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Review article

The tools used to assess psychological symptoms in women and their partners after termination of pregnancy for fetal anomaly: A scoping review

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ABSTRACT

Termination of pregnancy for fetal anomaly (TOPFA) represents a uniquely distressing and challenging situation for women and their partners. Having appropriate screening tools that best highlight the psychological symptoms experienced by women and their partners is important to be able to guide care. Many validated screening tools for pregnancy and psychological distress exist, with variation in the ease of application and the domains addressed in each. We undertook a scoping review of tools used to assess psychological symptoms in women and/or partners after TOPFA. Of 909 studies, 93 studies including 6248 women and 885 partners were included. Most of the included studies assessed symptoms within six months of TOPFA and highlighted high rates of distress, grief and trauma symptoms. There was broad variation in the tools used between studies and the timing of their implementation. Focusing the care of women and families who undergo TOPFA to validated, broadly available and easily applied screening tools that assess a range of psychological symptoms is key in being able to identify the potential interventions that may be of benefit.

Introduction

Termination of pregnancy for fetal anomaly (TOPFA) accounts for approximately 5% of all terminations of pregnancy (TOP) in high-income countries. Rates of TOPFA have slowly increased over time, reflecting clinical advances in ultrasound diagnosis, available prenatal screening tests and improved safety of invasive diagnostic procedures [1–4]. Women and their partners who end a pregnancy following a diagnosis of a fetal anomaly are frequently faced with the difficult emotional situation of the loss of a wanted pregnancy [5–7]. This situation presents a unique set of psychological challenges that require adequate support and recognition.

The importance of assessing psychological conditions such as anxiety and depression broadly in pregnancy is well-recognized, and the use of validated mental health screening tools is recommended in national and international guidelines for antenatal care [8,9]. However, specific guidance does not exist for the assessment of psychological symptoms in women with pregnancy complications, specifically women who undergo TOPFA [10]. This is despite recognition that these women have high rates of psychological morbidity [11], and the well-validated sensitivity and specificity of pregnancy-specific tools such as the Edinburgh Postnatal Depression Scale (EPDS) [12].

Most available psychological tools focus on a single particular domain of psychological wellbeing or screen specifically for isolated symptoms. For example, the EPDS specifically target symptoms of depression, whilst State Trait Anxiety Inventory, assesses anxiety symptoms. There are also tools that measure distress or grief such as the Impact of Events Scale [13], and the Perinatal Grief Scale [14], respectively. There are further tools available to assess women's social supports, relationships and attachment as well as general physical symptoms, all of which may be used in a variety of circumstances. These tools vary significantly in the number and complexity of questions asked, the emotional weight of the questions involved, and the scoring systems used for grading, although use of a Likert scale is common.

Many validated tools exist in assessing perinatal psychological symptoms [15], and many more are validated assessing post-traumatic stress symptoms in non-pregnant populations [16]. Although clinical care should always be individualised, having a consistent base to assess psychological symptoms, especially grief, distress, anxiety and depression for women and their families provides an initial step to understanding their specific needs. Importantly, the severity of symptoms, timing after the loss and change in symptoms over time, are all

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important considerations to inform targeted interventions and resource allocation.

This review was performed to investigate the types of tools used to screen for distress and psychological wellbeing in the setting of TOPFA and the symptoms and domains that are screened.

Methods

A scoping review of studies investigating the impact of TOPFA on emotional wellbeing was undertaken to understand the tools that are used to assess emotional wellbeing and distress.

PubMed, Ovid MEDLINE, EMBASE, CINAHL, Web of Science and PsycINFO were searched for studies regarding TOPFA for any fetal anomaly where quantitative outcomes with or without additional qualitative interviews regarding emotional wellbeing were reported.

All studies that reported psychological outcomes of women and/or their partners after a TOPFA or termination for medical reasons (TFMR) were included, regardless of method of sampling, time since diagnosis or country of study. Studies were restricted to those where the abstract was available in English. Studies were excluded if they focused only on reports of psychological outcomes relating to diagnosis of a fetal anomaly and did not mention TOFPA, or studies that explored women's views on termination of pregnancy in the setting of a hypothetical fetal anomaly. The abstract list was screened by two authors. The first author then screened the included full texts, with a random sample (10%) rechecked by the second author. Minor screening conflicts were resolved through discussions between the first and second authors and all authors agreed on the final sample of included studies.

Synthesis was undertaken to understand the types of tools and questionnaires used to assess psychological symptoms including the methodology and timing related to the diagnosis of fetal anomaly. Data were collected on the gestation of the TOPFA and whether the process of termination of pregnancy involved women alone or included their partner. Psychological tools were then grouped by the type of symptom or domain of psychological wellbeing assessed, including depression, anxiety, general health symptoms, grief, post-traumatic stress, general distress, and/or social domains including coping strategies and partner or family support.

Data were collected to understand the timing of application of the tools and whether women's partners were included in the screening.

Results

Overall 909 titles were screened, of which 149 abstracts were assessed and 93 studies were included in this review (Fig. 1). This includes a total of 6248 women who had undergone TOPFA and 885 of their partners. Most of the studies were conducted in Europe, and most were reported after 2010. Studies generally were of relatively small sample size, with an average of 41 women participants, and a quarter (23 studies) including less than 20 women. Overall, 24 studies included women's partners, with the majority assessing both women and their partner, while five studies assessed the partner alone (Table 1).

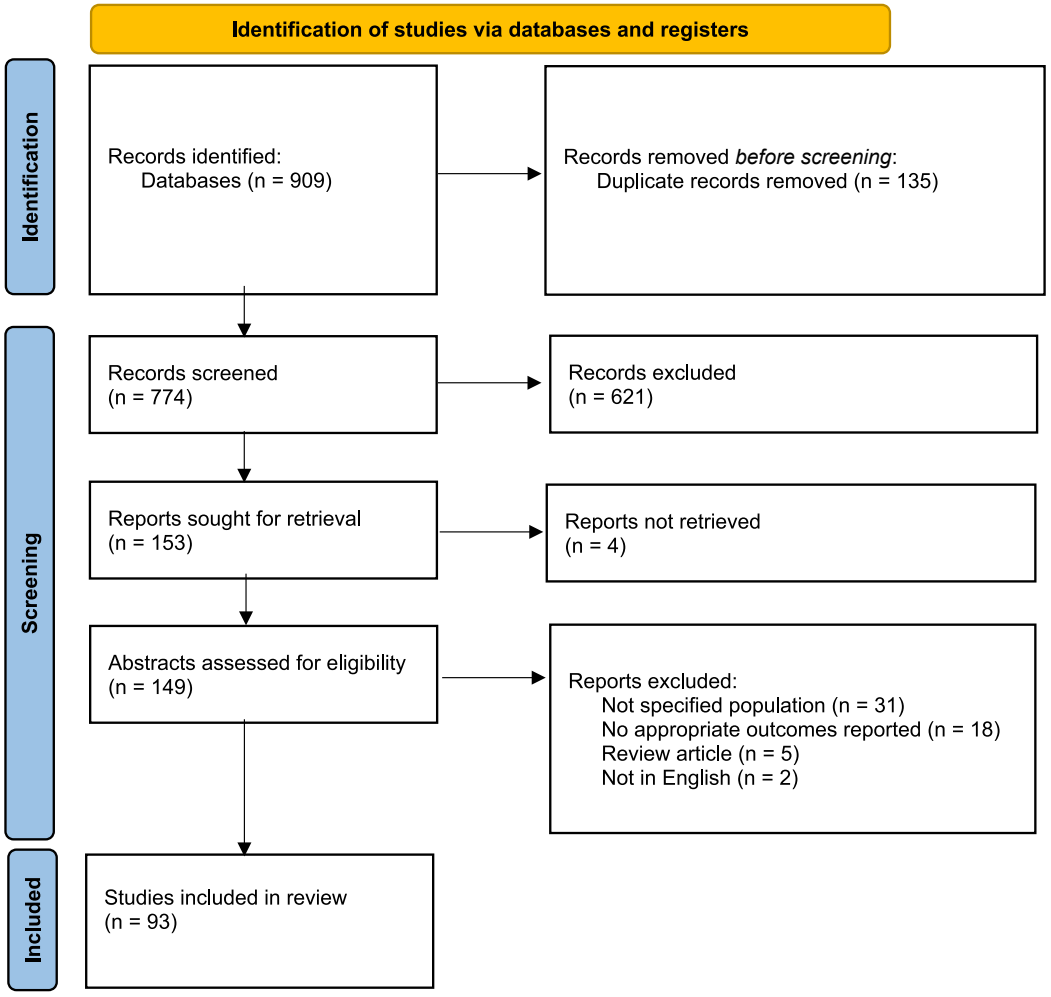

Fig. 1. PRISMA flow diagram. *From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. https://doi.org/10.1136/bmj.n71.

Table 1
Study characteristics of included studies.

Study characteristic	N(%)
Publication date	
- Before 2000	- 10
- 2000-2010	- 17
- 2010-2022	- 66
Studies addressing:	
- Women alone	- 69 (74%)
- Women and partners	- 19 (20%)
- Partners alone	- 5 (6%)
Number of participants (median, (IQR))	
- Women overall	- 41 (24, 100)
- Women undergoing TOPFA	- 36 (21, 89)
- Partners	- 15 (8, 86)
Location of study (n, %)	
- Africa	- 1 (1%)
- Asia	- 17 (18%)
- Europe	- 54 (58%)
- North America	- 14 (15%)
- Oceania	- 4 (4%)
- South America	- 3 (3%)
Including third trimester TOP (n, %)	16 (17%)
Assessment within 6 months of TOPFA (n, %)	- 54 (58%)
Repeated assessment	- 24 (26%)
Multiple psychological tools used for assessment within the same study (n, %)	37/93 (40%)
Included structured or semi/structured interview	52/93 (56%)

Psychological assessment was undertaken by most studies within six months of fetal anomaly diagnosis (58%, 54/93), and 26% (24/93) included assessments at repeated time points after TOFPA. Most studies included women undergoing TOP in the second trimester between 12 and 28 weeks, but 17% included third trimester TOP after 28 weeks of pregnancy. In total, 44 different psychological tools were used (Table 2).

The most commonly used psychological tool was the Perinatal Grief Scale 22% (20/93), closely followed by the Impact of Events Scale – Revised 19% (18/93). Overall, 31% (29/93) of the studies used a unique psychological tool not used by any other study, with another 6% (6/93) used by only two studies and 2% (2/93) were used by three studies (Table 2). There was broad variation in the length of the psychological tools used with a range of four to 144 questions per questionnaire. Many studies used structured or semi-structured interview question techniques 56% (52/93) with or without specific screening tools, including 17% (16/93) which included a specifically developed questionnaire that was not a formal psychological tool.

There was some variation in the timing and exact changes in psychological symptom scores, however overall a gradual reduction was seen with time [17–27]. These studies consistently showed high initial distress scores immediately after TOPFA, with the first follow-up often within a month following TOPFA. Although many of these studies did not show a reduction in symptom scores with time, there was often a broad range of symptom scores at the later follow-up, which was often at 12 months. Most often, the questionnaires used were broad and assessing general symptoms or social situations (Table 3). Depression, anxiety and grief were the most common psychological symptoms assessed.

Discussion

Our scoping review highlights that although a variety of different assessment tools have been used to assess psychological symptoms after TOPFA, there is little consistency either as to the timing of administration of the tools or the most relevant psychological domain assessed. Irrespective of which tool is used and when, the pattern of psychological symptoms appears similar, with high scores indicating distress, grief and symptoms of anxiety and depression in the months after TOPFA, that gradually improve, but do not necessarily resolve completely, at longer term follow-up.

Synthesis of these results was disadvantaged by several limitations.

Table 2
List of included psychological assessment tools included by n (%) of studies.

Tool	Number of studies using	Number of questions
Perinatal Grief Scale	20	33
Impact of Events Scale – Revised	18	22
Edinburgh Postnatal Depression Screen	9	12
Beck Depression Inventory	7	21
State Scale of State Trait Anxiety Inventory	6	20
Inventory of Complicated Grief	4	19
Symptom Checklist-90	4	90
Brief COPE	4	28
Hospital Anxiety and Depression Scale	3	14
Goldberg General Health Questionnaire	3	12
Multi-Dimensional Perceived Social Support	2	13
Generalised Self Efficacy Scale	2	10
Prenatal Attachment Inventory	2	21
Montgomery Asberg Depression Index	2	10
Post-Traumatic Growth Inventory	2	21
Event Related Rumination	2	20
Multidimensional Relationship Questionnaire	1	61
Adult Attachment Scale	1	18
Patient Health Questionnaire	1	9
General Help Seeking Questionnaire	1	20
Beck Anxiety Inventory	1	21
Post Traumatic Checklist Scale	1	20
Relationship Questionnaire	1	4
Brief Symptoms Inventory	1	53
Centrality of Events Scale	1	20
Decisional Conflict Scale	1	16
Hamilton Anxiety Scale	1	14
Engagement with Health Care	1	33
Numerical Rating Scale Fatigue	1	13
General Sleep Disturbance	1	21
Receipt of Spousal Support	1	20
Expanded Texas Inventory	1	13
Irritability Depression Index	1	18
Grief Patterns Inventory	1	10
Conformity to Masculine Norms	1	144
Male Role Norms Inventory	1	39
Crisis Support Scale	1	7
Zung Anxiety Scale	1	20
Family Adaptation Partnership Growth Affection and Resolve Index	1	5
Grief Experience Inventory	1	135
Life Experience Survey	1	57
Self-Rating Anxiety Scale	1	20
Self-Rating Depression Scale	1	20
Social Support Rating Scale	1	10

Table 3
Symptom or psychological domain assessed by included psychological screening tools.

Symptom or domain addressed	Number of studies (n)
Depression	5
Anxiety	6
Grief	6
Social	12
General symptoms	9
Distress	3
Post-traumatic stress	2
Anxiety and depression combined	1
Other	1

There was broad variation in the baseline demographics of women, including their pregnancy characteristics. There were also inconsistencies about whether or not partners were included or separately interviewed, as well as differences in the timing of assessment. None of the papers linked the results of psychological screening tools with validated psychiatric diagnoses, and there are few papers that propose or assess interventions that could be of benefit. Only four of the papers addressed aspects of care that contributed to psychological symptoms

using structured or semi-structured interview techniques, or specifically developed questionnaires [28–31].

To improve the care of families undergoing TOPFA, the most accurate, well-validated and easily applied tools for screening, and timing these to capture symptoms to provide preventative or supportive strategies should be used. There is however, little clarity on exactly what this should be. The choice of questionnaire is a balance between the time and emotional effort for the participant and the value and specificity of information gained. The wellbeing of the participant needs to be considered especially with lengthy questionnaires or questions that involve particularly sensitive or emotional phrasing. It is also important to consider the particular aspects of care that may have contributed to or caused distress as potential areas for improvement.

Assessing a broad range of symptoms and screening for multiple psychological conditions is important. High rates of anxiety, depression and post-traumatic stress can be seen in women and partners following TOPFA. Most of the tools used to assess distress screen for only one psychological symptom domain, which means that more assessments are required to be able to adequately screen for potential concerns. In addition to the particular symptoms that are screened, it is also important to investigate potential specific causes of distress and any factors in the experience that could be altered or moderated to try and minimise psychological distress.

Poor healthcare experiences are highlighted as a cause of specific distress in the setting of TOPFA [28]. A recent systematic review of the healthcare experiences and needs of parents undergoing TOPFA addressed 30 qualitative, quantitative and mixed methods studies. The authors noted the impact of context on care experience, in particular the legal environment and care framework that surrounds TOPFA, and how varied this can be in different locations. The included papers did not link this to psychological symptoms or wellbeing overall. Organisation of care, informed decision making and compassionate care were also highlighted as major themes across the included articles in this study. Finally, the experiences of the partners, who often felt excluded or ignored, emphasised the difficulties in the currently available support structures for partners following TOPFA.

Despite the variation in methods and tools between studies, several studies reported changes in symptoms over time for women who have undergone TOPFA. The range of scores and slow reduction over time highlights the window for potential intervention for women who have undergone TOPFA. Based on the timing of administering these questionnaires, assessment could commence within the initial follow-up period after the procedure, as this is when distress scores appeared to be highest from the limited information available.

In contrast, none of the studies identified in our review which involved partners utilised repeat assessments over time. The only included study of male partners of women undergoing TOPFA in Australia demonstrated that the timing of need for support may be very different for partners [32]. In this analysis, the partners who were interviewed described that in the initial stages they were overwhelmed with needing to support and protect their partners, and felt responsibility to take care of practical tasks. Then as the distress of their partner began to lessen, the grief became more noticeable [32]. This was, however, a small sample and it's likely that individual experiences vary greatly, and support would require tailoring to individual circumstances.

The approach to psychological support for families in the setting of TOPFA could mirror that of support in the setting of stillbirth or neonatal death. In this setting, collaborative psychological and practical support between hospitals, communities and families is recommended as part of routine care [33]. A small number of studies have compared women who have undergone TOPFA with women who have had other forms of pregnancy loss including stillbirth and neonatal death, and found that the levels of distress experienced are similar regardless of the mechanism of the loss [34–37]. Fewer studies still have addressed this same question in partners, although across these, similar rates of distress were reported [32,36].

Conclusion

Focusing the care of women and families who undergo TOPFA to validated, broadly available and easily applied screening tools that assess a range of psychological symptoms is key in being able to identify the potential interventions that may be of benefit. Currently, it appears there is substantial inconsistency in the types and timing of measures used, and few studies have investigated aspects of care that could be addressed or altered to improve psychological wellbeing. Repeated screening to track changes in symptoms over time may also be of benefit to track changes in symptoms and responses to interventions. Timing of both screening and intervention may need to be different for partners in comparison to women.

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Contributorship

The review was conducted by LS and KO, with LS preparing the manuscript which was reviewed by KO, AD and JD.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejogrb.2023.07.003.

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