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Irish women's experience of Ectopic pregnancy

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Introduction

Ectopic pregnancy occurs where a fertilized egg implants outside the uterus. The majority of Ectopic pregnancies (95%) occur within the fallopian tube, while the remainder can occur in the ovary, abdomen or cervix [20,15,9]. Early intervention plays a key role in treatment as this can be a life threatening event and is almost always incompatible with the delivery of a viable infant [24]. Ectopic pregnancy rates have increased over time [9] and it now accounts for 14.8 per 1000 pregnancies in Ireland [10]. This increase may be due to a number of risk factors which present more frequently today including pelvic inflammatory disease or tubal pathology as well as the presence of intrauterine systems [14,12,9]. Cigarette smoking is associated with Ectopic pregnancy, and while the exact reason is unknown it is thought that the inhalation of cigarette smoke may affect normal ciliary activity which in turn may affect fallopian tube function [6,4]. Another risk factor is a previous Ectopic pregnancy, where the associated scarring may interfere with embryo-tubal transport. Studies also indicate that couples attempting to achieve pregnancy through assisted reproductive technologies are more at risk, and are also generally older, which also increases the chance of Ectopic pregnancy [24,4].

Ectopic pregnancy remains the leading cause of maternal death in early pregnancy worldwide [5]. For the woman, the experience of Ectopic pregnancy begins with the process of determining the location of the Ectopic pregnancy and is followed by treatment, which may include expectant, surgical or medical treatment [1,24,14]. Given the specific nature of Ectopic pregnancy the resulting treatment can be complex and can cause uncertainty in relation to the woman's fertility [27]. Studies into early pregnancy loss have shown that women viewed their loss as a major life event [3] and although one in 80 women will experience an Ectopic pregnancy it remains relatively under researched in terms of the emotional impact [18]. Studies which have given exposure to Ectopic pregnancy have incorporated it with other early pregnancy losses [26] and review of the published literature shows little or no research specifically dedicated to Ectopic pregnancy [13].

The lack of focus on Ectopic pregnancy may be a consequence of its modern management, where Ectopic pregnancy is not viewed in the same light as other pregnancy losses such as miscarriage [14,7]. The increasing rates of medical management on an outpatient basis may translate into the woman being cared for in an environment that fails to acknowledge her loss and in doing so may discount the emotional aftermath of the experience. This type of environment may also do little to acknowledge the woman's mental wellbeing and may cause further feelings of isolation. This study provided an invaluable opportunity in research to gain insight into women's individual experience of Ectopic pregnancy. Importantly, through this article we believe the rarely heard voices of women who have experienced Ectopic pregnancy will be considered and help to shed light on this little understood experience.

Therefore, the objective of this study was to gain the views of women in relation to their interactions encountered from diagnosis to conclusive treatment of their Ectopic pregnancy.

Methods

This qualitative study, utilising an Interpretative Phenomenology Analysis (IPA), involved conducting in-depth semi-structured interviews with women who had experienced Ectopic pregnancy. The aim of this methodology is to study this life event from the viewpoint of the women as a subject as opposed to the woman as an object. The participants in an IPA study are sampled purposively because they can offer the researcher a profound insight into the study topic and its consequences. Smaller sample sizes are common in studies undertaking IPA as given the complexity of the human phenomena a rigorous focus on a small sample size is beneficial in order for the researcher to gain a complete understanding of the experience. [21].

Following extensive review of registers which outline the woman's details on admission to the various units within the maternity hospital, a sample of 14 women who were treated for an Ectopic pregnancy were identified during a period between September and December 2013. These registers provide an overview of the treatment women receive but do not include the woman's full medical record. The recruitment process ensured patients requiring expectant, medical or surgical management of their Ectopic pregnancy were within the sample (see Glossary). This search was carried out within NS's capacity as a research midwife and with ethical approval.

Ethical approval for the study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref: ECM 4 (c) 04/02/14). Invitation letters were sent out to the women inviting them to

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Table 1
Overview of the sample.

Participant	Pseudonym	Age	Parity	Time since loss	Treatment
Participant 1	Susan	33 yrs	Para 1	16 months	Medical
Participant 2	Deirdre	34 yrs	Para 1	14 months	Expectant/ Medical
Participant 3	Mary	30 yrs	Para 0	12 months	Surgical
Participant 4	Noelle	27 yrs	Para 0	14 months	Surgical
Participant 5	Clare	27 yrs	Para 1 + 3	16 months	Surgical/ Medical
Participant 6	Beth	37 yrs	Para 3 + 2	13 months	Surgical
Participant 7	Ruth	38 yrs	Para 2	15 months	Expectant

take part in the study. A follow up telephone call was made one week after letters were sent to answer any questions about the study and establish a rapport with the women.

Of the 14 women who received letters of invitation, 7 agreed to partake in the study. Table 1 outlines the sample demographics. The women recruited to the study came from varying backgrounds geographically and socially. The ages of the women ranged from 27 to 38 yrs. For 2 of the women this was their first pregnancy experience, the majority of the women had previously experienced a full-term pregnancy. Two of the women had previously been treated for an Ectopic pregnancy, and one woman had a miscarriage prior to her experience of Ectopic pregnancy.

A semi-structured topic guide which was developed based on existing literature, an information sheet and consent form were provided to the women. All the women provided written informed consent. The majority of the women were interviewed in their homes. One participant was unable to attend the interview and requested the interview to be conducted by telephone due to distance. This woman expressed her gratitude for facilitating her interview as she felt her story was important for other people to hear and she felt comfortable talking about it from her home. The interview process took approximately 60 min and all were digitally recorded and transcribed verbatim.

The analytic process for IPA involved the following: close listening and rereading of the interviews to gain familiarisation of the data and to ensure a general sense of the participant's account was captured. Secondly, preliminary themes were initially identified and then refined as patterns and connections emerged from the transcripts. Finally, a master table of themes was created and each theme was summarised in a table including evidence from each transcript by way of direct quotations. All analysis was carried out by NS, a research midwife. The analyses were then presented to SM (a health sociologist) and KOD (a Consultant Obstetrician) for peer review. NS's clinical background as a midwife with over 25 years' experience of interaction with women facilitated this interview process. This was further aided by the skills NS gathered during her 10 year's working as a research midwife.

Results

IPA analysis identified four superordinate themes of 1) Shattered expectations, 2) management: a weary procedure, with subordinate themes of treatment, follow up care and bereavement care 3) coping styles and acceptance, 4) acknowledgement of loss. In order to maintain confidentiality the women were assigned pseudonyms. Direct quotations from the women are used to illustrate these themes.

Theme 1: Coping with shattered expectations

As the interviews progressed it became clear that the women struggled to deal with having their hopes of a successful pregnancy dashed. The hopes for a new pregnancy brought excitement and plans for the future. Their expectation was to nurture a new pregnancy. However, the diagnosis of an Ectopic pregnancy shattered these expectations resulting in intense sadness and feelings of not knowing what to grieve for.

"I didn't know what to think…I didn't know what was happening…to this day I still don't know" Susan

"Surprised and excited…I never thought there would be a problem, so I was annoyed it was a negative experience…" Deirdre

These women reported never anticipating any potential problem with this new pregnancy until their happiness was quickly replaced by confusion, grief and blame. One participant had great difficulty accepting the diagnosis, in her mind she had never thought about the possibility of an Ectopic pregnancy, if anything went wrong it would just be a miscarriage. This woman believed she would have coped better with miscarriage as an outcome as she understood it better and would have felt supported.

"What did I do in my life to make this happen…" Ruth

"Didn't realise I was pregnant but I was so delighted with the positive test, Two days later I started bleeding… I was still hopeful it would be ok. In my head it was a normal miscarriage or there would be nothing…" Noelle

One of the women reported difficulty expressing her feelings on the diagnosis as she felt very vulnerable and didn't feel able to cope with the fallout of showing these emotions. The women also reported being selective about sharing their diagnosis with friends and colleagues in order to avoid explaining about their loss.

" I really didn't tell a lot of people…it was easier that way…" Clare

"It's not something I really talk about… Like its fine but even my family know don't bring it up unless I bring it up…(crying) because they just don't know and they don't want to upset me either…" Noelle

The resilience and hope within human nature is portrayed by two of the women who both suffered two Ectopic pregnancies. They reported feeling anxious to try for another pregnancy but were hopeful for a positive outcome. This optimistic outlook and positivity enabled these women to balance the negative emotions of the risk of another Ectopic pregnancy against their hopes for a normal pregnancy. These feelings outweighed the worry and possible risk of another Ectopic pregnancy.

"Start of pregnancy I was delighted because of the positive test but nervous because of previous loss…I knew [the] risk of [having] another Ectopic pregnancy but never thought it would happen again…I knew the scan was taking too long and the probe was moving around a lot…it's another Ectopic again isn't it? This diagnosis hit me like a tonne of bricks…" Clare

"Ah…second time was 100 times harder than the first, the baby was still alive but in a place it couldn't survive…… Very hard taking the tablets...still very hard today thinking about it....at the time I thought it would survive...when the Ectopic was diagnosed I was devastated but had a feeling before doctor confirmed..." Beth

Theme 2: Management: a lack of regard for this loss by caregivers

The women in this study were shocked and had to come to terms with the diagnosis and treatment over the weeks to come. The pathway of care required to treat an Ectopic pregnancy can be complex in nature. Each of the treatment options for Ectopic pregnancy can bring distress and upset for women. Upon diagnosis the woman can very quickly be required to sign consent forms for emergency surgery. The women reported the outcome of the diagnosis allowed little time to process fertility worries and recover from the loss. The women struggled with

repeat visits to the hospital for blood tests and medical review, as it became a weary procedure often involving many caregivers and was reported as clinical and uncaring. Understanding Ectopic pregnancy and the required treatment was perceived by these women as a crucial step towards acceptance of their diagnosis and how they would cope with this outcome. The management of these women will now be examined in the subordinate themes of communication, treatment and the follow-up care received.

Subordinate theme: communication

The basis of any care with patients begins with effective communication. Women conveyed their dissatisfaction with different aspects of care beginning at the early stage of diagnosis continuing throughout their care until they were ultimately discharged from the maternity hospital. Women expressed particular frustration with not being listened to and reported errors with blood results and lost blood samples which added unnecessarily to their suffering.

"You know as much as we do… nobody could actually sit me down, I didn't know myself what was going on… they lost my scan report and my bloods… I didn't know what was happening, hospital could have dealt with it a lot better…..… It still wrecks my head [slang term: frustrates me]..." Susan

" I just wanted to get out of there and get it over with……..I felt I was getting in the way..." Deirdre

"Most staff were supportive but only one stands out as giving me time to talk…" Clare

Women emphasised the importance of clear and detailed information about the diagnosis of Ectopic pregnancy and the treatment necessary in order for them to process what was involved and what to expect. They also expressed the importance of understanding the treatment options and the potential impact that each option would have on their future fertility. The information leaflets available on Ectopic pregnancy provided a certain level of explanation but these women reported feelings of shock and disbelief at their diagnosis and so found the literature on its own to be inadequate. They stated they had difficulties processing the information and that they deserved to be counselled rather than just receive the leaflets.

"I would like to have known where it was… (pregnancy of unknown location) I felt totally in the dark…" Susan.

"Hospital could have given me quicker answers… was I going to lose my tube? Would I have another baby? I really could have done with someone to talk me through it…" Deirdre.

Subordinate theme: treatment

Women attending for regular blood tests and review by medical staff recounted how this was a constant reminder of their grief. They struggled with witnessing other couples departing the unit with the joy of an ongoing pregnancy as this proved difficult in terms of acceptance and recovery.

"Upsetting experience sharing a room and listening to other people's experience…" Deirdre

"Oh seeing other people coming out with scan pictures… delighted and happy and you're sitting there waiting for the doctor to confirm what you're dreading… I felt sad and guilty for feeling jealous…how could this be happening again…" Clare

"I wouldn't be able to go through anything like that again…" Beth

The unspoken words between the women attending for frequent visits became a source of comfort and camaraderie for one woman who recounted her observations while sitting waiting to meet with a doctor. For this woman coping meant going outside her grief and acknowledging that other women were also dealing with loss.

"I think because I ended up coming in and out so often I was like, I knew I had to do it…I suppose a part of it… I knew I wasn't on my own, there were a lot of other women. I knew they were in the same situation I was in even though we never spoke to each other…" Ruth

Having to take methotrexate was a devastating experience for these women. This therapy works by stopping the growth of all rapidly dividing cells. With Ectopic pregnancy, treatment with methotrexate can stop the egg from growing before a rupture occurs. The importance of allowing appropriate time to discuss concerns and allow for questions was highlighted as a priority. It was highly emotional for two women as scans had shown a fetal heartbeat and so agreeing to the medication was difficult to come to terms with, as they felt they were terminating a wanted pregnancy.

"I found it very difficult to accept, I couldn't get my head around terminating the pregnancy" Noelle

"I said hold off and not do anything and see if the baby would survive…" Beth

"So when I woke up after the laparoscopy, they told me they couldn't remove it cos *where it was, I was shown the scan… this was so difficult* cos *the treatment was methotrexate…this baby was trying to grow… I was killing my own child…" Clare*

The importance of both seeing the ultrasound scan itself with a clear detailed explanation of the diagnosis was expressed throughout the interviews by the women. These women also reported that the scan helped them to emotionally detach from the pregnancy. The absence of a fetal heartbeat and an empty intrauterine sac was reported as central as to how they would cope and for some this was an important step towards their recovery. This coping strategy became particularly relevant for the women requiring methotrexate treatment.

"I was very very upset…first of all there was a new life and that's great and we would cope with it…then to be told no that's actually not the case… what I clung to all the time was even though they found a sac they never found a heartbeat… for me that was important…" Ruth

Subordinate theme: follow up care

With each of the interviews the women expressed concern with the lack of follow up care provided. This caused a lack of resolution and prolonged the grief process. Follow up care provides a good forum for discussion whereby concerns for future fertility can be addressed and potentially provide the women with the confidence to embark on future pregnancies[11]. One woman stated that a telephone call from one of her caregivers could have provided her with support in her recovery; instead the Internet became her source of information and support.

" Not once was this treated as a loss or any follow up offered to me… eighteen months on… I don't know what to do… I'm afraid to try for another pregnancy and now I feel guilty that I've started smoking again…" Clare

"Once my levels went down to 0… goodbye, good luck… I kinda felt… ok what do I do now? I kinda felt there's a cut off point and you're done. Part of me was glad I didn't have to be a pin cushion anymore but I really could have done with someone to talk to…" Ruth

Theme 3: Bereavement care and acknowledgement of loss

Grief and bereavement and how they manifest is individual and can leave the person feeling isolated. How healthcare professionals interact

with anyone grieving, however trivial a gesture it may seem, can hold a lasting memory and contribute greatly to recovery. Women reported despair with the clinical approach encountered from diagnosis to treatment of their Ectopic pregnancy. These women reported a lack of debriefing and bereavement care during and after their treatment. The women treated with surgery felt that their concern about the surgery and risks were minimalized and that this took from their grieving process. Throughout the interviews with these women it was very apparent that the impact of their loss and the bereavement suffered was underestimated by the care givers. It became apparent at interview that these women perceived that their sudden loss was compounded by the lack of sensitive support from their caregivers. This translated into prolonged grieving and the fear to try for another pregnancy in some cases.

"I got my meals and had my blood pressure taken and that was it…I remember one staff member with no empathy at all telling me to stop crying…I felt like a wreck when I went home…" Clare

"You don't even matter… you're just taking up people's time…" Susan

"Mentally trying to get that self-worth and self-confidence back to try again…mentally for me was the hardest part and there's just not enough support without having to take medication to help…" Mary

Positive affirmations by staff about their loss were reported as limited. Women reported that they had difficulty accepting the terms used to describe their loss, for example, "out of place" or "unknown location"; as a consequence these terms took away the chance the woman had to have a connection with her pregnancy. One woman relayed having experienced feelings of anger and frustration as she was not sure what to grieve for. This stemmed from the fact that she had told her partner the diagnosis over the phone as she had attended the hospital alone. His question to her was "Is this a natural baby?" The question itself shows how complex the diagnosis can be to couples and also how much emphasise should be put on the explanation of this diagnosis.

"To this day I still don't know where it was… [referring to pregnancy of unknown location]" Susan

"Always wonder whether the baby was a boy or a girl…" Deirdre

"It was a baby to me from the start, the baby would have been 2 today, I'm still not even over it…" Beth

"My little star that never happened…still a pregnancy… there was potential life there…just not in the right place…" Ruth

The women's grieving was primarily within their family unit and with close friends. Discovery of an undisclosed loss by one woman's mother was revealed highlighting how hidden early pregnancy loss and Ectopic pregnancy was in previous decades. This indicates progress in society's ability to cope with such a sensitive issue and helps open up dialogue to aid recovery [19]. This daughter reported that the discovery helped her resolve some of her grief and strengthened her bond with her mother.

"Ok, we lit a candle at Christmas in the church for the baby and stuff… ya know that was our way of kinda acknowledging it I suppose…" Deirdre

"My own mum, she got me an angel charm for my bracelet… I suppose it's only at that point that my mum told me that she had something similar happen between my brother and me…" Deirdre

Discussion

The women in this study revealed how devastating the diagnosis and treatment of Ectopic pregnancy can be, as responses included shock, disbelief and confusion following diagnosis. These women also reported a lack of regard for their loss which in turn compounded their ability to cope with the event. Expectations for their new pregnancy were shattered with the diagnosis of an Ectopic pregnancy and as care givers we appear to underestimate the impact of the diagnosis on the woman, which can have a lasting effect.

It is widely documented that early pregnancy loss leads to emotional suffering for the woman [16]. Previous studies of Ectopic pregnancy and miscarriage have shown that women struggle with allowing themselves to grieve or even deny the depth of their pain which can have a long lasting effect on their lives [24]. Seftel refers to pregnancy loss as an invisible loss that in turn becomes invisible grief, "while the loss seems small to some and even invisible, in fact these unborn already have life stories in the hearts of their parents" [19]. This is mirrored in our findings where women reported the sense of failure attached to their inability to achieve an intrauterine pregnancy. The different methods of treatment were also responsible for having an influence on the level of emotional suffering. The difficulty of "feeling in the way" was reported by women returning for numerous outpatient visits where little or no acknowledgement of their loss was reported. Surgical treatment brought the extra burden of recovery from the procedure and worry for family during their hospital stay. Incorporated into all this was also the worry about their future fertility and what outcome treatment could have on their ability to conceive successfully again.

Women in this study highlighted the importance of ultrasound to reassure themselves that the pregnancy was not viable. This could be interpreted as a form of coping from the loss of a new life. The bonding process is known to begin at the early stages of pregnancy [18]. Some of the women reported that they protected themselves by not bonding with the pregnancy and distanced themselves from thinking of this Ectopic pregnancy as a baby [14]. Other forms of coping became evident as women revealed that sharing their diagnosis with friends, colleagues and sometimes even family members was difficult and they felt it was easier to be selective who they told. These findings relate well to the study carried out by Van who examined strategies adopted by women who suffered involuntary pregnancy loss. Van found that for some women being introspective was beneficial. Yet, they also found that although women found positive conversations helped to process their grief some found it difficult to open up about these feelings and continued to live with the grief in isolation [25]. Our study also illustrates the individuality of each of these women and the different types of coping skills adopted to deal with the grief encountered with Ectopic pregnancy.

Implications for practice and/or policy

It is well documented that the care provided by healthcare professionals is crucial to the pregnant woman's experience [23,22]. As an outcome of this study, improvement of various areas of these women's care needs to be addressed. The main areas found lacking in their care were communication, acknowledgement, bereavement support and follow up care. Advances in the treatment of Ectopic pregnancy has translated into an increase in medical management rates on an outpatient basis. Deepa et al. [7] indicate that the longer the time interval between diagnosis and completion of treatment the less satisfied the women are with their care. At interview, with some women in this study, it became apparent that requiring surgery following failed medical treatment of the Ectopic pregnancy added to their dissatisfaction with their care. Staff that interact with these women should display empathy and understanding, and adequate training should be available to staff to facilitate coping with all aspects of their care. A checklist for

the treatment options could be developed which would ease the process for these women and reduce the possibility of errors and misunderstanding. A follow-up clinic should also be introduced to allow time for questioning and plan for a future pathway of care as it is important to educate on the risk of a repeat occurrence of Ectopic pregnancy.

Another point to consider is how the clinical setting can add to an already distressing situation. Communication at all levels of a woman's care is central to her level of satisfaction with her care and her ability to recover [7,22]. The outpatient department setting can be a busy atmosphere with quick patient turnover. This type of busy environment may be perceived by the woman to limit the acknowledgement that should be given to her experience with pregnancy loss [7]. Women in our study reported not being listened to, and insensitive comments about the loss they were experiencing were made by some healthcare professionals. Privacy and maintaining the woman's dignity will be central to the woman's satisfaction with her care. To enhance the quality of care delivered, the woman attending out-patient appointments should be accommodated by scheduling early morning appointments in order to limit any unnecessary distress. The woman's partner should also be included in the interactions with the woman by staff. This could also be an opportunity to introduce and encourage reading information leaflets on treatment options and also provide contact details for support groups.

Guidelines for the practice of the diagnosis and management of the patient experiencing an Ectopic pregnancy, as outlined in the glossary of terms, give key recommendations for patient care. However these guidelines are predominantly focused on the woman's medical management, and the emotional impact of Ectopic pregnancy is only briefly mentioned in the last paragraph [10]. With respect to the emotional impact of Ectopic pregnancy, positive developments for the future come in the form of the recent launch of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death [8]. The aim of the Standards is to enhance bereavement care services for parents who suffer pregnancy loss of any kind, including Ectopic pregnancy, or perinatal death in Ireland. These standards aim to put structures in place to guide hospitals and healthcare staff on how to lead and improve the services available to couples who experience the loss of a pregnancy or baby. Throughout the standards there is recognition that bereavement care and support is an integral part of the service that needs to be provided to women who have an Ectopic pregnancy.

Leaflets and websites are informative but the best practice would be careful explanation with supporting literature and the provision of a forum for the patient to ask questions [7]. The women in this study expressed the importance of clear and detailed information on the method of treatment, as this enabled closure and emotional recovery. Appropriate time should be given to validate the woman's loss and offer time for bereavement counselling. Recent findings from a study examining the concepts of empathy, knowledge and kindness details how the caregiver, having an emotional awareness of the woman's situation, can contribute greatly towards the woman's recovery and satisfaction with her care [2]

Follow-up care and methods of follow up were also shown to be relevant to the women's recovery in this study. These women wished for an opportunity to discuss their experience in order to help them develop an understanding of this loss and acknowledge their grief. During this time, results can be discussed and time portioned to answer questions and plan for a future pregnancy. This could take the form of an appointment or a follow up telephone call by the caregiver. This was reported by Wheeler to help greatly in the woman's recovery and also provides an opportunity to offer other support through bereavement support groups [27]. Apprehension to embark on a new pregnancy became a very real concern for two of the women in our study as they both had suffered previous Ectopic pregnancies. The impact of this loss on future fertility becomes a real concern for the woman and the caregiver; this needs careful discussion and planning for subsequent pregnancy. Early pregnancy assessment services are highlighted as crucial once a positive pregnancy is diagnosed when there is a history of prior Ectopic pregnancy [10]. This gives the woman confidence in the care she receives and allows early diagnosis of all possible outcomes.

Strengths and limitations

As with many study designs there may be sampling bias. Therefore it is important to note that the responses of these women may be differ to those who chose not to partake in the study. Due to the qualitative nature of the study these data may not be representative of women in the general population. The aim of the study was to gain in-depth insight to the experiences of these women and therefore, in-keeping with the qualitative methodology utilized, the purposive sample was deemed appropriate. The strength of this study stems from the fact that to our knowledge it is the first Irish qualitative study examining the experience of women following an Ectopic pregnancy. Given that the objective of this study was exploratory, qualitative methods were considered most appropriate. By examining these women's experience in detail it gives a voice to their needs and provides the caregiver with valuable feedback to help improve the effectiveness of their care. The lack of inclusion of the partner's understanding of this event also needs to be considered. This gap could be developed into a future study to gain insight into the experience shared by not only women but their partners and extended families.

Conclusions

This qualitative study reveals how individual grief is and also how the experience is greatly coloured by the encounter the woman has with her carers in relation to Ectopic pregnancy. Effective communication and positive interactions could empower these women to recover from their loss and prevent prolonged distress. Appropriate follow up care is crucial to allay the fears surrounding future fertility and provide the reassurance needed to potentially embark on a future pregnancy.

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Appendix A. Supplementary material

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.srhc.2018.04.002.

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