased baby (Bakker and Paris, 2013; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Tseng, Chen, & Wang, 2014).

**Experiencing spiritual struggles.** Many parents questioned their religious values and transcendent reality (or deity) in the quest for meaning and purpose behind the stillbirth. This process led to spiritual struggles involving God or higher power(s) and the religious community, characterized by a crisis of faith due to a sense of punishment, injustice, betrayal, unfairness, or abandonment of God (Bakker and Paris, 2013; Corbet-Owen and Kruger, 2001; Hsu et al., 2004; Nuzum, Meaney, O'Donoghue, and Jackson, 2017). The impairment in a sense of trust and belief in a caring divine figure resulted in feelings of anger towards God, a confusing sense of dependence on God, religious disorientation, change in practice and religious identity, loss of faith, and weakening or severing of relationship with God and religious community (Bakker and Paris, 2013; Hsu et al., 2004; Nuzum, Meaney, O'Donoghue, and Jackson, 2017).

Negative experiences of, or as members of, religious communities caused by the community's lack of ability to offer support, or the exclusion of unbaptized babies from religious rites and burial decreased the

engagement with religious institutions (Bakker and Paris, 2013; Hsu et al., 2004; Nuzum, Meaney, O'Donoghue, and Jackson, 2017). Moreover, religious issues hindering the induction of labor in hospital (Lee, 2012) and beliefs preventing seeing and/or touching the baby or participating in funeral practices for the dead baby widespread in many cultures and religious traditions (e.g. Muslim, Buddhism, Taiwanese folklore) were often questioned and sources of continuing distress (Lee, 2012; Osman et al., 2017; Tseng et al., 2014).

**Disconnectedness from the self and the surrounding world.** Stillbirth resulted in the sense of loss or disconnection with the self as a consequence of parental identity affected by feelings of guilt, religious crisis, and powerlessness to return to the prior (i.e. pre-loss) sense of self. Parents often believed that they had neglected the pregnancy and were responsible for the loss of the baby (Hsu et al., 2004; McCreight, 2008; Osman et al., 2017; Säflund, Sjögren, & Segesten, 2004; Sutan and Miskam, 2012; Tseng et al., 2014, 2017). These feelings of guilt and failure were often exacerbated by the absence of a medical explanation for the loss of the baby (Allahdadian et al., 2015; McCreight, 2008), and by a cultural context that strongly emphasizes family continuity (Corbet-Owen and Kruger, 2001; Hsu et al., 2002; Osman et al., 2017). Perceiving pregnancy loss as failures as a mother, wife, and/or daughter-in-law affected the women's identity (Corbet-Owen and Kruger, 2001; Hsu et al., 2002; Osman et al., 2017). The disconnection with self was also characterized by a profound sense of lack of self-knowledge, and feelings of personal incapacity to function effectively in life after the loss, on a social, professional and/or mental level; it also jeopardized the trust they had in themselves, in

others, and in a divine figure (Allahdadian et al., 2015; Bakker and Paris, 2013; Downe et al., 2013; Hsu et al., 2004; Samuelsson et al., 2001).

Parents also experienced a disconnection from the outside world and a deep sense of loneliness when health professionals, their spouse, relatives, and acquaintances did not acknowledge their feelings of loss, their identity as parents, or the baby's existence (Corbet-Owen and Kruger, 2001; Golan and Leichtenritt, 2016; Lee, 2012; McCreight, 2008; Nordlund et al., 2012; Samuelsson et al., 2001; Tseng et al., 2014, 2017). Hostility from their relatives or partner, the inability of health professionals to respond to their needs (including, importantly, their spiritual needs), fear of judgment by and questions of others, and cultural taboos against talking about death were also aspects which contributed to social isolation, feelings of abandonment, and lack of support in the grieving process (Nordlund et al., 2012; Osman et al., 2017; Tseng et al., 2014).

### ***Analytical theme 2: Moving through spirituality to adapt to the loss***

Parents adapt to their loss through spirituality by renewing the connection with the deceased baby, ensuring the ideal whereabouts of the deceased baby, embracing facilitating beliefs, and gaining strength in themselves, others, and nature.

#### ***Renewing the connection with the deceased baby.***

The parents sought to connect with and integrate the deceased baby in their lives, in both material and non-material dimensions, often through rituals associated with their cultural and religious traditions which influenced their bonding with the baby (Hsu et al., 2004; McCreight, 2008; Osman et al., 2017; Sutan & Miskam, 2012; Tseng et al., 2014). Thus, experiences of labor, bonding rituals with the deceased baby at the time of birth (e.g. dressing, bathing, holding their baby, etc.), physical mementos (e.g. photographs and clothes) and memorials (e.g. grave, altar, urn for the ashes) were valuable in the creation of precious memories and meaning (Downe et al., 2013; Lee, 2012; Lindgren et al., 2014; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Samuelsson et al., 2001; Santos et al., 2004). Moreover, mystical or mediumistic sense-of-presence experiences of contact with the deceased baby and occasions that mark moments in the calendar year (e.g. Dia de los Muertos, etc.) were of continuing comfort to parents as a form of ongoing connection with their baby (Bakker and Paris, 2013; Corbet-Owen and Kruger, 2001; Nuzum, Meaney,

O'Donoghue, and Jackson, 2017; Tseng et al., 2017; Yamazaki, 2010).

#### ***Ensuring the ideal whereabouts of the deceased baby.***

Parents were concerned to ensure an ideal destination for the deceased baby's spirit after the burial or cremation. The ideal destination was described as someplace safe, particularly associated with a sense of the after-life or reincarnation from religious traditions (e.g. in a good place, in the presence of divinity, in heaven, with other loved ones, reincarnated in a better family or rebirth in their own family again) (Bakker and Paris, 2013; Tseng et al., 2014, 2017; Yamazaki, 2010). Thus, parents dutifully engaged in religious rituals (e.g. naming ceremony, transformation, blessing, baptism, and prayer service) at the church/temple, hospital, or their home which often began before the induction of labor and continued in subsequent pregnancies. Besides ensuring the ideal whereabouts and well-being of the stillborn baby, these ceremonies helped parents to attribute spiritual significance and value to their baby's life, to feel peace of mind, hope and faith, as well as to express their grief, to alleviate guilt, to confront the reality of physical separation, and to say goodbye (Hsu et al., 2002; Lee, 2012; McCreight, 2008; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Tseng et al., 2014, 2017).

#### ***Embracing facilitating beliefs.***

Parents embraced constructive and meaningful beliefs and practices to facilitate the acceptance of the loss and move on (Golan and Leichtenritt, 2016; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Santos et al., 2004). Religion was an important source of meaning when parents believed in the divine action as part of a benevolent plan which, though painful, had the purpose of protection, spiritual growth, and blessing (Bakker and Paris, 2013; Hamama-Raz et al., 2014; Hsu et al., 2002; Osman et al., 2017). Parents reported profound spiritual experiences, feelings of gratitude to God or a Higher power, and a special or unchanged closeness to God in seeking support, comfort and forgiveness from religious practice (Osman et al., 2017; Santos et al., 2004; Tseng et al., 2014, 2017). Other meaningful beliefs included the beliefs that the baby's life had a greater purpose, that he/she was not suitable for or did not belong to their family, that the parenthood was a gift for which they had been chosen, that the painful event was a lesson to recognize the unpredictability of life or serve as an impetus for personal growth, maturation, and change in terms of attitude and appreciation for life (Corbet-Owen and Kruger,

2001; Downe et al., 2013; Hsu et al., 2004; Lee, 2012; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Samuelsson et al., 2001; Santos et al., 2004; Yamazaki, 2010).

### ***Gaining strength in themselves, others, and nature.***

Establishing meaningful and positive connections with themselves, others, and nature after stillbirth was an important way for parents to express meaning and purpose in life. The mutual support from each other and from relatives, friends, and fellow workers helped them to reduce their feeling of guilt, to openly express their grief, to be comforted, and, ultimately, to slowly recover (Allahdadian et al., 2015; Hsu et al., 2002; Osman et al., 2017; Säflund et al., 2004; Samuelsson et al., 2001; Sutan and Miskam, 2012; Tseng et al., 2014; Yamazaki, 2010). They also found comfort and hope through relationships with individuals and support groups of individuals who had the same experience (Allahdadian et al., 2015; Bakker and Paris, 2013; Corbet-Owen and Kruger, 2001; Yamazaki, 2010). The hospital staff, mainly within chaplaincy services and counseling support, were sources of spiritual comfort and helped provide access to a degree of joy and pride (Bakker and Paris, 2013; Downe et al., 2013; Lee, 2012; Nuzum, Meaney, O'Donoghue, and Jackson, 2017; Samuelsson et al., 2001).

The parents gathered qualities of personal strength such as love, optimism, and forgiveness (Yamazaki, 2010), and sought new purposes in life through caring for other children, in their professional life, in future projects, and through subsequent pregnancies that provided spiritual sustenance (Downe et al., 2013; Hsu et al., 2002; Samuelsson et al., 2001; Tseng et al., 2014). Spiritual practices described as especially helpful were meditation or being in nature (Bakker and Paris, 2013).

## **Discussion**

This meta-synthesis synthesized the experience of the spirituality of bereaved parents of stillborn infants and its relation to their adjustment following a stillbirth. Results from the review provide evidence of the parents' spiritual suffering following stillbirth and the aspects of the spirituality that facilitate the process of coping. These results are consistent with other spirituality reviews in the context of loss as they also identified spiritual struggles, spiritual beliefs and practices, and the relationships as sources of support and comfort after bereavement (Wortmann and Park, 2009), as well as the positive relationship of religion/spirituality

with adjustment to loss (Allahdadian and Irajpour, 2015; Becker et al., 2007; Wortmann and Park, 2008).

Our results are also consistent with other reviews on the psychosocial impact of stillbirth in identifying a change in spirituality as a means of recovery (Ogwulu et al., 2015), and the practice of religious activities and rituals as a way to alleviate suffering and facilitate acceptance of the loss (Burden et al., 2016; Cheer, 2016; Heazell et al., 2016). This meta-synthesis also extends the results of previous reviews by considering religion/spirituality in the context of stillbirth and identifying the nature of the spiritual suffering as a dimension of life impacted by the loss.

Parents' spiritual suffering in this review shows the negative spiritual impact of stillbirth, which is marked by conflict and lack of hope, difficult existential questions, lack of meaning, spiritual struggle, and a sense of disconnection from self and the surrounding world. Stillbirth experience shook parents' core beliefs about the self, the world, or a Superior Being, leading the parents to experience an inability to find meaning and purpose in life after the loss. A review of the literature supported these findings in identifying the grief experience as posing a risk of spiritual crisis through profound questioning of, or lack of meaning in, life (Agrimson & Taft, 2009). Moreover, our findings are in accordance with the definition of spiritual distress reported as "a state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being" (Caldeira, Carvalho, & Vieira, 2013, p. 82).

The lack of social recognition of parental grieving after stillbirth, the inadequacy of support, the lack of awareness of risk factors and causes of stillbirth exacerbate feelings of guilt, sense of failure, social isolation, and hopelessness and then contribute to parents' spiritual suffering experience. These findings confirm that of other studies which showed that when grief is unrecognized by the social network, including health professionals, parents' sense of identity and approach to life and death might change (Heazell et al., 2016; Lawn et al., 2016; Nuzum et al., 2018; Pollock et al., 2019).

Spiritual suffering may imply a negative effect on the resolution of grief. Inability to find meaning in the death as evidenced in this review has been linked to the development of CG, also termed "prolonged grief disorder" (Christian et al., 2018; Prigerson et al., 2009). Inability to make sense of death emerged as the most salient predictor of grief severity (Lobb et al., 2010). CSG, which is of a form of maladaptive bereavement related to a crisis of faith following the

loss, was also found in this review (Burke, Neimeyer, Holland, et al., 2014). CSG has been strongly linked to CG, and it refers to the collapse or erosion of the griever's sense of relationship to God and the faith community, notably with the spiritual struggle to find meaning in loss (Burke and Neimeyer, 2014).

Although our findings show that spirituality may be affected by stillbirth, it also may be a significant resource in dealing with the loss. Our results bring to light the complex dichotomy in the influence of spirituality in grief, which presents itself as a paradox experienced by parents between spiritual suffering and spiritual strategies that help the process of coping. The complexity of the grieving process reflects the holism and multidimensionality of the spiritual path which cannot be simplistically categorized as positive or negative (Klaassen, Young, & James, 2015). Spirituality may also be the path to a person's healing, wherein they find inner peace, solace, and meaning which may or may not be related to religion (Tanyi, 2002).

Our review also allows for a fuller understanding and conceptualization of spirituality, including its different aspects, such as religious and existential ones, which parents use to find or create meaning and purpose in their lives and the baby's life. The parents experience and integrate beliefs, practices, rituals, and deep connections with the deceased baby, deity, family, friends, nature, and other parents experiencing or who have experienced a stillbirth. These aspects show how spirituality is a relational and transcendental process, involving a search for meaning and beliefs influenced by culture and religion (Sadat Hoseini, Razaghi, Khosro Panah, & Dehghan Nayeri, 2019). A study with parents who have experienced the death of a teenager described their grief intimately connected to their spiritual lives, which shaped continuing bonds, religious practices, and relationships (Klaassen et al., 2015). Other studies also reported the search to maintain bonds with the deceased and the influence of the religious and social context on grief (Howarth, 2000; Walter, Hourizi, Moncur, & Pitsillides, 2012).

Finally, according to the results of this review, parents connect with and integrate the deceased baby in their lives in different ways to adapt to loss. Previous research has shown that rituals surrounding symbolic and spiritual connections with the deceased have positive implications for the acceptance of grief (Lewis and Hoy, 2011). Rituals have been found to act on three different levels: the psychic, the institutional, and the cultural (Zeghiche, *in press*). On the level of the psyche, they allow for one to distinguish the

bodies (that of the mother and that of the baby) and the time frames (that of death and that of birth) involved in the event, and to formulate words, speech, gestures on an event that was unspeakable and unthinkable (Soubieux, 2013), and therefore to allow the process of grieving to unfold. On the institutional level, rituals create a transitional space that links the medical and the social, the personal and the professional, the individual and the collective, and therefore reintroduce continuity where rupture took place (Fellous, 2006; Soubieux, 2013). Finally, on the cultural level, rituals help ensure social cohesion after a disruptive event such as stillbirth (Bacqué and Merg-Essadi, 2013) and to make the departed "close ones from afar" (Le Grand-Sébille, 2004), and therefore to allow for the discovery of a collective meaning behind an otherwise private event.

### **Strengths and limitations**

We know the challenges of studying spirituality, which is a rich, complex, and elusive phenomenon – likewise, we recognize the difficulties of defining it with a multiplicity and diversity of terms, which is a reflection of the richness of religious and spiritual life (Pargament, Mahoney, & Exline, 2013). Furthermore, spirituality may overlap with or elicit the expression of other constructs (Steinhauser et al., 2017). Thus, our review was placed under a conceptual umbrella of spirituality based on the literature and clinical care so as to be broad and inclusive of the many relationships and aspects of spirituality that can be found in different cultures and societies (Puchalski et al., 2014; Weathers et al., 2016).

The main strength of this review is that it is the first qualitative synthesis on the experience of the spirituality of the bereaved parents and its relation to parents' coping following a stillbirth. A second strength is the strategies used to enhance the validity of research findings throughout data collection, sampling, triangulation, and reflexivity (Finfgeld-Connett, 2018): (i) the literature on the topic was systematically explored throughout search strategy; (ii) expert researchers with differing backgrounds worked together in all steps of the review, which included a sample of multiple studies (multiple theoretical and methodological frameworks) to maximize triangulation; (iii) researchers continually reflected on the data (coding structure, interpretation of data, and themes); (iv) the quality of qualitative studies included was evaluated; and (v) the findings were compared to the existing literature.



Despite the inclusion of studies from different geographic regions, cultures, and religions, this meta-synthesis has limitations. The majority of the included studies did not report enough detail on the religious affiliations of the participants to allow for an exploration of the influence of the character of the belief system on each review finding. They also did not explicitly report the duration of feelings or spiritual experiences of suffering on the course of the grief process, although aspects of spiritual suffering seem to be related to periods close to the death of the loved one. In addition, the predominant sample of women may have influenced the review findings and it was not possible to explore gender differences of spiritual suffering and coping.

### **Implications for practice and research**

This study has important implications for maternity care providers and policymakers. The impact of stillbirth on spirituality is evidenced in this meta-synthesis. These results corroborate those of others reviews which showed the extensive psychological, social, and financial impact of stillbirth on parents (Burden et al., 2016; Heazell et al., 2016; Lawn et al., 2016). As such, stillbirth must be acknowledged as an important global health problem for which it is important to take actions in order to improve bereavement care. To promote contextual, respectful, and supportive care, which includes bereavement care after death, is among worldwide goals of professionals who aim to reduce preventable stillbirths and to improve health and developmental outcomes (Lawn et al., 2016). Our findings demonstrate the need to promote culturally and spiritually sensitive care to bereaved parents.

Multiple practice strategies can be performed to integrate the spiritual support in bereavement care. To demonstrate this, clinicians may perform compassionate care for parents to help them find consolation; for instance, through confirmation of their reactions, giving them time to self-adjust, and offering information and support to help them make decisions about the child's birth. Importantly, they can mobilize spiritual resources to assist parents to find meaning, hope and strength in the grief process, by, for example, facilitating the expression of love, good memories, and connections with the baby as well as promoting social support, respecting religious beliefs and folk customs, and supporting their attendance of rituals or ceremonies helpful to them. Notably, discussing spiritual needs as part of care, counseling support, and chaplaincy services for parents who wish to receive it are key aspects for relieving spiritual suffering in the grief process.

There is a need for more primary research concerning the phenomenon of religion/spirituality to be conducted on parents experiencing stillbirth. The area is still sparsely researched, considering the number of qualitative studies with the primary aim towards spirituality identified in this review. Suggestions for future studies would be to include fathers (Bonnette and Broom, 2012; de Montigny et al., 2017; Riggs et al., 2018) and to consider different religious traditions and beliefs on stillbirth bereavement in various societies. Moreover, studies regarding spiritual suffering can increase the understanding of risk factors and their influence on the course and severity of grief.

### **Conclusion**

This meta-synthesis has shown that stillbirth has a profound spiritual impact on parents. Spiritual resources that can facilitate or hamper parents' coping to the child's loss were identified. Spiritual resources utilized by parents in the grieving process helped them to find meaning, hope, and strength through ongoing connection to deceased baby; meaningful beliefs and practices; and connections to themselves, the divine, others, and nature. Finally, this study has offered practical recommendations for future research and for enhancing clinical practice through the promotion of culturally and spiritually sensitive care, which takes into account the parents' beliefs, folk customs, religion, values, and spiritual needs.


### **Note**

1. Although qualitative research of blogs is still emergent, blogs are naturalistic data in textual form built within cyberspace (Hookway, 2008).

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## Appendices

**Table A1.** Search strategy.

Elements of SPIDER		Search terms*
Sample	#1	"Family"[Mesh] OR (Families) OR (Relatives) OR (Extended Family) OR (Extended Families) OR (Families, Extended) OR (Family, Extended) OR (Family Research) OR (Research, Family) OR "Parents"[Mesh] OR (Parent) OR (Step-Parents) OR (Step Parents) OR (Step-Parent) OR (Stepparent) OR (Stepparents) OR "Mothers"[Mesh] OR (Mother) OR "Fathers"[Mesh] OR (Father) OR "Grandparents"[Mesh] OR (Grandparent) OR (Grandmother) OR (Grandmothers) OR (Grandfather) OR (Grandfathers) OR "Siblings"[Mesh] OR (Sibling) OR (Sisters) OR (Sister) OR (Brothers) OR (Brother) OR "Spouses"[Mesh] OR (Spouse) OR (Husbands) OR (Husband) OR (Wives) OR (Wife) OR (Couple)
	#2	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR (Death, Fetal) OR (Deaths, Fetal) OR (Fetal Deaths) OR (Intrauterine death) OR (Intra-uterine death) OR (in utero death) OR (fetal loss) OR "Perinatal Death"[Mesh] OR (Death, Perinatal) OR (Deaths, Perinatal) OR (Perinatal Deaths) OR (Neonatal Death) OR (Death, Neonatal) OR (Deaths, Neonatal) OR (Neonatal Deaths) OR "Embryo Loss"[Mesh] OR (Embryo Death) OR (Death, Embryo) OR (Embryo Deaths) OR (perinatal mortality) OR (Perinatal Loss) OR (Neonatal Death) OR (Death, Neonatal) OR (Deaths, Neonatal) OR (Neonatal Deaths) OR (Perinatal bereavement) OR (perinatal grief) OR (Pregnancy loss) OR "Abortion, Spontaneous"[Mesh] OR (Abortions, Spontaneous) OR (Spontaneous Abortions) OR (Spontaneous Abortion) OR (Early Pregnancy Loss) OR (Early Pregnancy Losses) OR (Pregnancy Loss, Early) OR (Pregnancy Losses, Early) OR (Miscarriage) OR (Miscarriages)
	#3	#1 AND #2
Phenomenon of Interest	#4	"Spirituality"[Mesh] OR "Religion"[Mesh] OR (religiousness) OR (beliefs) OR (spiritual care) OR (Religiosity) OR (Religious coping) OR (Religions) OR (Religious Beliefs) OR (Beliefs, Religious) OR (Religious Belief) OR "Faith Healing"[Mesh] OR (Healing, Faith) OR (Prayer Healing) OR (Healing, Prayer) OR (Faith)
Design	#5	"Focus Groups"[Mesh] OR (Focus Group) OR (Group, Focus) OR "Anthropology, Medical"[Mesh] OR (Medical Anthropology) OR "Grounded Theory"[Mesh] OR (Theory, Grounded) OR (Culture) OR (Thematic synthesis) OR "Hermeneutics"[Mesh] OR (Hermeneutic) OR (Ethnographic) OR (ethnographic research) OR (Phenomenology) OR (phenomenological research) OR (Narrative) OR "Interviews as Topic"[Mesh] OR (Interviewers) OR (Interviewer) OR (Interviewees) OR (Group Interviews) OR (Group Interview) OR (Interview, Group) OR (Interviews, Group) OR (in-depth interview) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation	#6	(Experience) OR (Experiences) OR (Feeling) OR (Feelings) OR (Meaning) OR (Meanings) OR "Life Change Events"[Mesh] OR (Event, Life Change) OR (Events, Life Change) OR (Life Change Event) OR (Life Experiences) OR (Experience, Life) OR (Experiences, Life) OR (Life Experience) OR (perspective) OR (perspectives) OR (Subjectivities) OR "Behavior"[Mesh] OR (Behaviors) OR (Acceptance Processes) OR (acceptance Process) OR (Process, Acceptance) OR (Processes, Acceptance)
Research type	#7	"Qualitative Research"[Mesh] OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR "Empirical Research"[Mesh] OR (Research, Empirical)
		#3 AND #4 AND #5 AND #6 AND #7

(\*)Search Strategy used in Pubmed (Medline) and adapted to the other databases, according to their specificities.

**Table A2.** Quality appraisal of included studies using the Critical Appraisal Skills Program Qualitative Research Checklist (Critical Appraisal Skills Programme, 2018).

(Author, year)	Items									
	1	2	3	4	5	6	7	8	9	10
(Allahdadian et al., 2015)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Bakker and Paris, 2013)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Corbet-Owen and Kruger, 2001)	✓	✓	✓	✓	✓	X	X	✓	✓	✓
(Downe et al., 2013)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Golan and Leichtenritt, 2016)	✓	✓	✓	✓	✓	X	X	✓	✓	✓
(Hamama-Raz et al., 2014)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Hsu et al., 2002)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
(Hsu et al., 2004)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Lee, 2012)	✓	✓	✓	✓	X	X	X	✓	✓	✓
(Lindgren et al., 2014)	✓	✓	✓	✓	✓	X	X	✓	✓	✓
(McCreight, 2008)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
(Nordlund et al., 2012)	✓	✓	✓	✓	✓	X	X	✓	✓	✓
(Nuzum, Meaney, O'Donoghue, and Jackson, 2017)	✓	✓	✓	✓	✓	X	X	✓	✓	✓
(Osman et al., 2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
(Säflund et al., 2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
(Samuelsson et al., 2001)	✓	✓	✓	X	✓	X	X	✓	✓	✓
(Santos et al., 2004)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Sutan and Miskam, 2012)	✓	✓	✓	✓	X	✓	✓	X	✓	✓
(Tseng et al., 2014)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Tseng et al., 2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
(Yamazaki, 2010)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓

Note: ✓ – Yes; X – Can't Tell or No.

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Were the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

