

Central Lancashire Online Knowledge (CLoK)

Title	Decision-making and future pregnancies after a positive fetal anomaly screen: A scoping review
Type	Article
URL	https://clock.uclan.ac.uk/45468/
DOI	https://doi.org/10.1111/jocn.16628
Date	2023
Citation	Shorey, Shefaly, Lalor, Joan, Pereira, Travis Lanz-Brian, Jarašiūnaitė-Fedosejeva, Gabija and Downe, Soo (2023) Decision-making and future pregnancies after a positive fetal anomaly screen: A scoping review. Journal of Clinical Nursing. ISSN 0962-1067
Creators	Shorey, Shefaly, Lalor, Joan, Pereira, Travis Lanz-Brian, Jarašiūnaitė-Fedosejeva, Gabija and Downe, Soo

It is advisable to refer to the publisher's version if you intend to cite from the work.
<https://doi.org/10.1111/jocn.16628>

For information about Research at UCLan please go to <http://www.uclan.ac.uk/research/>

All outputs in CLoK are protected by Intellectual Property Rights law, including Copyright law. Copyright, IPR and Moral Rights for the works on this site are retained by the individual authors and/or other copyright owners. Terms and conditions for use of this material are defined in the <http://clock.uclan.ac.uk/policies/>

Decision-making and future pregnancies after a positive fetal anomaly screen: A scoping review

1 Abstract

Aims and Objective: To examine and consolidate literature on the experiences and decision-making of parents following a screen positive result for a potential fetal anomaly and/or diagnosis of an actual anomaly in a previous pregnancy.

Background: Prenatal screening consists of any diagnostic modality that is aimed at acquiring information about a foetus or an embryo; however, the entire process is highly stressful for parents, especially if there was a previous screen positive result, but no abnormality was detected in the final result.

Methods: Eight electronic databases (PubMed, Embase, CINAHL, PsycINFO, Scopus, Web of Science, ProQuest Theses and Dissertations and ClinicalTrials.gov) were searched from each database's inception until February 2022. This scoping review was guided by Arksey and O'Malley's framework and was reported in accordance with the PRISMA-ScR checklist. Braun and Clarke's thematic analysis framework was utilized.

Results: Thirty-one studies were eligible for inclusion. Two main themes (reliving the fear while maintaining hope, and bridging the past and future pregnancies) and six sub-themes were identified.

Conclusions: A fetal anomaly diagnosis in pregnancy had a mixed impact on the attitudes of parents toward a future pregnancy. Some parents were fearful of reliving a traumatic experience, while others were determined to have a healthy child and grow their family. Parents generally expressed a greater preference for non-invasive over invasive prenatal testing due to the procedural risks involved.

1 **Relevance to clinical practice:** There is a need for healthcare professionals to provide
2 psychosocial and emotional support to parents so that they can achieve resolution for their
3 previous pregnancy. Healthcare professionals' ability to provide informational support also
4 enables these parents to make informed decision and understand their reproductive outcomes.
5 Additionally, healthcare administration and policymakers should reconsider current neonatal
6 or pregnancy loss bereavement guidelines to improve the inclusivity of fathers.

7 **Patient or Public contribution:** No patient or public contribution.

8 **Keywords:** Congenital abnormalities; forecasting; pregnancy; prenatal diagnosis; parents;
9 review

10 **2 Introduction**

11 Prenatal screening consists of any diagnostic modality that is aimed at acquiring
12 information about a foetus or an embryo, specifically for identifying prenatal genetic disorders
13 and their characteristics (Wieacker & Steinhard, 2010). Screening for birth defects was initiated
14 in the 1950s with the use of an ultrasound, and it has continued to remain the primary, routine,
15 and established screening method to date (Carlson & Vora, 2017). The World Health
16 Organization recommends pregnant women to have their first prenatal ultrasound within the
17 first 12 weeks of gestation (World Health Organization, 2016). Ultrasound is a basic screening
18 test on foetus, and women who receive a screen positive result for potential abnormalities are
19 generally offered more definitive diagnostic tests which can be invasive (usually more precise),
20 or non-invasive (usually less precise) (Allyse et al., 2015). The process of waiting to receive a
21 diagnostic test and undergoing the procedure, particularly if it is invasive, and waiting for the
22 results to be released can be highly stressful, even if the final result does not indicate the
23 presence of an abnormality. If an abnormality is present, the stress is accentuated by the need
24 for the woman, partner and family to decide on the next step (Lotto et al., 2017).

1 Prenatal ultrasound is usually a positive experience as parents can receive visual
2 confirmation of their pregnancy and many expectant parents consider this as a defining step in
3 their journey toward becoming a parent (Carlsson & Mattsson, 2018). However, in
4 approximately three percent of all cases, parents would receive a screening test result which
5 suggests a fetal anomaly, leaving them with the difficult decision to: (1) continue the pregnancy
6 without further testing and experience ongoing uncertainty until or even after birth, or (2)
7 undergo invasive diagnostic tests that may provide either more assurance of fetal well-being,
8 or certainty of abnormality but risking the loss of a healthy foetus (Carlson & Vora, 2017). If
9 a fetal anomaly is found, parents face a greater difficulty to decide whether to terminate the
10 pregnancy, or continue on with the pregnancy but bring an “affected” child into the world
11 (Carlson & Vora, 2017). Parents are often ill-prepared to receive adverse outcomes and
12 experience a wide range of emotions ranging from anger, disbelief, grief, isolation, and
13 adapting to adjustment (Lotto et al., 2017). In a recent review, a few women who had healthy
14 babies, but initially had screen positive result on their ultrasound which turned out to be
15 negative later on, continued to believe that their babies were not healthy. Hence, they were
16 reluctant to be pregnant again, even though they had originally planned to have more children
17 (Moncrieff et al., 2021).

18 To date, research on experiences of parents following a screen positive test result for
19 potential or actual fetal anomaly predominantly focused on the experiences and decision-
20 making of parents during the eventful pregnancy. There is a lack of systematic reviews which
21 explore the experiences and decision-making of parents during the current and subsequent
22 pregnancies. We managed to retrieve two qualitative systematic reviews that were similar to
23 our proposed review, but both only briefly touched on our phenomenon of interest (Blakeley
24 et al., 2019; Moncrieff et al., 2021). Blakeley et al. (2019) synthesized factors which influenced
25 parents who considered terminating their pregnancy, or those who continued with the

1 pregnancy following the identification of lethal, life-limiting, or severely debilitating fetal
2 abnormalities. On the other hand, Moncrieff et al. (2021) examined the short- and longer-term
3 beliefs, concerns, experiences and views of women, partners and health workers on routine
4 ultrasound in the first and second trimesters of pregnancy. Only five studies that focused on
5 future pregnancy outcomes out of a possible 104 included articles were found in both reviews;
6 one was from Blakeley et al. (2019) and the other four were from Moncrieff et al. (2021). This
7 shows that future pregnancy experiences and decision-making of parents following a screen
8 positive result for a potential fetal anomaly in a previous pregnancy, whether or not it was later
9 confirmed by other diagnostic procedures, is an emerging topic; literature on this topic has
10 different focuses and study designs. Therefore, we undertook a scoping review approach over
11 a traditional systematic review (Munn et al., 2018).

12 **3 Methods**

13 The methodological approach of this scoping review was guided by Arksey and
14 O'Malley (2005)'s five-stage framework consisting of: (1) identifying the research question,
15 (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating,
16 summarizing and reporting the results. This review was reported according to the guidelines
17 of the Preferred Reporting Items of Systematic Reviews and Meta-Analyses Extension for
18 scoping reviews (PRISMA-ScR) checklist (see Supplementary File 1) (Tricco et al., 2018).

19 **3.1 Stage 1: Identifying the research question**

20 This stage encompassed the identification of the research question and the purpose of the
21 scoping review. The research questions were as follows:

- 22 1. How does a positive fetal anomaly screening result in a previous pregnancy impact the
23 experiences and decision-making of parents (e.g., whether or not to pursue a future
24 pregnancy) before a future pregnancy?

- 1 2. How does a positive fetal anomaly screening result in a previous pregnancy impact the
2 experiences and decision-making of parents (e.g., about fetal anomaly screening during
3 a future pregnancy) during a future pregnancy?

4 **3.2 Stage 2: Identifying relevant studies**

5 Eight electronic databases (PubMed, Embase, CINAHL, PsycINFO, Scopus, Web of
6 Science, ProQuest Theses and Dissertations, and ClinicalTrials.gov) were searched from each
7 database's point of inception until February 2022. An academic librarian was consulted to
8 guide the search process, and an initial search was conducted in PubMed using the following
9 concepts: (“forecasting” OR “pregnancy”) AND (“prenatal diagnosis” OR “ultrasonography”)
10 AND (“congenital abnormalities” OR “life change events”). Keywords and index terms were
11 combined using Boolean operators and truncation symbols to optimize the results. To ensure
12 greater comprehensibility, a search on gray literature resources (OpenGrey and MedNar) was
13 carried out alongside a thorough hand-search of the bibliographies of relevant studies. The
14 detailed search strategies for the databases are presented in Supplementary File 2.

15 **3.3 Stage 3: Study selection**

16 All types of quantitative and qualitative study designs were eligible if they focused on
17 the experiences and decision-making of parents following a screen positive result for a potential
18 or actual diagnosis of a fetal anomaly in a previous pregnancy for future pregnancies. Studies
19 where parents received any abnormal prenatal screen positive result or definite diagnosis
20 during scheduled prenatal screenings for fetal anomaly, or as a chance or an unexpected finding
21 in any previous pregnancies were included even if the foetus or child was found to be free of
22 an anomaly upon detailed investigation (i.e., false-positive results). Studies exploring all fetal
23 anomalies regardless of lethality, life-limitability, severity of debilitation, and length of impact
24 were included, and participants were included regardless of their choice to continue or

1 terminate a previous affected pregnancy. To gather more inclusive and holistic evidence, all
2 publication types (e.g., conference abstracts, editorials and opinions) were included except for
3 books, book reviews and studies without full texts. Although the reviewers' native language is
4 English, no language restrictions were set and Google Translate was utilized to translate studies
5 outside of the reviewers' native language. Studies where parents: (1) received an expected
6 diagnosis, or who were known carriers of genetic conditions, (2) received an abnormal
7 diagnosis postnatally, and/or (3) received a non-fetal-related diagnosis during pregnancy such
8 as maternal or placental conditions, were excluded. The Endnote X9 program was used to
9 organize search results and remove duplicate records (The EndNote Team, 2013). Next, the
10 titles and abstracts of all the studies were screened according to the inclusion and exclusion
11 criteria. Thereafter, the full texts of selected studies were assessed for eligibility. Two
12 independent reviewers conducted the screening process using Rayyan (Ouzzani et al., 2016),
13 and any disagreements were discussed until consensus was met. An inter-rater reliability of
14 95% was maintained for the title or abstract screening, and full-text screening.

15 **3.4 Stage 4: Charting the data**

16 Based on the research question, the reviewers independently extracted the following:
17 study author(s), year, country, study design, aim, population characteristics (number of parents,
18 parents' age, and gender), type of diagnostic test, fetal diagnosis, pregnancy outcome,
19 methodology (data collection, measurement points), outcome measures (if applicable), and
20 findings related to the experiences, or decision-making of parents for future pregnancies
21 (qualitative themes or subthemes, quantitative data, narrative summary). Any disagreements
22 were discussed until consensus was met.

23 **3.5 Stage 5: Collating, summarizing and reporting the results**

1 A narrative synthesis approach guided by Popay et al. (2006) was utilized to summarize
2 the data from the included quantitative and qualitative studies. First, textual summaries of each
3 included study was systematically produced (including similar information for all studies
4 where possible and in the similar order) for the reviewers to gain familiarity with the included
5 studies, and to identify similarities and differences in findings across studies. Thereafter, the
6 reviewers organized the included studies into groups and clusters according to the research
7 questions to enhance the process of description and analysis, and identified patterns across and
8 within these groups and clusters. These initial groups were refined as the synthesis developed.
9 Subsequently, data from the included studies (e.g., study design details, outcome measures,
10 results, or themes) were presented in a tabular form to visually represent both quantitative and
11 qualitative data. Tabulation aided the reviewers in the preliminary synthesis of data across
12 studies and provided important foundations for future elements of the synthesis process. Next,
13 Thomas and Harden (2008)'s thematic synthesis approach was utilized to translate and interpret
14 the data from the included studies. This process consisted of inductive coding of the data,
15 development of descriptive themes and generalization of analytical themes. Inductive codes
16 were generated using manual color-coding method and then compared, grouped and organized
17 into subcategories to form descriptive themes(Nowell et al., 2017). These descriptive themes
18 underwent a process of constant targeted comparison with textual data of the included studies
19 to uncover and collate new and systematic understanding of parental experiences and decision-
20 making for future pregnancies, and eventually the development of analytical themes
21 (Sandelowski & Barroso, 2007). To enhance the reflexivity of the scoping review, a
22 collaborative approach between the reviewers from screening to analysis was adopted to
23 examine and reduce the influence of each reviewer's own beliefs, judgments and practices on
24 the research process (Dodgson, 2019). The inter-rater reliability between the reviewers was
25 approximately 90% for the data extraction and thematic analysis process, and any

1 disagreements were resolved through discussions. As the objective of scoping reviews was to
2 provide an overview of existing evidence, a quality appraisal of the included studies was not
3 conducted (Arksey & O'Malley, 2005; Levac et al., 2010). However, during data extraction,
4 the reviewers ensured that all included studies stated ethical approval and/or implemented
5 appropriate methodologies to obtain knowledge from their participants.

6 **4 Results**

7 **4.1 Database search**

8 A total of 39,333 studies were identified from the database search and manual search.
9 Upon the removal of 17,003 duplicate studies, the titles and abstracts of 22,330 studies were
10 screened based on the eligibility criteria, and 22,014 studies were excluded. The remaining 316
11 studies had their full texts screened for eligibility and 31 studies were included in the review.
12 The detailed PRISMA flow diagram along with reasons for exclusion is presented in Figure 1.

13 *Figure 1: PRISMA flow diagram (Insert Figure 1 above)*

14 **4.2 Characteristics of the included studies**

15 All included studies were published between 1984 and 2021. The 31 studies consisted
16 of three publication types: peer-review (n=27), theses or dissertations (n=3), and conference
17 abstract (n=1). Three study types were identified: qualitative (n=21), quantitative (n=9), and
18 mixed-method (n=1). Twenty-eight single-country studies were conducted across 14 different
19 countries: United States (USA; n=7), Brazil (n=3), Sweden (n=3), United Kingdom (UK; n=3),
20 Canada (n=2), the Netherlands (n=2), and one each in Belgium, Germany, Iceland, Iran,
21 Scotland, South Africa, Switzerland, and Vietnam. Three studies conducted multi-country
22 research: Lafarge et al. (2019) (France and UK), Samango-Sprouse et al. (2020) (Australia,
23 Canada, Israel, UK and USA) and Hammond et al. (2021) (Netherlands and UK). In total, 28

1 English language studies and three foreign language studies were retrieved, i.e., German
2 (Götzmann et al. (2002) and Wollenschein et al. (2007)) and Portuguese (Benute et al. (2006)).

3 **4.3 Characteristics of the population**

4 A total of 1338 responses were analyzed across 31 studies, of which 1192 were mothers,
5 121 were fathers or partners aged from 13 to 55 years old (25 participants' gender was
6 unidentifiable). Approximately 1251 pregnancies were recorded from the responses. Twenty-
7 one studies consisting of approximately 820 pregnancies reported on the type of prenatal
8 diagnostic test utilized by participants in their previous pregnancy. The use of only non-
9 invasive prenatal testing to confirm a prenatal diagnosis (i.e., ultrasound only or ultrasound
10 with a combination of maternal serum screening, e.g., free β -hCG level and PAPP-A level,
11 nuchal translucency, and/or fetal echography) was utilized in 504 pregnancies. Conversely,
12 ultrasound with invasive prenatal testing (i.e., amniocentesis, chorionic villus sampling, exome
13 sequencing, and/or fluorescence *in situ* hybridization) was utilized to confirm a prenatal
14 diagnosis in 316 pregnancies. Amniocentesis and chorionic villus sampling were the most
15 common choices, accounting for 241 and 62 invasive prenatal tests utilized, respectively.
16 Twenty-six studies consisting of approximately 967 pregnancies reported the decision of
17 parents after receiving their prenatal diagnosis. Termination of pregnancy was chosen by 750
18 parents, while 217 parents chose to continue the pregnancy. Approximately 65 unique fetal
19 conditions were reported; the most common diagnoses reported in the studies were trisomy 21
20 (n=14) and anencephaly (n=8). Detailed characteristics of the included studies and the specific
21 fetal diagnoses identified are presented in Supplementary Files 3 and 4, respectively.

22 The thematic analysis generated two main themes: (1) re-living the fear while
23 maintaining hope, and (2) bridging the past and , future pregnancies. Six subthemes were also
24 generated. Further details on the themes and subthemes are provided in Supplementary File 5.

1 **4.4 Theme 1: Re-living the Fear while Maintaining Hope**

2 This theme explored the experiences and decision-making of parents before a
3 subsequent pregnancy. They were categorized into three subthemes: (1) too traumatized to
4 move on; (2) seeking closure with future pregnancies; and (3) connecting the dots.

5 **4.4.1 Too traumatized to move on**

6 Nineteen studies (Baillie et al., 2000; Brandenburg et al., 1992; Bryar, 1997; Carolan
7 & Hodnett, 2009; Dallaire et al., 1995; Evers-Kiebooms et al., 1988; Fernandes et al., 2020;
8 Gammeltoft et al., 2008; Hammond et al., 2021; Irani et al., 2019; Jones et al., 1984; Kelly,
9 2009; Leuthner et al., 2003; Menary, 1987; Ndjapa-Ndamkou et al., 2013; Pelly, 2003;
10 Rillstone, 1999; White-Van Mourik, 1989; Wollenschein et al., 2007) highlighted the reasons
11 why parents were reluctant to become pregnant again following a diagnosis of a fetal anomaly
12 in a previous pregnancy. For these parents, the fear of the anomaly recurring and reliving the
13 trauma was sufficient to prevent them from becoming pregnant again (Baillie et al., 2000;
14 Brandenburg et al., 1992; Bryar, 1997; Carlsson & Mattsson, 2018; Fernandes et al., 2020;
15 Ferreira da Costa et al., 2005; Gammeltoft et al., 2008; Hammond et al., 2021; Irani et al., 2019;
16 Kelly, 2009; Leuthner et al., 2003; Menary, 1987; Rillstone, 1999; White-Van Mourik, 1989).
17 This fear also persisted in parents whose children received a normal diagnosis following
18 detailed investigations (Baillie et al., 2000). Additionally, parents felt that choosing not to
19 become pregnant again would allow them to ultimately avoid the difficult decisions associated
20 with another screen positive result, i.e. whether to do a test at all, terminate or continue the
21 pregnancy, or “choose” to bring a child with anomalies into the world (Kelly, 2009; Rillstone,
22 1999). Parents who previously believed a diagnosis of fetal anomaly only happen to others
23 were left feeling vulnerable to a sense of the arbitrariness of a diagnosis, particularly when they
24 had done all they could to ensure a healthy pregnancy (Baillie et al., 2000; Bryar, 1997; Carolan

1 & Hodnett, 2009; Gammeltoft et al., 2008; Kelly, 2009; Leuthner et al., 2003; Menary, 1987;
2 Rillstone, 1999; White-Van Mourik, 1989). A previous positive diagnosis of fetal anomaly
3 caused women to lose confidence in their reproductive capacity to produce a healthy baby
4 (Carolan & Hodnett, 2009; Fernandes et al., 2020; Hammond et al., 2021; Pelly, 2003), and
5 sowed doubts about their worth as wives and mothers. (Gammeltoft et al., 2008; Menary,
6 1987). In contrast, men in two studies reported fewer fears and vulnerabilities, and a shorter
7 duration of negative emotions compared to women (Leuthner et al., 2003; White-Van Mourik,
8 1989). Parents' willingness to only consider a future pregnancy if there is zero probability of
9 fetal anomalies coupled with the limitations of current medicine to predict and control risks
10 inherent to reproduction with absolute certainty, was another reason they reported for not
11 embarking on a subsequent pregnancy (Kelly, 2009; Rillstone, 1999).

12 Parents were more likely to decide against a future pregnancy if: (1) women were of
13 advanced maternal age due to concerns of reduced fertility and increased complications
14 following a possible future termination, or during birth and in the postpartum period; (2) they
15 received a more severe and potentially recurring fetal diagnosis (e.g., chromosomal anomalies)
16 previously, or (3) they had previously borne children with disability, or experienced fetal death,
17 stillbirth or neonatal death (Brandenburg et al., 1992; Menary, 1987; White-Van Mourik,
18 1989). Rates of subsequent pregnancies in these groups were lower than that of parents with
19 only healthy children, or no previous children (Brandenburg et al., 1992; Menary, 1987; White-
20 Van Mourik, 1989). Notably, parents in two studies were able to find closure with their
21 previous pregnancy through therapy, focusing on their education and careers, and adoption
22 (Menary, 1987).

23 **4.4.2 Seeking closure with future pregnancies**

1 Eighteen studies (Baillie et al., 2000; Brandenburg et al., 1992; Bryar, 1997; Carolan
2 & Hodnett, 2009; Dallaire et al., 1995; Evers-Kiebooms et al., 1988; Fernandes et al., 2020;
3 Gammeltoft et al., 2008; Irani et al., 2019; Kelly, 2009; Lafarge et al., 2013; Lafarge et al.,
4 2019; Menary, 1987; Ndjapa-Ndamkou et al., 2013; Pelly, 2003; Rillstone, 1999; White-Van
5 Mourik, 1989; Wollenschein et al., 2007) highlighted the reasons why parents had a future
6 pregnancy, or tried for one following a screen positive result for a potential or actual fetal
7 anomaly in a previous pregnancy. Parents in seven studies highlighted that giving birth to a
8 healthy child was essential to achieve a closure for their previous pregnancy since they could:
9 (1) heal emotional wounds, (2) restore a sense of equilibrium in the family unit, and (3) remove
10 doubts about their reproductive capabilities (Dallaire et al., 1995; Gammeltoft et al., 2008;
11 Lafarge et al., 2013; Menary, 1987; Rillstone, 1999; White-Van Mourik, 1989). Additionally,
12 a new pregnancy helped them focus on the future instead of the past and allowed them to
13 rebuild their lives (Dallaire et al., 1995; Menary, 1987). These parents overcame the situation
14 and accepted their experience with the previous pregnancy, and were optimistic that their
15 subsequent child would be a different child, a child unto itself, and not a replacement or a
16 means to forget the previous child (Gammeltoft et al., 2008; Lafarge et al., 2013; Lafarge et
17 al., 2019; Rillstone, 1999). However, a new pregnancy also created ambivalence for parents
18 who dealt with feelings of excitement and hope at a chance at regaining normality, while still
19 feeling anxious about their increased risk of adverse obstetrical and perinatal consequences
20 (Bryar, 1997; Lafarge et al., 2019; Pelly, 2003). Parents' determination to conceive again
21 transcended these fears (Carolan & Hodnett, 2009; Ferreira da Costa et al., 2005; Gammeltoft
22 et al., 2008; Menary, 1987; Pelly, 2003; Rillstone, 1999), and this desire was more significant
23 for parents who did not have children and those who had experienced spontaneous fetal loss or
24 terminated their previous pregnancy following a diagnosis of fetal anomaly (Brandenburg et
25 al., 1992; Fernandes et al., 2020; Irani et al., 2019).

1 For other parents, the source of their determination came from their faith and their
2 confidence in surviving another “ordeal” from previous hardships and losses in their life, which
3 demonstrated their post-traumatic growth (Menary, 1987). Other parents felt they were capable
4 of parenting another affected child after already caring for one and highlighted that increasing
5 social acceptance of individuals with disabilities reaffirmed their decision (Kelly, 2009). While
6 parents in three studies waited before trying for a future pregnancy to recuperate physically
7 and emotionally, strengthen their marriage, or seek a medical opinion (Gammeltoft et al., 2008;
8 Ndjapa-Ndamkou et al., 2013; Wollenschein et al., 2007), others did so as soon as their
9 postpartum fertility returned. At times this was earlier than the medical staff advised (Menary,
10 1987). A small group of parents in the review reportedly tried for a future pregnancy without
11 first resolving their grief and issues from the previous pregnancy, or did not have a plan on
12 how they would cope if they receive a screen positive result for a fetal anomaly again (Ferreira
13 da Costa et al., 2005; Menary, 1987).

14 **4.4.3 Connecting the dots**

15 Nine studies (Gammeltoft et al., 2008; Irani et al., 2019; Kelly, 2009; Menary, 1987;
16 Pelly, 2003; Rillstone, 1999; Samango-Sprouse et al., 2020; Smith et al., 2021; White-Van
17 Mourik, 1989) highlighted how parents navigated the period before or immediately after a
18 screen positive result for a potential or actual fetal anomaly. Parents who wanted a future
19 pregnancy reportedly had unprotected sex and copulated more frequently to reinforce closeness
20 and to conceive, while parents who were against a future pregnancy abstained from intercourse
21 (Kelly, 2009; Menary, 1987; White-Van Mourik, 1989). Parents who abstained from
22 copulation did not trust contraceptives to avert an unplanned pregnancy, and their depression
23 and sadness contributed to their lack of interest in a future pregnancy (Menary, 1987; White-
24 Van Mourik, 1989). Parents in three studies underwent invasive permanent birth control (e.g.,

1 tubal ligation, vasectomy) to alleviate their worries (Kelly, 2009; Menary, 1987; White-Van
2 Mourik, 1989).

3 Attitudes toward genetic counselling were largely positive, and parents in this review
4 reported having sought a genetic counsellor, or intended to do so for a future pregnancy.
5 Parents in seven studies viewed genetic counselling essential to increase awareness of their
6 unique risks and the likelihood of recurrence for anomalies, enhance their odds of having a
7 healthy child, ensure the well-being and safety of their future child, organize treatments and
8 link parents with resources, and advocate for and provide objective, non-judgmental and
9 compassionate support to improve parents' quality of life (Gammeltoft et al., 2008; Irani et al.,
10 2019; Menary, 1987; Pelly, 2003; Rillstone, 1999; Samango-Sprouse et al., 2020; Smith et al.,
11 2021). Some parents reluctantly attended genetic counselling as it was compulsory for prenatal
12 testing (Smith et al., 2021). Parents did not utilize this service when they had negative past
13 experiences with genetic counsellors, or when they already possessed the information they
14 desired (Smith et al., 2021). Only a few parents in the review mentioned seeking professional
15 psychological counselling for previous traumatic pregnancy experiences (Gammeltoft et al.,
16 2008; Menary, 1987; Rillstone, 1999).

17 **4.5 Theme 2: Bridging the Past and Future Pregnancies**

18 This theme detailed parents' attitudes and behaviors in making decisions during a
19 future pregnancy. They were categorized into three subthemes: (1) taking charge of the
20 situation, (2) attitudes toward invasive prenatal testing, and (3) managing expectations and
21 staying guarded during future pregnancy.

22 **4.5.1 Taking charge of the situation**

23 Fifteen studies (Bakkeren et al., 2020; Brandenburg et al., 1992; Carlsson & Mattsson,
24 2018; Evers-Kiebooms et al., 1988; Georgsson Öhman et al., 2006; Götzmann et al., 2002;

1 Irani et al., 2019; Kelly, 2009; Kristjansdottir & Gottfredsdottir, 2014; Larsson et al., 2010;
2 Leuthner et al., 2003; Pelly, 2003; Rillstone, 1999; Samango-Sprouse et al., 2020; White-Van
3 Mourik, 1989) highlighted parents' attitudes toward non-invasive prenatal testing for future
4 pregnancies. Experiencing fetal anomaly detection changed parents' views and awareness
5 about non-invasive prenatal testing and its medical purpose (Carlsson & Mattsson, 2018;
6 Götzmann et al., 2002; Irani et al., 2019; Samango-Sprouse et al., 2020). They reported that
7 non-invasive prenatal testing allowed fetal issues to potentially be detected early and allowed
8 them to be well-equipped for the future, such as healing their psycho-emotional wounds and
9 grief to ensure a smooth postpartum period, preparing for how their child will look and making
10 arrangements for a good delivery, or death post-birth if the child had a poor outcome
11 (Georgsson Öhman et al., 2006; Götzmann et al., 2002; Larsson et al., 2010; Leuthner et al.,
12 2003; Rillstone, 1999; Samango-Sprouse et al., 2020). Additionally, an early diagnosis gave
13 parents more time to research, and discuss different prognoses and views about the treatment
14 to have a better understanding of their child's diagnosis (Georgsson Öhman et al., 2006;
15 Götzmann et al., 2002; Larsson et al., 2010; Rillstone, 1999; Samango-Sprouse et al., 2020).
16 Consequently, parents who took up this option were not only more proactive and more
17 medically capable to care for their children, but were also advocates for their child's needs.
18 Parents engaged in assembling and coordinating a team of medical specialists (on their own
19 and without referrals) from different disciplines to ensure the best care plans, sought out
20 community doctors and therapists and supplemental resources such as enrichment activities
21 and support groups, and applied early for treatments, therapies and subsidies which often had
22 long waiting lists (Larsson et al., 2010; Rillstone, 1999; Samango-Sprouse et al., 2020).

23 Parents in eleven studies had utilized or intended to use non-invasive prenatal testing
24 (especially ultrasound examinations) for a future pregnancy (Bakkeren et al., 2020; Evers-
25 Kiebooms et al., 1988; Georgsson Öhman et al., 2006; Götzmann et al., 2002; Irani et al., 2019;

1 Kelly, 2009; Kristjansdottir & Gottfredsdottir, 2014; Larsson et al., 2010; Leuthner et al., 2003;
2 Samango-Sprouse et al., 2020; White-Van Mourik, 1989). The skills of the healthcare
3 professionals who performed the procedure, the comprehensiveness and comprehensibility of
4 the information received, and confidence with the efficiency and diagnostic reliability of non-
5 invasive prenatal testing were the common external reasons why parents chose non-invasive
6 prenatal testing in a future pregnancy (Götzmann et al., 2002; Samango-Sprouse et al., 2020).

7 Parents in two studies felt that the window of optimal intervention for their future child
8 was narrow, hence they felt responsible to strategize their child's care. This meant that they
9 were not willing to wait until after birth to decide on care plans and treatment options (Leuthner
10 et al., 2003; Samango-Sprouse et al., 2020). To diminish the fear and emotional pain associated
11 with waiting for a diagnosis confirmation, parents in one study sought to “accelerate the
12 diagnosis” by pushing for non-invasive prenatal testing to be done at the earliest possible date,
13 choosing alternative tests with shorter waitlists or quicker results, and traveled across states or
14 cities if the technology was not available in their area (Rillstone, 1999). Parents in the
15 aforementioned study even opted for invasive prenatal testing (which can be done as early as
16 in the first trimester) rather than waiting and seeing, despite the increased risks; this will be
17 discussed in the subsequent section (Rillstone, 1999).

18 Parents in three studies reported either believing that non-invasive prenatal testing
19 should be a mandatory and routine part of prenatal care (Götzmann et al., 2002; Samango-
20 Sprouse et al., 2020), or had undergone multiple non-invasive prenatal testing and opted in for
21 optional incidental findings for comprehensiveness (Bakkeren et al., 2020). Parents in three
22 studies (Kelly, 2009; Kristjansdottir & Gottfredsdottir, 2014; Samango-Sprouse et al., 2020)
23 were against utilizing non-invasive prenatal testing for future pregnancies as they did not wish
24 to be confronted with the choice of continuing or terminating an affected pregnancy. They felt
25 such procedures caused psychological suffering and prevented a “happy” pregnancy, or they

1 were not going to terminate the foetus regardless of the diagnosis, or they had doubts over the
2 reliability and consistency of non-invasive prenatal testing.

3 **4.5.2 Attitudes toward invasive prenatal testing**

4 Twelve studies (Brandenburg et al., 1992; Carlsson & Mattsson, 2018; Evers-
5 Kiebooms et al., 1988; Georgsson Öhman et al., 2006; Jones et al., 1984; Kelly, 2009;
6 Kristjansdottir & Gottfredsdottir, 2014; Larsson et al., 2010; Pelly, 2003; Rillstone, 1999;
7 Samango-Sprouse et al., 2020; White-Van Mourik, 1989) highlighted parents' attitudes toward
8 invasive prenatal testing for future pregnancies following a screen positive result for a fetal
9 anomaly in a previous pregnancy. Parent in six studies did not, or had no intention to utilize
10 invasive prenatal testing for a future pregnancy (Georgsson Öhman et al., 2006; Kelly, 2009;
11 Kristjansdottir & Gottfredsdottir, 2014; Rillstone, 1999; Samango-Sprouse et al., 2020; White-
12 Van Mourik, 1989). Parents, especially women of younger maternal age, were concerned with
13 procedural complications such as injury to the foetus or mother, infection, preterm labour,
14 miscarriage and stillbirth (Evers-Kiebooms et al., 1988; Kelly, 2009; Rillstone, 1999;
15 Samango-Sprouse et al., 2020). Choosing whether or not to have invasive testing appeared to
16 either be an emotional decision or based on incorrect beliefs on the distinct differences between
17 non-invasive prenatal testing and invasive prenatal testing. Parents in two studies refused
18 invasive prenatal testing. They chose to deal with the anomalies (if any) and stressors after the
19 child was born as they believed that despite very low risks, their odds would somehow not be
20 in their favor. Others believed that invasive prenatal testing was unnecessary as their
21 experience with their previous affected pregnancy or child adequately prepared them to manage
22 any impairments (Kelly, 2009; Rillstone, 1999). Parents in four studies reported that they used
23 or intended to use invasive prenatal testing in a future pregnancy as they believed that invasive
24 prenatal testing would enhance the safety and well-being of the foetus, and had higher

1 sensitivity and specificity compared to non-invasive prenatal testing (Evers-Kiebooms et al.,
2 1988; Jones et al., 1984; Larsson et al., 2010; Samango-Sprouse et al., 2020).

3 **4.5.3 Managing expectations and staying guarded during a future pregnancy**

4 Fifteen studies (Baillie et al., 2000; Benute et al., 2006; Bryar, 1997; Carolan &
5 Hodnett, 2009; Gammeltoft et al., 2008; Kelly, 2009; Lafarge et al., 2013; Lafarge et al., 2019;
6 Leuthner et al., 2003; Menary, 1987; Rillstone, 1999; Samango-Sprouse et al., 2020; Smith et
7 al., 2021; White-Van Mourik, 1989; Wollenschein et al., 2007) highlighted how parents
8 navigated the prenatal period in a subsequent pregnancy following a screen positive result for
9 a fetal anomaly in a previous pregnancy. If faced with a similar situation as their previous
10 pregnancy, parents reported wanting to change how they would deal with the question of
11 terminating or continuing the pregnancy. Parents in three studies who were younger women
12 not of advanced maternal age were more accepting of their decision to terminate their previous
13 pregnancy and were in favor of doing so again if an abnormality is diagnosed in a future
14 pregnancy (Benute et al., 2006; Kelly, 2009; White-Van Mourik, 1989). Conversely, women
15 of advanced maternal age, who generally were pro-terminating their previous pregnancy, had
16 lower expectations and gravitated toward continuing the pregnancy regardless of the diagnosis
17 (Kelly, 2009; Menary, 1987; Rillstone, 1999). These parents greatly reconsidered their hopes
18 and desires for a “perfect baby” who would outlive them since the ability to journey through
19 life as a “normal” family became their priority (Kelly, 2009).

20 A large number of parents included in the review approached their subsequent
21 pregnancy, or intended to approach their future pregnancy with caution and not take things for
22 granted. To manage this uncertainty, they expected and prepared for the worse (Baillie et al.,
23 2000; Bryar, 1997; Carolan & Hodnett, 2009; Gammeltoft et al., 2008; Kelly, 2009; Leuthner
24 et al., 2003; Menary, 1987; Rillstone, 1999; White-Van Mourik, 1989). This attitude was

1 associated with an increase in fear, insecurity, worry and stress (Rillstone, 1999; Wollenschein
2 et al., 2007). To manage this, parents in three studies deliberately delayed acknowledging and
3 investing in the pregnancy and avoided developing emotional attachment with their foetus
4 (Lafarge et al., 2013; Lafarge et al., 2019; Wollenschein et al., 2007). They did so either out of
5 self-protection and self-preservation against a bad fetal outcome, or because they were still
6 grieving the loss of the previous child and could not bond with the present child (Rillstone,
7 1999). Parents who did not resolve this “denial” promptly found themselves investing late into
8 the pregnancy and this left them with less time to prepare for the birth and more anxiety closer
9 to the delivery (Rillstone, 1999).

10 Compared to previous pregnancies, more parents withheld or said they would withhold
11 news of a new pregnancy until they were completely certain that their child had a normal
12 diagnosis (Lafarge et al., 2019). Parents were afraid that receiving love and support from others
13 would prematurely raise their hopes and worsen their pain if unsuccessful, and having to break
14 bad news to others and witnessing their pain, would add to their pain (Rillstone, 1999). On the
15 other hand, parents in two studies (Rillstone, 1999; Wollenschein et al., 2007) experienced a
16 better pregnancy experience in their subsequent pregnancy. By acknowledging they could lose
17 their child at any moment, and not wishing to have any regrets, these parents actively shared
18 about their pregnancy and made a bond with their child to ensure that their child felt important
19 and loved.

20 Parents needed an “enhanced level of hand-holding” during the subsequent pregnancy.
21 Compared to an average pregnant woman or birthing person, they made more visits to medical
22 institutions and even requested for extra checkups, saw various healthcare professionals,
23 depended more heavily on healthcare professionals for informational and emotional support,
24 and had a more therapeutic physician-patient relationship (Lafarge et al., 2013; Lafarge et al.,
25 2019; Rillstone, 1999). Additionally, parents in two studies reported utilizing local and online

1 pregnancy support groups to share their experiences, seek connection, reassurance and support
2 from “credible” parents, and manage plans while coping with the pain of a difficult pregnancy
3 (Rillstone, 1999; Smith et al., 2021).

4 **5 Discussion**

5 This review consolidated evidence on the experiences and decision-making of parents
6 for future pregnancies following a screen positive result for potential or diagnosis of an actual
7 fetal anomaly in a previous pregnancy. In subsequent pregnancy, many parents reported higher
8 levels of anxiety due to the increased risk of an adverse outcome. This phenomenon was also
9 identified by Campbell-Jackson et al. (2014) who found that women who suffered a perinatal
10 loss experienced higher levels of post-traumatic stress, anxiety and depression compared to
11 women who have not had any experience of loss. Poorer prenatal psychological health was also
12 associated with an increased risk of negative perinatal outcomes in a future pregnancy such as
13 preterm birth and low birth weight (Grote et al., 2010). Furthermore, compared to uneventful
14 pregnancies which are generally associated with positive emotions and expectations,
15 pregnancies following a perinatal loss (stillbirth or neonatal death) are emotional-laden and
16 increases anxiety level due to parental fears of a recurring loss (Mills et al., 2014). Additionally,
17 studies found that women who underwent a previous induced abortion also had higher anxiety
18 and depression scores in their subsequent pregnancy (particularly in the first trimester), and
19 these scores were statistically similar to women who had experienced spontaneous abortion
20 (Broen et al., 2005; Huang et al., 2012). Therefore, healthcare professionals should routinely
21 consider women’s history of prenatal or perinatal loss and history of positive screening test
22 results during their risk assessment for prenatal and postpartum anxiety and depression so that
23 high-risk women and partners can be identified and supported.

1 Parents in this review reported that giving birth to a healthy child would help to heal
2 emotional wounds, rebalance their family, and alleviate the anxieties surrounding their
3 reproductive ability. This finding was corroborated by Barr (2006) and Gold et al. (2010) who
4 found that a future pregnancy would provide the wished-for-baby to facilitate the integration
5 of the prior loss, while a healthy pregnancy would restore maternal self-esteem often ravaged
6 by perinatal loss. However, Blackmore et al. (2011) showed that the depression and anxiety
7 symptoms related to a previous perinatal loss can persist well beyond the subsequent pregnancy
8 despite the birth of a healthy child. Furthermore, Dekel et al. (2017) reported that despite a
9 successful birth, post-traumatic stress response brought about by the childbirth experience may
10 still manifest in mothers and they may also suffer from childbirth-related postpartum traumatic
11 stress disorder. Therefore, healthcare professionals must remain vigilant to recognize early
12 symptoms of these phenomena (especially in new mothers) and provide ongoing long-term
13 support even after a subsequent healthy pregnancy to promote smooth adaptation. Although
14 many parents were prepared to move on and proceed with a subsequent pregnancy, they were
15 adamant that doing so was not a means to forget or replace their previous child. These findings
16 were similarly reported in Campbell-Jackson et al. (2014) and Brooten et al. (2015) who found
17 that although the parents' emphasis was on the next child, it was still important for them to
18 maintain a "relationship" and keep the memory of their previous child alive for themselves,
19 their families and communities. Healthcare administrations should ensure that healthcare
20 professionals receive adequate and necessary training so that they can be more wary and
21 sensitive to such needs and allow open conversations where parents can discuss previous
22 losses.

23 While there were parents in our review who chose to wait to process the physiological
24 and emotional stress of a previous pregnancy, other parents (specifically those who did not
25 have children and were of advanced maternal age) were determined to conceive again as soon

1 as possible. Although this group of parents were often the more fearful and had more
2 unresolved previous pregnancy issues, they were more likely to go against medical advice
3 regarding recovery. This could be because they might feel that they had limited time as their
4 biological clock was ticking. However, the World Health Organization (2007) recommends
5 that women should have a minimum birth interval of 6 months after an abortion or fetal loss,
6 or a minimum of 24 months after a live birth for optimal maternal and perinatal outcomes.
7 Conversely, other studies have shown that pregnancy spacing of 18-23 months was associated
8 with lower incidence of low birth weight, preterm birth and small for gestational age, among
9 other adverse perinatal outcomes (Conde-Agudelo et al., 2006; Grisaru-Granovsky et al.,
10 2009). This waiting period poses a particular problem for parents in high-income countries who
11 may be toward the end of their childbearing years, given the growing trend of delayed
12 childbearing due to economic and social reasons (Nargund, 2009). There is a positive
13 relationship between increasing maternal age and adverse maternal (i.e., gestational diabetes,
14 hypertension and preeclampsia) and child outcomes (cesarean birth, fetal growth restriction,
15 miscarriage, placental abruption, preterm birth) (Lean et al., 2017). Aref-Adib et al. (2008)
16 reported a 30% increase in miscarriages for mothers who were 40 years of age, which then rose
17 to 50% after 45 years old. Additionally, Alio et al. (2012) reported a 24% increase in
18 miscarriages for paternal ages ranging 40-45 years old, which further rose to 50% after 45 years
19 old. As reflected in our review, parents of advanced childbearing age (≥ 35 years) were aware
20 that every delay in attempting conception would severely lower the chance of a healthy baby.
21 Therefore, parents (especially first time parents) were more likely to plan a subsequent
22 pregnancy shortly after the first one. Healthcare professionals should provide parents,
23 especially bereaved parents, counselling on how to optimize their health before preparing for
24 a future pregnancy, and discuss the medical risks and benefits of delaying versus trying to
25 ensure that parents can make an informed decision.

1 Parents who chose not to have a future pregnancy wanted to avoid reliving their
2 traumatic pregnancy and felt that they were more vulnerable to the recurrence of fetal
3 anomalies. This was the case even for parents whose subsequent diagnosis ruled out
4 abnormality after an initial screen positive result. Healthcare providers need to understand this
5 phenomenon since the usual assumption of a woman who had a healthy baby is to assume that
6 there are no residual concerns following an earlier screen positive result. This area is
7 underreported and requires more primary research.

8 Our findings showed that men reported a lower level of fear and vulnerability, and
9 experienced a shorter duration of negative emotions compared to women. These findings were
10 also reported by Kersting and Wagner (2012) who found that men grieved less intensely and
11 for a shorter period compared to women after prenatal loss. However, this does not
12 conclusively reflect a causal relationship between gender and how they cope with perinatal
13 loss. We hypothesize that men are generally less likely to outwardly express emotions due to
14 societal expectations of how men should behave (Obst et al., 2020). This is further supported
15 by Due et al. (2017) who showed that men had a higher propensity than women to engage in
16 maladaptive compensatory mechanisms (e.g., substance abuse), had higher scores on
17 avoidance scales and expressed greater difficulty approaching and accessing support services.
18 Additionally, Williams et al. (2020) found that men whose wife experienced a miscarriage felt
19 less entitled than women to describe their feelings due to the fear of being shamed and rejected
20 since it was not them who physically lost the baby. Our hypothesis was also reinforced when
21 Miller et al. (2019) reported that although men experience grief of a similar intensity to women
22 over a perinatal loss, they understand that their primary role is to support their partner and are
23 less likely to report their feelings to, or in the presence of their partners. Given that current
24 perinatal support services and information are largely targeted at women, men are often
25 unintentionally neglected by healthcare professionals. Therefore, more research into the

1 experiences of men in perinatal research, specifically regarding their coping mechanism and
2 how they express themselves in situations like this, are warranted.

3 According to Cacciatore et al. (2013), positive experiences with healthcare
4 professionals increase psychosocial care and support group participation, and reduce grief and
5 depressive symptoms in men. As there is a tendency to focus on women's expression of grief
6 and view men in a primarily supportive role to women (McCreight, 2004), healthcare
7 professionals must first recognize and break negative preconceived notions related to paternal
8 grief. Healthcare administrations should ensure that healthcare professionals receive adequate
9 and necessary training so that they can better validate the experiences of men, and display
10 empathy and sensitivity toward their needs, similar to how they would with women. Doing so
11 could build more therapeutic alliance between healthcare professionals and men, and improve
12 male receptiveness to subsequent psychosocial interventions. Additionally, healthcare
13 administrations should also reform current neonatal or pregnancy loss bereavement guidelines
14 which primarily focus on the experiences and needs of women.

15 We realize that parents' emotional state plays a significant role in deciding whether or
16 not they choose to have invasive testing, i.e., some parents are willing to absorb the risks
17 associated with invasive testing, while others avoid receiving a diagnosis. Additionally, we
18 also highlighted that there were parents who associated non-invasive prenatal testing with
19 confirmation of a diagnosis. This indicates that those parents either did not comprehend the
20 information or were not adequately educated about non-invasive prenatal testing. Non-invasive
21 prenatal testing is a screening test that can only determine the risk profile of women toward a
22 fetal anomaly, and not refute or confirm a diagnosis (Allyse et al., 2015). Misinformation is
23 further exacerbated as parents tend to have a tunnel vision on the safety aspects of different
24 prenatal tests. This is confirmed by Hill et al. (2012) who found that a prenatal test with zero
25 or negligible risk of procedure-related complications, or loss was the most important factor

1 that women considered before deciding to undergo prenatal testing. Compared to parents of
2 older childbearing age, younger parents were more likely to decline invasive prenatal testing
3 due to concerns with complications. Both Mujezinovic and Alfirevic (2007) and Hill et al.
4 (2012) reported similar findings observed in our review. They also found that women of
5 advanced maternal age generally valued tests with the highest accuracy and produced the
6 quickest results. However, these tests often presented with greater risks. Conversely, younger
7 women (<35 years) generally valued tests with the lowest possible false-positive rate and risk.
8 However, these tests usually had longer waiting times and lower accuracy. Mujezinovic and
9 Alfirevic (2007) and Hill et al. (2012) hypothesized that this difference between age groups
10 could be due to personal experiences and experiential knowledge. Therefore, as safety weighs
11 heavily on parents' minds, healthcare professionals must clearly and carefully counsel parents
12 on the differences between the available prenatal tests and their implications to ensure that
13 parents can make informed decision and achieve reproductive autonomy, and tailor a care
14 pathway according to their needs and level of risk.

15 Parents, especially women, in our review tended to compartmentalize their pregnancy
16 to avoid the emotional aspects for as long as possible until they received a greater certainty of
17 success, or had a live baby in their arms. More parents withheld news of their subsequent
18 pregnancy and only informed a smaller circle of contacts. This conscious and at times
19 subconscious defensive mechanism has been investigated in previous studies and is known as
20 'bracing for the worst' (Bailey et al., 2019; Ockhuijsen et al., 2013), 'emotional cushioning'
21 (Côté-Arsenault & Donato, 2011), or 'holding back emotions' (Côté-Arsenault & Dombeck,
22 2001). Generally, this is a normal and adaptive process as parents are still able to maintain good
23 quality relationships and function normally in society while being protected from the potential
24 pain of another loss (Côté-Arsenault & Donato, 2011). However, maternity care professionals
25 must still recognize the existence and prevalence of this behaviour, and keep a close eye as

1 parents (especially men) may not reach out for support and underreport their true anxiety levels.
2 Maternity care professionals should adopt an authentic listening approach and provide ample
3 space and time for parents to make a decision on their support needs.

4 **5.1 Limitations**

5 A limitation of this review is that although efforts were made to include non-English
6 language articles in this review using Google Translate, relevant studies may have been left out
7 due to limitations in translating. Furthermore, the majority of the articles included in this review
8 were from high-income settings (n=24), where prenatal testing and termination of pregnancy
9 for fetal abnormality are generally (though not always) socially acceptable. Thus, our findings
10 may not be generalizable to other contexts with a different ethical and legal landscape. More
11 geographically and culturally diverse research on the experiences of parents from Africa, Asia
12 or Middle East is warranted in future. This is to account for socio-cultural and political
13 differences, and inequalities in access to good quality maternity care, screening and counselling
14 services in some of these settings. Although the Arksey and O'Malley (2005) framework
15 highlights that a review of the findings by stakeholders and consumers with an interest in the
16 topic would provide additional references and insights beyond those in literature, we did not
17 undertake this step due to time and resource constraints. Additionally, we did not register an *a*
18 *priori* protocol as scoping reviews are presently ineligible for registration on PROSPERO.
19 However, we acknowledge that doing so aids in enhancing the comprehensibility,
20 reproducibility and transparency of a scoping review, and we encourage future researchers to
21 undertake this step in alternative registries such as Figshare (<https://figshare.com/>) or Open
22 Science Framework (<https://osf.io/>) (Aromataris & Munn, 2020).

23 **5.2 Relevance to future research**

1 The Patterns, Advances, Gaps, Evidence for practice and Research recommendations
2 (PAGER) framework guided this section (see Table 1) (Bradbury-Jones et al., 2021).

3 *Table 1: PAGER framework for practice & research implications (insert Figure 1 above)*

4 Men accounted for less than 10% of the responses in the included studies, and only one
5 study (Carlsson & Mattsson, 2018) focused exclusively on the experiences and decision-
6 making of men. Future studies should focus on improving the representation of fathers in
7 perinatal health research, specifically understanding how fathers cope with and express grief,
8 and identifying strategies to increase male involvement. As all of the included studies were
9 conducted before the coronavirus disease 2019 (COVID-19) pandemic, future studies should
10 account for the effects of the COVID-19 pandemic restrictions and their concomitant impact
11 on healthcare delivery when examining the phenomenon of interest. Additionally, as the
12 objective of scoping reviews is to provide a holistic overview of existing evidence, we did not
13 set any date restrictions, and thus some dated studies were included. Within the past few years,
14 social and political views regarding termination of pregnancy access have shifted dramatically
15 across continents, particularly in the United States. Additionally, the introduction of new
16 technologies in the last decade has also drastically changed the current practice of prenatal
17 screening and testing for fetal anomalies. Therefore, as parents' experiences and views may be
18 influenced by societal discourses and what is available to them, the consensus of some dated
19 studies may not be relevant in today's society. Therefore, there is an urgent need for newer
20 primary qualitative and quantitative studies, ideally with a longitudinal design, so that a
21 comprehensive understanding of the phenomenon can be achieved and parents can be provided
22 with timely support.

23 **6 Conclusion**

1 This review consolidated the experiences and decision-making of parents for future
2 pregnancies following a screen positive result for potential fetal anomaly or diagnosis of an
3 actual problem in a previous pregnancy. Our findings demonstrated that both scenarios had a
4 mixed impact on the attitudes of parents toward having a future pregnancy. While some parents
5 became more fearful of living through a traumatic experience again (in some cases even if their
6 baby was healthy), other parents were more determined to give themselves a chance to have a
7 healthy child and a normal family. Many parents expressed a greater preference for non-
8 invasive prenatal testing over invasive prenatal testing due to the procedural risks involved.
9 Our findings highlight the need to focus on the roles that healthcare professionals play in terms
10 of providing psychosocial and emotional support to parents so that they can achieve resolution
11 for their previous pregnancy, and also as a source of informational support to ensure that
12 parents make informed decisions and understand the reproductive outcomes. Additionally, our
13 findings also indicate the need to reform current neonatal or pregnancy loss (bereavement)
14 guidelines to create greater inclusivity by including bereaved men.

15 **7 Relevance to Clinical Practice**

16 Healthcare professionals must ensure that parents are well supported from the moment
17 they receive a screen positive result for potential fetal anomaly or a diagnosis of actual fetal
18 abnormality until well after, regardless of whether they decide on a future pregnancy. During
19 this process, healthcare professionals must be sensitive to the needs of parents and allow them
20 to openly discuss their experiences to aid in the grieving process. For parents who wish to
21 embark on a subsequent pregnancy, healthcare professionals should provide continuity of care,
22 if possible. Even if this is not possible, those caring for parents in this situation should carefully
23 counsel them on inter-pregnancy interval timings, the various types of prenatal tests available
24 and their implications, and the distinct differences between non-invasive prenatal testing and
25 invasive prenatal testing to ensure that they make informed decisions and obtain optimal

1 reproductive outcome. Healthcare professionals should also refrain from stereotyping men, and
2 neglecting their experiences and needs. This would enable the development of a therapeutic
3 relationship and improve health-seeking behaviors in men. Lastly, healthcare administrations
4 and policymakers could work toward reforming current neonatal or pregnancy loss
5 bereavement guidelines, which currently are primarily focused on the experiences and needs
6 of women, to ensure greater inclusivity for bereaved men.

7 **Data availability statement:** The data that supports the findings of this study are available in
8 the supplementary files of this article

9 **8 References**

10 Alio, A. P., Salihu, H. M., McIntosh, C., August, E. M., Weldeselasse, H., Sanchez, E., &
11 Mbah, A. K. (2012, 2012/09/01). The Effect of Paternal Age on Fetal Birth Outcomes.
12 American Journal of Men's Health, 6(5), 427-435.
13 <https://doi.org/10.1177/1557988312440718>

14
15 Allyse, M., Minear, M. A., Berson, E., Sridhar, S., Rote, M., Hung, A., & Chandrasekharan, S.
16 (2015). Non-invasive prenatal testing: a review of international implementation and
17 challenges. International journal of women's health, 7, 113-126.
18 <https://doi.org/10.2147/IJWH.S67124>

19
20 Aref-Adib, M., Freeman-Wang, T., & Atallah, I. (2008, 2008/02/01/). The older obstetric
21 patient. Obstetrics, Gynaecology & Reproductive Medicine, 18(2), 43-48.
22 <https://doi.org/https://doi.org/10.1016/j.ogrm.2007.12.001>

23
24 Arksey, H., & O'Malley, L. (2005, 2005/02/01). Scoping studies: towards a methodological
25 framework. International Journal of Social Research Methodology, 8(1), 19-32.
26 <https://doi.org/10.1080/1364557032000119616>

27
28 Aromataris, E., & Munn, Z. (2020). JBI Manual for Evidence Synthesis. JBI.
29 <https://doi.org/10.46658/JBIMES-20-01>

30
31 Bailey, S. L., Boivin, J., Cheong, Y. C., Kitson-Reynolds, E., Bailey, C., & Macklon, N. (2019,
32 Jun 1). Hope for the best ...but expect the worst: a qualitative study to explore how

- 1 women with recurrent miscarriage experience the early waiting period of a new
2 pregnancy. *BMJ Open*, 9(5), e029354. <https://doi.org/10.1136/bmjopen-2019-029354>
3
- 4 Baillie, C., Smith, J., Hewison, J., & Mason, G. (2000, 2000/11/01). Ultrasound screening for
5 chromosomal abnormality: Women's reactions to false positive results
6 [10.1348/135910700168991]. *British Journal of Health Psychology*, 5(4), 377-394.
7 <https://doi.org/10.1348/135910700168991>
8
- 9 Bakkeren, I. M., Henneman, L., Bekker, M. N., van Vliet-Lachotzki, E. H., & Galjaard, R. H.
10 (2020, 2020-12). The psychological impact of receiving an incidental finding with Non-
11 Invasive Prenatal Testing (NIPT). *European Journal of Human Genetics*, 28(SUPPL 1),
12 792 - 792.
13
- 14 Barr, P. (2006). Relation between grief and subsequent pregnancy status 13 months after
15 perinatal bereavement. *J Perinat Med*, 34(3), 207-211.
16 <https://doi.org/10.1515/jpm.2006.036>
17
- 18 Benute, G., Nomura, R., Lucia, M., & Zugaib, M. (2006, 01/01). Termination of pregnancy
19 after the diagnosis of lethal fetal malformation: Emotional aspects. *Revista Brasileira*
20 *de Ginecologia e Obstetrícia*, 28(1). [https://doi.org/10.1590/S0100-](https://doi.org/10.1590/S0100-72032006000100003)
21 [72032006000100003](https://doi.org/10.1590/S0100-72032006000100003)
22
- 23 Blackmore, E. R., Côté-Arsenault, D., Tang, W., Glover, V., Evans, J., Golding, J., &
24 O'Connor, T. G. (2011, May). Previous prenatal loss as a predictor of perinatal
25 depression and anxiety. *Br J Psychiatry*, 198(5), 373-378.
26 <https://doi.org/10.1192/bjp.bp.110.083105>
27
- 28 Blakeley, C., Smith, D. M., Johnstone, E. D., & Wittkowski, A. (2019, 2019/08/08). Parental
29 decision-making following a prenatal diagnosis that is lethal, life-limiting, or has long
30 term implications for the future child and family: a meta-synthesis of qualitative
31 literature. *BMC Medical Ethics*, 20(1), 56. <https://doi.org/10.1186/s12910-019-0393-7>
32
- 33 Bradbury-Jones, C., Aveyard, H., Herber, O. R., Isham, L., Taylor, J., & O'Malley, L. (2021).
34 Scoping reviews: the PAGER framework for improving the quality of reporting.
35 *International Journal of Social Research Methodology*, 1-14.
36 <https://doi.org/10.1080/13645579.2021.1899596>
37
- 38 Brandenburg, H., De Koning, W., Jahoda, M. G. J., Stijnen, T., De Ridder, M. A. J., Sachs, E.
39 S., & Wladimiroff, J. W. (1992, 1992/12/01). Reproductive behaviour and prenatal
40 diagnosis following genetic termination of pregnancy in women of advanced maternal

- 1 age [10.1002/pd.1970121208]. *Prenatal Diagnosis*, 12(12), 1031-1035.
2 <https://doi.org/10.1002/pd.1970121208>
- 3
- 4 Broen, A. N., Moum, T., Bødtker, A. S., & Ekeberg, Ø. (2005, 2005/12/12). The course of
5 mental health after miscarriage and induced abortion: a longitudinal, five-year follow-
6 up study. *BMC Medicine*, 3(1), 18. <https://doi.org/10.1186/1741-7015-3-18>
- 7
- 8 Brooten, D., Youngblut, J. M., Hannan, J., Caicedo, C., Roche, R., & Malkawi, F. (2015).
9 Infant and child deaths: Parent concerns about subsequent pregnancies. *Journal of the*
10 American Association of Nurse Practitioners, 27(12), 690-697.
11 <https://doi.org/10.1002/2327-6924.12243>
- 12
- 13 Bryar, S. H. (1997, 1997/09/01). One day you're pregnant and one day you're not: Pregnancy
14 interruption for fetal anomalies [10.1111/j.1552-6909.1997.tb02159.x]. *Journal of*
15 Obstetric, Gynecologic, & Neonatal Nursing, 26(5), 559-566.
16 <https://doi.org/10.1111/j.1552-6909.1997.tb02159.x>
- 17
- 18 Cacciatore, J., Erlandsson, K., & Rådestad, I. (2013, 2013/05/01/). Fatherhood and suffering:
19 A qualitative exploration of Swedish men's experiences of care after the death of a baby.
20 *International Journal of Nursing Studies*, 50(5), 664-670.
21 <https://doi.org/https://doi.org/10.1016/j.ijnurstu.2012.10.014>
- 22
- 23 Campbell-Jackson, L., Bezance, J., & Horsch, A. (2014). "A renewed sense of purpose":
24 mothers' and fathers' experience of having a child following a recent stillbirth. *BMC*
25 *Pregnancy and Childbirth*, 14, 423-423. <https://doi.org/10.1186/s12884-014-0423-x>
- 26
- 27 Carlson, L. M., & Vora, N. L. (2017). Prenatal Diagnosis: Screening and Diagnostic Tools.
28 *Obstetrics and gynecology clinics of North America*, 44(2), 245-256.
29 <https://doi.org/10.1016/j.ogc.2017.02.004>
- 30
- 31 Carlsson, T., & Mattsson, E. (2018, 2018/01/12). Emotional and cognitive experiences during
32 the time of diagnosis and decision-making following a prenatal diagnosis: A qualitative
33 study of males presented with congenital heart defect in the fetus carried by their
34 pregnant partner. *BMC Pregnancy and Childbirth*, 18(1), 26.
35 <https://doi.org/10.1186/s12884-017-1607-y>
- 36
- 37 Carolan, M., & Hodnett, E. (2009, 2009/12/01/). Discovery of soft markers on fetal ultrasound:
38 Maternal implications. *Midwifery*, 25(6), 654-664.
39 <https://doi.org/10.1016/j.midw.2007.11.002>
- 40

- 1 Cjté-Arsenault, D., & Dombeck, M. T. (2001, Oct-Nov). Maternal assignment of fetal
2 personhood to a previous pregnancy loss: relationship to anxiety in the current
3 pregnancy. *Health Care Women Int*, 22(7), 649-665.
4 <https://doi.org/10.1080/07399330127171>
- 5
- 6 Conde-Agudelo, A., Rosas-Bermúdez, A., & Kafury-Goeta, A. C. (2006). Birth Spacing and
7 Risk of Adverse Perinatal OutcomesA Meta-analysis. *JAMA*, 295(15), 1809-1823.
8 <https://doi.org/10.1001/jama.295.15.1809>
- 9
- 10 Côté-Arsenault, D., & Donato, K. (2011, 2011/02/01). Emotional cushioning in pregnancy
11 after perinatal loss. *Journal of Reproductive and Infant Psychology*, 29(1), 81-92.
12 <https://doi.org/10.1080/02646838.2010.513115>
- 13
- 14 Dallaire, L., Lortie, G., Des Rochers, M., Clermont, R., & Vachon, C. (1995, 1995/03/01).
15 Parental reaction and adaptability to the prenatal diagnosis of fetal defect or genetic
16 disease leading to pregnancy interruption. *Prenatal Diagnosis*, 15(3), 249-259.
17 <https://doi.org/10.1002/pd.1970150308>
- 18
- 19 Dekel, S., Stuebe, C., & Dishy, G. (2017). Childbirth Induced Posttraumatic Stress Syndrome:
20 A Systematic Review of Prevalence and Risk Factors. *Frontiers in psychology*, 8, 560-
21 560. <https://doi.org/10.3389/fpsyg.2017.00560>
- 22
- 23 Dodgson, J. E. (2019, 2019/05/01). Reflexivity in Qualitative Research. *Journal of Human*
24 *Lactation*, 35(2), 220-222. <https://doi.org/10.1177/0890334419830990>
- 25
- 26 Due, C., Chiarolli, S., & Riggs, D. W. (2017, 2017/11/15). The impact of pregnancy loss on
27 men's health and wellbeing: a systematic review. *BMC Pregnancy and Childbirth*,
28 17(1), 380. <https://doi.org/10.1186/s12884-017-1560-9>
- 29
- 30 Evers-Kiebooms, G., Swerts, A., & van den Berghe, H. (1988, 1988/03/01). Psychological
31 aspects of amniocentesis: Anxiety feelings in three different risk groups
32 [10.1111/j.1399-0004.1988.tb03437.x]. *Clinical Genetics*, 33(3), 196-206.
33 <https://doi.org/10.1111/j.1399-0004.1988.tb03437.x>
- 34
- 35 Fernandes, I. B., Xavier, R. B., São Bento, P. A. S., & Rodrigues, A. (2020, Feb). On the way
36 to interrupting the gestation or not: Experiences of pregnant women with anencephalic
37 fetuses. *Cien Saude Colet*, 25(2), 429-438. <https://doi.org/10.1590/1413-81232020252.14812018> (Nas vias de interromper ou não a gestação: vivências de
38 gestantes de fetos com anencefalia.)
- 39
- 40

- 1 Ferreira da Costa, L. d. L., Hardy, E., Duarte Osis, M. J., & Faúndes, A. (2005, 2005/11/01/).
2 Termination of pregnancy for fetal abnormality incompatible with life: Women's
3 experiences in Brazil. *Reproductive Health Matters*, 13(26), 139-146.
4 [https://doi.org/10.1016/S0968-8080\(05\)26198-0](https://doi.org/10.1016/S0968-8080(05)26198-0)
- 5
- 6 Gammeltoft, T., Minh Hằng, T., Thị Hiệp, N., & Thị Thúy Hạnh, N. (2008, 2008/05/01/). Late-
7 term abortion for fetal anomaly: Vietnamese women's experiences. *Reproductive*
8 *Health Matters*, 16(31, Supplement), 46-56. [https://doi.org/10.1016/S0968-](https://doi.org/10.1016/S0968-8080(08)31373-1)
9 [8080\(08\)31373-1](https://doi.org/10.1016/S0968-8080(08)31373-1)
- 10
- 11 Georgsson Öhman, S., Saltvedt, S., Waldenström, U., Grunewald, C., & Olin-Lauritzen, S.
12 (2006, 2006/03/01). Pregnant women's responses to information about an increased risk
13 of carrying a baby with down syndrome [10.1111/j.0730-7659.2006.00075.x]. *Birth*,
14 33(1), 64-73. <https://doi.org/10.1111/j.0730-7659.2006.00075.x>
- 15
- 16 Gold, K. J., Leon, I., & Chames, M. C. (2010, Apr). National survey of obstetrician attitudes
17 about timing the subsequent pregnancy after perinatal death. *Am J Obstet Gynecol*,
18 202(4), 357.e351-356. <https://doi.org/10.1016/j.ajog.2009.11.039>
- 19
- 20 Götzmann, L., Schönholzer, S. M., Kölbl, N., Klaghofer, R., Scheuer, E., Huch, R.,
21 Buddeberg, C., & Zimmermann, R. (2002, 2002/02//). Ultrasound examinations in the
22 context of suspected fetal malformations: Satisfaction of concerned women and their
23 appraisals. *Ultraschall in der Medizin*, 23(1), 27-32. [https://doi.org/10.1055/s-2002-](https://doi.org/10.1055/s-2002-20072)
24 [20072](https://doi.org/10.1055/s-2002-20072)
- 25
- 26 Grisarú-Granovsky, S., Gordon, E.-S., Haklai, Z., Samueloff, A., & Schimmel, M. M. (2009,
27 2009/12/01/). Effect of interpregnancy interval on adverse perinatal outcomes — a
28 national study. *Contraception*, 80(6), 512-518.
29 <https://doi.org/10.1016/j.contraception.2009.06.006>
- 30
- 31 Grote, N. K., Bridge, J. A., Gavin, A. R., Melville, J. L., Iyengar, S., & Katon, W. J. (2010). A
32 meta-analysis of depression during pregnancy and the risk of preterm birth, low birth
33 weight, and intrauterine growth restriction. *Archives of general psychiatry*, 67(10),
34 1012-1024. <https://doi.org/10.1001/archgenpsychiatry.2010.111>
- 35
- 36 Hammond, J., Klapwijk, J. E., Hill, M., Lou, S., Ormond, K. E., Diderich, K. E. M., Riedijk,
37 S., & Lewis, C. (2021, 2021/02/01). Parental experiences of uncertainty following an
38 abnormal fetal anomaly scan: Insights using Han's taxonomy of uncertainty. *Journal of*
39 *Genetic Counseling*, 30(1), 198-210. <https://doi.org/10.1002/jgc4.1311>

- 1 Hill, M., Fisher, J., Chitty, L. S., & Morris, S. (2012, 2012/11/01). Women's and health
2 professionals' preferences for prenatal tests for Down syndrome: a discrete choice
3 experiment to contrast noninvasive prenatal diagnosis with current invasive tests.
4 *Genetics in Medicine*, 14(11), 905-913. <https://doi.org/10.1038/gim.2012.68>
- 5
- 6 Huang, Z., Hao, J., Su, P., Huang, K., Xing, X., Cheng, D., Xiao, L., Xu, Y., Zhu, X., & Tao,
7 F. (2012, 2012/03/01). The Impact of Prior Abortion on Anxiety and Depression
8 Symptoms During a Subsequent Pregnancy: Data From a Population-Based Cohort
9 Study in China. *Klinik Psikofarmakoloji Bülteni-Bulletin of Clinical*
10 *Psychopharmacology*, 22(1), 51-58. <https://doi.org/10.5455/bcp.20111102040509>
- 11
- 12 Irani, M., Khadivzadeh, T., Asghari Nekah, S. M., Ebrahimipour, H., & Tara, F. (2019).
13 Emotional and cognitive experiences of pregnant women following prenatal diagnosis
14 of fetal anomalies: A qualitative study in Iran. *International journal of community based*
15 *nursing and midwifery*, 7(1), 22-31. <https://doi.org/10.30476/IJCBNM.2019.40843>
- 16
- 17 Jones, O. W., Penn, N. E., Shuchter, S., Stafford, C. A., Richards, T., Kernahan, C., Gutierrez,
18 J., Cherkin, P., Reinsch, S., & Dixson, B. (1984, 1984/07/01). Parental response to mid-
19 trimester therapeutic abortion following amniocentesis [10.1002/pd.1970040403].
20 *Prenatal Diagnosis*, 4(4), 249-256. <https://doi.org/10.1002/pd.1970040403>
- 21
- 22 Kelly, S. E. (2009, 2009/01/01). Choosing not to choose: Reproductive responses of parents of
23 children with genetic conditions or impairments. *Sociology of Health & Illness*, 31(1),
24 81-97. <https://doi.org/10.1111/j.1467-9566.2008.01110.x>
- 25
- 26 Kersting, A., & Wagner, B. (2012). Complicated grief after perinatal loss. *Dialogues in clinical*
27 *neuroscience*, 14(2), 187-194. <https://doi.org/10.31887/DCNS.2012.14.2/akersting>
- 28
- 29 Kristjansdottir, H., & Gottfredsdottir, H. (2014, 2014/06/01/). Making sense of the situation:
30 Women's reflection of positive fetal screening 11–21 months after giving birth.
31 *Midwifery*, 30(6), 643-649. <https://doi.org/10.1016/j.midw.2013.10.024>
- 32
- 33 Lafarge, C., Mitchell, K., & Fox, P. (2013, 2013/07/01). Women's experiences of coping with
34 pregnancy termination for fetal abnormality. *Qualitative Health Research*, 23(7), 924-
35 936. <https://doi.org/10.1177/1049732313484198>
- 36
- 37 Lafarge, C., Rosman, S., & Ville, I. (2019, 2019/05/01/). Pregnancy termination for fetal
38 abnormality: Ambivalence at the heart of women's experience. *Women's Studies*
39 *International Forum*, 74, 42-51. <https://doi.org/10.1016/j.wsif.2019.02.007>
- 40

- 1 Larsson, A.-K., Svalenius, E. C., Lundqvist, A., & Dykes, A.-K. (2010, 2010/06/14). Parents'
2 experiences of an abnormal ultrasound examination - Vacillating between emotional
3 confusion and sense of reality. *Reproductive Health*, 7(1), 10.
4 <https://doi.org/10.1186/1742-4755-7-10>
- 5
- 6 Lean, S. C., Derricott, H., Jones, R. L., & Heazell, A. E. P. (2017). Advanced maternal age and
7 adverse pregnancy outcomes: A systematic review and meta-analysis. *PloS one*, 12(10),
8 e0186287-e0186287. <https://doi.org/10.1371/journal.pone.0186287>
- 9
- 10 Leuthner, S. R., Bolger, M., Frommelt, M., & Nelson, R. (2003, 2003/01/01). The impact of
11 abnormal fetal echocardiography on expectant parents' experience of pregnancy: A
12 pilot study. *Journal of Psychosomatic Obstetrics & Gynecology*, 24(2), 121-129.
13 <https://doi.org/10.3109/01674820309042809>
- 14
- 15 Levac, D., Colquhoun, H., & O'Brien, K. K. (2010, 2010/09/20). Scoping studies: advancing
16 the methodology. *Implementation Science*, 5(1), 69. [https://doi.org/10.1186/1748-](https://doi.org/10.1186/1748-5908-5-69)
17 [5908-5-69](https://doi.org/10.1186/1748-5908-5-69)
- 18
- 19 Lotto, R., Smith, L. K., & Armstrong, N. (2017). Clinicians' perspectives of parental decision-
20 making following diagnosis of a severe congenital anomaly: a qualitative study. *BMJ*
21 *Open*, 7(5), e014716-e014716. <https://doi.org/10.1136/bmjopen-2016-014716>
- 22
- 23 McCreight, B. S. (2004). A grief ignored: narratives of pregnancy loss from a male perspective.
24 *Sociology of Health & Illness*, 26(3), 326-350. [https://doi.org/10.1111/j.1467-](https://doi.org/10.1111/j.1467-9566.2004.00393.x)
25 [9566.2004.00393.x](https://doi.org/10.1111/j.1467-9566.2004.00393.x)
- 26
- 27 Menary, J. E. (1987). *The amniocentesis - Abortion experience: A study of psychological*
28 *effects and healing process (Publication Number 8711669) [EdD, Harvard University].*
29 *ProQuest Dissertations & Theses Global.*
- 30
- 31 Miller, E. J., Temple-Smith, M. J., & Bilardi, J. E. (2019). 'There was just no-one there to
32 acknowledge that it happened to me as well': A qualitative study of male partner's
33 experience of miscarriage. *PloS one*, 14(5), e0217395.
34 <https://doi.org/10.1371/journal.pone.0217395>
- 35
- 36 Mills, T. A., Ricklesford, C., Cooke, A., Heazell, A. E. P., Whitworth, M., & Lavender, T.
37 (2014, 2014/07/01). Parents' experiences and expectations of care in pregnancy after
38 stillbirth or neonatal death: a metasynthesis. *BJOG: An International Journal of*
39 *Obstetrics & Gynaecology*, 121(8), 943-950. <https://doi.org/10.1111/1471-0528.12656>

- 1 Moncrieff, G., Finlayson, K., Cordey, S., McCrimmon, R., Harris, C., Barreix, M., Tunçalp,
2 Ö., & Downe, S. (2021). First and second trimester ultrasound in pregnancy: A
3 systematic review and metasynthesis of the views and experiences of pregnant women,
4 partners, and health workers. *PloS one*, 16(12), e0261096.
5 <https://doi.org/10.1371/journal.pone.0261096>
6
- 7 Mujezinovic, F., & Alfirevic, Z. (2007). Procedure-Related Complications of Amniocentesis
8 and Chorionic Villous Sampling: A Systematic Review. *Obstetrics & Gynecology*,
9 110(3).
10
- 11 Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018,
12 2018/11/19). Systematic review or scoping review? Guidance for authors when
13 choosing between a systematic or scoping review approach. *BMC Medical Research*
14 *Methodology*, 18(1), 143. <https://doi.org/10.1186/s12874-018-0611-x>
15
- 16 Nargund, G. (2009). Declining birth rate in Developed Countries: A radical policy re-think is
17 required. *Facts, views & vision in ObGyn*, 1(3), 191-193.
18
- 19 Ndjapa-Ndamkou, C., Govender, L., & Moodley, J. (2013, 2013/05/01). Views and attitudes
20 of pregnant women regarding late termination of pregnancy for severe fetal
21 abnormalities at a tertiary hospital in KwaZulu-Natal : Research. *South African Journal*
22 *of Obstetrics and Gynaecology*, 19(2), 49-52. <https://doi.org/10.10520/EJC135029>
23
- 24 Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017, 2017/12/01). Thematic
25 Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of*
26 *Qualitative Methods*, 16(1), 1609406917733847.
27 <https://doi.org/10.1177/1609406917733847>
28
- 29 Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2020, 2020/01/10). Men's grief following
30 pregnancy loss and neonatal loss: a systematic review and emerging theoretical model.
31 *BMC Pregnancy and Childbirth*, 20(1), 11. <https://doi.org/10.1186/s12884-019-2677-9>
32
- 33 Ockhuijsen, H. D., Boivin, J., van den Hoogen, A., & Macklon, N. S. (2013, Oct). Coping after
34 recurrent miscarriage: uncertainty and bracing for the worst. *J Fam Plann Reprod*
35 *Health Care*, 39(4), 250-256. <https://doi.org/10.1136/jfprhc-2012-100346>
36
- 37 Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016, 2016/12/05). Rayyan—
38 A web and mobile app for systematic reviews. *Systematic Reviews*, 5(1), 210.
39 <https://doi.org/10.1186/s13643-016-0384-4>
40

- 1 Pelly, D. (2003, 2003/03/01). Women's experiences of fetal abnormality. *British Journal of*
2 *Midwifery*, 11(3), 154-159. <https://doi.org/10.12968/bjom.2003.11.3.11125>
3
- 4 Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K.,
5 & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic
6 reviews: A product from the ESRC Methods Programme.
7 <https://doi.org/10.13140/2.1.1018.4643>
8
- 9 Rillstone, P. B. (1999). Prenatal diagnosis of fetal abnormalities: Managing catastrophic
10 psychic pain in a subsequent pregnancy (Publication Number 9946036) [Ph.D.,
11 University of Florida]. ProQuest Dissertations & Theses Global.
12
- 13 Samango-Sprouse, C. A., Porter, G. F., Lasutschinkow, P. C., Tran, S. L., Sadeghin, T., &
14 Gropman, A. L. (2020, 2020/03/01). Impact of early diagnosis and noninvasive prenatal
15 testing (NIPT): Knowledge, attitudes, and experiences of parents of children with sex
16 chromosome aneuploidies (SCAs). *Prenatal Diagnosis*, 40(4), 470-480.
17 <https://doi.org/10.1002/pd.5580>
18
- 19 Sandelowski, M., & Barroso, J. (2007). *Handbook for synthesizing qualitative research*.
20 Springer Pub. Co.
21
- 22 Smith, C., Hashmi, S. S., Czerwinski, J., Wagner, V. F., Promecene, P., Milentijevic, I., &
23 Ramdaney, A. (2021, 2021/04/01). The impact of genetic counseling on women's grief
24 and coping following termination of pregnancy for fetal anomaly [10.1002/jgc4.1338].
25 *Journal of Genetic Counseling*, 30(2), 522-532. <https://doi.org/10.1002/jgc4.1338>
26
- 27 The EndNote Team. (2013). EndNote. In (Version EndNote X9) Clarivate.
28
- 29 Thomas, J., & Harden, A. (2008, Jul 10). Methods for the thematic synthesis of qualitative
30 research in systematic reviews. *BMC Med Res Methodol*, 8, 45.
31 <https://doi.org/10.1186/1471-2288-8-45>
32
- 33 Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D.,
34 Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan,
35 J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., Lewin, S.,
36 Godfrey, C. M., Macdonald, M. T., Langlois, E. V., Soares-Weiser, K., Moriarty, J.,
37 Clifford, T., Tunçalp, Ö., & Straus, S. E. (2018, Oct 2). PRISMA Extension for Scoping
38 Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*, 169(7), 467-
39 473. <https://doi.org/10.7326/m18-0850>
40

- 1 White-Van Mourik, M. C. A. (1989). The psycho-social sequelae of a termination of pregnancy
2 for fetal abnormality (Publication Number 11003330) [M.Sc., University of Glasgow
3]. ProQuest Dissertations & Theses Global.
4
- 5 Wieacker, P., & Steinhard, J. (2010). The prenatal diagnosis of genetic diseases. *Deutsches*
6 *Arzteblatt international*, 107(48), 857-862. <https://doi.org/10.3238/arztebl.2010.0857>
7
- 8 Williams, H. M., Topping, A., Coomarasamy, A., & Jones, L. L. (2020). Men and Miscarriage:
9 A Systematic Review and Thematic Synthesis. *Qualitative Health Research*, 30(1),
10 133-145. <https://doi.org/10.1177/1049732319870270>
11
- 12 Wollenschein, M., Gustke, M., Woopen, C., & Rohde, A. (2007, 2007). A subsequent
13 pregnancy after a termination of pregnancy because of fetal anomaly--All forgotten and
14 a new beginning? *Praxis der Kinderpsychologie und Kinderpsychiatrie*, 56(9), 741-757.
15 <https://doi.org/10.13109/prkk.2007.56.9.741>
16
- 17 World Health Organization. (2007). Report of a WHO technical consultation on birth spacing:
18 Geneva, Switzerland 13-15 June 2005. <https://apps.who.int/iris/handle/10665/69855>
19
- 20 World Health Organization. (2016). WHO Guidelines Approved by the Guidelines Review
21 Committee. In *WHO Recommendations on Antenatal Care for a Positive Pregnancy*
22 *Experience*. World Health Organization.
23
24
25
26
27
28