Termination of Pregnancy for Fetal Anomaly: A Systematic Review of the Healthcare Experiences and Needs of Parents

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Abstract

Background

Improved technology and advances in clinical testing have resulted in increased detection rates of congenital anomalies during pregnancy, resulting in more parents being confronted with the possibility of terminating a pregnancy for this reason. There is a large body of research on the psychological experience and impact of terminating a pregnancy for fetal anomaly. However, there remains a lack of evidence on the holistic healthcare experience of parents in this situation. To develop a comprehensive understanding of the healthcare experience and needs of parents, this systematic review sought to summarise and appraise the literature on parents' experiences following a termination of pregnancy for fetal anomaly.

Review Question:

What are the healthcare experiences and needs of parents who undergo a termination of pregnancy following an antenatal diagnosis of a fetal anomaly?

Methods

A systematic review was undertaken with searches completed across six multi-disciplinary electronic databases (Medline, Embase, PsycINFO, CINAHL, Web of Science, and Cochrane). Eligible records were qualitative, quantitative or mixed methods studies, published between January 2010 and August 2021, reporting the results of primary data on the healthcare experiences or healthcare needs in relation to termination of pregnancy for fetal anomaly for either or both parents. Findings were synthesised using Thematic Analysis.

Results

A total of 30 records were selected for inclusion in this review of which 24 were qualitative, five quantitative and one mixed-methods. Five overarching themes emerged from the synthesis of findings: (1) Context of Care, (2) Person-centred Care, (3) Compassionate Care, (4) Co-ordinated Care, and (5) Inclusive Care.

Conclusion

Compassionate healthcare professionals who provide non-judgemental and sensitive care can impact positively on parents' satisfaction with the care they receive. A well organised and co-ordinated healthcare system is needed to provide an effective and high-quality service.

Registration:

PROSPERO registration number: CRD42020175970

Introduction

Congenital anomalies are defined as structural or functional abnormalities that occur prior to birth (World Health Organization (WHO), 2020a), often resulting in high levels of morbidity and mortality (Lozano et al., 2012; Modell et al. 2012; Sitkin et al., 2015; WHO, 2020b). Improved technology and advances in clinical testing have resulted in increased detection rates of congenital anomalies during pregnancy (Boyd et al., 2008; Daum et al., 2019; Ganesamoorthy et al., 2013; Pan et al., 2018). This is mainly seen in high-income countries (HICs) where sufficient resources and equipment enables increased routine antenatal testing and screening by adequately trained health professionals (Bricker et al., 2015; Jiwani et al., 2020; Public Health England, 2013; Whitworth et al., 2015; WHO, 2016). However, while detection rates have improved, few in-utero treatments are available for major anomalies (Adzick et al., 2011; Fisher and Lafarge, 2015; Zwiers et al., 2018), leaving parents with limited options following diagnosis. They can continue with the pregnancy, or in the case of the detection of a fetal anomaly, they can request a Termination of Pregnancy (TOP) in the 113 (out of 199 (57%)) countries and territories around the world where it is legal to do so (Boyd et al., 2008; Maurice et al., 2019; Remez et al., 2020).

In countries where TOP is legal, there are often variations with the definition and clauses of what types of anomalies are included to be able to access a termination of pregnancy for fetal anomaly (TOPFA). For example, in the United Kingdom (UK) the law stipulates that where the anomaly represents a 'substantial risk' that the child who would be born would be 'seriously handicapped', would be accepted as grounds (Ground E) for a TOPFA (The Abortion Act 1967 (as amended in the Human Fertilisation and Embryology Act, 1990 (House of Commons, 1990)). Conversely, in the Republic of Ireland (in accordance with the Health (Regulation of Termination of Pregnancy) Act, 2018) two medical practitioners must be of the agreed opinion that the baby will die during pregnancy, labour or within twenty-eight days of birth for a TOPFA to be sanctioned (Institute of Obstetricians and Gynecologists, 2019). In the United States, access to TOP varies from State to State, due to differing government, healthcare provider and medical insurance restrictions (American College of Obstetrics and Gynecologists, 2020). Six States entirely prohibit TOPFA, while a further four require mandatory counselling on available perinatal hospice services before it can be performed (Guttmacher Institute, 2021). Worldwide, of the 86 countries and territories where TOPFA is prohibited, 81% are low- and middle-income countries (LMICs)(Remez et al., 2020).

Legal differences regarding the definition or threshold of congenital anomalies considered severe enough to access TOPFA, means that obtaining accurate data pertaining to TOPFA is challenging (Berer, 2017; Myers and Seif, 2010; Singh et al., 2017). European figures for TOPFA suggest a prevalence rate of 4.6 per 1,000 births (Boyle et al., 2018). In the UK, over 70% of congenital anomalies are detected during pregnancy, and, of those, around 37% will result in a TOPFA (Public Health England, 2020). Government figures for England and Wales reported that, in 2019, 3,183 TOPFAs were carried out, in the context of 640,370 livebirths and 2,522 stillbirths in the same year (Department of Health and Social Care, 2020; Office for National Statistics, 2020). However, groups working in this area of healthcare, such as the British Pregnancy Advisory Service (BPAS) and Antenatal Results and Choices suggest that actual rates of TOPFA are much higher (BPAS, 2015). A possible reason for the disparity in figures could be that in the UK if a TOP is carried out under 24 weeks it could be

recorded under Ground C of the Abortion Act (the risk to a woman's physical or mental health is greater than if she continued the pregnancy) (House of Commons, 1990). Figures from 2019 state 98% of all abortions in England and Wales were performed under Ground C (Department of Health and Social Care, 2020).

Existing reviews have explored the psychological experience and impact of TOPFA (Deas, 2017; Statham et al., 2000; Statham, 2002; Steinberg, 2011; Sullivan and De Faoite, 2017; Wool, 2011) yet limited consideration of the holistic healthcare experience of parents. One exception is Lafarge et al.'s (2014), study which offers a more holistic view and interpretation of the experience of TOPFA via a meta-ethnography of women's experiences. This study was not, however, specifically focused on healthcare experiences and did not include partners, an issue that is seen across the field of perinatal loss (Badenhorst et al., 2006; Due et al., 2017; McCreight, 2004; O'Leary and Thorwick, 2006). Another qualitative review explores the labour and birth experiences of women who have had a TOPFA (Jones et al., 2017) and while offering useful insights, is only one part of the overall healthcare experience. Another review of the needs of women who have experienced a TOPFA did report needs related to the healthcare system, however it did not use systematic review methodology (Kamranpour et al., 2018).

The dearth of research looking at the entire TOPFA healthcare experience, as well as from both parents' experience warrants further investigation. Thus, the overall aims of this literature review were to (a) synthesise findings from the international literature on the healthcare experiences and needs of parents who undergo a termination of pregnancy following an antenatal diagnosis of a fetal anomaly, (b) carry out a thematic analysis of the evidence, and (c) provide a comprehensive narrative synthesis, focusing on the views, experiences, feelings, opinions and needs of both parents.

Methods

This mixed-methods systematic review adhered to a PROSPERO pre-registered protocol (CRD42020175970) (Heaney et al., 2020). It was conducted using Covidence Systematic Review Software (2019), NVivo Version 12 for Windows (QSR International, 2018) and in accordance with PRISMA 2020 guidelines (Page et al. 2021).

Search Strategy And Sources

The search strategy was developed by reviewing and extracting search terms from existing relevant reviews (Jones et al., 2017; Lafarge et al., 2014) or published studies with a similar sample (Fisher and Lafarge, 2015; Hanschmidt et al., 2018a, b; Hyatt, 2019). A combination of Medical Subject Headings (MeSH) and keyword search terms were employed, following consultation with a search specialist. Search terms used were structured within the PICO framework (see Table 1) (Raich and Skelly, 2013).

Table 1
PICO Framework Search Terms

PICO Acronym	MeSH search terms	Additional search terms
Population	Parents, Parenting, Pregnant Women, Men, Postpartum Period, Peripartum Period, Women's Health, Men's Health, Maternal-Fetal Relations	Famil*, Parent*, Mother, Father, Wom?n, M?n, M?m, Dad, Maternal, Paternal, Pregnant Wom?n, Pregnant Person, Pregnant*
Intervention	Aborted Fetus, Abortion Applicants, Abortion, Eugenic, Abortion, Induced	Abortion, Termination, Fet?cide, Medical Abortion, Medical Miscarriage, Medical Termination, Induced Abortion, Termination of Pregnancy, TOP
Condition	Fetal Viability, Congenital Abnormalities, Congenital, Hereditary, and Neonatal Diseases and Abnormalities	F?etal Anomal*, Fatal F?etal Anomal*, Incompatible with life, Abnormality, Anomal* Scan, Life Limiting, Fatal Anomal*, Gene? Condition, Gene? Disorder, Congenital Anomal*, Congenital malformation, FA, FFA
Outcome		Experience*, Opinion*, View*, Need*, Health?, Healthcare, Health service, Support, Care, Access*, Travel*, Financ*, Cost, Stigma, Psychological outcome*, Physical outcome*, Patient satisfaction, Social support, Mental health, Family, Family relations, Family conflict, Maternal behavior?, Paternal behavior?, Life Change Events, Trauma?, Stress disorders, Life stress event\$.tw, Health?related quality of life.tw, Parent morbidity.tw, Satisfaction with care.tw

Six multi-disciplinary electronic databases (Medline, Embase, PsycINFO, CINAHL, Web of Science, and Cochrane) were searched on 23rd March 2020 with an updated search carried out on 6th August 2021 using the search terms in Table 1. Beyond the databases, lateral and manual searches were also conducted. The strategy for this included searches in: grey literature databases (Open Grey, BASE, GreyNet); clinical trial registers (Clinicaltrials.gov, ISRCTN Registry, NIHR UK, WHO ICTRP); web searches (Google, Google Scholar, Grey Literature Report, National Health Service (NHS) Evidence); dissertation/thesis searches (OATD International, ProQuest); and through examination of the reference lists of included studies. The lead author, SH carried out all searches.

Study Selection

Included studies were of qualitative, quantitative or mixed methods design, published between 1st January 2010 and 6th August 2021, reporting the results of primary data on the healthcare experiences or healthcare needs in relation to TOPFA for either or both parents. No limitation was set on the type of anomaly or

study location. Exclusion criteria included: studies not published in English; non-empirical studies, such as case reports, opinion pieces or reviews; and studies reporting experience of TOP for a reason other than fetal anomaly. Studies were also excluded if they only reported health professionals' or other family members' experiences of TOPFA. SH screened all records and AA independently screened a randomly selected 10% (n=9) of the full text records for eligibility.

Quality Appraisal

While acknowledging the lack of consensus relating to how, what (and perhaps if) qualitative research should be quality assessed (Hannes et al., 2010; Murphy et al., 1998; Spencer et al., 2003), we carried out quality assessment for the purposes of transparency (Thomas and Harden, 2008). The Mixed Methods Appraisal Tool (MMAT) Version 2018 (Hong et al., 2018) was used given its value for appraising the quality of a variety of study designs (Pluye et al., 2009). The quality of studies was evaluated primarily on the appropriateness of the study design and interpretation of the results substantiated by findings and data. As per the guidelines of the tool no overall score was calculated. In line with MMAT guidelines, two reviewers (SH and AA) were independently involved in the appraisal process (Hong et al., 2018). SH reviewed all of the included studies and AA quality assured a random sample (10%) of the records.

Data Extraction And Synthesis

Descriptive data were initially extracted by SH into the Covidence Systematic Review Software (2019), using a pre-designed data extraction form to collate and manage the information. AA cross-checked this information. The descriptive data extracted summarised the key characteristics of the selected studies and included: year of publication, the country where the research was conducted, study design, participants, data collection methods and analysis and study aims (see Table 2).

Table 2
Characteristics of Included Studies

Study	Country	Participants	Data Collection	Methodology	Study Aim
Asplin et al., 2014 1	Sweden	11 women	Semi-structured interviews	Qualitative Exploratory Descriptive Design Retrospective	The aim of the study was to explore what women who have had a pregnancy termination due to a detected fetal malformation perceive as being important in their encounters with caregivers for promoting their healthy adjustment and well-being.
Atienza-Carrasco et al., 2020 2	Spain	27 women	Nonparticipant observation Semi-structured interviews	Qualitative Phenomenological Approach Retrospective	To determine and describe the experiences of pregnant women who receive a diagnosis of chromosomopathy and/or foetal malformation during a prenatal check-up and who decide to legally terminate the pregnancy.
Carlsson et al., 2016 3	Sweden	112 women 1 man 9 not disclosed	Cross-sectional study of messages in virtual communities	Qualitative Content analysis Retrospective	To explore experiences described by posters in Swedish virtual communities before, during and after termination of pregnancy due to a fetal anomaly.
Chaloumsuk, 2013 4	Thailand	12 women	Unstructured interviews	Qualitative Interpretive phenomenology Retrospective	This study aimed to gain an understanding of experiences of miscarriage and termination of pregnancy for fetal anomaly among a group of Thai women
Cowchock et al., 2011 5	USA	9 women 5 men	Survey	Quantitative Survey Retrospective	The spiritual needs of couples (9 mothers and 5 fathers) who were planning to terminate wanted second trimester pregnancies because of serious fetal anomalies were surveyed.
Dekkers et al., 2019 6	The Netherlands	76 women 36 partners	Semi-structured online questionnaire	Quantitative Cross-sectional Retrospective cohort study Retrospective	To investigate, from the perspective of women and partners, at what stage of a termination of pregnancy (TOP) for fetal anomalies psychosocial care (PSC) is most meaningful, what topics should be discussed, and who should provide PSC
Desrochers, 2011 7	USA	7 men	Semi-structured interviews	Qualitative Retrospective	The purpose of this study was to explore the thoughts and feelings of fathers throughout the experience including the initial diagnosis and the decision-making process, as well as the journey of grieving and coping.
Fisher and Lafarge, 2015 8	UK (England)	361 women	Cross sectional online survey	Qualitative Retrospective	This study investigated women's experience of care when undergoing termination of pregnancy for fetal anomaly (TOPFA)
Fisher et al., 2015 9	UK (England)	351 women	Self-administered online questionnaire	Quantitative Retrospective	We investigated whether women are offered a choice of method, by surveying members of a UK parent support organisation.
Gawron et al., 2013 10	USA	30 women	Semi-structured interviews	Qualitative Latent content analysis Retrospective	The objectives of this study were to explore reasons for pregnancy termination timing among patients with fetal abnormalities by analyzing their pregnancy care timeline and their decision-making process.
Hassan, 2015 11	Canada & USA	10 women	Un-structured in-depth interviews	Qualitative Interpretive phenomenology Retrospective	To gain an in-depth understanding of the long-term experiences of women who terminated their pregnancy for fetal abnormalities and reveal the meanings embedded in their experiences.
Irani et al., 2019 12	Iran	7 women	Semi-structured in-depth interviews	Qualitative Conventional content analysis Retrospective	To explore the emotional and cognitive experiences of pregnant women following prenatal diagnosis of fetal anomalies in Mashhad, Iran.

Study	Country	Participants	Data Collection	Methodology	Study Aim
Kamranpour et al., 2020 13	Iran	25 women 2 men	In depth semi-structured interviews	Qualitative Conventional qualitative content analysis Retrospective	This study aimed to explore the needs related to the health system in women with experience of pregnancy termination due to fetal anomalies.
Kamranpour et al., 2021 14	Iran	25 women 2 men	In depth semi-structured interviews	Qualitative Conventional qualitative content analysis Retrospective	This study aimed to explore the informational and educational needs of women who have experienced pregnancy termination because of fetal anomalies.
Kecir et al., 2020 15	France	8 men	Semi-structured interviews	Qualitative Retrospective	Aim of this qualitative study is to describe how fathers perceive the TOP, their feelings about caregivers and their strategies for coping.
Koponen et al., 2013 16	Finland	8 women	Written accounts	Qualitative Linguistic discourse analysis Retrospective	This study explores the construction of parental and professional agency in the written accounts by women who have undergone selective abortion.
Lafarge et al., 2013 17	UK	27 women	Online survey	Qualitative Interpretative phenomenological analysis Retrospective	To examine the coping strategies women use both during and after a TFA procedure.
Lafarge et al., 2019 18	UK (England) and France	27 women (England) 17 women (France) *UK sample is the same as study 17	Online survey (open-ended questions) Interviews	Qualitative Thematic analysis Retrospective	The aim of this article is to demonstrate the relevance of ambivalence to the experience of TFA. Data from two qualitative studies conducted with women who had undergone TFA, one in England, the other in France, have been used to convey and illustrate the ambivalence that characterises the TFA experience.
Leichtentritt, 2011 19	Israel	13 women	Semi-structured in-depth interviews	Qualitative Narrative analysis Retrospective	The present study aims to understand the experience of women who undergo feticide in Israel.
Leichtentritt and Weinberg-Kurnik, 2016 20	Israel	17 men	Semi-structured in-depth interviews	Qualitative Hermeneutic phenomenology Retrospective	To examine the experience of Israeli fathers whose fetuses underwent feticide.
Leichtentritt and Mahat-Shamir, 2017 21	Israel	28 women	In-depth interviews	Qualitative Hermeneutic methodology Retrospective	The goal of this research was to reach an interpretive understanding of the continuing bond experience among Israeli mothers who underwent feticide, examining the strategies they use in maintaining a post death relationship with a child they did not know, whose death they chose and witnessed, within a social context that ignores their loss and forces them to silence their grief.
Lotto et al., 2016 22	UK	10 women 8 men	Semi-structured interviews	Qualitative Constant comparative-based approach Retrospective	To understand the experiences of women and their partners following the decision to terminate a pregnancy affected by a severe congenital anomaly.
Mitchell, 2016 23	Canada	19 women	Interviews	Qualitative Retrospective	To explore what are women's responses to the opportunity to see their fetal bodies.
Obst et al., 2021 24	Australia	10 men	Semi-structured interviews	Qualitative Thematic analysis Retrospective	This study aimed to explore men's experiences of grief and support following TOPFA including how healthcare providers, systems and policies can best support men and their families.

Study	Country	Participants	Data Collection	Methodology	Study Aim
Pitt et al., 2016 25	Australia	59 women	In-depth interviews	Qualitative Thematic analysis Retrospective	Our aim in reporting on women's embodied experiences is to add detail and depth to health-care professionals' understanding of the experience of diagnosis and TFA, and to suggest recommendations as to how care provided to women who undergo TFA could be enhanced.
Qin et al., 2019 26	China	41 women	In-depth interviews	Qualitative Grounded theory Prospective	To understand the cognition, emotions, and behaviour of women who had recently undergone termination due to a foetal anomaly. In this study, we developed and tested a theoretical model to describe how women went through the process after termination.
Ramdaney et al., 2015 27	USA	51 women	Survey	Quantitative Prospective	Our study aim was to identify what support, if any, women desire following a termination of pregnancy for a fetal anomaly. Our study also investigated if the initial desire for support represented what women felt they needed in the weeks and months following the procedure.
Smith et al., 2020a 28	USA	124 women	Online survey	Mixed-Methods Quantitative – both surveys were scored using respective analysis tools. Qualitative – inductive content analysis Retrospective	This study aimed to assess whether there is a significant difference in ability to cope post-procedure between women who see a genetic counselor and women who do not see a genetic counsellor prior to their termination for fetal anomaly. Additionally, we explored factors that lead women to accept or decline genetic counselling prior to a termination for fetal anomaly and expectations for future genetic counselling appointments.
Sun et al., 2018 29	Taiwan	20 fathers	Semi-structured in-depth interviews	Qualitative Descriptive phenomenological approach Retrospective	The aims of this study were to explore and reveal the essence and structure of the experiences of Taiwanese fathers whose spouses are hospitalized for pregnancy termination due to fetal chromosome abnormality.
Zareba et al., 2018 30	Poland	150 women	Survey	Quantitative Retrospective	The aim of the paper is to determine the patients' needs with regard to support provided by medical personnel and the healthcare system as well as to establish what forms of support the patients expect from their partner, family and people in their surroundings to experience their period of grief in the least traumatic way.

Next, empirical findings were imported to NVivo Version 12 for Windows (QSR International, 2018). The findings were then thematically synthesized (Thomas and Harden, 2008) allowing for the analysis of both qualitative and quantitative data as well as providing a transparent and logical framework to explore the experiences and perspectives within a healthcare context (Gamondi et al., 2019). This inductive approach comprised of three stages: 1) line-by-line coding; 2) organisation of codes into descriptive themes; and 3) development of analytical themes (Bazeley, 2009; Sandelowski, 2004). To foster rigour of the coding process, AA independently coded a randomly selected 10% of the included records (Bettany-Saltikov and McSherry, 2016). This was followed by regular discussions amongst authors to examine emerging codes, connections, meanings and themes. Consensus between the reviewers remained high throughout the process.

Results

A total of 33,261 records were identified through the six databases used in this review. A further 12 records were found as a result of the additional searches. A PRISMA flowchart (Figure 1) presents an overview of the identification and screening process of included studies. 5,523 duplicates were removed, the title and abstract of the remaining 27,738 records were screened and 179 records were assessed as eligible for full text screening. Due to this high volume of studies yielded from the original search (March 2020), the research team agreed to enhance the initial exclusion criteria to ensure a manageable review. The deviations from the original protocol are detailed in Table 3 and an updated search was carried out in August 2021 following the same process using the enhanced exclusion criteria. The updated search in August 2021 followed the same process using the enhanced exclusion criteria (Table 3). With the amended criteria, 89 records were excluded. The full text of 90 records were screened, 60 of which were excluded. A total of 30 records (26 identified from the original search (March 2020) and 4 from the updated search (August 2021)) were selected for inclusion in this review and were agreed upon by all authors.

Table 3
Deviations to Original Protocol

Original Protocol	Deviation
No exclusion of type of study	Exclusion criteria - Non-empirical research, case reports, opinion pieces, conference abstracts, editorials
Studies that involve health professionals' needs and experiences will be included	Exclusion criteria - Studies that involve health professionals' needs and experiences
Records published between 2000-current will be included	Inclusion criteria – records published between 2010-current

Overview Of Included Studies

Of the thirty records, twenty-four were qualitative, five quantitative and one mixed-methods (Asplin et al., 2014; Atienza-Carrasco et al., 2020; Carlsson et al., 2016; Chaloumsuk, 2013; Cowchock et al., 2011; Dekkers et al., 2019; Desrochers, 2011; Fisher and Lafarge, 2015; Fisher et al., 2015; Gawron et al., 2013; Hassan, 2015; Irani et al., 2019; Kamranpour et al., 2020a; 2021; Kecir et al., 2021; Koponen et al., 2013; Lafarge et al., 2013; Lafarge et al., 2019; Leichtentritt, 2011; Leichtentritt and Weinberg-Kurnik, 2016; Leichtentritt and Mahat-Shamir, 2017; Lotto et al., 2016; Mitchell, 2016; Obst et al., 2020; Pitt et al., 2016; Qin et al., 2019; Ramdaney et al., 2015; Smith et al., 2020a; Sun et al., 2018; Zareba et al., 2018). The findings presented are based on twenty-eight studies as findings from two studies are reported in four records (Fisher and Lafarge, 2015 and Fisher et al., 2015; and Kamranpour et al., 2020a; 2021). The records were published between 2010 and 2021, with the majority (22) published in 2015 or after (see Figure 2). Sample size of included studies ranged from 7 - 361 participants, with an average of 48 participants per study. Eighteen studies included women only, five involved men only and five included both women and men. Collectively, this review is based on a total sample size of 1,227 women and 114 men.

Study characteristics are summarised in Table 2. The geographical spread of the studies includes, United States of America (USA) (5), UK (4), Israel (3), Iran (2), Sweden (2), Australia (2), and one each from Spain, Thailand, The Netherlands, France, Finland, Canada, China, Taiwan and Poland. One study includes participants from USA and Canada (Hassan, 2015). Twenty-six of the studies are retrospective designs and two prospective (Qin et al., 2019; Ramdaney et al., 2015).

Quality Appraisal Of Included Studies

Using MMAT Version 2018 (Hong et al., 2018) study quality overall was acceptable. Due to the paucity of research and wide scope of this review no records were excluded on the basis of quality. Two studies did not state whether ethical approval had been sought or obtained (Desrochers, 2011; Koponen et al., 2013), however, the majority of (29 out of 30) records reported on their adherence to appropriate ethical standards. Two studies acknowledged potential conflicts of interest (Fisher et al., 2015; Lafarge et al., 2013), both relating to the author being involved with the charity that was used as a gatekeeper for recruitment. Two US studies reported offering participants a financial incentive for taking part (Desrochers, 2011; Gawron et al., 2013).

Thematic Synthesis Findings

Five overarching themes emerged from the synthesis of findings: (1) Context of Care, (2) Person-centred Care, (3) Compassionate Care, (4) Co-ordinated Care, and (5) Inclusive Care. Table 4 summarises the themes and subthemes identified as part of this narrative synthesis. For ease of reading, throughout the findings section, references to the reviewed studies are made using numbers as displayed in Table 2.

Table 4
Mapping of themes to the included studies

Theme	Subtheme
Context of Care	Political-legal context
The perceived impact and importance of broader contextual factors in parents' access to and experience of care	Socio-cultural context
	Financial implications
Person-Centred Care	Information
The perceived impact of responsive and respectful healthcare in helping parents feel empowered through this experience	Choice
	Decision Making
Compassionate Care	Empathy
The perceived quality of the relationship a healthcare professional makes with parents and the impact on their satisfaction with their care experience	Experienced Staff
	Non-judgemental Staff
Co-ordinated Care	Internal Organisation
The perceived impact of the administrative arrangements, service availability and physical environment on the perceived quality of the care experience	Care Provision and Pathway
	Environment
Inclusive Care	Invisible Parent
The perceived impact of the health system and healthcare professionals in recognising and facilitating the involvement of partners	Supporting Carers

Context of Care

Political, legal and cultural contexts are pertinent to both the healthcare system and experience of parents undergoing a TOPFA and can shape and impact healthcare service provision, directly and indirectly, including how it is accessed and experienced. Despite TOPFA being legal in 113 countries (Remez et al., 2020), 15 countries of which are represented in this review, there is evidence from the studies that parents' experiences of TOPFA were impacted negatively by wider contextual factors including legislation, local procedures, professional practices and societal attitudes about TOP (10, 12, 13, 17, 21, 24, 30).

Challenges associated with legislation and policy included access to and availability of healthcare. These impacted on parents in a variety of ways, from having to travel or self-fund to access a TOPFA, to experiencing delays because of administrative 'red-tape' which led to delays in decision-making and referrals for the termination, leaving parents anxious about whether the outcome would support their choice or not (10, 19, 20, 21, 24).

Funding of the TOP was a pertinent issue for participants from studies in the USA where private medical insurance added a layer of complexity and debate over whether the procedure was *'elective'* or *'medical'* with the answer determining whether funding would be provided or not (10). This led to women taking action into their own hands with one woman, while awaiting insurance approval searching ways to *'self-abort'*, and another self-funding the procedure (10). An Iranian study (13) also reported on the financial issues experienced by parents, with some not able to access advanced screening or diagnostic tests and services such as genetic and psychological counselling due to high costs.

Person-centred Care

Most records (26 out of 30) addressed parents' need for information and the impact it had on their experience (1-20, 22, 24, 26, 28, 29, 30). While most parents acquired information themselves from a range of sources, such as, *"healthcare professionals, books, the Internet and from individuals who have been in similar situations"* (11), clear and unbiased information provided by healthcare professionals was greatly valued. When parents were given relevant and timely information, particularly about the diagnosed anomaly and healthcare procedures (1-6, 8, 9, 11, 12, 14, 17, 18, 19, 22, 24, 26, 28, 29, 30), it had a positive impact by reducing their fears and worries, helping them understand their choices, feeling more empowered (1-4, 8, 10, 11, 12, 16, 17, 19, 22, 24, 29, 30). Parents who felt ill-informed at any stage in the process felt less well-prepared physically and psychologically about what to expect and, for some, their experience was more traumatic (1-4, 8, 9, 10, 11, 13, 14, 16, 19, 20, 22, 29).

Some studies reported parents' frustration at trying to find information, while others expressed frustration about inconsistent and conflicting information (1, 2, 8, 10, 11, 16, 19), *"every time I phoned asking this very same question, I received different answers. Very exhausting"* (1). This also resulted in dissatisfaction and suspicion about the quality of any information provided, with some feeling that medical staff were withholding information, *"we deserved to know what they knew"* (10). Being given inappropriate information was distressing, *"[it was unhelpful] being handed a leaflet about dealing with a miscarriage almost immediately afterwards when I was clearly dealing with an awful decision which was NOT a miscarriage"* (8).

Several studies reported how parents rated the way information was communicated to them (1-5, 8, 11, 16, 17, 18, 19, 21, 22, 24, 28). Parents generally felt that written information without the opportunity to discuss it and ask questions was not helpful, *"they just gave me a piece of paper [a brochure], but that's not the same as actually talking it through with someone in person"* (16). There was no consensus about the use of language by healthcare providers, with some

parents critical of the use of medicalised terminology (2, 8, 11, 16, 19, 21), for example, referring to the baby as a *“product of conception”* (8) while others were critical of those who referred, *“to the fetus as a baby”* (8).

For many study participants the point of diagnosis was pivotal, marking the beginning of a different journey where decisions about the future of the pregnancy had to be made (2, 3, 4, 7, 10, 11, 12, 15, 18, 24, 25, 26) and was emotional and stressful (2, 3, 4, 7, 8, 11, 12, 15, 16, 18, 19, 26, 27). Overall, being given choices was seen as positive and empowering, not just the choice to end the pregnancy but other choices throughout the process (1, 2, 6, 7, 8, 9, 10, 11, 16, 18, 19, 24, 26, 27), but making the choices was also difficult involving conflicting feelings. Pain relief, for example, was identified as an important choice by some, both the choice to have it and the choice of what pain relief medication they had (1, 2, 3, 16, 17, 19, 22). Being overwhelmed by the choices and decisions to be made was reported in several studies (2, 3, 4, 6, 7, 8, 9, 11, 14, 18, 26, 29). A study which focused entirely on whether women were given a choice of method of TOPFA (9) found that only 14% of the sample were, with this number falling to 8% after 14 weeks gestation.

Compassionate Care

Healthcare providers' capacity to provide compassionate and empathetic care presented as potentially the most influential element in how parents perceived their experience, positively and negatively. It was explored in 21 out of the 30 records (1-8, 11, 12, 13, 15, 16, 17, 18, 19, 21, 22, 24, 28, 30). Women were most satisfied with providers when they responded to their communication and emotional needs (1-6, 8, 11, 12, 16, 17, 18, 19, 21, 22, 28, 30), as highlighted in a UK study, *“The consultant also held my hand tight . . . this warmth from the staff I will always remember”* (17). A perceived lack of empathy and kindness had lasting impact after the experience, as highlighted by a study in Canada and USA, *“the supervisor nurse was kind of brusque and not very friendly and I unfortunately remember that quite clearly”* (11).

Healthcare professionals who were perceived to be non-judgmental and who showed kindness and support for parents was greatly valued, *“one of the kindest people during the whole process was the anaesthesiologist who held my hand ....and said he understood I was making the right choice”* (11). The importance of non-judgmental staff was highlighted as a recurring theme linked to stigma, which was reported in eleven studies (2, 7, 8, 10, 11, 12, 18, 19, 22, 24, 30). Parents used words such as 'shame' and 'guilt' to describe how they felt, and perceived judgement or stigmatisation from healthcare professionals was experienced negatively, *“I felt she [midwife] made me feel unworthy for my decision”* (8).

Parents appreciated practitioners who cared for their baby with tenderness (8, 11, 16, 17, 18, 22, 23, 24, 29), *“the care and attention the midwife on duty showed to our son, ... talking to him as she washed and dressed him”* (8) and were distressed when this was not the case. While some parents were ambivalent about spending time with their baby, most positive experiences were reported by those parents who were encouraged and helped to create memories as well as being given as much time as they wanted with their baby (2, 3, 4, 6, 11, 15, 16, 17, 18, 21, 22, 23, 24, 29). The facilitation of this by health practitioners was appreciated by parents, *“we were allowed to look at him in peace. He was only taken away when we were ready”* (16).

Parents valued being cared for by experienced members of staff (1, 4, 6, 8, 10, 11, 13, 15, 16, 22, 26) and found it reassuring, *“I felt I was being treated by experts”* (8). Conversely, being cared for by junior or inexperienced members of staff was found to be distressing and impacted on how confident and safe parents felt by their care, *“normal midwives seemed not to know what to do. One told me that she had never delivered a stillborn baby. This was the last thing I needed to hear”* (8).

Co-ordinated Care

Well organised care, which is timely, efficient, and properly resourced was identified as a major contributor in parent satisfaction and was addressed in 18 of the 30 included records (1, 2, 4, 5, 8, 9, 10, 11, 13, 15, 18, 19, 21, 22, 24, 25, 27, 29). Delays in appointments for further diagnostic tests and slow turnaround times for results were experienced as frustrating and increased parents' anxiety (2, 8, 9, 10, 11, 18, 19, 24, 30). Any delay post diagnosis was significant and, in some cases, seemed to impact on the choices available due to the gestational age of the fetus (8, 9, 10, 11, 18, 19). One UK study reported, *“increasing pressures around 13–14 weeks' gestation, after which surgical terminations are harder to access in the NHS”* (8). Any obstacle or delay once the decision to have a TOPFA had been made increased parent's stress with one participant comparing the wait for the procedure as, *“being on death row”* (8).

Positive experiences of the healthcare system were reported in terms of the capacity and flexibility of the system and the willingness of staff to be responsive to the particular circumstances of parents (1, 4, 8, 15). This included fast-tracking people for basic procedures, such blood samples, so they did not have any additional waiting (8, 25). There was also appreciation when staff ensured women spent little time in open public waiting areas or escorted them quickly and discreetly to a private space (4, 8, 11, 22). Satisfaction was also expressed when staff helped make others aware of their loss to avoid inappropriate comments or questions by staff, *“they put a white flower on my door to let them (the staff) know that I was not leaving with a baby”* (11).

Co-ordination and continuity of care were also highlighted as important elements of effective care (1, 2, 4, 5, 8, 9, 10, 11, 13, 18, 19, 21, 22, 25, 29, 30). In some instances, the handover of a woman's medical history, notes and ongoing care between practitioners were inadequate, meaning those taking over the care were ill-informed, resulting in poor communication (1, 2, 4, 8, 17). Failure to read case notes before seeing a patient led to upsetting experiences for some parents, *“I had to tell her the baby had died. She hadn't read the notes properly! I was furious and very distressed”* (17). For some, seeing a different doctor every time they attended the clinic impacted on their confidence and resulted in them withholding their fears and concerns (2). A call for continuity of care was specifically reported in four studies (1, 2, 8, 22).

In terms of setting, TOPFAs were carried out in hospital, clinic settings and in abortion clinics. Ten records explored the significance to parents about being cared for in an appropriate environment (2, 4, 8, 11, 13, 19, 22, 23, 25, 29). Negative experiences included, being surrounded by women with healthy

pregnancies, being close to new mothers and crying newborns, physical indicators of celebration for a newborn, posters on walls of healthy newborns, waiting with women getting an early abortion for an unwanted pregnancy, or waiting with women going for a caesarean section.

There was no consensus about parents' preferences on the most appropriate environment. For those at an earlier gestation, gynaecological wards were preferred by some who wished to avoid being in close proximity to newborns (8) and found the experience of being cared for in settings where other people were giving birth uncomfortable (2, 4, 11, 22, 25, 29). For others being in a delivery unit validated them as *"a pregnant mum"* (8) and the gynaecological ward felt inappropriate as it didn't acknowledge their pregnancy was wanted and being separated from 'normal birth' compounded their sense of isolation (8, 22).

Aftercare was identified by some parents as a gap in the services available to them within the healthcare system, and for many was not routinely provided (1, 2, 3, 6, 7, 8, 11, 13, 14, 16, 17, 20, 24, 27, 28). In the absence of aftercare being provided women expected and wanted healthcare practitioners to signpost them to support organisations (1, 2, 6, 7, 8, 11, 16, 17, 22, 25, 27, 28). However, it was reported that this often did not happen, and they had to assume personal responsibility to find, and in some cases privately fund aftercare (1, 2, 3, 6, 7, 8, 11, 16, 17, 22). For those who were signposted to or who accessed aftercare, they found it to be helpful and beneficial (1, 2, 3, 4, 5, 7, 8, 10, 11, 17, 21, 26), *"the care was very good. [The] bereavement midwife [was] excellent and I saw her lots after"* (8). Parents expressed the view that the aftercare for those who had undergone TOPFA should be bespoke as it was not the same as other perinatal losses and support groups for other infant losses were mostly considered to be unhelpful or inappropriate (1, 2, 8, 11, 17, 22, 24). Preparation, information, and support before a potential future pregnancy was also raised as a concern and need for parents in two studies (14, 28).

Inclusive Care

Several studies reported that many partners felt excluded or ignored by healthcare staff, and highlighted how the healthcare system in general, and organisational issues in particular, were not designed to cater for them or enable them to support the pregnant woman (7, 13, 15, 20, 22, 24, 29), *"it's a no man's land"* (20). Partners often felt excluded, ill-prepared and unwelcome, with a partner in one study stating, *"it does feel a bit like they forget the father sometimes you know. It was like the bed in the hospital and there was no bed for me. You know, not even a blanket, and [the midwife] said there wasn't enough pillows [for me to have one]"* (22). Some rationalised their exclusion because, *"pregnancy is a woman's issue"* (20). Additional to the hospital environment, fathers also reported a lack of specific aftercare and support targeted towards men, resulting in them feeling uncertain and conflicted between their roles as grieving father and supporting their partner (24).

In some studies, partners identified themselves as the main or only support for their pregnant partner (6, 7, 15, 20, 24, 29). Women also recognised the central support role their partners played (2, 4, 10, 17, 22, 30). While partners wanted to care and support their pregnant partner throughout the process, this was more difficult for some when there was, *"little professional assistance, empathy or caring"* (20). One woman reported, *"my husband actually delivered the baby 'cause there was nobody there"* (22). In another case, the partner reported, *"she was bleeding ... and they [professionals] did nothing! I felt abandoned... I took care of her"* (20). Partners, in these circumstances, felt, *"forced to take the situation in your own hands"* (20). When professionals supported women and their partners, the experiences of partners were much more positive, *"all the people who assisted us [...] were very competent and very nice and that greatly helped"* (15).

Discussion

This systematic review synthesises findings from the international literature on the healthcare experiences and needs of parents who undergo a termination of pregnancy following an antenatal diagnosis of a fetal anomaly. While others have reviewed the evidence concerning this phenomenon from other timeframes and perspectives (Deas, 2017; Lafarge et al., 2014; Jones et al., 2017; Statham et al., 2000; Statham, 2002; Steinberg, 2011; Sullivan and De Faoite, 2017; Wool, 2011), to our knowledge, this is the first review exploring the holistic TOPFA healthcare experience, from diagnosis to aftercare from both parents' perspectives. Using the process of thematic analysis this review enhances the knowledge and understanding of the TOPFA healthcare experience and needs of parents and identifies factors that may impact positively and negatively.

Five over-arching themes containing 14 sub-themes (Table 4), generated from 30 records (28 studies), were interpreted in the thematic synthesis. Findings suggested that a trusting relationship with healthcare professionals who provide compassionate care positively impacts on parents' experience of TOPFA. This review also identifies key components that may optimise healthcare practice and enhance quality of care, as well as implications for policy, providing opportunity to improve healthcare provision, organisation and delivery.

Trusting and Compassionate Relationships

For individuals, their experiences of TOPFA were influenced most by the attitudes, communication style and small acts of kindness shown by healthcare professionals, rather than by their clinical competence. Individual's experiences were more positive, and they felt supported and cared for when staff showed empathy and kindness, listened, took time to explain things, provided relevant information and showed thoughtfulness and compassion by their actions. The converse was true for those who felt they were treated coldly or dismissively, who felt judged or abandoned and were treated by staff who were paternalistic in their approach. While these findings are not dissimilar to the experiences of every pregnant woman (Eds. Byrom and Downe, 2015), the circumstances and the outcome of a TOPFA makes this different (Depoers-Beal et al., 2019; Coleman, 2015; Kamranpour 2020b). Women and their partners want and need staff to connect with them as grieving parents and to acknowledge and respond to the loss of their baby (Davies et al., 2005; Kersting and Wagner, 2012; Smith et al., 2020b).

Effective communication skills are essential for all healthcare staff to navigate the complex interactions involved in supporting parents through TOPFA (Ahmed, 2020; Lafarge et al., 2017; Leonard, 2017). The findings highlight that what and how professionals communicate impacts on how intended and unintended messages can be perceived or interpreted and whether parents feel judged or supported. Effective communication and its role in delivering quality

care is already recognised by its inclusion in health professional training (Chan et al., 2020; Slade et al., 2015). However, the findings suggest that a regular focus on communication skills throughout practitioners' careers would be beneficial and could support a better quality service. Examples of how this could be achieved include, through patient feedback, staff appraisal, refresher training or revalidation.

Encouraging and helping individuals to take more responsibility for their health and wellbeing and to have a greater say and choice about the care they receive (Morley and Floridi, 2020; Petrakaki et al., 2018) is in keeping with the shift from a paternalistic model of care to an inclusive and empowering person-centred model (Armstrong, 2014; WHO, 2015) where care is responsive and individualised to a persons' needs (Byrne et al., 2020; Department of Health, 2014). The provision of timely and relevant information by staff is one practical step that would help empower parents to understand what choices they have and give them a greater sense of autonomy in a situation over which they feel they have little control (El-Haddad et al., 2020; Zolkefli, 2017). A sustained focus on developing healthcare staff's understanding of and skills in providing compassionate, person-centred care that supports choice and autonomy of patients throughout their careers could empower staff to improve the experiences not only of parents in these particular circumstances, but of all parents using maternity services (NHS, 2016).

Research in pediatric and neonatal bereavement has seen an increasing focus on meeting the needs of the father following the loss of a child (Aschenbrenner et al., 2012; Leemann et al., 2020; Macdonald et al., 2010; Melin-Johansson et al., 2014). The findings in this review suggest that, with a few exceptions, partners had a negative experience and felt excluded and ignored and need more support both as a grieving parent and in their role as carer to the pregnant woman. Family members have always played an important role as informal carers, particularly in the care of older people or those with disabilities, complementing formal healthcare provision (HM Government, 2019; NICE, 2021) and there is a growing recognition in healthcare policies and laws about the role of carers and their need for support (Carers Trust, 2021, Carers UK, 2019). Awareness raising and training about the need to be inclusive of a woman's primary support (with her permission), and the partner's needs for support both as a grieving parent and as a carer could enhance their experience in the future (Nazaré et al., 2014; Robson, 2002; Sun et al., 2020).

Over recent years there has been an increasing focus on baby loss in maternity care and a recognition of the need for specialist bereavement midwives and services (Abramson, 2019; All-Party Parliamentary Group on Baby Loss, 2016; Helps et al., 2020). This development has the potential to benefit all parents who lose a baby whatever the circumstances, including TOPFA. While lack of experience in dealing with loss is one possible reason why some healthcare staff do not show compassion or empathy to parents experiencing TOPFA, there are a number of other possible reasons why this might be the case. These include lack of knowledge about TOPFA, wanting to remain clinically detached, self-preservation/burnout or, in the respect of TOPFA, disapproval or non-acceptance of termination of pregnancy as an intervention. Exploring the views and feelings of healthcare professionals working in this area of practice would increase an understanding of their needs for support and development as well as consideration of whether there should be specialist and/or designated staff assigned to work with women in these circumstances.

Practice Implications

Practice refers to the organisation, delivery and administration of care and includes policies, care pathways, clinical guidelines, workforce, caseloads and professional training and how cumulatively these affect the practice within a setting and people's experiences of care. Co-ordination, continuity of care, training, physical setting and aftercare were the common themes identified through this review that impacted positively or negatively on the quality of care and on people's experiences.

For parents who receive a diagnosis of a fetal anomaly, time is critical as a pregnancy has a natural lifespan with a finite time in which decisions can be made. The decision to end the pregnancy and the methods of TOPFA are also time sensitive, particularly when a diagnosis is made at a later gestation and any delays or obstacles following diagnosis can impact on choices available in terms of procedures. Examples in the review of how individual staff facilitated parents through systems in a sensitive and timely manner highlight how practice can be improved. Having a clear care pathway for the management and co-ordination of the care of parents who receive a diagnosis of fetal anomaly with indicative timelines could also improve practice and the pathway for parents.

Continuity of care could potentially also support better experiences for parents following the diagnosis of a fetal anomaly. A single contact point with whom the parents can build a relationship, discuss their choices, agree their preferred care options and who can then facilitate, organise and advocate for the delivery of that care would be the ideal. The evidence supporting continuity of care is well documented in literature (Hewitt et al., 2021; Homer, 2016; Sandall et al., 2016) and is increasingly seen in government policy and strategies across healthcare disciplines (Hill and Freeman, 2011; NHS, 2017; Sandall, 2018; WHO, 2018).

Healthcare professionals need to be supported and trained to support and meet the needs of parents undergoing TOPFA. The review highlights how people feel more positive when they had confidence in the competence and experience in those caring for them. Where resources permit, experienced or trained staff should provide this service (Leitao et al., 2021). There may be a case for the development of a specialist post but this would need to be based on need which would require accurate and reliable data about prevalence.

The literature review highlighted there was no consensus about the preferred setting for a TOPFA procedure. Where feasible, women should be given the choice of setting. Where it is not feasible and women have to be treated in a maternity ward, this needs to be managed sensitively in ways that minimise further distress for those who have lost a baby.

It appears from the findings that aftercare is not routinely offered following a TOPFA, although many would welcome it. The lack of aftercare can have emotional and physical implications for women's overall health, wellbeing and functioning, including their reproductive health. A care pathway should include aftercare as well as signposting to other services that may be of help to parents in this situation.

There were examples of good practice and of individuals making exceptions in normal practices to facilitate parents experiencing TOPFA. Gathering, sharing, and showcasing examples of good practice could support and empower staff and teams in other settings to introduce small changes in practice that would improve the quality of care and people's experiences in their care.

Policy Implications

The findings confirm that the provision of services and care provided by healthcare professionals in respect of TOPFA varies between and within countries for a wide range of legal, socio-economic and cultural reasons. There was, however, one common theme that impacted on individual's experiences that was the stigma and guilt surrounding termination of pregnancy which continues to be a divisive issue within most societies. The attitudes and opinions of people's families and friends, of healthcare professionals, of politicians and of every citizen regarding termination of pregnancy are reflective of those of the wider society with some for, some against and others somewhere in the middle. With limited to no social discourse, TOPFA is shrouded in secrecy and shame (Hanschmidt et al., 2018c), and 'off limits' due to concerns about others' reactions (Traumer et al., 2019). The impact of this results in parents self-silencing, leaving them feeling alone, excluded and marginalized with society creating and maintaining censorship (Chan, 2019; O'Brien, 1993).

In countries where TOPFA is legal, awareness raising, education and information about ethical practice, human rights and conscientious objection could lead to greater understanding and respect for differing viewpoints and help reduce the taboo, stigma and silence surrounding TOP. Anonymised stories of parents who have experienced TOPFA and the experiences of healthcare professionals could also be used to raise awareness of the issues and break the silence.

The stigma and silence can impact on the availability and quality of services, contributing to a 'postcode lottery' of healthcare, which has long been criticised (De Matteis et al., 2019; Graley et al., 2011; McKenzie, 2019). Where TOPFA is legal, clear national policies, guidance about the law, its meaning and intent, as well as the expectations of those providing the service and the rights of those using the service could contribute to a fair system for all. The availability of national clinical guidelines for TOPFA based on evidence and good practice would also provide clarity about what is expected of the service by those using it as well as providing guidance for staff. As with any guidance or care pathway, scope for professional judgement (Schrijvers et al., 2012) would need to be included to allow for a person-centred care approach to meet the specific needs and preferences of each woman and her partner and the unique circumstances of their case.

Additional resources may be required to ensure a quality service for TOPFA. To inform this there needs to be more accurate and reliable data collection to indicate prevalence and need, including the need for specialist medical equipment to improve diagnosis, for training of staff and potentially the need for additional staff to support continuity of care, specialist posts and adequate time to support parents meaningfully through diagnosis, decision-making, treatment and to provide ongoing support and development of new services such as aftercare. There is also a responsibility on governments and healthcare systems to monitor and evaluate how policy and legislation are being implemented and to hold decision-makers and providers to account to provide the expected level of service and comply with the legislation and uphold people's human rights.

Strengths And Limitations

This systematic literature review and thematic synthesis enhances previous literature, offering another perspective. To our knowledge, it is the first mixed-methods systematic examination and narrative synthesis of the healthcare experiences of both parents of TOPFA. A strength of the review is the utilisation of guidelines and best practice procedures, such as protocol publication to ensure a robust and transparent process. The inductive approach to data analysis, as well as the rigorous and comprehensive search strategy for relevant literature and the evident auditable trail clearly demonstrated the journey from primary studies to interpretations. Independent analysis by two members of the review team enhances credibility.

This review has several limitations. Firstly, it only includes records written in English, possibly omitting significant or insightful studies. There is a small evidence base per country context, and although not the purpose of this review, subsequently means results may not be directly transferrable to dissimilar settings, contexts or samples. There is an over-representation from high-income countries (The World Bank, 2021), drawing attention to possible differences in antenatal care pathways and availability and access of screening and diagnostic services in different countries. Studies in the UK and USA were also over-represented as well as the majority of participants in studies being from a white ethnic background, middle-class and well educated. This possibility of cultural bias has been noted in other studies exploring this phenomenon (Korenromp et al., 2009; Lafarge et al., 2014; Statham et al., 2001). All studies used convenience, purposive or snowball sampling to recruit participants. While ethically appropriate and justified in relation to the nature of the research, it is important to note that results may not be representative of all parents who experience TOPFA. For a review focusing on both parents' experiences, those of the partner made up less than 10% of the total sample the findings are based upon, highlighting the dearth of, and need for, more research involving partners in the field of maternity and perinatal care and loss.

Opportunities For Future Research

In-depth primary research with both parents and health professionals would be beneficial and could help inform and improve service delivery. This knowledge would have the potential to positively impact on parents' experience and improve the quality of care provided. Researching health professionals' experiences would help identify their needs in providing this service. Primary qualitative research exploring other family members experience may also be beneficial as literature alludes to the main support for parents being firstly their respective partner followed by their family network. There is also a need to develop and evaluate interventions with this group aimed at improving their healthcare experience and health outcomes.

Conclusions

The findings from this review identify the individual nature of people's experiences, needs and responses to the healthcare they received in respect of TOPFA. It has also, importantly, identified a degree of consensus about how compassionate and person-centred care good information and co-ordination can help make parents feel supported and cared for through what is and emotionally traumatic experience.

The skills and attitudes identified are already taught in professional training programmes, although, opportunities to care for parents experiencing TOPFA as part of maternity care are more limited in some settings. Consideration needs to be given to how to ensure expertise and experience can continue to be developed within the workforce to more effectively meet the needs of these parents.

Likewise, a healthcare system that is well-organised and co-ordinated and involves and empowers people in choices and decisions about their care are valued. Improving availability, consistency and quality of services within each jurisdiction should be based on compliance with extant law, human rights, professional leadership, evidence, good practice, sufficient well-trained practitioners and a culture of continuous improvement.

Declarations

Ethics approval and consent to participate

Not applicable - Ethical approval was not required for this literature review as no participants, human or animal were involved in the research.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

SH – Conceptualisation, data collection of literature, analysis, writing and editing

ÁA – Conceptualisation, data collection of literature, analysis, writing and editing

MT – Conceptualisation, analysis, review and editing

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Figures

Figure 1

Search strategy and identification of records included in this review

Figure 2

Year of Publication