We, the undersigned, welcome the opportunity to provide a submission to the parliamentary enquiry regarding the current situation relating to the health, care and wellbeing of mothers and babies in Victoria during the perinatal period. We refer specifically to patient experiences of prenatal testing, increasingly a routine part of the pregnancy experience for many women and couples in Victoria. Our submission draws upon recently published findings from ARC funded empirical research performed at two Victorian public hospital and one private obstetric setting (the PeTALS project). The study investigated over 100 patient experiences in Victoria after they received a prenatal diagnosis of a fetal abnormality, and findings are supported by health practitioners’ experiences in clinical practice and a clinical ethicist. Two relevant peer reviewed publications are attached. (Hodgson et al 2016, Pitt et al 2016)

In summary, our research provides clear evidence that, following prenatal diagnosis of a fetal abnormality, Victorian couples are receiving less than optimal levels of care. Patients frequently reported feeling unsupported during this highly stressful time that was characterised by shock, overwhelming sadness, isolation and feelings of guilt. We highlight three major areas of concern:

1. **Lack of relevant, accurate information on which to base important decisions**

   Once they received a prenatal diagnosis participants commonly experienced significant distress and many highlighted a lack of support in decision-making about whether or not to continue their pregnancy. For many participants, the information given about conditions such as Down syndrome appeared to be based on negative, outdated stereotypes that do not accurately reflect the lived experience of many parents of children with these conditions. As a result couples may be unable to make fully informed choices following prenatal diagnosis.

2. **Those who received a diagnosis of a life-limiting condition and chose to continue their pregnancy often described a lack of appropriate support.**

   In other countries, perinatal hospice care programs exist to provide quality care for couples in these circumstances so that they may maximise their pregnancy experience and the well-being of their baby before and after birth and death. The care offered to couples in our study who received such a diagnosis varied greatly between settings.

3. **Those who decided to terminate their pregnancy after a diagnosis of a fetal anomaly frequently reported inadequate levels of care and support at the time of the procedure and in the often difficult months that followed.**

   The PeTALS study highlighted two major issues for these women and their partners: (a) lack of access to abortion services (b) negative attitudes of health professionals involved in patient care

   **a) Difficult access to abortion services**

   Across the public and private sector, many participants in our research waited up to 2 weeks for an abortion procedure. Some described a lack of assistance from their health professionals in identifying an appropriate clinician and needed to resort to Google or the Yellow Pages to locate a private abortion provider at a high financial cost. Access in the public system was complicated by internal referral to “Termination Review Panels” (TRPs) at some public hospitals that exist to assess who should be allowed to receive abortion services after 20 weeks gestation. Some of our participants reported difficult experiences with these TRPs. They created delays at a medically crucial and emotionally fraught time, and led to some patients having to seek abortion service provision for themselves elsewhere at their own cost, even though their prenatal testing was performed in the public system. The TRPs exist despite Victorian law that allows abortion to be
performed for any reason up to 24 weeks gestation. The structure and makeup of these committees is far from transparent, with no clear evidence that the views and situation of the women or couples will be well represented. A further concern is that the type of abortion procedure offered (e.g. dilation and curettage (D&C), dilation and extraction (D&E) and Induction of Labour) arbitrarily varied between sites with no evidence of patients being offered choices about this.

b) Perceived negative attitudes from health professionals involved in care

Some research participants described feeling that the health professionals involved in their care lacked empathy for their situation and both women and men frequently perceived being negatively ‘judged’ by a range of health providers for choosing to end their pregnancy.

The long-term consequences appeared to be very significant and many described how their challenging experience continues to impact negatively over time, particularly when contemplating further pregnancies. The willingness of so many couples to relate their story at length for research (interviews lasted 1-3 hours) is particularly poignant as many reported feeling constrained in talking about this event with other family members and friends for fear of being ‘shamed’ for their decision.

It is puzzling that this lack of adequate care provision exists when prenatal screening and testing is actively encouraged in the community. Other types of health screening such as Bowelscreen and Breastcare are enshrined within reliable, carefully planned pathways of care and follow up support that were established prior to the establishment of the screening services. We question whether it is the association of prenatal testing with politicised concepts such as disability or abortion or both that makes it different to other health programs.

Involvement in our project was limited to couples who could communicate in English so it is very likely that our findings under-represent the distress for patients who have a low level of English. Despite the current inadequate service provision, processes are underway to facilitate greater access to more sophisticated tests such as non-invasive prenatal testing (NIPT). While these tests can provide more information at an earlier gestation than has previously been possible, they have the potential to increase anxiety and uncertainty. Before that happens it is vital to ensure that prenatal testing programmes are sufficiently and appropriately resourced.

Our recommendations are:

- Prior to offering prenatal diagnostic tests, all pregnant women and their partners need to receive sufficient information about available tests and the conditions that are tested for. Individuals should understand that tests may lead to a need for challenging decisions.
- Patients receiving a prenatal diagnosis of a fetal abnormality need to be referred to appropriate services such as genetic counselling in a timely fashion so they can make choices that are informed by accurate and relevant information, deliberation and support regardless of the choice they make.
- Patients who choose to continue their pregnancy need to receive relevant support in preparing for the birth of a baby with additional needs or a baby who is likely to die before or after birth.
- Patients who choose to terminate their pregnancy require timely access to abortion procedures, non-judgemental care and follow up. Resources need to be available to ensure there is adequate provision of abortion procedures and trained staff.

Offering prenatal testing without providing necessary support and follow up incurs financial and psychological costs to Victorian couples. It is also unethical.
Experiences of prenatal diagnosis and decision-making about termination of pregnancy: A qualitative study

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Background: Advances in genetic technologies and ultrasound screening techniques have increased the ability to predict and diagnose congenital anomalies during pregnancy. As a result more prospective parents than ever before will receive a prenatal diagnosis of a fetal abnormality. Little is known about how Australian women and men experience receiving a prenatal diagnosis and how they make their decision about whether or not to continue the pregnancy.

Aims: This qualitative study aims to describe parental experiences and examine how best to provide support after a prenatal diagnosis.

Results: Individual in-depth interviews were conducted with 102 women and men approximately six weeks post-diagnosis of fetal abnormality. Data were elicited using a narrative, chronological approach and women (n=75) and a sample of male partners (n=27) were separately interviewed. Thematic analysis, involving a rigorous process of qualitative coding, enabled iterative development and validation of emergent themes. Participants identified that the shock of the diagnosis can be lessened when good care is delivered, by provision of: clear, accurate and respectful communication; empathic, non-judgemental, professional support; timely access to further testing and appointments; seamless interactions with services and administration; appropriate choices about invasive testing; acknowledgment of the enormity and unexpected nature of the diagnosis, and of the subsequent decision-making challenges; and discussion of the myriad feelings likely to emerge throughout the process.

Conclusions: This study has demonstrated the importance of providing timely access to accurate information and supportive, non-judgemental care for women and their partners following prenatal diagnosis of a fetal abnormality.

Key words: decision-making, fetal abnormality, prenatal diagnosis, qualitative, termination of pregnancy.

Introduction

Little is known of Australian women’s and couples’ experiences of prenatal diagnosis and subsequent decision-making; international data reveal shock, anxiety and acute grief reactions1-4 and report intense distress, regardless of the severity of the condition diagnosed.2,3,5,6 Decision-making after prenatal diagnosis is known to be challenging for women and their partners3 and can arouse decisional conflict and decision regret.7

Recent data from Victoria, Australia indicate that, when a fetal abnormality such as Down syndrome is diagnosed prenatally, the majority of pregnancies are terminated.8 Termination of pregnancy (TOP) performed in these circumstances is associated with greater psychological morbidity than TOP for non-fetal indications.9 It is therefore imperative to determine how best to support parents after a prenatal diagnosis and facilitate informed decision-making about TOP.

The PeTALS project (Prenatal Testing: A Longitudinal Study) is exploring the experiences of women and their male partners who receive a prenatal diagnosis for a variety of conditions with variable severity. The study aims to identify social and professional supports needed and used at the time of diagnosis and in the months and years that follow. Here we report a large sample of individual interviews conducted approximately six weeks after a definitive prenatal diagnosis, describing women’s and men’s experiences, their support needs and the factors...
they considered when making a decision about whether or
not to terminate their pregnancy.

Materials and Methods

Setting
Prenatal screening is utilised by over 80% of pregnant
women in Victoria.\textsuperscript{10} While second trimester serum
screening is fully funded by the Victorian Department of
Health, first trimester combined screening (first trimester
nuchal, nasal bone and serum screening) incurs a private
fee. Non-invasive testing of cell-free DNA (maternal
plasma) is commercially available in Australia and is a
user-pays test.\textsuperscript{†} Genetic counselling is usually available to
Victorian couples who receive a prenatal diagnosis.\textsuperscript{11}

Ethics approval
Human Research Ethics Committee approvals were
obtained to recruit patients from three antenatal settings
in Victoria, Australia: one private ultrasound practice and
two public hospitals (University of Melbourne: 1237351; Monash Surgical Private Hospital 12100;
Mercy Hospital for Women: R12/60; Royal Women's
Hospital: R12/41).

Participants
Purposive, convenience sampling identified eligible
participants who: had recently received a prenatal
diagnosis of a fetal chromosomal, cardiac or other
structural abnormality; were \( \geq \) 18 years of age; had
attended genetic counselling; and were English speaking.

Recruitment
Genetic counsellors approached eligible women and
couples at, or shortly after, the time of diagnosis and
provided verbal and written study information. Those who
agreed to their contact details being passed on to
researchers were telephoned after two weeks to enrol in
the study.

Participation
Telephone interviews involved participants relating their
story of prenatal diagnosis and the events that followed.
Eligible couples agreed to be interviewed separately, at the
same time or within a few days of each other.

The semi-structured interview guide followed a
narrative and chronological style, exploring experiences of:
early pregnancy, undertaking screening in pregnancy, first
indication of abnormality, considering and undertaking
invasive testing, making a decision about termination of

\(^{†}\)http://www.vcgs.org.au/perceptNIPT/

pregnancy, support sources utilised during this time
(formal and informal) and perceptions of impact on the
couple’s relationship. Experiences of termination
procedure and after-care, or expectations of remaining
months of pregnancy will be reported elsewhere.

Data management and analysis
Interviews were audio recorded and transcribed verbatim.
Transcripts were validated, de-identified and participants
assigned pseudonyms. Analysis was managed in NVivo 10
(QSR International Pty Ltd, Melbourne, Australia). Thematic
analysis, involving a rigorous process of qualitative
coding and discussion by several team members
to identify similarities and differences, enabled iterative
development and validation of emergent themes.\textsuperscript{12}

Results

Participation
Between July 2012 and October 2013, 59 women were
invited to participate; of these, 39 women agreed.
Additionally between May 2014 and April 2015, 61
couples were approached with 36 consenting, comprising
27 male/female couples (interviewed as individuals) and
nine women who participated without their partner.
Overall, 75 pregnancies are represented by the 102
participants in this sample, from 120 eligible pregnancies,
giving a participation rate of 62.5%. Characteristics of
the participants and the pregnancies are described in
Table 1.

Findings are presented using quotes as exemplars and
attributed to participants by pseudonym, diagnostic
category and pregnancy outcome, either a TOP or
intention to continue the pregnancy (CP). Some quotes
have been truncated for ease of reading without changing
meaning as indicated by ‘…..’.

‘…..we didn’t see it coming’
First indications that something was amiss often occurred
during a ‘routine’ ultrasound; participants anticipated
seeing their baby and felt unprepared for an extreme
shift in emotional state after disclosure of a high-risk
result:

I just thought …..it would be a routine
ultrasound…..we didn’t see it coming. Kate, other
chromosomal, TOP

Being given a private space to absorb the unexpected
information was appreciated:

They said, ‘OK we’ll leave you in the room for a
minute just to get yourselves together’. And then (my
partner) and I cried together. They came back in, and
that’s when I felt like we could hear more information.
Rochelle, structural anomalies, TOP
Prenatal diagnosis & decision-making

Table 1 Characteristics of participants (n = 102) and the 75 pregnancies represented in this sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>75 (74)</td>
</tr>
<tr>
<td>Men</td>
<td>27 (26)</td>
</tr>
<tr>
<td>Age range of participants</td>
<td></td>
</tr>
<tr>
<td>18–29 years</td>
<td>18 (18)</td>
</tr>
<tr>
<td>30–35 years</td>
<td>40 (39)</td>
</tr>
<tr>
<td>36–39 years</td>
<td>28 (27)</td>
</tr>
<tr>
<td>40–49 years</td>
<td>16 (16)</td>
</tr>
<tr>
<td>Gravidity, n = 75</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>19 (25)</td>
</tr>
<tr>
<td>2+</td>
<td>56 (75)</td>
</tr>
<tr>
<td>Parity, n = 75</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>32 (43)</td>
</tr>
<tr>
<td>1+</td>
<td>43 (57)</td>
</tr>
<tr>
<td>Prenatal diagnosis, n = 75</td>
<td></td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>24 (32)</td>
</tr>
<tr>
<td>Structural anomalies:</td>
<td></td>
</tr>
<tr>
<td>(arthrogryposis, renal agenesis, unilateral cleft lip and absent corpus callosum, acrania, omphalocele, ventriculomegaly, intrauterine growth restriction, posterior urethral valves, multiple brain abnormalities, hydrocephalus, limb and bone abnormalities)</td>
<td>15 (20)</td>
</tr>
<tr>
<td>Other trisomies:</td>
<td>12 (16)</td>
</tr>
<tr>
<td>(T18, T13)</td>
<td></td>
</tr>
<tr>
<td>Other chromosomal:</td>
<td>11 (15)</td>
</tr>
<tr>
<td>(monosomy X, uniparental disomy 14, derivative chromosome, mosaic T4, triploidy, Smith-magenis, 22q11 triplication)</td>
<td></td>
</tr>
<tr>
<td>Cardiac anomalies:</td>
<td>10 (13)</td>
</tr>
<tr>
<td>(hypoplastic right heart, hypoplastic left heart, tetralogy of Fallot, right atrial isomerism, ventricular septal defect, transposition of great arteries, right aortic arch)</td>
<td></td>
</tr>
<tr>
<td>Single gene mutation:</td>
<td>3 (4)</td>
</tr>
<tr>
<td>(spinal muscular atrophy, Marfan syndrome)</td>
<td></td>
</tr>
<tr>
<td>Pregnancy outcome, n = 75</td>
<td></td>
</tr>
<tr>
<td>Termination of pregnancy</td>
<td>59 (79)</td>
</tr>
<tr>
<td>Intention to continue pregnancy†</td>
<td>16 (21)</td>
</tr>
<tr>
<td>Gestation at diagnosis</td>
<td>Range: 10–21 weeks</td>
</tr>
<tr>
<td>Interview length, mean</td>
<td>84 min</td>
</tr>
<tr>
<td>(range: 35–179 min)</td>
<td></td>
</tr>
</tbody>
</table>

†At the time of the first interview, two of these pregnancies had resulted in fetal death in utero.
‡A mean gestation cannot be calculated as these data were often approximated or self-reported gestation.

Considering and experiencing diagnostic testing

When considering further invasive diagnostic testing, participants commonly assessed the risk of a procedure-related miscarriage and sought advice from health professionals to allay fears:

The risk of miscarriage from chorionic villus sampling (CVS) was a lot less likely than the chances of it being (condition) so there was really no issue in my decision. Melinda, other trisomy, TOP

I actually spoke to (health professional) quite a bit during that week because she was a really good support, just to have someone to talk to. Grace, structural anomalies, TOP

Confidence in the practitioner was cited as reassuring and contributed to the decision to have invasive testing:

You hear that the amnio risks depend on who does them and I was confident that (health professional) had done many of them. Zoe, other trisomy, TOP

Prompt referral for the diagnostic procedure was highly valued (row 1, Table 2). Despite diagnostic testing being incredibly stressful, participants reported aspects of care that contributed to a better experience. In particular: being given choices about viewing ultrasound images (row 2, Table 2) and feeling well treated by caring staff (row 3, Table 2).

An agonising wait

Following prenatal diagnosis, participants who paid a surcharge could access fluorescent in situ hybridisation (FISH) testing with preliminary results available the following day but others waited ≥ 2 weeks for the full karyotype. Results were usually disclosed over the telephone and aspects of the disclosure process that were important included: being informed about when results would be available and, for those having FISH testing, when results would be finalised and having choice in how and to whom results would be disclosed (row 4, Table 2). When expectations of receiving results were not met, stress and anxiety were exacerbated:

(Health professional) was supposed to ring with the results on Friday but she wasn’t working that day… I was planning to tell family and friends on the weekend…. I thought ‘oh my god, how am I going to go the whole weekend?’… I was constantly ringing the hospital to see if they had my results. Kylie, other chromosomal, TOP

A ‘shocking’ disclosure

Even when participants knew when and how they would receive results, hearing the result was described as ‘shocking’. In some cases this was made worse by the perceived insensitivity of the person involved:

I don’t like the way they delivered the news at all…. ‘oh well that’s what you expected wasn’t it?’
was trying to hold on to some hope. Madeline, trisomy 21, TOP

Many participants recalled feeling unsupported immediately after receiving the diagnosis and expressed a need for better access to comprehensive information:

We weren’t given any particular booklets or brochures or directed to any particular website . . . .we had to go seek the information ourselves. Poppy, trisomy 21, TOP

Empathic acknowledgement of the enormity of the news by health professionals and access to timely follow up were greatly valued (rows 5 and 6, Table 2).

The ‘hardest part’ of the process

Participants identified the ‘hardest part’ of their experience as having to make a decision about continuing or terminating the pregnancy:

Table 2 Perceptions of ‘good care’ during diagnostic testing and results disclosure

<table>
<thead>
<tr>
<th>Description of care received</th>
<th>Representative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Being given a prompt referral for procedure</td>
<td>We had an amnio the next day,(health professional?) did offer to do it that night but by that point we had been at the hospital for about three hours and it was the end of the day and we were both pretty worked up and we just needed time to take a deep breath. Fiona, structural anomalies, TOP</td>
</tr>
<tr>
<td>2. Being given choice about viewing the image on ultrasound</td>
<td>It’s a pretty brutal procedure to see on the screen….you can see an unborn child on the screen and you can see a needle penetrating through the womb and the amniotic sac. Daniel, trisomy 21, TOP. I had my eyes closed the whole time I didn’t want to see the procedure, my husband was next to me. Heather, trisomy 21, TOP. I think if (my partner) had her time over again….she wouldn’t have access to viewing the screen at the time of scanning….in hindsight it might have been just a little bit too much. Ben, single gene mutation, TOP</td>
</tr>
<tr>
<td>3. Feeling supported and well treated by staff</td>
<td>I was nervous about it, but the (health professional) was fantastic. …it was just really normal and over in a couple of seconds. Isla, structural anomalies, TOP. We went and had our amnio which was surprisingly uncomfortable…..like a sore ache sort of thing. But they were really nice while they did that. Evelyn, other trisomy, CP</td>
</tr>
<tr>
<td>4. Setting expectations and having a choice about results disclosure</td>
<td>I didn’t want to handle any more bad news so I actually contacted the (health professional) and said ‘can you call my husband with the results and he can give the results to me?’ I didn’t want to take bad news over the phone. Beth, cardiac anomaly, CP. They gave us the option of getting the results within 24 hours, you pay a little extra to get them quicker or we can just wait the 2 weeks. (Partner) wanted to wait the two weeks to give it, you never know if time can heal or something might change in two weeks and it fixes itself or some miracle. Richard, trisomy 21, TOP</td>
</tr>
<tr>
<td>5. Having the enormity of the news acknowledged by the health professional</td>
<td>(The health professional) was fantastic, he laid it out very clearly for us just simply said ‘Look you have a crap decision between really crap options’ Fiona, structural anomalies, TOP. It was probably the clearest, thing, words I’ll ever, I’ll always remember them. She introduced herself and then she said, ‘look I’m afraid it’s not good news’. And, I could feel straight away like my heart kind of thumping up, all those things and then she said ‘the baby’s got Down syndrome’. Dianne, trisomy 21, TOP</td>
</tr>
<tr>
<td>6. Receiving timely follow-up after being given the results</td>
<td>After (the health professional) delivered the news she was concerned about where I was and whether I was supported….she offered a taxi to get me to her office and then offered to see me, she asked could my husband come…..she met with the both of us and talked it through. Poppy, trisomy 21, TOP</td>
</tr>
</tbody>
</table>

In describing their experiences, participants talked about the health professionals involved in their care. In this paper, the term ‘health professional’ has been used in quotes to replace identifying information as participants sometimes used names as well as titles, and it was not always possible to determine a precise profession category. The health professional types involved in care included: obstetricians, midwives, general practitioners, genetic counsellors, nurses, geneticists, sonologists.
...that’s the hardest part; it’s not whether you have a test or not, it’s what you do about that result. Natalie, other trisomy, CP

For most participants the decision was not immediately clear:

Being confronted with it you have no choice but to make a decision...at the time I just thought I don’t want to make a decision because I don’t want either option, I wish that neither of them were there. Janet, trisomy 21, TOP

Several described changing their prior views about termination of pregnancy:

At first we thought we will terminate if (baby) turns out to be sick but once we got the diagnosis and we were in the counselling session, we were sort of ambiguous but we were leaning towards keeping (baby) Evelyn, other trisomy, CP

Many described having to choose between two horrible options:

Making that decision......I felt like I’d been given two bags, or two buckets of shit and I was being asked to choose which bucket I’d like. Dianne, trisomy 21, TOP

Provision of relevant, unbiased information, in a caring way, about likely prognosis and termination procedure options contributed to more positive experiences:

(Health professional) went through all of the results and was really open and honest, went through the process of being induced and again it was still my choice and I didn’t feel like I was being rushed into making the decision. Georgia, structural anomalies, TOP

Participants articulated important elements of their decision-making about whether or not to continue the pregnancy (Table 3). In addition to specific information about the condition, these included consideration of: prior views on abortion and disability, perceived impact on family life, what/how others might think about their decision and what others would do/have done in similar circumstances.

Valuing confirmation of the decision about the pregnancy

Those who chose to terminate their pregnancy appreciated having their decision validated by others and viewed this as a subtle, but very helpful, aspect of the care they received:

When we had that conversation, the specialist then said ‘what you’ve decided is what the majority of people do in your situation, I couldn’t tell you that before because I can’t influence your decision, but you have really made the right decision for the baby’. Patricia, cardiac anomaly, TOP

Discussion

This study describes experiences of a large sample of women and their male partners at the time of prenatal diagnosis and during decision-making about TOP for a range of conditions with variable severity. The findings provide further evidence of the significant demands imposed on parents’ psychological resources after prenatal diagnosis of fetal anomaly.

Despite limited empirical evidence, practitioners in this area are likely aware that effective preparation for disclosure of a prenatal diagnosis can reduce shock and distress and thereby increase ability to process information and deliberate about further options. The present study provides critical evidence to support this and demonstrates how the emotional impact of the diagnosis can be lessened when good care is delivered, namely by ensuring: timely communication of clear, unbiased information; seamless access to appointments; acknowledgment of the enormity of the news of the diagnosis; and discussion and validation of the decision to terminate the pregnancy. A recent Swedish study also articulated the positive impact of well co-ordinated care when women receive clear and consistent information and help with navigating health systems and are treated with dignity by health professionals.13

In the present study, and others, the detection of a fetal abnormality continues to be unexpected and shocking1,4,14,15 Ultrasound is increasingly seen as a ‘routine’ part of pregnancy,16 and non-invasive prenatal tests and chromosomal microarray analyses now frequently provide more detailed information earlier in pregnancy than has hitherto been possible.14,15 It is therefore vital to consider how extreme emotional responses to prenatal diagnosis may impact upon an individual’s capacity to process information and make informed choices.

Supportive care from health professionals appeared to ameliorate participants’ anxiety about diagnostic procedures and test results. Ideal care included being given a number of acknowledgments: of the enormity and unexpected nature of the diagnosis; of the subsequent decision-making challenges; and of the myriad feelings likely to emerge throughout the process. Sensitive communication in prenatal testing is essential.2,17 Many participants clearly recalled words spoken, words that either caused further distress or provided great solace (Table 2). Words and statements that conveyed information or results, as well as acknowledging the emotional impact were the most helpful: ‘I’m afraid, it’s not good news’. In contrast, when information was given without overt empathy and acknowledgment of the enormity of the diagnosis, ‘oh well that’s what you expected wasn’t it’, distress was exacerbated.

Decision-making was a complex process; sourcing accurate and balanced information about the condition that had been diagnosed was a particular challenge. Many were wary about accessing information from condition-specific support groups, anticipating biased perspectives.
### Table 3 Considerations in the decision about whether to terminate the pregnancy

<table>
<thead>
<tr>
<th>Elements</th>
<th>Representative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Understanding of the diagnosis and prognosis</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Uncertainty about diagnosis/unclear results   | I didn’t feel like I wanted to have or needed to have that conversation (about termination of pregnancy) until we actually had some solid results.  
_Eloise, cardiac anomalies, CP_  
We had the FISH results....‘Everything is clear’ and I burst into tears I was so happy....It was the best news in the world. She said ‘the full results haven’t come back, they will come back in two weeks’....she phoned us back and said ‘I’m really sorry we found that there’s a (chromosomal) abnormality’....it just felt like the world had ended and I don’t think we really functioned that night....we just didn’t know what to do at that point you know. It couldn’t get any worse.  
_Ava, other chromosomal, TOP_  
Uncertainty about prognosis or severity        | At first I didn’t know what I wanted to do… I thought that with surgery it might be alright…..but then each scan, once it was like three or four or five things going wrong with the baby’s heart….That’s when I realised that it’s probably not the best thing for me or for the baby (to continue the pregnancy)  
_Clare, cardiac anomaly, TOP_  
Expected survival: to term or shortly after    | Every now and then I still think ‘did I do the right thing?’ The thing which keeps me going is, I don’t know if I’m just grasping on it to make myself feel better or not, that it’s more than likely that the baby wouldn’t make it past 5 months, and I couldn’t go through that  
_Heather, trisomy 21, TOP_  
Worry about baby experiencing pain              | We both felt we didn’t want to bring (baby) to term for (baby) only to survive a little while and it to be very painful and lots of tubes  
_Fiona, structural anomalies, TOP_  
**Drawing on prior views about what they might do**  
Personal views on abortion and disability      | It has never been an option for my husband and I, we would never consider it.....just our beliefs, and our religious beliefs.....we’ve always known  
_Beth, cardiac anomaly, CP_  
While it was really hard to deal with, unfortunately that’s life, everything happens for a reason. We made the decision before we even found out that I was pregnant that if the baby had Down syndrome that we couldn’t go ahead because that wasn’t a life that we wanted for our child, we knew that we were never going to go ahead and our families supported that 100%  
_Deborah, trisomy 21, TOP_  
Self-perceived ability to parent a child with a disability | I guess quality of life for the actual child as well as everybody around them is something that I really took into consideration. ....if you had a child who had severe problems it would have an impact in so many ways on so many people.....it just got to a point where I felt that it was just beyond our capabilities I suppose  
_Janet, trisomy 21, TOP_  
It doesn’t scare me to have that sort of a challenge.....I feel I have the ability to deal with these things if they came along  
_Natalie, other trisomy, CP_  
Considering impact on family life  
Potential for long-term care needs             | I think I have safeguarded him (baby) as well.....it comes to a point when I can’t, I can’t you know, can’t take care of him  
_Caitlin, trisomy 21, TOP_  
For me the real thing that I couldn’t get past was the fact that they always need so much care and that they never leave us so I felt like I could’ve had that child, if at 20 (years of age) it was going to leave home but knowing that it would live with us forever. ....that’s what I couldn’t resolve  
_Suzanne, trisomy 21, TOP_  
Societal treatment of people with disabilities  | We decided because of this society we couldn’t bring a Down syndrome child into the world because I know how cruel people can be and I saw it at school....it’s already hard enough for a child these days let alone having you know disabilities and so we couldn’t do that, we just thought it was too unfair and it would’ve been selfish....for us to have the child because we need a child, we thought of the child first before us  
_Madeline, trisomy 21, TOP_  
Impact on other children                      | If something was to happen to us.....it would put a huge burden on our other children too, for the responsibility  
_Dianne, trisomy 21, TOP_
<table>
<thead>
<tr>
<th>Elements</th>
<th>Representative quotes</th>
</tr>
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<tbody>
<tr>
<td>Impact on career and finances</td>
<td>My ability to work, my family’s quality of life and my son is going to need a decade or so of follow up. Bringing a child into this world that could have serious complications with their health was going to just make everything even so much more hard. …we wouldn’t have the home that we have and it’d be very difficult but it’s just heart breaking to have to make a choice to end the life of a child that you so dearly wanted Poppa, trisomy 21, TOP</td>
</tr>
<tr>
<td>Potential maternal risks in pregnancy</td>
<td>I had to consider my own health obviously as well. If the baby didn’t do well with the right side of the heart that could put stress on my organs. Claire, cardiac anomaly, TOP</td>
</tr>
<tr>
<td>Not the life they imagined for their child</td>
<td>We were both very much on the same page straight away that if there was any sense of disability where they wouldn’t get to live the kind of life, a full life that (baby) should get to live then we didn’t feel it was fair to bring (baby) into the world Fiona, structural anomalies, TOP</td>
</tr>
<tr>
<td>Considering what others might think about their decision to have a TOP</td>
<td>Because as much as it doesn’t really matter what other people think, unfortunately I do care, and if people thought I was an evil person that would hurt Patricia, cardiac anomaly, TOP</td>
</tr>
<tr>
<td>Fearing judgment</td>
<td>(Partner) she was you know having real difficulty. …what would people, judge her you know, she did have a problem with the perception of judgement that other people might judge her Trevor, other trisomy, TOP</td>
</tr>
<tr>
<td>Societal views about abortion</td>
<td>I didn’t want to make that decision but I was just in a way hoping it would take care of itself or something….I was watching a TV show I think the day after (the amniocentesis).….about how abortions are wrong no matter what reason….I was watching that and I was thinking ‘oh my god how bad’ Kylie, other chromosomal, TOP</td>
</tr>
<tr>
<td>Wondering what others would do/have done in the same situation</td>
<td>I think it’s still a bit of a sensitive issue with a lot of people as well in terms of abortion Ben, single gene change, TOP</td>
</tr>
<tr>
<td>Seeking out shared experiences, eg blogs and forums</td>
<td>So I was feeling very much like I was only getting one side of the story (from an online support group). ….I started feeling a little bit, no one was forceful at all, like they were all really supportive but obviously encouraging of one side (to continue the pregnancy) Patricia, cardiac anomaly, TOP</td>
</tr>
<tr>
<td>Asking health professionals about their experience</td>
<td>I asked (the health professional) kind of to reassure me, I said ‘oh, how many people go ahead with a termination with this diagnosis?’….I was trying to get some validation of what other people do and if it was the right thing to do and I kept asking ‘so patients do this with this syndrome?’ Kylie, other chromosomal, TOP</td>
</tr>
<tr>
<td>© 2016 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists</td>
<td><strong>Table 3 (Continued)</strong></td>
</tr>
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</table>
Instead pregnancy or pregnancy loss-related internet sites, largely unmoderated and lacking evidence-based information, were sought. Popularity of web-based resources means health professionals are becoming less likely to be the primary information source. As such they have a new and important role in assisting patients to navigate and discriminate between these resources.18 In our sample it was evident that understandings of Down syndrome were highly variable. Negative perceptions about what it might mean to care for a child with Down syndrome (Table 3) included outdated stereotypes about disability that portrayed ‘exclusion’ and ‘burden’ rather than a more contemporary reality of ‘inclusion’ and ‘potential’. A challenge in prenatal testing, particularly with conditions of variable phenotypes, is to provide realistic condition-specific information that does not overplay or underplay lived experiences.19 Participants who chose to terminate their pregnancy were often fearful of being negatively ‘judged’ by others (Table 3). Many appreciated having their ultimate decision validated and sought reassurance from health professionals. If parental decisions about whether or not to terminate a pregnancy are indeed considered to be a choice between two equal options, are informed by accurate information and, have been deliberated upon, knowingly that would perhaps not have a normal life
Melinda, other trisomy, TOP

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Conflict of Interest

The authors have no conflicts of interest to disclose.

References

Embodied experiences of prenatal diagnosis of fetal abnormality and pregnancy termination

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Abstract: Pregnant women routinely undergo prenatal screening in Australia and this has become a common experience of motherhood. When prenatal screening or prenatal testing results in diagnosis of a serious fetal abnormality, women are presented with a decision to continue or terminate their pregnancy. Few recent studies have explored women’s psychosocial experience of prenatal diagnosis and pregnancy termination for fetal abnormality, and within this small group of studies it is rare for research to consider the embodied aspect of women’s experiences. This paper reports on qualitative findings from in-depth interviews with 59 women in Melbourne, Australia who received a prenatal diagnosis of a significant abnormality and decided to terminate the pregnancy. Interview transcripts were coded inductively through thematic analysis. Two themes about embodiment were generated from the interviews: transitioning embodiment, and vulnerable bodies in un/comfortable spaces. Theory of pregnant embodiment was drawn on in interpreting women’s narratives. Recommendations arising from the analysis include health professionals recognising, acknowledging and accommodating the transitioning embodied state of women as they consider, prepare for, undergo and recover from pregnancy termination for fetal abnormality. Further recommendations address the connections and disconnections between this transitioning embodied state and the spaces of clinics, hospitals and home. © 2016 Reproductive Health Matters. Published by Elsevier BV. All rights reserved.

Keywords: embodiment, pregnancy termination, fetal abnormality, prenatal diagnosis and testing, environment, space

Introduction

Pregnant women routinely undergo prenatal screening in Australia and this has become a common experience of motherhood.1 When prenatal screening or prenatal testing results in diagnosis of a serious fetal abnormality, women are presented with a decision to continue or terminate their pregnancy. While termination rates vary across countries and jurisdictions, in Victoria, Australia the majority of pregnancies diagnosed with a serious fetal abnormality are terminated.2 Pregnancy termination in second trimester can be either a surgical procedure – dilation and curettage (D&C)/dilation and evacuation (D&E) – or a medical induction of labour. Few qualitative studies have explored women’s psychosocial experience of pregnancy termination for fetal abnormality.3 In this article, we provide an in-depth account of women’s embodied experiences of prenatal diagnosis and termination in Melbourne, Australia and consider the implications for healthcare professionals’ practice.

Termination for fetal abnormality (TFA): embodied experiences

Research reports drawing on qualitative data about psychosocial experiences of TFA have focused on women’s psychological and emotional responses,4–6 women’s decision making about terminating the pregnancy and further decisions following the termination,7–9 and women’s coping strategies and adjustment to loss.10–13 Few recent reports have considered women’s embodied experiences during and following the events of prenatal diagnosis and
subsequent termination.\(^{10,14}\) Research with three women who experienced TFA shows that the women experienced a transition from being a pregnant woman to being a woman dealing with loss, but that future research was needed with a larger participant group.\(^{10}\) Scarcely other research has pointed to the significance of spatial or environmental aspects of women’s experiences of care. A US study found that requiring women who are waiting to have TFA to share environments with women waiting to have caesarean sections can cause distress.\(^{14}\) A UK study found women’s preferences varied regarding whether they should have TFA in a gynaecological ward or a birthing unit and that denying women choice about this can contribute to distress.\(^{15}\)

It is not uncommon for research reports on the psychological and emotional impact of TFA to include participant quotes that suggest the embodied nature of the experience. However, researchers have tended to interpret these descriptions as indicative of grief, trauma or psychological disorder,\(^{16–17}\) rather than to explore the detail of women’s experiences of embodiment and the meaning they attribute to these experiences. For example, in a report on Israeli mothers’ experiences of TFA, one woman’s recount of her bodily experience is interpreted as suggestive of Acute Stress Disorder and its dissociative symptoms.\(^{16}\) In this article, we focus on women’s embodied experiences of TFA in order to add a further complementary dimension to current understanding of the psychosocial experience of prenatal diagnosis and termination.

The politicised and polarising nature of international critiques of pregnancy termination mean that the voices of women who experience TFA often remain unheard.\(^{3,18}\) These critiques include the anti-abortion movement and the disability rights critiques of prenatal diagnosis and subsequent pregnancy termination decisions.\(^{19}\) Societal taboo and stigma about pregnancy termination arguably curbs public discussion about the experiences and care needs of women going through TFA. Our aim in reporting on women’s embodied experiences is to add detail and depth to healthcare professionals’ understanding of the experience of diagnosis and TFA, and to suggest recommendations as to how care provided to women who undergo TFA could be enhanced.

**Research context: TFA in Melbourne, Australia**

Women’s experiences of TFA are known to vary across cultural, legal and national contexts.\(^3\) Prenatal screening, diagnosis, and pregnancy termination are offered in private and public healthcare settings in Australia; there are no previous published reports of studies of women’s experiences of TFA in the Australian context. Termination methods vary between healthcare settings and practitioners, as do abortion laws in Australian states. In Victoria, an abortion may be lawfully performed by a doctor in any circumstance before 24 weeks gestation. After this gestation an abortion can be lawfully performed if two doctors agree that it is appropriate.\(^20\) In Victoria, genetic counsellors often provide ongoing care for women who receive a prenatal diagnosis.

**Methods**

The data reported here are a subset of data from a larger mixed methods study entitled Prenatal Testing: A Longitudinal Study (PeTALS), which is exploring women’s and couples’ experiences of prenatal diagnosis of fetal abnormality and their support needs. Participants were eligible for the PeTALS study if: they had recently received a prenatal diagnosis of a fetal chromosomal, single gene, cardiac or other structural abnormality; were aged 18 years and over; and were fluent in English. There were three recruitment sites, selected to represent a range of experiences: two public hospitals and one private ultrasound clinic in Melbourne. Ethical approval was obtained from all sites and recruitment occurred between July 2012 and April 2015. Genetic counsellors approached all women in their care who met the eligibility criteria, gave written and verbal information about the study and invited them to provide their contact details for the researchers. Those who agreed to be contacted were subsequently telephoned by a researcher and given a full explanation of the study. Recruitment continued until no new perspectives were emerging in data analysis.

Data collection is occurring at three time-points: six weeks (time-point 1), six to nine months (time-point 2), and two years (time-point 3) after prenatal diagnosis of fetal abnormality. Time-point 1 interviews and analysis have now been completed with a total of 102 participants (women n = 75; men n = 27) who received a prenatal diagnosis of fetal abnormality and made a decision about termination of pregnancy. The time-point 1 interviews were performed as close as possible to six weeks after diagnosis, ensuring that women who had chosen to terminate their pregnancy had undergone the procedure at least two weeks earlier.
Interviews were conducted by telephone by members of the research team with genetic counselling qualifications and experience in conducting qualitative research interviews. The semi-structured interview invited participants to relate their story about receiving a prenatal diagnosis and the events that followed. Audio-recordings were made, with participant consent. The interview guide contained the broad topics of women’s experiences of: first finding out they were pregnant; becoming aware that something might be wrong; screening and/or testing; making a decision about continuing or terminating the pregnancy; formal and informal sources of support; care from health professionals. Follow-up calls were offered to all participants the day after their interview to check that the interview had not caused distress and to refer to a counsellor or support organisation if appropriate.

Audio-recordings of interviews were transcribed verbatim and de-identified. A member of the research team then reviewed the recording to check the accuracy of the transcript and amend any errors. The de-identified transcripts were imported into NVivo 10 (QSR International Pty Ltd, Melbourne, Australia) to manage the data for thematic analysis. A process of inductive coding was carried out by several members of the research team. This involved reading and re-reading the transcripts to look for similarities and differences in the experiences of participants. Sections of the text were assigned researcher-developed codes, transcripts were co-coded and emergent themes were discussed.

Here we report specifically on qualitative data generated from time-point 1 interviews with women who had a pregnancy termination. We draw on pregnant embodiment theory in interpreting women’s experiences of prenatal diagnosis of fetal abnormality and pregnancy termination. Feminist scholars have described the bodily experience of pregnancy as disrupting our understanding of subjectivity as singular and fixed.21–22 Drawing on phenomenology, Young has suggested the pregnant subject is “decentered, split, or doubled” and “experiences herself as a source and participant in a creative process.”22 p46,p51 The embodied experience of pregnancy is understood to be influenced and shaped by medical practices and technologies. In particular, feminist scholars have argued that the development of medical technologies for prenatal screening has contributed to the conceptual separation of fetus and pregnant woman in the obstetrical view of pregnancy.21,23–24 During the coding process, a number of codes pointed to themes of embodiment and we turned to the above-mentioned literature on pregnant embodiment to inform the development of these codes into themes.

Results
In the larger PeTALS study, the research team was provided with contact details of 59 women and 61 couples who were potential participants. Of these, 39 women, 27 couples (interviewed as individuals) and a further 9 women who participated without their partner, agreed to be interviewed when contacted and were provided with further information about the study. Overall, 75 pregnancies are represented in the larger study, from a potential 120 pregnancies (62.5% participation rate). Of these 75 pregnancies, 59 women had a termination of pregnancy and the time-point 1 interviews (six weeks post diagnosis) with these women are the focus of this article.

Of the 59 women who terminated their pregnancy, 23 women were recruited from Tertiary Hospital 1, 20 from Tertiary Hospital 2, and 16 from the Private Ultrasound Clinic. Women were aged between 18–49 years and had each received a confirmed diagnosis of a serious fetal abnormality at 10–21 weeks gestation including: trisomy 21 (n = 23), structural anomalies (n = 10), other trisomies (n = 9), other chromosomal anomalies (n = 9), cardiac anomalies (n = 5), single gene mutations (n = 3). Whilst not all of the pregnancies were planned, all women described their pregnancies as “wanted” before receiving the diagnosis. Termination of pregnancy took place between 12–23 weeks gestation. Of the 59 terminations, 35 were surgical terminations (D&C/D&E) and 24 were medical terminations (induction of labour). Telephone interviews ranged in length from 43 to 179 minutes.

Two key themes are presented below: 1. transitioning embodiment, and 2. vulnerable bodies in un/comfortable spaces. The words “fetus” and “baby” are each used to reflect the language used by individual participant women in interviews. Sometimes the term “fetus/baby” is used when discussing more than one participant woman to convey both differences in the ways women conceptualised their pregnancy and that this shifted over time for some women. Some quotes have been truncated without changing the meaning for ease of reading and this is indicated in the text by “…….”. Pseudonyms have been used to preserve the participants’ anonymity.
Theme 1: Transitioning embodiment

Threatened pregnant embodiment

Women emphasised the physical bodily impact of receiving the news of a suspected or confirmed fetal abnormality. Becky explained that the day after her 12 week ultrasound scan she received a phone call from her doctor disclosing a suspected abnormality:

“My whole body just went into shock and ….. I was shaking and I dropped the phone.”

Women commonly used metaphors of physical trauma and devastation caused by an undiscriminating exterior force. Lydia described receiving the result of her CVS:

“I got a phone call and we found out the baby had Trisomy 21. It was ….. just a blast. You’ve been dropped this bomb.”

Melinda, who had previously terminated a pregnancy for a fetal abnormality, described receiving the news at her 12 week scan that her current pregnancy had abnormalities as “looking down the barrel of another termination”. Women experienced their pregnant embodiment as threatened by the disclosure of abnormality, and for many this marked the start of their shift away from pregnant embodiment.

In-between embodiment

Women described how difficult it was for them to continue to experience the physical changes of pregnancy and the movement of the fetus/baby after having made the decision to terminate the pregnancy. Kylie expressed her distress at being physically reminded of her pregnant embodiment whilst preparing to undergo a termination:

“I’d just felt the baby moving and I thought, ‘What type of mother am I, who wants to kill her child?’”

Young suggests a key aspect of pregnant embodiment is a woman’s “bodily self-location” being “focused on her trunk in addition to her head”. It was common for the women to describe how they deliberately turned their focus away from their “trunk” during the period of decision making and waiting for pregnancy termination. Some described how they avoided looking in mirrors at this time as they didn’t want to see their pregnant body reflected back at them. Many women, including Georgia, described ultrasound scans as very difficult after having made the decision to terminate:

“[The health professional] said, ‘If you want we can do another scan and show you things’, but at that stage both me and my husband couldn’t bear to see his heartbeat again.”

Georgia’s experience can be interpreted as disengaging from a normative pregnant embodiment of focusing on her trunk. There were a few women in our study, however, who sought out additional ultrasound scans in order to repeatedly confirm the diagnosis and to see the abnormality. Whilst visualising the fetus/baby and abnormalities on the screen was emotionally difficult for these women, it assisted them to decide that a pregnancy termination was the right course of action for them.

Women’s narratives of the period of decision making and waiting to have a pregnancy termination suggested they experienced themselves as no longer living a normative pregnant embodiment but as not yet living a “no longer pregnant” or “post-termination” embodiment. Rochelle described her experience at this time as like being in “limbo-land”. Several women used the metaphor of “robot” to describe how they disconnected from the fetus/baby during the decision making and waiting period. Louise described the two-and-a-half weeks between diagnosis and feticide as an “in-between stage”:

“I ended up quite disconnected. I was walking around able to cope, managing quite well ….. I almost felt cold. I put myself in this state of mind ….. so I was robotic, I was disconnecting from the baby.”

Louise, like many of the women, turned her focus away from her “trunk” to her head during this period. For a few women, disconnecting from the fetus/baby after deciding to terminate involved consuming food and substances they had previously eschewed whilst living a pregnant embodiment. Alcohol and other drugs became a way to move away from pregnant embodiment and to numb the pain of living an in-between embodiment.

Beginning the end

Women described how physically taking the medication to begin the termination process was experienced as an ending; a point of no return when they
“said goodbye” to the fetus/baby. Dianne explained what it was like to take the tablet as the first physical step in her pregnancy termination:

“It was the longest time I swirled [the tablet] around on the table. I knew that once I had taken the tablet it was the beginning of the end, so it was very, very hard for me to take that tablet.”

Similarly, Suzanne described how the physical action of inserting vaginal pessaries in preparation for her termination was:

“the hardest part of the whole experience because.....it was me initiating that. It wasn’t like the doctor doing it, it was me......It was really like I was physically starting this thing. I would’ve liked the doctor to have done that.”

Those women who were administered the medication to begin the termination by a health professional also experienced this as a significant moment. Melinda, who had a surgical termination, described her response to having the pessaries inserted:

“I was so scared......and that’s when it all became really real for me, when they put the [pessaries] in to start the termination......That’s when it all hit me.”

This significance for women of taking medication to begin their pregnancy termination is rarely noted in recent previous studies, with an exception being research with six women in Sweden. When pregnant, the delineation of what is part of a woman’s body and what is separate to her is blurred. This embodiment changes when women take the first medication to facilitate the termination; the medication begins the physical process of the separation of the fetus from the woman’s body. Those women who were required to self-administer the medication struggled with their agental role in physically ending the entwined relation of their body with the fetus/baby’s body.

Separating
One of the most difficult parts of the experience of TFA described by many of the women who went through induction of labour was their final physical separation from their deceased fetus/baby. Georgia narrated how post-mortem changes in her baby’s appearance led her to think:

“We need to go home......I wanted him [to come] home too......I never wanted to leave but I couldn’t stay there forever.……The hardest thing you’ll ever do is leave your baby there.”

Similarly, Patricia was distressed by the need to physically move away from her deceased fetus/baby, to create distance between them:

“We went home......That was the worst week because I knew that he was here, but he wasn’t with me. It’s so unnatural......it’s not what a mother should go through. He was in the morgue......We were here and he was there and we weren’t together. I really struggled with that.”

Patricia contrasts her physical separation from her deceased baby with a woman’s normative experience following the birth of a live baby as one of continued physical closeness.

Post-termination embodiment
The days or weeks women spent at home following the termination entailed a period of adjustment to no longer being noticeably pregnant. Audrey described the first week after returning home:

“When you’re pregnant, you touch your tummy......[In the first week] I found myself touching my tummy and I suddenly realised while I’m touching my tummy, ‘I’m not pregnant anymore’ ……and it’s hard.”

Similarly, the first menstrual period after the termination was experienced as distressing for some women. Lydia stated that several weeks after her termination:

“I was really, really upset……because I got my period, which is a sort of visual reminder (crying).”

Some women described how the aspects of their pregnant embodiment continued for weeks after their termination of pregnancy, making it difficult to “move on”. For some women, this was because they were found to have retained products of conception and needed to undergo a procedure to remove these. For other women, this was because their breasts were leaking Colostrum and their body shape and weight had changed as a
result of their pregnancy. Weeks after her termination, Caitlin explained:

“I feel like I’m carrying all this weight, but I don’t have a baby to show for it. And so sometimes I find that I’m ……wanting to move on quickly, but physically I’m not there yet.”

We can read “moving on” as transitioning from a post-termination embodiment to a non-pregnant female embodiment.

The gradual nature of women’s embodied adjustment to no longer being pregnant was not always understood or acknowledged by health professionals who categorised women as simply pregnant and not pregnant. Olive had an appointment to see her doctor which had been booked when she was pregnant:

“I thought, ‘I’ll just leave that appointment so then I can have a check-up and speak to him’. One morning I called and spoke to the receptionist just to confirm my appointment and she said, ‘Oh, it’s been cancelled’. I said, ‘Why?’ And she said, ‘You’re not pregnant anymore. That’s an antenatal appointment’ …… I hung up and I was really upset …… She knew what had happened.”

Olive experienced an abrupt switch from being categorised and treated as a pregnant woman to a non-pregnant woman. This did not reflect her lived state of post-termination embodiment.

Theme 2: Vulnerable bodies in un/comfortable spaces

Many women indicated a heightened sensitivity and vulnerability of their body within physical environments such as ultrasound rooms, clinician and counsellor consulting rooms, hospital waiting areas, labour wards, private abortion clinics, and home. This was evidenced in the words and metaphors women used to narrate their experiences. The materiality of environments played a role in shaping women’s embodied experiences of diagnosis and termination.

Out of place in clinics and hospitals

Women described feeling out of place in the foyers and waiting areas of clinics and hospitals on the day/s of disclosure of fetal abnormality and on the day/s of pregnancy termination. Grace described attending a hospital for a genetics appointment after an abnormality was disclosed to her by phone:

“As soon as you get [to the hospital], you’re confronted by bouquets of flowers and little teddies and ‘it’s a girl!’ balloons, things like that. When everything’s very raw, it’s quite confronting to see all that sort of baby paraphernalia all over the place and happy women and little babies……. It was very uncomfortable.”

Women appreciated it when health professionals recognised the distress caused by the hospital foyer and waiting areas and provided speedy passage through uncomfortable spaces. Georgia said on the day of her termination:

“[The midwife] said she would meet us at [the hospital entrance] and take us straight through so we didn’t have to sit around with everyone.”

Women described how being required to wait for both ultrasound scans and their termination in general waiting areas added to their discomfort and distress. Narelle, who had a termination in a hospital, stated:

“The thing that bothered me was the way the room was arranged. Where I was sitting I was facing all the women who were coming in to have their C-sections…… watching all the big pregnant women come with all their suitcases.”

Hailey suggested a reconfiguration of hospital waiting areas could alleviate some of the negative impact of the experience:

“I think that’s definitely something that could be improved……. to physically separate those areas.”

Women who attended a private termination clinic described their distress at having to share a waiting area with women having terminations for reasons other than fetal abnormality. Hailey stated:

“Mentally it was really hard and I don’t think anyone should ever have to do that (sigh) in our situation……. You sit there with all these women who are pregnant who don’t want to be pregnant and I’m sitting there wanting my baby.”

Women whose termination procedure involved feticide and induction of labour described what it
was like to prepare to deliver a deceased baby within the same labour ward as women delivering healthy babies. Dianne described her response to the physical space of the labour ward on the day of her termination:

“I didn’t realise I was going into the actual labour ward where there were babies being born…….I thought there might have been a separate area for people who had to terminate……I had a bit of a panic attack. Then the nurse put us into a waiting room……and then another nurse actually brought into that room a brand new newborn baby. I lost my mind.”

Palpable in these quotes is the exacerbation of distress women experienced as a result of the built environment of hospitals and clinics. These environments require women who have received a diagnosis of fetal abnormality to share waiting areas with the general public and with women waiting to see health professionals about their “normal” pregnancies. They require women to share treatment spaces with women having terminations for reasons other than fetal abnormality, and with women delivering live healthy babies.

**Home as place of sanctuary, isolation and remembrance**

In the weeks following pregnancy termination, the women experienced home as a place of both sanctuary and isolation. Some women narrated how they felt they wanted to return home as soon as possible after the procedure/delivery. Fiona described how the emotional and physical contours of the room in which she delivered her (deceased) baby drove her desire to return home:

“There was a lot of trauma in that room. Obviously it’s where we got to spend time with our [baby], but there was a lot of trauma in there……. We both really felt that if we could get home……we could start healing.”

Home was a place where women felt they could retreat from the world to recover after the termination. For some women, home also became a place of isolation, particularly once their partner returned to work. Lucy stated:

“Tjust retreated really from the whole world, I didn’t go to work……I basically spent those two weeks at home, just waiting for my partner to come home at night and honestly that was it, he was the only person I saw for two weeks. I couldn’t even see my family, I just didn’t want to explain what was happening. All up, it was probably about five weeks where I just shut myself away, didn’t see anyone, other than my partner.”

Some women described the spaces of remembrance they created within their homes. It was common for women to keep a memory box of objects relating to their baby and their pregnancy in a cupboard in their home. These boxes contained items such as photos of the baby, the baby’s handprints or footprints, blanket, booties, cards from family and friends, ultrasound images and DVD, remaining folic acid tablets, and letters about the pregnancy. Women could choose when to handle the memorial objects. Some women also displayed memorial objects by which to remember the baby. Deborah explained that the hospital where she had the termination gave her booties to take home:

“I still have the booties on my bedside table, I can’t let go of them just yet.”

Audrey told us she created a visual display in a more public area within her home:

“I want people to know that I have a baby (crying)…….We have a family picture (crying), I’m holding the baby and my husband’s kissing my baby’s head. It’s hanging in the living room.”

Women generally reported appreciating being offered the opportunity to create mementos such as photographs and footprints of the baby. However not all women wanted mementos; some women were concerned about the impact on themselves and their family members of encountering mementos in their home in the years ahead. Grace stated:

“I didn’t feel I needed to keep anything because I’ve still got memories (crying)…….Also I didn’t want to keep stumbling upon things down the track and I didn’t want my children to find things.”

**Returning to sites of devastation**

Women described returning to the clinics and hospitals where they had first learnt of the indication or diagnosis of fetal abnormality, or had their termination, as an emotionally charged experience. Some women told us they avoided or delayed returning for follow-up appointments to these physical sites. Grace
described what it was like to drive past the place where an ultrasound scan had led to a diagnosis:

“Going past that scan building is just (sigh) horrible. It’s quite traumatic for us to go back and see the same building.”

Women sometimes anticipated what it might be like to return to the place where they had the termination for their future pregnancies. Dianne described mixed feelings at being told she was unable to have the termination at her usual hospital and had to go to a second unfamiliar hospital:

“That was a bit overwhelming……but I also looked at the good side, that if we ever did get pregnant again, I could go to [my usual hospital] without having those feelings of being in the labour ward and delivering a stillborn baby.”

Discussion

We have suggested thinking about women who receive an indication of significant fetal abnormality as experiencing “threatened pregnant embodiment” and as at the threshold of a likely transition to “in-between embodiment” and “post-termination embodiment”. We have detailed how women’s experience of prenatal diagnosis and termination for fetal abnormality involves transitioning between different embodied states. These findings contribute an additional complementary dimension to current understandings of the psychosocial experience of prenatal diagnosis and termination for fetal abnormality reported in the small body of literature in this area.

For the women in our study, the environments of the clinics and hospitals they attended were often not appropriate to their psychosocial needs. We found that physical and social dimensions of these environments often appeared to add to women’s distress. This finding is consistent with limited previous findings in USA and England. Our findings build on this previous research in describing women’s experiences across a range of clinical settings, and in describing women’s experiences of feeling “out of place” not only on the day of the termination but also at the appointments both preceding and after it. The spaces of clinics and hospitals contribute to the production of the events of diagnosis of fetal abnormality and termination as unusual and outside the normal practice of these institutions, and the marking of the women who experience these events as different or other.

Consideration by healthcare professionals of both the transitioning embodied state of women as they consider, prepare for, undergo and recover from diagnosis and termination, and the connections and disconnections between this transitioning embodied state and the spaces of clinics, hospitals and home, is needed. We recommend that healthcare professionals recognise and acknowledge the difficulty of the transition from pregnant to no-longer-pregnant embodiment and accommodate this within their clinical practice. Our findings also suggest that healthcare professionals should acknowledge the moment of taking the medication to begin the termination as very difficult. It is experienced by many women as “beginning the end” of their pregnancy. Healthcare professionals could offer extra empathic support at this moment.

Measures to minimise and alleviate women’s discomfort in the environments of clinics and hospitals should be taken wherever possible. A woman can be met at the hospital entrance by a health professional and guided directly through to a private room. Separate waiting areas can be set up for women attending clinics and hospitals for appointments following indication of fetal abnormality and appointments for termination. Through these care protocols, women attending for these reasons would not be required to share space with the rest of the maternity population or with women preparing for and undergoing terminations for reasons other than fetal abnormality. For many women, returning to the physical site where they received bad news or the site of the termination can be difficult. Given the impact of such “sites of devastation” on women, as well as the uncomfortable experience of post-termination embodiment, we suggest enabling women to have a choice about where they receive follow-up care. Rather than requiring women to return to the site of devastation, telephone follow-up could be offered. During the telephone follow-up, the offer of a home visit could be extended to women as appropriate. Healthcare professionals can provide women with individualised options about the environment/s in which they receive follow-up care and support.

A limitation of the study was the linguistic homogeneity of the participants: the women all spoke English. The extent to which these findings are relevant to women of diverse cultural and
linguistic backgrounds is unknown. However, the study was bolstered by the participation of women who attended both public and private healthcare settings.

Our findings suggest that developing care protocols that aim to accommodate women’s transitional embodiment and to minimise the negative impact of physical spaces of clinics and hospitals, could lead to the alleviation of some of the additional distress and discomfort experienced by women at the time of diagnosis of fetal abnormality and pregnancy termination. Research in this area remains limited and there is a need for further research looking at variations in the care needs of women and how these needs relate to particular characteristics such as specific diagnoses.

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References

Résumé
En Australie, les femmes enceintes font l’objet d’un dépistage prénatal systématique, qui est désormais une caractéristique ordinaire de la maternité. Quand le dépistage ou les examens prénatals révèlent une grave anomalie fœtale, les femmes doivent décider de poursuivre ou d’interrompre leur grossesse. Peu d’études récentes ont analysé l’expérience psychosociale des femmes face au diagnostic prénatal et à l’interruption de grossesse pour anomalie fœtale, et dans ce petit groupe d’études, il est rare que la recherche envisage la corporalité de l’expérience des femmes. Cet article relate les conclusions qualitatives d’entretiens approfondis avec 59 femmes à Melbourne, Australie, qui avaient reçu un diagnostic prénatal d’anomalie importante et avaient décidé d’interrompre leur grossesse. Les transcriptions des entretiens ont été codées de manière inductive par une analyse thématique. Deux thèmes sur la corporalité sont apparus dans les entretiens : corporalité en transition et corps vulnérables dans des espaces in/confortables. La théorie de la corporalité de la grossesse a été fondée sur l’interprétation des récits des femmes. Les recommandations émanant de l’analyse concernent les professionnels de santé qui doivent déceler, reconnaître et faciliter la corporalité en transition des femmes alors qu’elles envisagent l’interruption de grossesse pour anomalie fœtale, s’y préparent, la mettent en œuvre et en récupèrent. D’autres recommandations se réfèrent aux connexions et déconnexions entre cette corporalité en transition et les espaces des dispensaires, des hôpitaux et de la maison.

Resumen
En Australia, el tamizaje prenatal es realizado de manera rutinaria en mujeres embarazadas y es una experiencia común de la maternidad. Cuando el resultado del tamizaje prenatal (o examen prenatal de detección) es el diagnóstico de una anomalía fetal grave, se le presenta a la mujer la opción de continuar o interrumpir su embarazo. Pocos estudios recientes han explorado la experiencia psicosocial de las mujeres con relación al diagnóstico prenatal y la interrupción del embarazo por anomalia fetal. En este pequeño grupo de estudios, es raro que las investigaciones consideren el aspecto de corporalidad de las experiencias de las mujeres. Este artículo informa sobre los hallazgos cualitativos de entrevistas a profundidad con 59 mujeres en Melbourne, Australia, quienes recibieron un diagnóstico prenatal de una anomalía significativa y decidieron interrumpir su embarazo. Las transcripciones de las entrevistas fueron codificadas inductivamente por medio de un análisis temático. Dos temáticas sobre la corporalidad fueron generadas de las entrevistas: corporalidad en transición y cuerpos vulnerables en espacios in/cómodos. La teoría de corporalidad del embarazo sirvió de base para interpretar los relatos de las mujeres. Entre las recomendaciones que surgieron del análisis figuran: profesionales de la salud reconocen, admiten y aceptan el estado de corporalidad en transición de las mujeres a medida que ellas consideran, se preparan para, experimentan y se recuperan de la interrupción del embarazo por anomalía fetal. Otras recomendaciones analizan las conexiones y desconexiones entre este estado de corporalidad en transición y los espacios de clínicas, hospitales y el hogar.