

ORIGINAL ARTICLE

Termination of pregnancy for fetal anomalies: Parents' preferences for psychosocial care

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Abstract

Objective: To investigate, from the perspective of women and partners, at *what stage* of a termination of pregnancy (TOP) for fetal anomalies psychosocial care (PSC) is most meaningful, *what topics* should be discussed, and *who* should provide PSC.

Method: A cross-sectional retrospective cohort study was conducted with a consecutive series of 76 women and 36 partners, who completed a semi-structured online questionnaire.

Results: Overall, women expressed a greater need for PSC than their partners. Parents expressed a preference for receiving support from a maternal-fetal medicine specialist to help them understand the severity and consequences of the anomalies found and to counsel them in their decision regarding termination. Parents showed a preference for support from mental healthcare providers to help with their emotional responses. Forty-one percent of the women visited a psychosocial professional outside of the hospital after the TOP, indicating a clear need for a well-organised aftercare.

Conclusion: Different disciplines should work together in a complementary way during the diagnosis, decision making, TOP, and aftercare stages. Parents' need for PSC should be discussed at the beginning of the process. During aftercare, attention should be paid to grief counselling, acknowledgement of the lost baby's existence, and possible future pregnancies.

1 | INTRODUCTION

Developments in prenatal screening, prenatal ultrasound, and genetic testing have enabled the detection of a growing range of fetal anomalies and genetic conditions.¹⁻⁴ Consequently, increasing numbers of women and their partners are confronted with the difficult decision of whether to continue with or terminate a pregnancy. In 2015, 19% of all second-trimester (more than 13 weeks) terminations in the Netherlands were conducted in a university centre.⁵ In the Erasmus University Medical Center, Rotterdam, the Netherlands, between 50

and 84 second-trimester pregnancy terminations were conducted each year between 2012 and 2015 because of fetal anomalies.

Pregnant women hope they will never be faced with an active, voluntary decision concerning termination of their pregnancy.⁶ The decision to terminate a desired pregnancy, which in many cases is on account of nonlethal fetal anomalies, is an emotionally overwhelming and complex process for prospective parents.⁷

Previous studies on the psychological consequences of a termination of pregnancy (TOP) have reported high levels of posttraumatic stress symptoms and symptoms of depression in women and their

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partners.⁸⁻¹⁰ Kersting et al¹¹ also found that posttraumatic stress and clinician-rated depressive symptoms 14 months after a late TOP for fetal anomalies (between 15 and 32 weeks, mean of 20.2 weeks) were more pronounced than in women who delivered a premature or a healthy child. A more recent study demonstrated high levels of grief in women up to 6 months following a TOP for a fetal anomaly despite the use of adaptive coping strategies.¹² Ramdaney et al¹³ found that at 6 weeks and 3 months after TOP, many women reported that they were not coping as well as they had anticipated. They were unaware in advance of what psychosocial support they would like to receive and felt unprepared for the psychological consequences of the TOP. Studies have also demonstrated that women are unprepared for the level and duration of the emotional pain and the “roller coaster” of emotions experienced after TOP.^{14,15} This indicates the need for sensitive, nondirective care, which acknowledges the unique nature of anomaly-related TOP.¹⁶ Moreover, identifying women at risk of poor psychological adjustment would provide the opportunity to suggest coping strategies that are associated with lower levels of grief (such as acceptance and positive reframing).¹² In one study, only half of a group of women who were aware of available psychosocial care (PSC) resources reported that they had contemplated their individual need for support. The other half did not anticipate any need for care and rejected this provision both during and after TOP.¹³ Lafarge et al conclude that coordinated care pathways are needed to enable women to make their own decisions regarding supportive care.¹⁴

Post-TOP psychosocial support is perceived as not well organised.^{13,14,17} A study by Ramdaney et al¹³ indicated that women may not realise what their long-term support needs will be. A suggestion has been made for the establishment of guidelines for follow-up care in a flexible timeframe that takes into account the target population's initial decision to decline offered support.¹³

In the Erasmus Medical Center (MC), prenatal diagnostics in the period 2012 to 2015 were performed by a team of specialists comprising prenatal ultrasound specialists, maternal-fetal medicine specialist (MFM specialist), and clinical geneticists. An MFM specialist and a clinical geneticist provided pretest and posttest counselling, with attention to psychosocial aspects. All parents were offered additional PSC from a multidisciplinary PSC team consisting of medical social workers, psychologists, and spiritual caregivers (Christian and Islamic). During hospitalisation, attention was paid to grief counselling, empathic support during and after delivery, and the creation of lasting memories, among other things. If requested by the MFM specialist or by the parents themselves, a member of the PSC team was consulted. Parents were offered two follow-up sessions with an MFM specialist in which medical and psychosocial aspects were discussed. If requested by the MFM specialist or by parents themselves, a maximum of three psychosocial aftercare sessions were offered. These sessions were provided by a medical social worker or psychologist at the hospital centre. Alternatively, parents were referred to a regional healthcare facility outside the hospital.

To the best of our knowledge, no large systematic study has yet been published that has retrospectively examined, from the perspective of the women and their partners, when PSC is most needed, what

What's already known about this topic?

- Pregnancy termination for fetal anomalies has multiple psychological consequences for parents.
- Parents are mostly unaware of the need for psychosocial care during and after pregnancy termination.

What does this study add?

- Knowledge about which stage parents consider to be most meaningful for psychosocial care, the topics that should be discussed, and who should provide psychosocial care.
- Awareness that different disciplines should collaborate during and after the pregnancy termination.

topics most need to be addressed, and who should provide PSC. Therefore, this study aims to answer the following three questions: (a) *At what stage* in the TOP process is PSC most meaningful? (b) *What topics* should be discussed? (c) *Who* should provide PSC?

PSC was defined to the participants in the following terms: (a) attention to, and help with, psychosocial topics, alongside provision of medical and clinical information about the anomalies; (b) help in fully understanding the severity and magnitude of the anomalies found; (c) counselling for the decision whether or not to continue with the pregnancy; and (d) help with emotional reactions during and after the TOP.

Four timeframes were distinguished in the TOP process¹⁷: (a) prenatal testing; (b) diagnosis, counselling, and decision making; (c) giving birth and saying goodbye to the child; and (d) post-termination.

2 | METHODS

2.1 | Inclusion criteria

All women and their partners, who underwent a TOP—by medical treatment—for a detected fetal anomaly in the period 2012 to 2015 at Erasmus MC, were eligible for inclusion in the study. Women treated in 2016 onwards were not included in the study. This was to avoid conflicts of interest, since the research psychologist involved in the study was providing psychological care to this population from this time on.

2.2 | Exclusion criteria

Women were excluded from the study if they (a) were not fluent in Dutch; (b) had proven intellectual disability; (c) underwent a medical TOP because of their own health issues (eg, severe preeclampsia); or (d) were undergoing another TOP at the time the invitations for this study were sent out.

2.3 | Assessment procedure

The Erasmus MC Medical Research and Ethics Committee granted permission for this study. All women received a written invitation and an information letter composed by an MFM specialist and the research psychologist. They were asked to pass on the information letter to their partner or, in cases where the relationship had ended, to their partner at the time of the pregnancy termination. Those willing to participate were asked to return the signed informed consent document (which included their email address) in an enclosed prepaid return envelope.

After informed consent had been provided, a secure online questionnaire was sent by email. Women and partners were instructed to complete this independently of each other. Anonymity was guaranteed. Those who did not respond to the invitation or did not complete the online questionnaire were reminded once by email or telephone.

2.4 | Instrument

At the time of this study, no validated Dutch questionnaire was available with which to answer the current research questions. The authors therefore developed a semi-structured online questionnaire based on a questionnaire used by Levert et al,¹⁸ which aimed to study the PSC needs of children with coronary heart disease and their parents. Adjustments were made as necessary for the specific needs of the respondents in this

study. These adjustments were derived from the international literature^{13,14} and from the clinical expertise of the researchers.

The questionnaire assessed whether women and partners would have liked to receive PSC on a variety of issues. It consisted of 90 multiple-choice questions and 12 open-ended (not mandatory) questions, specific to the abovementioned four timeframes. Responses could be given on a 4-point scale (*No need, Little need, Need, and Very great need*). If the respondents confirmed any degree of need for PSC, they were asked from whom they would have liked to receive this: members of the PSC team (psychologists, medical social workers, and spiritual caregivers [eg, chaplains]), MFM specialist, clinical geneticists, professionals outside the hospital (eg, midwives or general practitioners), or nonprofessionals (partner, family, or friends). For this question, multiple answers were allowed.

2.5 | Data analysis

Descriptive statistics—frequencies and percentages—were applied to describe the need for PSC as reported by women and partners separately, as well as to express preferences regarding from whom to receive support from. Differences in levels of need between the women and the partners were examined with Chi-square tests. Correcting for multiple testing (eg, Bonferroni) was considered but deemed too strict a criterion¹⁹ in view of the exploratory nature of this study.

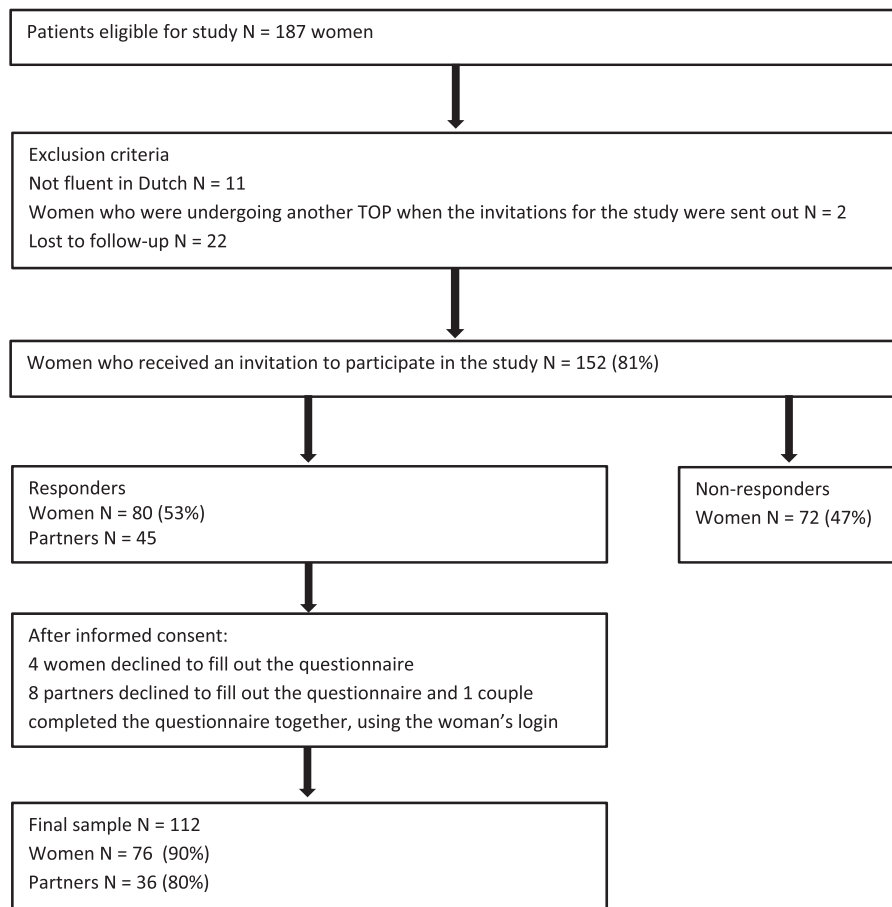


FIGURE 1 Patient flowchart

3 | RESULTS

3.1 | Population

The target population consisted of 187 women. Eighty women and 45 partners (all male) were included in the study (for details, see

Figure 1). Four women and eight partners declined to fill in the online questionnaire after giving their consent. Six women and three partners did not complete the whole questionnaire. One couple completed the questionnaire together. The final sample (complete and incomplete data) therefore consisted of 76 women and 36 partners.

TABLE 1 Demographic characteristics of the respondents

Total sample N = 112	Women N = 76	68%	Partners N = 36	32%
Age	32 years (SD = 5.0)		34 years (SD = 5.1)	
Nationality	European	99%	European	97%
	Canadian	1%	Indonesian	3%
Religion	N = 74		N = 35	
	None	74%	None	80%
	Catholic	14%	Catholic	6%
	Protestant	7%	Protestant	14%
	Muslim	3%		
	Hindu	1%		
	Jehovah	1%		
Education	Low	5%	Low	3%
	Middle	29%	Middle	39%
	High	66%	High	58%
Living status at time of termination. Living with:	Father of child	66%	Mother of child	81%
	Father of child + other children	32%	Mother of child + other children	19%
	Single	1%		
Current living status	Father of child	36%	Mother of child	47%
	Father of child + other children	62%	Mother of child + other children	53%
	Single	1%		
First consultation Mean gestational age:	17 weeks (range 4–23)		17 weeks (range 4–21)	
Term of termination Mean gestational age:	21 weeks (range 12–23)		21 weeks (range 10–23)	
New pregnancy after TOP	N = 73 (100%)		N = 31 (100%)	
	Yes	84%	Yes	74%
How many times pregnant since TOP	N = 61		N = 23	
	One time	63%	Ones	61%
	Twice	28%	Twice	26%
	Three times	7%	Three times	13%
	Four times	2%		
	Five times	2%		
Another pregnancy loss	N = 61		N = 23	
	No	74%	No	78%
	One time	20%	One time	17%
	More than one time	7%	More than one time	4%
How did you lose the next pregnancy?	N = 12		N = 4	
	Miscarriage	83%	Miscarriage	75%
	TOP for fetal anomalies	17%	TOP for fetal anomalies	25%
How many children after the TOP	N = 57		N = 21	
	One	84%	One	71%
	Two	14%	Two	24%
	Three	2%	Three	5%
Are they healthy?	N = 57		N = 21	
	Yes	91%	Yes	100%
	No	9%	(one carrier of thyroid gland disease, one born at 27 weeks pregnancy)	
	(Ieri Weill, skin disease, carrier of thyroid gland disease, schisis, carrier ciliopathy)			

3.2 | Biographical and demographic characteristics

In total, 112 respondents filled in the questionnaire; of these, 68% were women and 32% partners. At the time of data collection, all respondents had the same partner as at the time of the TOP. In the 4-year period of data collection, 27% of the women lost another pregnancy, and in the partner population, 21% had more than one loss of pregnancy (Table 1).

3.3 | Prenatal diagnosis stage

Overall, women and partners reported similar degrees of need for PSC—*Need* and *Very great need*—on the following topics: *information about the anomalies, feelings of insecurity about the severity of the anomalies, fear of losing the pregnancy, feelings of lack of control, and having to decide about further prenatal diagnostics*. Overall, women and partners agreed that an MFM specialist should provide this PSC, with the exception of the topic *feelings of lack of control*, for which a member of the PSC team was preferred.

Significant differences between women and partners were found in the areas *dealing with conflicting feelings* and *dealing with intense emotions*; on these issues, the women expressed *Very great need* and the partners *No need*. On the topic *how prenatal diagnostics had affected them as a person*, women expressed a *Need* for care, whereas partners expressed *No need*. Women preferred counselling from a PSC team member on this topic (Table 2).

3.4 | Diagnosis and decision-making stage

Regarding this period, women and partners both expressed having *Very great need* for *understanding of information regarding the anomalies* and *deciding whether to continue with or terminate the pregnancy*. Both women and partners expressed they would prefer an MFM specialist to provide this information. Significant differences in need level between women and partners were seen on the following topics: *impact on me as a person, dealing with conflicting feelings, dealing with intense emotions, and having no control*. Partners indicated *No need* on these topics, whereas women expressed *Need* on the first three topics and *Little need* for *having no control* (Table 3).

3.5 | Hospitalisation and delivery stage

Both women and partners expressed *Very great need* for information on *emotional impact after the termination* and *Need* for *information about grieving*. Women expressed *Need* for *information about coping with pain during delivery*, whereas partners reported *No need* regarding this topic. This difference was statistically significant. Partners most frequently expressed *Need* on the topic *information about aftercare*; women expressed varying needs on this topic but, overall, expressed *Little need* most often. Women expressed *Very great need*, and partners reported *Need* for PSC regarding *the delivery, what to expect after delivery, counselling in seeing the baby for the first time and holding the*

baby, coping with strong feelings, different possibilities for creating lasting memories, and practical information. In general, women and partners agreed about from whom (what discipline) they preferred to receive PSC from (Table 4).

3.6 | Post-termination stage

Regarding the follow-up period (between 1 and 4 years after TOP), women and partners both expressed a *Need* for PSC to *discuss their desire for another pregnancy and future plans*. Partners expressed *Need* for *explanation about the grieving process* and *No need* for *active counselling for their grieving process*. Notable differences between women and partners were seen in the following: *acknowledgement of the existence of your lost child and counselling during a future pregnancy*, with women selecting *Very great need* but partners expressing *No need*. Regarding the topic *knowing what kind of aftercare was available and how to receive it*, women selected *Need*, whereas partners mostly reported *No need*. There was almost total agreement between women and partners regarding preferences for who (the preferred discipline) should provide this PSC. On all topics, a member of the PSC team was favoured—except in the case of counselling during a future pregnancy, where both women and partners preferred a member of the PSC team and an MFM specialist (Table 5).

3.7 | Follow-up counselling by professionals outside the hospital

Forty-one percent of the women reported having sought support from a professional outside of the hospital, mostly on account of the following: *their grieving process* (65%), *finding a balance between grieving and returning to "normal life"* (61%), *depressive symptoms* (32%), *differences in coping between themselves and their partners* (29%), *"feeling like myself" again* (26%), *anxiety symptoms* (23%), and *posttraumatic stress disorder (PTSD) symptoms* (19%). Almost one-third of the partners had sought professional counselling outside the hospital. Reasons expressed were *their grieving process* (81%), *differences in coping between themselves and their partners* (50%), *depressive symptoms* (40%), *finding a balance between grieving and returning to normal life* (40%), and *coping with other children in the family* (30%) (Table 6).

4 | DISCUSSION

4.1 | Preferences around the timing of PSC and topics to discuss

Overall, the women reported a greater need for PSC than their partners. Regarding the stages of diagnosis and decision making, the women expressed significantly more need for PSC in dealing with emotional responses. Both women and partners reported a need for PSC to fully understand the severity and the consequences of the anomalies found and for help with making the decision whether to continue with or terminate the pregnancy.

TABLE 2 Percentage desired PSC, and if PSC is desired, which discipline is favoured to discuss specific topics during the prenatal diagnosis stage

Topics	Percentage of Desired PSC (total 100%) Women (N = 76) / Partners (N = 35)						If Desire for PSC is Expressed, Percentage Discipline That is Favoured for Each Subject ^a													
	No Need		Little Need		Need		Lots of Need		Physician			Psychosocial Care Team			Professional Outside Hospital			Nonprofessional		
	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P
Understanding the information about the anomalies	17.1 N = 13	20.0 N = 7	21.1 N = 16	17.1 N = 6	23.7 N = 18	28.6 N = 10	38.2 N = 29	34.3 N = 12	95.2 N = 60	100.0 N = 28	14.3 N = 9	14.3 N = 9	7.1 N = 2	1.6 N = 1	3.6 N = 1	4.8 N = 3	7.1 N = 2			
Insecurities about the severity of the anomalies	14.5 N = 11	20.0 N = 7	19.7 N = 15	17.1 N = 6	28.9 N = 22	25.7 N = 9	36.8 N = 28	37.1 N = 13	90.8 N = 59	92.9 N = 26	15.4 N = 10	15.4 N = 10	0.0 N = 0	4.6 N = 3	0.0 N = 0	7.7 N = 5	3.6 N = 1			
Feelings of lack of control over the situation	13.2 N = 10	31.4 N = 11	28.9 N = 22	25.7 N = 9	23.7 N = 18	28.6 N = 10	34.2 N = 26	14.3 N = 5	30.3 N = 20	25.0 N = 6	65.2 N = 43	65.2 N = 43	54.2 N = 13	12.1 N = 8	16.7 N = 4	27.3 N = 18	20.8 N = 5			
Fear of losing the pregnancy	18.4 N = 14	20.0 N = 7	23.7 N = 18	25.7 N = 9	36.8 N = 28	37.1 N = 13	21.1 N = 16	17.1 N = 6	59.7 N = 37	71.4 N = 20	41.9 N = 26	41.9 N = 26	39.3 N = 11	12.9 N = 8	0.0 N = 0	22.6 N = 14	14.3 N = 4			
Deciding about further prenatal diagnostics	27.6 N = 21	28.6 N = 10	26.3 N = 20	25.7 N = 9	28.9 N = 22	31.4 N = 11	17.1 N = 13	14.3 N = 5	85.5 N = 47	72.0 N = 18	25.5 N = 14	25.5 N = 14	40.0 N = 10	3.6 N = 2	20.0 N = 5	16.4 N = 9	16.0 N = 4			
Dealing with intense emotions	14.5 N = 13	48.6 ^b N = 17	25.0 N = 20	17.1 N = 6	28.9 N = 20	25.7 N = 9	31.6 ^b N = 23	8.6 N = 3	16.9 N = 11	11.1 N = 2	67.7 N = 44	67.7 N = 44	55.6 N = 10	20.0 N = 13	22.2 N = 4	27.7 N = 18	27.8 N = 5			
Dealing with conflicting feelings	17.1 N = 11	45.7 ^b N = 16	26.3 N = 19	8.6 N = 3	26.3 N = 22	28.6 N = 10	30.3 ^b N = 24	17.1 N = 6	20.6 N = 13	15.8 N = 3	74.6 N = 47	74.6 N = 47	57.9 N = 11	23.8 N = 15	26.3 N = 5	22.2 N = 14	31.6 N = 6			
Effect on me as a person	26.3 N = 20	40.0 ^b N = 14	17.1 N = 13	22.9 N = 8	32.9 ^b N = 25	28.6 N = 10	23.7 N = 18	8.6 N = 3	19.6 N = 11	23.8 N = 5	64.3 N = 36	64.3 N = 36	47.6 N = 10	17.9 N = 10	28.6 N = 6	39.3 N = 22	23.8 N = 5			
Extra compassion and comprehension	34.2 N = 26	57.1 N = 20	28.9 N = 22	28.6 N = 10	23.7 N = 18	8.6 N = 3	13.2 N = 10	5.7 N = 2	20.0 N = 10	13.3 N = 2	54.0 N = 27	54.0 N = 27	60.0 N = 9	22.0 N = 11	20.0 N = 3	42.0 N = 21	20.0 N = 3			
Reactions of network	39.5 N = 30	5.7 N = 16	31.6 N = 24	17.1 N = 6	13.2 N = 10	31.4 N = 11	15.8 N = 12	5.7 N = 2	8.7 N = 4	15.8 N = 3	63.0 N = 29	63.0 N = 29	57.9 N = 11	19.6 N = 9	26.3 N = 5	34.8 N = 16	36.8 N = 7			
Dealing with family and friends	44.7 N = 34	60.0 N = 21	32.9 N = 25	20.0 N = 7	17.1 N = 13	14.3 N = 5	5.3 N = 4	5.7 N = 2	7.1 N = 3	7.1 N = 1	64.3 N = 27	64.3 N = 27	57.1 N = 8	21.4 N = 9	21.4 N = 3	31.0 N = 13	28.6 N = 4			
Dealing with (future) siblings	64.5 N = 49	60.0 N = 21	18.4 N = 14	22.9 N = 8	14.5 N = 11	11.4 N = 4	2.6 N = 2	5.7 N = 2	11.1 N = 3	7.1 N = 1	74.1 N = 20	74.1 N = 20	57.1 N = 8	18.5 N = 5	21.4 N = 3	22.2 N = 6	35.7 N = 5			
Difference of opinion between partners	65.8 N = 50	74.3 N = 26	15.8 N = 12	8.3 N = 3	11.8 N = 9	8.3 N = 3	6.6 N = 5	8.3 N = 3	11.5 N = 3	22.2 N = 2	61.5 N = 16	61.5 N = 16	44.4 N = 4	15.4 N = 4	33.3 N = 3	42.3 N = 11	0.0 N = 0			

Abbreviation: PSC, psychosocial care.

^aTotal does not add up to 100%; women and partners were allowed to choose multiple discipline.^bStatistically significant difference between women and partners.

TABLE 3 Percentage desired PSC, and if PSC is desired, which discipline is favoured to discuss specific topics during diagnosis and decision-making stage

Topics	Percentage of Desired PSC (total 100%) Women (N = 74) / Partners (N = 34)						If Desire for PSC is Expressed, Percentage Discipline That is Favoured for Each Subject ^a									
	No Need		Little Need		Need		Lots of Need		Physician		Psychosocial Care Team		Professional Outside Hospital		Nonprofessional	
	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P
Understanding of information regarding the anomalies	23.0 N = 17	20.6 N = 7	17.6 N = 13	14.7 N = 5	23.0 N = 17	32.4 N = 11	36.5 N = 27	32.4 N = 11	93.0 N = 53	100 N = 27	17.5 N = 1	3.7 N = 1	1.8 N = 1	0.0 N = 0	7.0 N = 4	3.7 N = 1
Deciding whether to continue or terminate the pregnancy	18.9 N = 14	29.4 N = 10	20.3 N = 15	17.6 N = 6	24.3 N = 18	17.6 N = 6	36.5 N = 27	35.3 N = 12	85.0 N = 51	95.8 N = 23	40.0 N = 24	33.3 N = 8	5.0 N = 3	0.0 N = 0	16.7 N = 10	16.7 N = 4
Impact on me as a person	18.9 N = 14	44.1 ^b N = 15	31.1 N = 23	23.5 N = 8	33.8 ^b N = 25	17.6 N = 6	16.2 N = 12	14.7 N = 5	25.0 N = 15	21.1 N = 4	63.3 N = 38	73.7 N = 14	16.7 N = 10	26.3 N = 5	28.3 N = 17	31.6 N = 6
Dealing with conflicting feelings	21.6 N = 16	47.1 ^b N = 16	25.7 N = 19	20.6 N = 7	29.7 ^b N = 22	26.5 N = 9	23.0 N = 17	5.9 N = 2	19.0 N = 11	16.7 N = 3	67.2 N = 39	55.6 N = 10	17.2 N = 10	33.3 N = 6	24.1 N = 14	50.0 N = 9
Dealing with intense emotions	20.3 N = 15	50.0 ^b N = 17	27.0 N = 20	29.4 N = 10	29.7 ^b N = 22	11.8 N = 4	23.0 N = 17	8.8 N = 3	8.5 N = 5	5.9 N = 1	71.2 N = 42	58.8 N = 10	16.9 N = 10	29.4 N = 5	27.1 N = 16	35.3 N = 6
Feelings of lack of control	23.0 N = 17	50.0 ^b N = 17	32.4 ^b N = 24	20.6 N = 7	27.0 N = 20	20.6 N = 7	17.6 N = 13	8.8 N = 3	31.6 N = 18	11.8 N = 2	61.4 N = 35	58.8 N = 10	14.0 N = 8	35.3 N = 6	15.8 N = 9	35.3 N = 6
Extra compassion and comprehension	35.1 N = 26	58.8 N = 20	29.7 N = 22	36.5 N = 9	24.3 N = 18	11.8 N = 4	10.8 N = 8	2.9 N = 1	22.9 N = 11	0.0 N = 0	58.3 N = 28	71.4 N = 10	18.8 N = 9	35.7 N = 5	39.6 N = 19	35.7 N = 5
Dealing with family and friends	51.4 N = 38	55.9 N = 19	27.0 N = 20	29.4 N = 10	13.5 N = 10	14.7 N = 5	8.1 N = 6	0.0 N = 0	11.1 N = 4	13.3 N = 2	52.8 N = 19	46.7 N = 7	19.4 N = 7	33.3 N = 5	44.4 N = 16	53.3 N = 8
Dealing with (future) siblings	67.6 N = 50	67.6 N = 23	20.3 N = 15	20.6 N = 7	9.5 N = 7	11.8 N = 4	2.7 N = 2	0.0 N = 0	12.5 N = 3	18.2 N = 2	70.8 N = 17	36.4 N = 4	8.3 N = 2	36.4 N = 4	20.8 N = 5	54.5 N = 6
Difference of opinion between partners	70.3 N = 52	67.6 N = 23	10.8 N = 8	23.5 N = 8	12.2 N = 9	0.0 N = 0	6.8 N = 5	8.8 N = 3	27.3 N = 6	18.2 N = 2	59.1 N = 13	72.7 N = 8	4.5 N = 1	18.2 N = 2	13.6 N = 3	9.1 N = 1
Culture and religion	81.1 N = 60	85.3 N = 29	9.5 N = 7	5.9 N = 2	5.4 N = 4	5.9 N = 2	4.1 N = 3	2.9 N = 1	14.3 N = 2	0.0 N = 0	50.0 N = 7	40.0 N = 2	28.6 N = 4	60.0 N = 3	42.9 N = 6	80.0 N = 4

Abbreviation: PSC, psychosocial care.

^aTotal does not add up to 100%; women and partners were allowed to choose multiple discipline.^bStatistically significant difference between women and partners.

TABLE 4 Percentage desired PSC and if PSC is desired which discipline is favoured, to discuss specific topics during hospitalisation and delivery stage

Topics	Percentage of Desired PSC (total 100%) Women (N = 73) / Partners (N = 33)						If Desire for PSC is Expressed, Percentage Discipline That is Favoured for Each Subject ^a									
	No Need		Little Need		Need		Lots of Need		Physician/Nurse		PSC Team		Professional Outside Hospital		Nonprofessional	
	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P
Emotional impact after the termination	16.4 N = 12	15.2 N = 5	19.2 N = 14	27.3 N = 9	24.7 N = 18	27.3 N = 9	39.7 N = 29	30.3 N = 10	53.6 N = 15	59.0 N = 36	57.4 N = 35	67.9 N = 19	6.6 N = 4	17.9 N = 5	3.3 N = 2	10.7 N = 3
What to expect after delivery (eg, appearance)	11.0 N = 8	15.2 N = 5	17.8 N = 13	9.1 N = 3	27.4 N = 20	45.5 N = 15	43.8 N = 32	30.3 N = 10	85.7 N = 24	83.1 N = 54	26.2 N = 17	28.6 N = 8	4.6 N = 3	3.6 N = 1	9.2 N = 6	3.6 N = 1
Counselling in seeing and holding the baby	20.5 N = 15	21.2 N = 7	11.0 N = 8	15.2 N = 5	24.7 N = 18	36.4 N = 12	43.8 N = 32	27.3 N = 9	80.8 N = 21	72.4 N = 42	44.8 N = 26	53.8 N = 14	3.4 N = 2	3.8 N = 1	8.6 N = 5	11.5 N = 3
Different possibilities of creating lasting memories	11.0 N = 8	12.1 N = 4	16.4 N = 12	24.2 N = 8	30.1 N = 22	33.3 N = 11	42.5 N = 31	30.3 N = 10	58.6 N = 17	55.4 N = 36	58.5 N = 38	58.6 N = 17	9.2 N = 6	13.8 N = 4	16.9 N = 11	17.2 N = 5
Information about the delivery	9.6 N = 7	18.2 N = 6	13.7 N = 10	12.1 N = 4	37.0 N = 27	45.5 N = 15	39.7 N = 29	24.2 N = 8	88.9 N = 24	97.0 N = 64	9.1 N = 6	25.9 N = 7	3.0 N = 2	3.7 N = 1	3.0 N = 2	3.7 N = 1
Counselling in coping with strong feelings after birth	15.1 N = 11	24.2 N = 8	20.5 N = 15	21.2 N = 7	27.4 N = 20	33.3 N = 11	37.0 N = 27	21.2 N = 7	36.0 N = 9	40.3 N = 25	62.9 N = 39	68.0 N = 17	8.1 N = 5	12.0 N = 3	21.0 N = 13	20.0 N = 5
Practical information (eg, funeral, insurance)	13.7 N = 10	18.2 N = 6	21.9 N = 16	15.2 N = 5	31.5 N = 23	36.4 N = 12	32.9 N = 24	30.3 N = 10	40.7 N = 11	61.9 N = 39	57.1 N = 36	66.7 N = 18	9.5 N = 6	18.5 N = 5	3.2 N = 2	11.1 N = 3
Information about grieving	21.9 N = 16	21.2 N = 7	21.9 N = 16	24.2 N = 8	31.5 N = 23	33.3 N = 11	24.7 N = 18	21.2 N = 7	30.8 N = 8	26.3 N = 15	75.4 N = 43	80.8 N = 21	15.8 N = 9	23.1 N = 6	12.3 N = 7	19.2 N = 5
Information about aftercare	12.3 N = 9	21.2 N = 7	34.2 ^b N = 25	12.1 N = 4	21.9 N = 16	51.5 ^b N = 17	31.5 N = 23	15.2 N = 5	34.6 N = 9	46.9 N = 30	62.5 N = 40	76.9 N = 20	12.5 N = 8	23.1 N = 6	1.6 N = 1	7.7 N = 2
Coping with pain during the delivery	13.7 N = 10	39.4 ^b N = 13	26.0 N = 19	15.2 N = 5	35.6 ^b N = 26	33.3 N = 11	24.7 N = 18	12.1 N = 4	85.0 N = 17	93.7 N = 59	7.9 N = 15	30.0 N = 6	4.8 N = 13	5.0 N = 11	1.6 N = 11	5.0 N = 11
Dealing with doubt or conflicting feelings	32.9 N = 24	51.5 N = 17	26.0 N = 19	21.2 N = 7	15.1 N = 11	15.2 N = 5	26.0 N = 19	12.1 N = 4	43.8 N = 7	30.6 N = 15	77.6 N = 38	81.3 N = 13	6.1 N = 3	12.5 N = 2	16.3 N = 8	25.0 N = 4
Dealing with (future) siblings	71.2 N = 52	72.7 N = 24	11.0 N = 8	9.1 N = 3	8.2 N = 6	15.2 N = 5	9.6 N = 7	3.0 N = 1	22.2 N = 2	28.6 N = 6	71.4 N = 15	77.8 N = 7	14.3 N = 3	22.2 N = 2	9.5 N = 2	33.3 N = 3
Dealing with family and friends	56.2 N = 41	66.7 N = 22	20.5 N = 15	15.2 N = 5	9.6 N = 7	12.1 N = 4	13.7 N = 10	6.1 N = 2	27.3 N = 3	21.9 N = 7	56.3 N = 18	63.6 N = 7	12.5 N = 4	18.2 N = 2	25.0 N = 8	45.5 N = 5
Culture and religion	79.5 N = 58	90.9 N = 30	9.6 N = 7	3.0 N = 1	2.7 N = 2	3.0 N = 1	8.2 N = 6	3.0 N = 1	0.0 N = 0	46.7 N = 7	53.3 N = 8	66.7 N = 2	6.7 N = 1	66.7 N = 2	20.0 N = 3	0.0 N = 0

Abbreviation: PSC, psychosocial care.

^aTotal does not add up to 100%; women and partners were allowed to choose multiple discipline.^bStatistically significant difference between women and partners.

TABLE 5 Percentage desired PSC and if PSC is desired which discipline is favoured, to discuss specific topics during the post-termination stage

Topics	Percentage of Desired PSC (total 100%) Women (N = 73) / Partners (N = 33)												If Desire for PSC is Expressed, Percentage Discipline That is Favoured for Each Subject ^a																																																																																																																																																																																																																																																																			
	No Need				Little Need				Need				Lots of Need				Physician				Psychosocial Care Team				Hospital				Professional Outside				Nonprofessional																																																																																																																																																																																																																																															
	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P																																																																																																																																																																																																																																																
Explanation about the grieving process	24.7	27.3	26.0	15.2	23.3	42.4	26.0	15.2	12.7	8.3	81.8	91.7	30.9	33.3	10.9	8.3	17.8	21.2	30.1	27.3	27.4	24.2	24.7	27.3	60.0	61.5	51.7	61.5	13.3	11.5	13.3	11.5	27.4	48.5	23.3	12.1	16.4	24.2	32.9	15.2	15.1	5.9	81.1	88.2	30.2	47.1	22.6	23.5	23.3	42.4	21.9	9.1	24.7	30.3	30.1	18.2	66.1	47.4	51.8	73.7	23.2	26.3	8.9	10.5	30.1	27.3	19.2	21.2	30.1	33.3	20.5	18.2	52.9	50.0	52.9	62.5	27.5	25.0	15.7	16.7	23.3	36.4	24.7	12.1	32.9	33.3	19.2	18.2	30.4	23.8	73.2	90.5	25.0	33.3	8.9	9.5	27.4	36.4	27.4	27.3	21.9	18.2	23.3	18.2	3.8	0.0	62.3	81.0	41.5	38.1	15.1	19.0	30.1	45.5	21.9	24.2	27.4	18.2	20.5	12.1	3.9	0.0	70.6	88.9	39.2	38.9	29.4	27.8	31.5	48.5	30.1	24.2	20.5	18.2	17.8	9.1	6.0	0.0	66.0	82.4	38.0	35.3	24.0	35.3	35.6	57.6	21.9	12.1	20.5	9.1	21.9	21.2	6.4	0.0	66.0	92.9	42.6	42.9	17.0	21.4	39.7	60.6	17.8	12.1	19.2	9.1	23.3	18.2	15.9	0.0	61.4	92.3	34.1	46.2	20.5	23.1	41.1	60.6	20.5	15.2	20.5	12.1	17.8	12.1	7.0	0.0	65.1	84.6	32.6	46.2	30.2	15.4	43.8	54.5	17.8	15.2	23.3	18.2	15.1	12.1	12.2	13.3	68.3	86.7	39.0	40.0	26.8	20.0	49.3 ^b	69.7 ^b	24.7	3.0	8.2	12.1	17.8	15.2	5.4	0.0	67.6	90.0	35.1	50.0	24.3	10.0	50.7	63.6	19.2	9.1	16.4	18.2	13.7	9.1	5.6	0.0	72.2	83.3	38.9	41.7	27.8	16.7	52.1	66.7	24.7	9.1	15.1	12.1	8.2	12.1	5.7	0.0	68.6	90.9	40.0	36.4	28.6	27.3	56.2	63.6	19.2	15.2	8.2	9.1	16.4	12.1	12.5	0.0	71.9	75.0	40.6	50.0	18.8	16.7

(Continues)

TABLE 5 (Continued)

Topics	Percentage of Desired PSC (total 100%) Women (N = 73) / Partners (N = 33)						If Desire for PSC is Expressed, Percentage Discipline That is Favoured for Each Subject ^a									
	No Need		Little Need		Need		Lots of Need		Physician		Psychosocial Care Team		Professional Outside Hospital		Nonprofessional	
	W	P	W	P	W	P	W	P	W	P	W	P	W	P	W	P
Problems in my relation following the termination	N = 41	N = 21	N = 14	N = 5	N = 6	N = 3	N = 12	N = 4	N = 4	N = 0	N = 23	N = 9	N = 13	N = 6	N = 6	N = 3
	68.5	78.8	9.6	3.0	9.6	12.1	12.3	6.1	8.7	0.0	69.6	100.0	34.8	42.9	30.4	14.3
Dealing with (future) siblings	N = 50	N = 26	N = 7	N = 1	N = 7	N = 4	N = 9	N = 2	N = 2	N = 0	N = 16	N = 7	N = 8	N = 3	N = 7	N = 1
	71.2	72.7	15.1	3.0	5.5	15.2	8.2	9.1	14.3	0.0	71.4	88.9	23.8	33.3	19.0	33.3
Sexual problems following the termination	N = 52	N = 24	N = 11	N = 1	N = 4	N = 5	N = 6	N = 3	N = 3	N = 0	N = 15	N = 8	N = 5	N = 3	N = 4	N = 3
	72.6	78.8	13.7	3.0	5.5	12.1	8.2	6.1	15.0	0.0	70.0	100.0	30.0	71.4	20.0	14.3
Culture and religion	N = 53	N = 26	N = 10	N = 1	N = 4	N = 4	N = 6	N = 2	N = 3	N = 0	N = 14	N = 7	N = 6	N = 5	N = 4	N = 1
	75.3	87.9	15.1	3.0	6.8	3.0	2.7	6.1	11.1	0.0	55.6	100.0	27.8	75.0	33.3	50.0
	N = 55	N = 29	N = 11	N = 1	N = 5	N = 1	N = 2	N = 2	N = 2	N = 0	N = 10	N = 4	N = 5	N = 3	N = 6	N = 2

Abbreviation: PSC, psychosocial care.

^aTotal does not add up to 100%; women and partners were allowed to choose multiple discipline.

^bStatistically significant difference between women and partners.

Regarding the stages of hospitalisation and delivery, both women and partners expressed need or a great need for information about the delivery and what emotions to expect after the birth—such as when saying goodbye to the baby, creating lasting memories, and in the grieving process. They also expressed a need for practical information (such as about the funeral and insurance). Although previous studies have acknowledged the importance of aftercare,^{13,14} the results of this study clarify for which topics in particular women and partners would like to receive PSC. Additionally, these results emphasise the importance of discussing the possibility of a future pregnancy and, for women, active counselling in the event a future pregnancy.

Acknowledgement of the baby's existence and of the parents' suffering were also identified as topics for counselling, in corroboration of previous studies^{14,15} and stressing that healthcare professionals should pay sufficient attention to these aspects. Regret about the decision to terminate the pregnancy was not mentioned as a motivator for seeking professional counselling, in line with previous literature.^{8,9,20,21}

All respondents were part of a couple, but all filled-in the questionnaire individually (except for one couple). Of course, as a couple, they had shared the same experience, which may explain the overall agreement found on 50 of the 59 topics (85%). Previous research also has shown corresponding emotional reactions in women and partners on a prenatal or postnatal diagnosis of a congenital anomaly.²²

Remarkably, the respondents did not express a need for PSC for depressive symptoms, grieving, or finding the balance between grieving and resuming normal life in the period following TOP. This is even more remarkable considering that 41% of the women sought professional aftercare outside of the hospital: for counselling in their grieving process, to help them find a balance between grieving and resuming normal life, and to cope with depressive symptoms. This latter finding is consistent with previous literature.^{8-11,13,23} A possible explanation for this tendency to seek aftercare is that grieving the loss of a pregnancy and a child is a logical and natural process, and parents are likely to choose their own time and place to cope with the loss. They may feel no PSC is needed from a university medical centre or may prefer a professional outside the hospital setting.

4.2 | Preference regarding from whom to receive PSC

Lalor et al²⁴ concluded that the way in which healthcare professionals communicate adverse diagnoses to parents leaves room for improvement and suggested that specific education on this issue should be offered. The results of this study make it clear from whom/what discipline women and partners would have preferred to receive PSC in the different stages of the TOP process. This knowledge may help improve the counselling of this population and the organisation of PSC.

Regarding the first two stages, both women and partners reported a preference for their MFM specialist supporting them in making the decision about further prenatal diagnostics. For discussion of parallel psychological themes, such as overwhelming and intense emotion,

TABLE 6 Professional counselling outside the hospital following the TOP

	Women (N = 76)		Partners (N = 36)		
Professional counselling outside the hospital	Yes	41%	Yes	28%	
	No	59%	No	72%	
Counselling from which discipline? (multiple caregivers possible)	N = 31		N = 10		
	Psychologist	81%	Psychologist	60%	
	General practitioner	19%	General practitioner	30%	
	General practice counsellor	19%	General practitioner counsellor	20%	
	Social worker	13%	Spiritual leader	20%	
	Psychiatrist	3%	social worker	10%	
	Spiritual leader	3%			
Reason for need of counselling (multiple reasons possible)	N = 31		N = 10		
	Grieving process	65%	Grieving process	80%	
	Balance grieving and returning to 'normal life'	61%	Difference in coping between partners	50%	
	Coping with network	36%	Depressive symptoms	40%	
	Depressive symptoms	32%	Balance grieving and returning to 'normal life'	40%	
	Difference in coping between partners	29%	Coping with network	40%	
	Feeling like myself again	26%	Coping with other children in the family	30%	
	Anxiety symptoms	23%			
	PTSD symptoms	19%	Feeling like myself again	20%	
	Problems in relationship	3%	Anxiety symptoms	10%	
	Sexual problems	3%	Sexual problems	10%	
	Coping with other children in the family	3%			
	Coping with physical problems	3%			
	<i>other: Counselling for a new pregnancy, burn-out, lack of counselling from the hospital</i>				

Abbreviation: TOP, termination of pregnancy.

the preference would be for a member of the PSC team. Regarding hospitalisation and information about delivery, coping with pain, and what to expect post-delivery, both women and partners expressed a preference for an MFM specialist and a nurse. An MFM specialist or a nurse and a member of the PSC team were the preferred providers of information about emotional effects and the possibilities for creating lasting memories. The importance of creating and sharing lasting memories has been shown previously.^{15,25-27} Crawley et al²⁸ found that a high degree of memory sharing after the loss of a child was associated with fewer PTSD symptoms in the mothers. Women should therefore be encouraged to not only create lasting memories but also share them with their partner, family, and friends.

Parents reported a preference for discussing the desire for a future pregnancy with both a member of the PSC team and an MFM specialist. In the event of a new pregnancy, women expressed a slightly greater preference for active counselling from an MFM specialist than from a member of the PSC team.

Nonprofessionals (eg, partners, family, and friends) were infrequently mentioned as preferred persons from whom to receive PSC. This is remarkable, because all respondents indicated that they had remained in the same relationship. In the study by Korenromp et al,⁹ support from partners was shown to be associated with less distress during and after a TOP. It may well be that women and partners primarily focused on what PSC the professionals from the hospital could provide. Furthermore, some parents might find it hard to disclose their reasons for terminating the pregnancy with family and

friends. Receiving PSC from them might therefore be awkward.²⁹ The fact that all the participating couples in this study had stayed together following the TOP could indicate that they were in stable and supportive relationships. Thus, their need for PSC could perhaps be taken as a baseline need for couples confronted with a TOP. Couples facing more psychological consequences post-TOP, such as those implicit in the breakdown of a relationship, may have an even greater need for PSC.

Receiving 'solid' information and PSC from professionals can help prevent psychological symptoms from developing post-TOP,^{14,23,30} but until now, it is not clear what disciplines should be involved at the different stages. The results of our study provide guidance on this issue.

4.3 | Limitations

This was a single-centre study, and one in which respondents with the highest level of education were overrepresented. Both factors may have induced selection bias. Selection bias was found in a large-scale cohort study investigating nonparticipation³¹ and in other studies into similar subjects.^{9,12,16,23}

In this study, 74% of the women respondents and 80% of the partners reported having no religion. This largely nonreligious character of the sample may have influenced the answers and emotions expressed. More research is needed to study the need for PSC of religious people, as concluded in previous literature.^{32,33}

Assessing data retrospectively may have introduced recall and recollection bias. A previous study¹³ revealed, however, that half of the women respondents were unaware of their psychosocial needs when questioned on these, during and immediately after the TOP process. It can therefore be considered a strength of the current study that the respondents were given time to recollect their memories and reflect on their PSC needs.

In this study, only those parents who decided to terminate the pregnancy following diagnosis of a fetal anomaly were studied. It is suggested that future research might address the specific PSC needs of parents who decide to continue with the pregnancy after such a diagnosis.

4.4 | Clinical implications

Even though increasing attention is being paid to the psychosocial aspects of TOP, the results from this study demonstrate a substantial existing need for PSC across all TOP phases. It is recommended that in all phases, professionals from different disciplines should work together in a complementary way.

PSC during hospitalisation should be offered as standard to all women and partners, with special attention to preparation for the delivery, seeing their baby, the creating of lasting memories (involving photos, footprints and handprints if possible, or the baby's cap), practical information, grief counselling, and information about emotional effects.

This study recommends discussing the need for PSC and aftercare in the early stages of the process, preparing parents for reflection on their own needs and making them aware of what is available in terms of aftercare. Counselling on the desire for a future pregnancy, and PSC in the event of a new pregnancy, should be provided by an MFM specialist and a member of the PSC team.

More than a quarter of the women in our study endured a further loss through miscarriage or another TOP. Further research should address the psychological consequences and specific PSC needs of women at high risk of another pregnancy loss.

Studies conducted in the United States, the United Kingdom, and Switzerland have shown that patients perceive aftercare as unorganised.^{13,17,23} However, a bereavement intervention (involving, for instance, acknowledgement of the loss, honouring special requests around the passing of the baby, lasting memories, participation in a naming ceremony, follow-up telephone calls validating the loss, and the encouraging of women to seek support), administered immediately after the loss, enhanced women's ability to cope with this.²⁵ Forty-one percent of the women and 28% of the partners in the present study had sought professional care outside the hospital. Taking into account these high percentages, the psychological consequences of TOP,^{11,12,20} and the beneficial effect of a bereavement intervention,¹⁵ this study recommends easily accessible, well-organised aftercare from professionals trained in working with this specific population. Fisher et al³⁴ found that women saw support organisations (such as Antenatal Results and Choices [ARC] or the Stillbirth and Neonatal

Death Charity [SANDS] in the United Kingdom)—alongside healthcare professionals—as a major source of information and emotional support. Efforts should be made, therefore, to set up country-based support organisations. The results of this study may serve as recommendations for professionals working with this population to further optimise their PSC.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available because of privacy or ethical restrictions.

CONFLICT OF INTEREST

None of the authors has a conflict of interest to declare.

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How to cite this article: Dekkers FHW, Go ATJI, Stapersma L, Eggink AJ, Utens EMWJ. Termination of pregnancy for fetal anomalies: Parents' preferences for psychosocial care. *Prenatal Diagnosis.* 2019;39:575-587. <https://doi.org/10.1002/pd.5464>