THE UNIVERSITY OF HULL

Psychological Distress in Women Following Early Pregnancy Loss

Being a Thesis submitted in fulfilment of the requirements for the degree of Doctor of Clinical Psychology

By

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Overview

This portfolio thesis comprises of three main parts. Part one is a systematic literature review entitled, 'Response to & Factors Associated with Coping in Early Pregnancy Loss – A systematic Review of the Literature.' Part two of this portfolio presents an empirical paper based on the research project designed and carried out by the author. This is entitled, 'An Exploration of Psychological Distress in Women Following Ectopic Pregnancy.' The purpose of this study was to investigate levels of psychological distress within this client group and explore women's experiences of having had Ectopic pregnancy. Part three comprises of the appendices.

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PART ONE.

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PART ONE: SYSTEMATIC LITERATURE REVIEW

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Review Article

Response To & Factors Associated With Coping Following Early Pregnancy Loss: A Systematic Review of the Literature

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(This literature review is written in the format ready for submission to the Journal of Health Psychology Review. Please see Appendix 1 for the Authors' Guidelines)

Abstract

The main objectives of this review were to explore psychological responses following an early pregnancy loss (EPL) and identify factors associated with an individual's ability to cope in this situation. A systematic literature review was conducted. A variety of electronic databases, covering a range of disciplines were searched for relevant articles. Titles and abstracts were searched, and inclusion and exclusion criteria were used to determine relevance. General themes of anxiety, depression, PTSD and grief emerged as responses to EPL. Personal resources (sense of coherence, hardiness, locus of control and feelings of personal responsibility), gestational age, attachment, cognitive appraisal, goal investment, social support and experiences with healthcare were identified as factors associated with coping following EPL. There appeared to be a degree of variance in levels of psychological distress and the extent to which particular factors affected women. Results of this review indicate women require support following EPL; however it is difficult to determine which women may suffer more than others. Therefore each case should be considered on an individual basis. Suggestions for future research are discussed.

Keywords: Pregnancy Loss, Miscarriage, Coping, Factors, Responses, Systematic Literature Review

Response To and Factors Associated With Coping Following Early Pregnancy Loss – A Systematic Review of the Literature

Introduction

This review will explore the effects of early pregnancy loss (EPL). An EPL is recognised as being before the twentieth week of gestation [1]. There are several forms of EPL including miscarriage, chemical pregnancy, molar pregnancy and ectopic pregnancy [2]. Miscarriage is the most common form of EPL occurring in approximately one in six pregnancies [3]. Miscarriage can be defined as, 'the unintended end of a pregnancy before a foetus can survive outside of the womb' [4]. A chemical pregnancy is a term used to define very early pregnancy loss in which a pregnancy test is positive before the woman's period but the pregnancy is miscarried before there is a detectable heartbeat [1]. A molar pregnancy is an abnormal overgrowth of all or part of the placenta [2]. Finally, an ectopic pregnancy is one that forms outside of the womb, usually within a fallopian tube. In the majority of cases, EPL is not a life threatening condition [5]; however it is recognised to have a significant physical and psychological impact on women and those who are close to them [6]. For the purposes of this review EPL will include miscarriage and ectopic pregnancy.

In 1984, The Institute of Medicine's Committee for the Study of Health Consequences reported that it was important to recognise factors placing an individual at risk of complications in grief following the loss of somebody close to them [7]. Researchers began to question how this relates to the acute nature of pregnancy loss [8]. The death of a child is possibly one of the most difficult losses a person may experience in their lifetime [9]. However, an EPL is different from other child deaths, as often there is no viable foetus or body to say goodbye to [5]. Despite this, to date no national

guidelines exist regarding the support of parents following EPL. It is rare that women are offered the opportunity to take part in rituals such as burial or cremation to aid in the resolution of their grief [10]. It is not uncommon for a woman to be told, 'it's only a miscarriage and you can try again.' [11] Thus it is not surprising women often describe feeling isolated by society and report their EPL is not recognised as a loss.

Despite the common occurrence of EPL, it is only within the last 15 to 20 years that research has begun to explore the psychological impact of it. Existing research consists of three types: qualitative studies describing what it is like to miscarry, descriptive studies of incidence of distressing emotional outcomes, and correlational studies of antecedents of distress [12]. Research into this area has consistently identified high levels of symptoms of anxiety [13], depression [14], Post Traumatic Stress Disorder [6] and grief [9]. A high percentage of women score highly enough on validated measures of distress to count as clinical cases [15]. Parental distress can be complicated and long – lasting and symptoms may fluctuate over time [16].

To suggest that all women experience distress following EPL may be a generalisation [11]. Within this population there appear to be 'subgroups' divided into those continuing to struggle following EPL and those able to find meaning in their loss and move on. Existing literature has been unable to understand what factors contribute to lessening or heightening of psychological distress following EPL [17]. Thus at the time of this review there are a number of studies emerging regarding factors associated with women's reactions to, and ability to cope with EPL.

This paper presents a systematic review of the literature regarding responses to and factors associated with coping following EPL. To the author's knowledge, no

systematic literature review regarding this topic has been done before. It is anticipated this review will bring findings together in order to consider the collective literature regarding this topic.

Objectives

The main objectives of this review were to explore psychological responses following an EPL and identify factors associated with an individual's ability to cope in this situation. For the purposes of this review a psychological response was considered to be one that relates to mental activity including – cognition, emotion, attitude, mental state, personality, and perception.

Method

Identification of Studies

A systematic review was conducted. A variety of electronic databases were searched for relevant articles. Databases had to be available resources, cover a range of disciplines including psychology and related fields, include full texts from a number of leading journals, have access to dissertations and book, be regularly updated but still allow access to many years worth of research from historically significant journals and finally the databases had to be accessible through the university of Hull.

The databases chosen were: Academic Search Elite, PsychInfo, PsychARTICLES, and MEDLINE. The search terms used were 'Pregnancy Loss' OR 'Early Pregnancy Loss' OR 'Miscarriage' OR 'Perinatal Loss' OR 'Spontaneous Abortion' OR 'Foetal Loss' AND 'Coping' OR Manage* OR Handl* OR Surviv* OR (Adjust OR Adjusting OR Adjust*). No limit was specified for the date of publication of studies. Only peer-reviewed journals written in English language were reviewed

because some studies involved qualitative data, and translation of this could be misleading. Databases such as Medline were limited to human research only.

Study Selection Strategy

An initial search was conducted before the systematic literature review in which the researcher tested the search strategy and terms included in the review, and read abstracts of papers identified. This allowed exploration of important elements of studies and resulted in the creation of inclusion and exclusion criteria. Articles had to meet these criteria in order to be included the review. The inclusion and exclusion criteria are shown in Table ١.

Table ١. Inclusion & Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
✓ Papers had to be written on EPL including - ectopic pregnancy, miscarriage and recurrent miscarriage. ✓ Qualitative & Quantitative Papers ✓ Papers not published in the UK	- Medical Papers - Papers written on – abortion, still birth or neonatal death. - Papers written exclusively from a male perspective - Papers not written in English - Translated papers

Quality Assessment

Quality of studies meeting inclusion and exclusion criteria was assessed using the National Institute for Health of Clinical Excellence (NICE) methodological checklists and guidance [18]. This is a widely used tool in quality assessment. NICE make recommendations for practice based on extensive and empirical research. It would therefore seem reasonable to assume that as an institute they would produce a

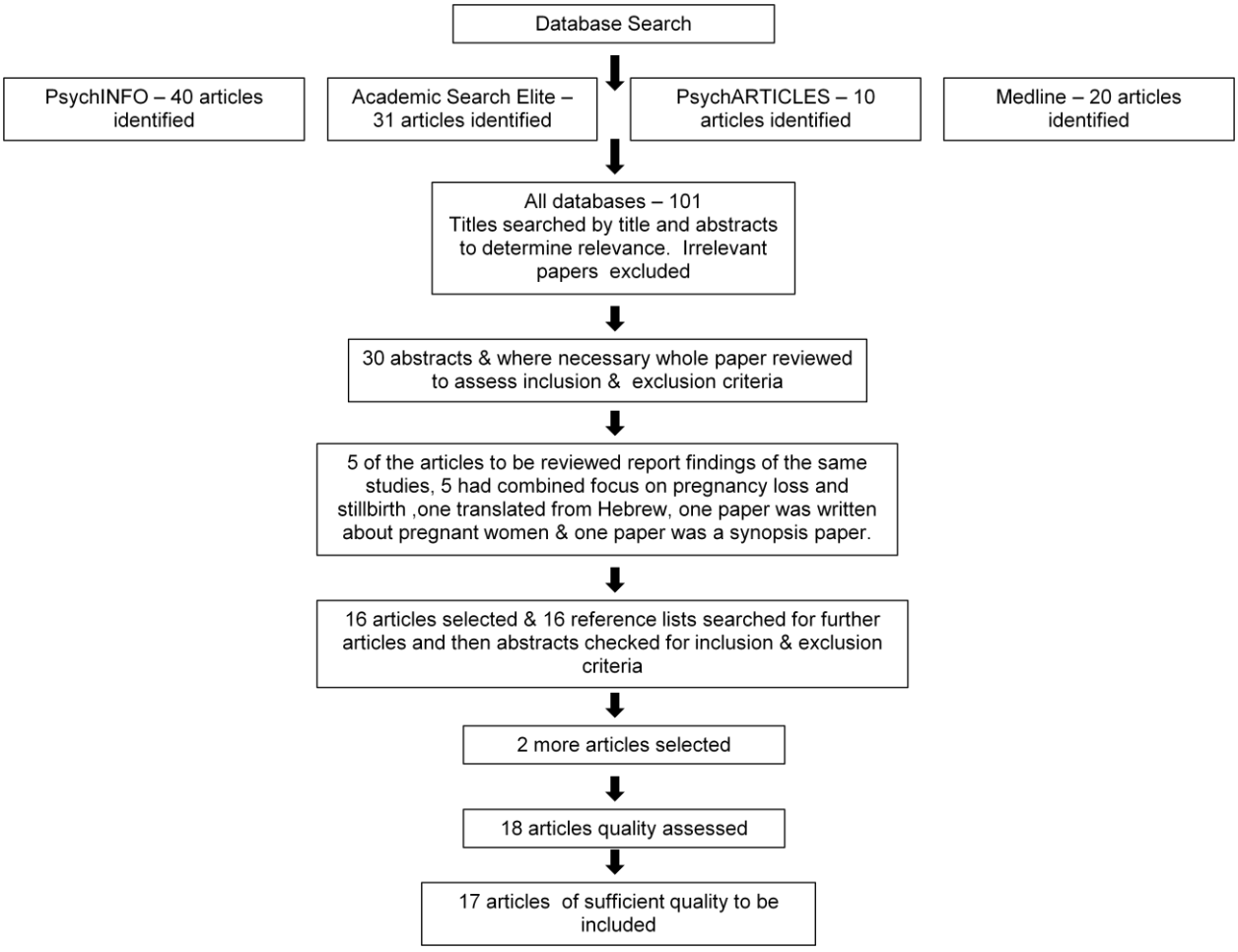
strict list of relevant questions to assess the quality of the research they are reviewing. Alongside this, there are several checklists to account for differing research designs (e.g. quantitative, qualitative, case studies). As this literature review included both quantitative and qualitative studies the checklists were deemed appropriate as a quality assessment tool.

Results

The procedure for study selection is shown in Figure ١. The process resulted in 17 studies meeting inclusion criteria. Initially 101 relevant papers were identified when all four databases were searched: 40 from PsychINFO, 31 from Academic Search Elite, 10 from PsychARTICLES and 20 from Medline. These papers were examined by title and abstracts to determine relevance. This allowed exclusion of those that were clearly irrelevant.

There were 30 articles remaining, the full printed articles of which were retrieved. Five of these reviewed the same findings and were excluded from the review. There were five papers with a combined focus on miscarriage and stillbirth and therefore these papers were excluded. One paper was excluded as it had been translated from Hebrew. One paper was found to be written about pregnant women as opposed to those suffering a loss and one was a synopsis rather than a full article and for these reasons these papers were excluded. 16 articles met the inclusion criteria and a further two were identified from reference lists. 18 articles remained for use in the review.

Figure ١. Study Selection Process



Quality Assessment

Studies were given a quality rating (++, +, or -). Quality assessments allowed the researcher to make informal judgements about the findings from studies and whether they were of high or low quality. Studies receiving a negative rating (-) were excluded. The results of quality assessment are presented in Tables ٢ and ٣. A summary of excluded papers is presented in Table ٤. Of the papers included in the review, 12 were quantitative and five were qualitative studies.

Quantitative Studies

The main limitations of quantitative studies were a lack of comparison of participants and non-participants and applicability of findings. The strongest studies

(++) in this review were the Engelhard et al [19], Renner et al [20] and Lasker et al [9] studies. There were 9 studies receiving + ratings.

Qualitative Studies

Overall the qualitative studies were good quality. The studies by Abboud et al [6], Lasker et al [21] and Maker et al [15] were of the highest quality (++) with the other studies receiving + ratings. One qualitative study was excluded.

Table ٢. Quality Assessment of Quantitative Studies

Criteria	Callander, G et al (2007)	Cote-Aresenault D et al (2001)	Engelhard, I M et al (2003)	Goldbach et al (1991)	Lasker, N et al (1991)	Magee, PL et al (2003)
Appropriate & clearly focused question	Well covered	Well covered	Adequately covered	Adequately covered	Well covered	Well covered
Groups taken from comparable populations	Well covered	Well covered	Well covered	Adequately covered	Well covered	Well covered
Same criteria used for all groups	Well covered	Well covered	Well covered	Well covered	Well covered	Well covered
Participation rate	35.4%	97%	94%	100%	84.6%	100%
Comparison of participants and non-participants	Adequately addressed	Not applicable	Well covered	Not applicable	Not applicable	Adequately addressed
Groups differentiated & clearly defined	Well covered	Adequately addressed	Well covered	Well covered	Well covered	Adequately addressed
Takes into account main potential confounders	Well covered	Adequately addressed	Well covered	Well covered	Well covered	Well covered
Confidence intervals &/or p values provided	P values reported	P values reported	P values reported	P values reported	P values reported	P values
Effects appear to be due to factors under investigation	Likely – Only applicable to a single trauma	Likely – strong methodology and good sample size.	Quite likely - correlations weaker compared to other studies.	Likely – Strong correlations	Likely - Confident in methodology	Quite likely Few values reported or tests of significance.
Applicability	Somewhat	Applicable	Somewhat	Applicable	Applicable	Somewhat
Quality rating	+	+	++	+	++	+

Table ٢. Quality Assessment of Quantitative Studies Continued

Criteria	Nikcevic A et al (1998)	Nikcevic A et al (2000)	Renner, C et al (2000)	Swanson, K M et al (2000)	Swanson, K.M et al (2007)	Walker, T et al (2001)
Appropriate & clearly focused question	Well covered	Well covered	Well covered	Well covered	Well covered	Well covered
Group taken from comparable populations	Well covered	Well covered	Well covered	Adequately addressed	Well covered	Well covered
Sane exclusion criteria used for all groups	Well covered	Well covered	Well covered	Well addressed	Well covered	Well covered
Participation rate	Not reported	85.5%	100%	76%	76%	100%
Comparison of participants and non-participants	Adequately addressed	Adequately addressed	Well covered	Well covered	Not applicable	Adequately addressed
Groups differentiated & clearly defined	Well covered	Well covered	Well covered	Well covered	Adequately addressed	Well covered
Takes into account main potential confounders	Well covered	Well covered	Well covered	Well covered	Well covered	Well covered
Confidence intervals &/or p values provided	P values	P values	P values reported	P values	P values	P values
Effects appear to be due to factors under investigation	Likely – correlations.	No but interesting findings	Likely. Sample biases.	Quite likely - concerns regarding some findings.	Quite likely - good analysis of the data.	Likely – Small sample size
Applicability	Applicable	Applicable	Applicable	Somewhat	Somewhat	Somewhat
Quality rating	+	+	++	+	+	+

Table ٣. Quality Assessment of Qualitative Studies

Criteria	Abboud et al (2005)	Defrian et al (1996)	Lang et al (2001)	Lasker et al (2003)	Maker et al (2003)
Aims Clear	Clear	Clear	Clear	Clear	Clear
Appropriate Qualitative Approach	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
Defined & focussed research questions	Not applicable	Not reported	Yes	Yes	Yes
Appropriate methodology	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
Appropriate recruitment strategy	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
Adequate data collection methods	Adequate	Adequate	Adequate	Adequate	Adequate
Clear researcher roles	Clear	Clear	Clear	Clear	Clear
Adequately addressed ethical issues	Adequate	Not reported	Adequate	Adequate	Adequate
Rigorous data analysis	Yes	Yes	Yes	Yes	Yes
Findings internally coherent and credible	Yes	Yes	Yes	Yes	Yes
Relevant findings	Yes	Yes	Yes	Yes	Yes
Clear implications	Clear	Clear	Yes	Yes	Yes
Discusses limitations	Yes	Yes	Yes	Yes	Yes
Applicability of findings	Applicable	Applicable	Somewhat applicable	Applicable	Applicable
Quality rating	++	+	+	++	++

Table ۴. Summary of Studies Excluded Following Quality Assessment

Author	Summary	Response & Factors Associated With Coping with Pregnancy Loss	Reason for Exclusion
Gerber-Epstein et al (2009)	19 Interviews with Israeli women who lost their first pregnancy. Clear aims. Qualitative research using thematic analysis	5 themes – The Greater The joy the more painful the crash. The loss: its intensity & nature, Sources of support, Life after miscarriage and recommendations to professionals.	Results were somewhat applicable but limited by the participant group. This paper does not reach inclusion criteria as the participant interviews were translated from Hebrew.

Studies Excluded based on Quality Assessment

The paper by Gerber- Epstein et al [22] received did not meet the inclusion and exclusion criteria and received a negative quality rating. This study was excluded due to being translated from Hebrew to English. However, the paper presented some interesting findings. It highlights the levels of investment in a child, medical procedures, attempts to define what was lost, and an expected return to everyday routine following miscarriage as contributing factors to high levels of psychological distress. Interestingly, it discusses how social support can be experienced as both supportive and intrusive.

The data collated from included papers is displayed below in Table ۵.

Table ᕗ. Data from Studies Included in the Review

Author & Date	Study Design	Aims	Number & Characteristics of Participants	Main findings
Abboud & Liamputtong (2005)	Qualitative	To examine how women & their partners cope with miscarriage and explore experiences with healthcare.	6 women 22-45 & partners all lived in Melbourne. All born in the Middle East, except 1 born in the Philippines. Recruited via 'snowball technique.'	Several coping strategies identified in grief – resting, future pregnancy, working & existing children. Men being encouraging is helpful in women's recovery. Friends helpful particularly to women. Men shift focus to women. Lack of community support & poor experiences of healthcare affected women's decisions regarding future pregnancy.
Callander et al (2007)	Quantitative	To explore cognitive & emotional processes following recurrent miscarriage (counterfactual thinking).	62 women aged 22-44 who had experienced 3 miscarriages or more.	Upward counterfactual thoughts associated with anxiety not depression. Variability in results not explained by individual differences. Search for meaning associated with low levels of anxiety & depression. Duration of thoughts results in depression.
Cote-Arsenault & Dombeck (2001)	Quantitative	To understand how assignment of foetal personhood relates to state anxiety and anxiety in future pregnancy.	Convenience sample of 74 currently pregnant multigravidas (n=74).	75% lost more than a pregnancy. Gestational age positively related to assignment of personhood and high levels of personhood relate to anxiety regarding current pregnancy. Lower levels of personhood in 2nd loss as defence against distress. Recognises affects of anxiety on future pregnancies.
Defrain et al (1996)	Qualitative	To take explore in-depth the emotional, social and physical effects of miscarriage on family members.	172 mothers and 21 fathers. Parents ranged in age from 20 to 67 years of age.	94% of parents felt they were grieving, 33% blamed someone else for the loss. Parents thought about lost child 11.3 times a month. 72% state memories fade over time. 49% experience flashbacks. 11.4% of mothers considered suicide. 1.8% actually attempted suicide. Social support positive means of support. Women report good experiences of care.

Table ᕃ. Data from Studies Included in the Review Continued

Author & Date	Study Design	Aims	Number & Characteristics of Participants	Main findings
Engelhard et al (2003)	Quantitative	To explore sense of coherence (SOC), PTSD & depressive symptoms after pregnancy loss.	118 women. Average age 31.	Stronger SOC in early pregnancy = less PTSD symptoms after loss. SOC predicted avoidance symptoms = less depressive symptoms.
Goldbach et al (1991)	Quantitative	To explore effects of gestational age & gender in grief following pregnancy loss.	138 women and 56 of their partners.	Gestational age affects attachment & grief following loss. Incongruent grief reactions between partners add to distress.
Lang et al (2001)	Qualitative	Introduce hardiness as concept to help grieving parents following loss.	Presents short case studies for discussion.	Bereaved parents who can learn to draw upon hardiness may overcome loss and perceive positive outcomes such as personal growth.
Lasker & Toedter (1991)	Mixed design	To develop a measure of grief in order to identify who is at risk of developing prolonged grief following pregnancy loss.	Longitudinal study of 138 women and 56 men.	Possible to distinguish between dimensions of grief and identify long-term chronic grief after pregnancy loss. Depressive symptoms before loss & poor support from family are best predictors of grief. Gestational age important predictor of active grief. Low scores indicate delayed grief.
Lasker & Toedter (2003)	Qualitative	To re-interview women who had participated in a first wave of interviews regarding their experiences of EP.	13 European American women with a range of 37–53 years.	The experience of EP continues to have a long-lasting impact on women in this sample. Two women still cry about the loss, and four others frequently think about the event and about the baby they did not have.

Table ᕃ. Data from Studies Included in the Review Continued

Author & Date	Study Design	Aims	Number & Characteristics of Participants	Main findings
Magee et al (2003)	Quantitative	To examine over investment in parent role and child related thoughts about the future following pregnancy loss.	61 women recruited from a recurrent miscarriage clinic. Median age of 33.	Women over - invested in parent role and who had negative child related thoughts and few non child related thoughts had higher distress. Being invested in other areas of life acts as a protective factor in pregnancy loss.
Maker et al (2003)	Qualitative	To examine how biographical factors impact upon how miscarriage was experienced.	13 women diagnosed with a miscarriage within 14 weeks of their pregnancy. Age of sample ranged from 22 to 43.	Women's experiences conceptualised in three stages – Turmoil, Adjustment & Resolution. Factors such as whether the pregnancy was wanted, whether the miscarriage was their first and the existence of other children influenced women's ability to incorporate their experiences into their lives.
Nikcevic et al (1998)	Quantitative	To explore relationship between feelings of personal responsibility & personal coping resources (self – esteem and self – efficacy) with symptoms of anxiety and depression.	138 women at 19 to 400 days following the diagnosis of a miscarriage.	High feelings of personal responsibility & lowered personal resources results in anxiety and depression. Self – esteem had most effect on distress. Those reporting higher self-esteem reported lower levels of anxiety and depression and also had lower levels of personal responsibility for the miscarriage.
Nikcevic et al (2000)	Quantitative	To examine if knowledge of the cause of the loss leads to an increase in distress in 'blunters' and decrease in 'monitors.'	124 women with miscarriage following ultrasound at 10-14 weeks of gestation. Age ranged from 18 to 43 years.	Coping style not associated with decreased distress neither was having knowledge of cause of the loss. Women's mood improved as result of follow - up appointment. Counselling from the appointment may have facilitated women's understanding of and feelings regarding their loss.

Table ᕃ. Data from Studies Included in the Review Continued

Author & Date	Study Design	Aims	Number & Characteristics of Participants	Main findings
Renner et al (2000)	Quantitative	To explore influence of valuative meaning of miscarriage and how it influences how others will respond to a woman following a miscarriage	393 students who knew somebody who had a miscarriage.	90% of participants described miscarriage as a loss. Participants had grounded meaning (understand elements of experience) but cannot identify with valuative meaning (personal response to the miscarriage).
Swanson et al (2000)	Quantitative	To focus on linkages among context of loss, appraisals of meaning, coping and emotional responses, using the Lazarus Paradigm.	Participants conveniently recruited. 185 completed the whole study. Ages ranged from 19 to 45 years.	Model accounted for 63% of the variance in depressive symptoms at 4 months and 54% at 1 year. Pregnancy status at 1 year associated with reduction in personal significance and passive coping and depression. Lazarus paradigm holds promise for understanding variability in women's responses to miscarriage.
Swanson et al (2007)	Mixed design	Describe women's feelings over the first year after miscarriage and explore the influence of life contexts before and after loss on women's responses to miscarriage at 1 week and 1 year.	185 women predominantly white, married or partnered, employed and well-educated.	Variability in responses increased over time. Women grieving at 1 year likely to have experienced further negative events. Women healing likely to be pregnant again. 77% expected difficulty in next pregnancy. Responses at 6 weeks good indicator of feelings at 1 year.
Walker et al (2001)	Quantitative	To explore if predictability of problems in pregnancy minimises distress once early pregnancy loss is detected.	34 women recruited for the study.	No difference between women. 92.5% experienced flashbacks. Previous psychiatric history as vulnerability factor. Levels of distress reduced at follow up, however anxiety levels did not.

Main Findings

Response to Early Pregnancy Loss

Overall it appeared that all studies found some degree of distress in the women they were investigating regardless of what they were measuring. The studies included in this review appear to focus mainly on anxiety, depression and grief. Although to a lesser extent, trauma was also described as a response to EPL

Anxiety

The unexpected and sudden nature of EPL can be anxiety provoking [23]. Maker and Ogden [15] conducted interviews with 13 women following a miscarriage. Immediately following miscarriage, women experienced a stage of 'turmoil' characterised by unprepared for the physical affects of it. Swanson et al [3] measured 85 women's feelings about miscarriage at 1, 6, 16, and 52 weeks. Women experienced heightened levels of anxiety immediately after and up to six months following miscarriage. The proportion of women healing steadily increased over the year and women's responses at six weeks were a good indicator of reactions at one year. Brier [23] reported that women's anxieties remain focussed on pregnancy related issues and although anxiety levels reduce they may only fully remit when a subsequent pregnancy has a positive outcome. Between 50-62% of women conceive shortly following their loss, however these pregnancies are often anxiety provoking [24].

Post – Traumatic Stress Disorder (PTSD)

Walker & Davidson [25] suggest miscarriage should be conceptualised from a trauma perspective. PTSD involves re-experiencing the traumatic event, avoidance of its reminders and hyper-arousal. Several of the studies included in this review refer to

the Lazarus Emotions and Adaptations Model [26], a model related to trauma which suggests people make sense of events based on what is at stake for them [3, 14, 25].

Swanson et al [3] describe women experiencing confusion, alarm, and a struggle to find meaning in their loss, a lack of control and feeling afraid regarding the future. In this study women described miscarriage as 'a senseless assault' which left them feeling empty and disconnected. Women described a desire to become pregnant again but at the same time dreaded putting themselves in a position where they may miscarry again. In this study, 92.5% of 40 women reported re-experiencing their EPL (through flashbacks) and obtained similar scores on intrusion subscales as female stress clinic patients reported by Horowitz et al [27].

Depression

During the first six months after miscarriage, women are at increased risk of developing a depressive disorder [28]. Magee et al [29] discuss the social cognitive model of depression which proposes depression occurs when an event disrupts a role that provided the basis of an individual's self-worth, and no alternatives exist to allow sense of self to be maintained. Often the causes of EPL are unknown and women attribute it to their own behaviour [14]. This may result in feelings of guilt, self-blame, and depression [4]. Approximately 11.45% of women in the study by Defrain et al [4] described feeling so depressed they considered suicide following miscarriage and 1.8% actually attempted to take their own life. Maker & Ogden [15] conclude miscarriage acts as a trigger to distress and should be understood as a process involving fluctuating emotions.

Grief

Although EPL is not always recognised as bereavement, Cote – Aresenault [24] found that three quarters of women with a history of EPL reported losing more than a pregnancy and 10% held a memorial service following their loss. Swanson et al [3] found that the number of women actively grieving over the course of a year decreased. However, 60% of women who reported feeling 'overwhelmed' at one week were actively grieving up to one year after miscarriage. Lasker & Toedter [9] suggest it is possible to distinguish differing dimensions of grief. Less severe dimensions refer to visible manifestations of grief such as crying and sadness. Withdrawal and despair are severe dimensions of grief and are thought to be related to more disturbed reactions. Difficulty coping and feelings of despair are thought to indicate a need for support.

Factors Associated with Coping

There is a wide range in level and type of distress reported by women and researchers are beginning to explore why this is the case. Factors highlighted by the studies included in this review are discussed below.

Personal Resources

Personal resources are described as personality characteristics and psychological factors which individuals draw upon in times of adversity. The paper by Lang et al [30] suggests that individuals better able to draw on personal resources thrive in adversity.

'Hardiness' & Sense of Coherence

Lang et al [30] discussed the concept of hardiness, defined as a sense of personal control over the outcome of life events, an active orientation towards meeting

the challenges of stressful events, and a belief that one has the ability to meet challenges brought by such an event [31]. This study suggests everybody harbours some degree of hardiness and it may be possible to develop skills to draw upon it. The consequences of hardiness within the context of pregnancy loss are reported to include, 'self – actualisation, ability to transcend and well-being.'

Lang et al [30] describe self – actualisation as the realisation of one's potential and is thought to develop personal growth. They found that despite pregnancy loss resulting in heightened distress, hardiness allowed parents to develop deeper meaning in their lives and relationships. Ability to transcend was reported to refer to parents' recognition that they can adjust not only to the death of their child but other difficult life events also and well-being occurred in individuals who were able to attribute meaning to their loss and come to terms with the fact that it is unchangeable.

Sense of Coherence (SOC) is a similar concept to hardiness and relates to an ability to perceive a stressor as comprehensible, meaningful and manageable. Engelhard et al [19] found that a stronger SOC in early pregnancy predicted less PTSD symptoms following a pregnancy loss. A stronger SOC also related to fewer symptoms of depression. These results suggest that SOC acts as a resilience factor for distress following EPL.

Locus of Control (LOC) & Personal Responsibility

Maker and Ogden [15] suggested that women experience three stages following their EPL. Alongside the aforementioned stage of 'turmoil,' women experience stages of adjustment' and 'resolution.' Adjustment involves the use of coping mechanisms including LOC. LOC refers to the extent to which individuals

believe they have control over events that happen to them [32]. Women with internal LOC blame themselves for loss and cope less well than women with an external LOC who attribute reasons such as 'bad luck' to their loss [15]. An external LOC may allow women to move into the resolution stage which begins when there is a shift in emotional accounts about loss such as feeling they have learned something about themselves.

Nikcevic and Nicolaides [33] found a relationship between feelings of personal responsibility for miscarriage, self – esteem and self efficacy, and symptoms of anxiety and depression. Higher feelings of personal responsibility and lower self – esteem and self efficacy resulted in clinically significant levels of anxiety and depression. Self – esteem was most influential on women's psychological health. Findings from this study indicated that enhancing feelings of self-worth and reducing women's exaggerated feelings of personal responsibility is thought to lessen the negative emotional impact of EPL.

External Determinants of Distress

External determinants of distress refer to factors and contexts associated with pregnancy loss.

Gestational Age at the Time of Loss & Attachment

Lasker and Toedter [9] define gestational age as 'the length of the pregnancy, in weeks, since the menstrual period.' Findings regarding the effects of gestational age at the time of loss are ambiguous. Some researchers' hypothesise gestational age is important in development of psychological distress, particularly grief, whereas others believe it has no influence [12]. The main factor related to gestational age is attachment. The process of attachment between mother and child begins at the

discovery of the pregnancy and continues throughout it [34]. Cote – Arsenault and Dombeck [24] discuss the assignment of 'personhood' to a foetus. As pregnancy progresses women begin to fantasise about the child, name the foetus and describe its personality. A greater gestational age results in more assignment of personhood and a stronger sense of attachment.

In relation to EPL, women feel confused about what was lost. However, attachment may still be strong. Cote-Arsenault and Dombeck [24] found that although mean gestational age in their study was 10 weeks, 75% of women felt they lost more than a pregnancy and 50% felt they lost a baby. Goldbach et al [35] found gestational age had a distinct effect on grief following EPL and believed their findings support the argument that gestational age is an important variable affecting attachment and levels of distress. Higher levels of grief may result from women feeling less able to dismiss EPL as an unhealthy conception that was not meant to be [3].

Cognitive Appraisal & Goal Investment

Callander et al [17] explored the influence of a specific cognitive process called 'Counterfactual thinking.' Considered ruminative in nature, this process relates to simulating 'could' or 'should' to an event. Considerable variation occurred in the levels of distress in their sample which could not be accounted for by individual differences. Women most commonly experienced self – referent thoughts which included blaming thoughts such as 'if only I hadn't ….. then the miscarriage would not have happened.' Such thoughts were significantly related to heightened levels of anxiety. They found duration of such thoughts related to an increased risk of depression. Counterfactual thoughts may be used as a woman attempts to make sense of her loss but if a woman is

unable to access thoughts related to other areas of her life, counterfactual thoughts may result in symptoms of depression.

Difficulty focussing on other areas of life relates to the study of prospective thinking and goal investment in miscarriage by Magee et al [29]. Women who were highly invested in becoming a parent demonstrated highest levels of distress. It was also found that prospective thinking (thoughts about the future) were likely to be negative and child related and there was an absence of positive thoughts about other, non-child related experiences. Findings from this study suggested that being invested in other areas of life acts as a protective factor to distress.

Social Support

Abboud and Liamputtong [6] found women believed support from their partners was their main coping strategy. Partners were reported to support and encourage women to change negative thoughts in order to have a more positive perspective. Men were found to use different methods of coping. Defrian et al [5] found women wanted to process the loss with others whereas men prefer to process the loss alone. Spouses were found to understand each other well enough to survive the loss and 61% of participants reported their marriage was strengthened. However, 11% encountered problems in their relationship due to difficulty communicating with one another. Goldbach et al [35] reported incongruent grieving between parents can result in heightened distress levels for both parties.

The women in the study by Abboud and Liamputtong [6] reported positive experiences with friends and family. Female family members, especially mothers and sisters were most supportive following miscarriage. Friends were reported to have sent

flowers and cards which made women and their partners feel others were there for them. The study by Renner et al [20] supports the findings that women find input from friends and family extremely helpful in the aftermath of their loss. However, they also report women experience a lack of recognition of their loss from society. They explored how society views miscarriage and found that 90% of participants in their study indicated that women experience a loss following a miscarriage. Interestingly, they found that participants understood the grounded meaning of EPL in that they identify specific attributes and elements that surround such a loss but they did not demonstrate valuative meaning. Valuative meanings are personal and significant and are only understood by those with similar experiences [19]. Therefore society may understand what a miscarriage entails for a woman but are not able to identify with her personal experience resulting in women feeling emotionally invalidated.

Experiences with Healthcare

Defrain et al [4] reported that medical professionals generally receive good feedback following pregnancy loss but can become targets of severe criticism from parents. Women in the study by Abboud and Liamputtong [6] who experienced healthcare professionals as reassuring and accessible adjusted better than those who felt medical professionals were dismissing and unavailable. A majority of women in this study were dissatisfied with care in the public sector and reported feeling angered by conflicting information from professionals and being left to wait not knowing what to expect. Several women changed hospitals due to consistent mistakes and negative experiences with the health care system. In some cases experiences of healthcare had a bearing on women's wishes to conceive again, with those having negative experiences deciding to wait before attempting to conceive.

Discussion

General themes of anxiety, depression, PTSD and grief emerged as responses to EPL. Although levels of distress were not universally high, all studies reported a certain degree of distress regardless of what was being measured. Many studies focused specifically on a single emotional response and did not explore mixed reactions to EPL and how this might complicate women's experiences. For example, a woman may report high levels of anxiety and further assessment might reveal that anxiety is affecting mood and therefore she is experiencing symptoms of depression. Additionally, studies predominantly centred on anxiety, depression and grief. There were fewer studies investigating trauma responses. It was unclear why this was the case and may highlight a need for further research in this area.

Assessment methods used in the studies were extremely varied and outcomes depended on the measures used and the criteria included in classification of responses. Diversity in the articles was pronounced which hindered comparison and limited summarising of findings in order to estimate the prevalence of individual responses to EPL. Alongside this, classification of responses were often based on recommended scale cut-offs which does not always result in a clear picture of women's experiences as raw scores are not reported. For example, if the recommended cut – off of on a measure is 50 but several women score 49, these women would be classified as 'not distressed', when there appears to be little difference between scores. Several studies reported that levels of distress decreased over time. As with other difficult life events, levels of distress reduce as an individual comes to terms with their experiences [31]. What is interesting in the case of EPL is that some women seem unable to adjust in this situation and levels of distress remain persistently high. This is where qualitative

research is indispensable as it adds richness and allows a more in-depth exploration of experiences. However, difficulties exist within these types of studies as researchers use differing forms of analysis and data is influenced by the scope of conducted interviews.

After describing psychological responses to EPL, a majority of studies went on to explore reasons for women's varied experiences of EPL. Again there seemed to be discrepancies in findings, with some studies reporting particular factors are influential in women's ability to cope and others stating the contrary. Factors identified as being associated with coping following EPL included women's ability to access personal resources (SOC, hardiness, feelings of personal responsibility and LOC), gestational age, attachment, cognitive appraisal, goal investment, social support and experiences with healthcare. However, Walker et al [23] reported it is the actual pregnancy loss itself that is stressful and did not find evidence of a particular factor affecting this. In line with this, Defrain et al [4] explicitly stated that women's distress could not be accounted for by individual factors. Therefore it seems reasonable to suggest that findings regarding factors associated with coping following EPL are ambiguous.

Quality was assessed using the NICE methodology checklists [18]. This is a widely used quality assessment tool; but does require a certain degree of subjective judgement which will inevitably impact on the quality of papers included in a review. However this tool provides checklists for quality assessment of qualitative and quantitative studies. As aforementioned using papers of differing designs can hinder comparison of findings however in a review such as this where the literature base is relatively sparse using studies of both qualitative and quantitative allows a more in-

depth exploration of the topic area. Quantitative studies allow description of incidence of distress and qualitative studies allow further investigation of women's experiences.

Studies included in this review were of mixed quality and had several limitations. The studies that were of the highest quality met all the standards listed in the checklists. Often papers not of the highest quality did not use appropriate methodology or recruitment strategies. The studies by Lasker et al [9, 21] were of good quality as they used longitudinal designs. The results of this review highlighted that levels of distress vary between women and emotions fluctuate over time. Swanson et al [13] found that factors influencing distress immediately after EPL may not have such an influence at one month or one year after. Longitudinal designs would allow further exploration of such findings to aid in identification of factors contributing to continued distress. Such designs would also help identify key intervention times to minimise enduring distress.

Cohort studies may also be useful in understanding variance in experiences. Participants in the pregnancy loss studies in this review ranged in age from eighteen to late forties. A woman in her twenties may be more or less affected by particular factors than a woman in her forties. This type of design would identify the responses most prevalent in certain cohorts and factors which influence the individual context of women's lives. In addition to quality of papers being affected by methodology it was also affected by recruitment strategy. Using an appropriate recruitment strategy ensures investigation of a relevant sample. As it is impossible to study the entire population, it is important to recruit a smaller but representative sample of the population of interest.

The majority of studies recruited from appropriate settings such as early pregnancy units, gynaecology wards and other outpatient clinics. One study used the

'snowball' technique, which is a useful method of identifying suitable participants but does depend on participants being able to identify others who have had similar experiences. Two studies recruited through advertisements in a newspaper which is a recruitment strategy that relies on people identifying that the study is relevant to themselves and coming forward to participate. Such recruitment strategies result in a self – selected sample. Participant numbers in EPL studies are typically low and it is unclear why this is the case [12]. It is possible that women who do not take part are the most distressed.

One study recruited a sample of university students. Many studies use students because they are easily accessible and it is possible to recruit a large sample. However, such samples are not representative and this affects generalisability of findings. Finally one paper was a secondary analysis of data from a previous study. The difficulty with secondary analysis is that data was not primarily collected for the aims of the study it is being used for and therefore may not be a true reflection of factors being explored. One recommendation that arises for future research is to investigate why women in this population do not participate in research, this will inform future study designs and allow recruitment of more representative samples.

There were a number of studies included in this review which did not originally aim to explore response to and factors associated with coping following pregnancy loss. One study aimed to develop a measure of grief following EPL, one paper focussed specifically on women's experiences of ectopic pregnancy and two on recurrent miscarriage. A number of articles stated that it was unclear how findings would relate to recurrent loss [29] and studies on recurrent miscarriage have not always gone onto explore how findings relate to single trauma populations. Additionally, one paper aimed to explore the applicability of a theoretical model in EPL and one paper

explored other people's views of miscarriage. These papers were still included in the review as they reported relevant findings. However, it is important to acknowledge the purpose of studies under review if it has an impact on findings.

Response to EPL appears to be individualised and complex and as literature in this area is still relatively sparse, it is important that research continues so that we can further understand women's experiences. Qualitative research should be carried out as it allows more in – depth exploration of women's experiences and factors associated with coping. Reasons for variability can be further explored and themes may emerge offering insight into why some women continue to experience heightened levels of distress. Additionally, research should consider the experiences of those closest to the women. Research has identified that social support is important in women's emotional recovery and that incongruent grieving can cause tension in relationships. Several studies included in this review recruited women's partners, but numbers were often low and focus typically remained on the woman. Research regarding partner's experiences may be an important validation that they too experience distress following EPL.

Summary & Implications

The most cited responses to EPL were anxiety, depression, PTSD and grief although findings identified variance in levels of such responses. Factors cited as affecting coping following EPL included women's ability to draw upon inner personal resources such as hardiness and LOC and external factors such as gestational age, social support and experiences of healthcare. Given the variance in findings, it is difficult to make definitive conclusions about women's experiences following EPL. This however should not result in women feeling their distress is unrecognised or not having access to suitable care and support. Given the common occurrence of EPL, the fact that women

are having negative experiences of healthcare and feeling isolated by society is unacceptable. The main recommendation arising from this review is that each case should be considered on an individual basis until further research identifies clearer methods of identifying and supporting women who are vulnerable to experiencing heightened and continued distress.

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*** Relates to Papers Reviewed for This Review**

Total Word Count for Systematic Literature Review – 5,195

PART TWO.

An Exploration of Psychological Distress in Women Following Ectopic Pregnancy

PART TWO: EMPIRICAL PAPER

Running Head:

Psychological Distress Following Ectopic Pregnancy

RESEARCH ARTICLE

An Exploration of Psychological Distress in Women Following Ectopic Pregnancy

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(Please see Appendix 3 for the Authors' Guidelines).

Abstract

Objectives This study aimed to explore women's experiences of Ectopic pregnancy (EP).

Design This study implemented a mixed quantitative and qualitative, non-experimental, retrospective design.

Method Standardised measures were used to investigate levels of psychological distress in a self - selected population of women. Measures were supplemented with a Locus of Control (LOC) measure and a researcher constructed questionnaire designed to explore the relationship between factors from medical and obstetric history and distress. This measure included the opportunity for a written account of EP.

Results Participants reported mild levels of anxiety and levels of grief indicative of psychological morbidity. Small sample size (N=24) meant it was not possible to conduct some analyses regarding the medical and obstetric history. However, age, length of time since EP, number of symptoms and gestational age at onset of symptoms, were found to be related levels of distress. Thematic analysis (TA) of written responses identified themes of physical pain, changed relationships, appraisal and adjustment, changed perception of pregnancy and experiences of hospital care.

Conclusions Levels of psychological distress were not universally high and variance could not be accounted for by factors in a woman's medical and obstetric history. Implications for healthcare professionals and suggestions for future research are discussed.

Keywords: Ectopic pregnancy, Psychological Distress, Experiences, Factors.

Psychological Distress Following Ectopic Pregnancy

An Ectopic Pregnancy (EP) forms outside the womb usually within a fallopian tube. One in 80 pregnancies in the United Kingdom is Ectopic and incidence is increasing (Association of Early Pregnancy Units [AEPU], 2007). All woman of childbearing age can be affected; however risk factors are associated with 25 – 50% of cases and include Pelvic Inflammatory Disease (PID), Chlamydia, using an Intrauterine Device (IUD) or taking the contraceptive mini pill, In vitro fertilisation (IVF) and being of older maternal age. EP results in approximately five deaths per year and is a leading cause of maternal death (CEMACH, 2007). Early EP can be treated using Methotrexate (medication for clearing products of conception [Stabile, 1996]), however most women are treated with surgery particularly if a fallopian tube is ruptured.

It seems reasonable to suggest the acute nature of EP may result in psychological distress. Research on EP is medically dominated and psychological perspectives are limited. Existing literature highlights anxiety (Nepomnaschy et al, 2006), depression (Maker & Ogden, 2003), Post Traumatic Stress Disorder (PTSD [Engelhard et al, 2001]) and grief (Robinson, 1999) as responses to pregnancy loss. Research is beginning to explore which factors might result in vulnerability to heightened levels of distress following a pregnancy loss. Such factors include poor support networks (Cote – Arsenault & Dombeck, 2001), high level of investment in the child (Moulder, 1994) and poor treatment from health professionals (Hey et al, 1996). Current literature on miscarriage and EP is discussed below. While EP has features differentiating it from other pregnancy losses, it is feasible that themes of psychological distress following miscarriage may be similar in EP, given they are both forms of early pregnancy loss.

Pregnancy Loss

Miscarriage occurs in approximately 20% of known pregnancies (Broquet, 1999). Miscarriage has been defined as, 'the unintended end of a pregnancy before the foetus can survive outside of the womb, usually before 20 weeks' (Maker & Ogden, 2003). For staff in Early Pregnancy Units, miscarriage is routine. However women report feeling that personal meaning is not acknowledged (Gross & Pattison, 2007). With EP, women are often not aware of the pregnancy until they experience symptoms. They encounter discovery and loss of pregnancy simultaneously alongside facing physical pain from treatment (Hey et al, 1996). Due to potential seriousness of this condition, EP is dealt with quickly by hospital staff. It is possible under such circumstances to see how women might feel personal meaning is not acknowledged.

Grief, Depression & Locus of Control

Herz (1986) suggested grief is similar to when a loved one is lost. However, Robinson et al (1999) describe grief issues *unique* to pregnancy loss. The mother will never know or have shared experiences with the child (Bowlby, 1969). In a study of EP, women obtained the same scores on the Perinatal Grief Scale (validated measure of grief following perinatal loss, [Lasker & Toedter, 2003]) as women who had stillbirths. Farhi et al (1994) reported out of 160 women treated surgically for EP in Israel, six had attempted suicide, one of whom was successful. In this study, women reported feeling a failure and guilty for taking fertility for granted. Although it is important to acknowledge cultural differences, this study indicates the serious impact of EP.

Moulder (1994) suggested women's grief is affected by the degree of investment in the pregnancy including the status of the pregnancy (i.e. a first baby or conception

through IVF) and also level of emotional investment. Cote – Arsenault & Dombeck (2001) describe the concept of assigning 'personhood' to a foetus. In this study, most women assigned some degree of personhood to their loss which intensified attachment. This attachment is often not recognised by society and 'social ignorance' can contribute to psychological distress when women feel their identity as a parent is lost (Cote – Arsenault & Dombeck, 2001).

Maker and Ogden (2003) identified three stages following miscarriage – 'Turmoil, Adjustment and Resolution.' Turmoil includes feelings of anger and anxiety. The Adjustment stage involves coping mechanisms and locus of control. Locus of control refers to the extent to which individuals believe they have control over events in their lives (Rotter, 1986). Women with an internal locus of control often blame themselves for loss and cope less well than women with external locus of control that attribute external reasons to loss such as 'bad luck.' Resolution begins when there is a shift in emotional accounts such as seeing the miscarriage as a learning experience (Maker & Ogden, 2003).

Anxiety & Post Traumatic Stress

Similar to other traumatic events, pregnancy loss causes altered self-perception and re-evaluation of life (Bansen & Stevens, 1992). Engelhard et al (2001) found 25% of women of childbearing age with a diagnosis of PTSD experienced pregnancy losses. Heightened anxiety levels are unlikely to decrease until a subsequent pregnancy has been successful. This may explain why desire to conceive is high following pregnancy loss. However further pregnancies are often fraught with distress and professionals are

recognising the effects of anxiety on mother and foetus (Cote – Arsenault & Dombeck, 2001). Nepomnaschy (2006) addressed a potential physiological link between distress and pregnancy loss. Anxiety alters levels of the hormone Cortisol which shuts down the reproductive system and may cause miscarriage. Further pregnancy following EP depends on the health of the fallopian tubes and many women struggle to conceive. Alongside this, women are 10% more likely to re-experience EP which might result from heightened levels of anxiety as many women report feeling too frightened to conceive again (Stabile, 1996). Despite this, by 18 months following EP approximately 68% of women will have successfully conceived (The Ectopic Pregnancy Trust, 2010) and therefore managing anxiety following pregnancy loss is important as success of future pregnancies may be affected.

EP is associated with a triple risk to mental health as women lose the pregnancy, face infertility and often their own mortality (Hey et al, 1996). Engelhard et al (2001) suggested suicidal reactions following EP are a direct result of long-term trauma effects related to it. Lakser et al (2001), in a longitudinal study of 15 women following EP found women often thought about their loss and cried about it. Such findings highlight powerful psychological effects of EP.

This brief review of the literature has considered some of the psychological consequences of pregnancy loss and highlights issues relating to EP. The aim of this study was to explore levels of psychological distress in women following EP and examine what factors may relate to such distress, specifically locus of control and medical and obstetric history (see appendix 5 for research questions and hypotheses).

Method

Design

A non-experimental, retrospective design was implemented. Standardised measures were used to investigate levels of psychological distress in a self - selected population of women following EP. The measures were supplemented with an open-ended questionnaire designed to explore women's subjective experiences of EP.

Participants

Women were recruited from an Early Pregnancy Unit and Emergency Gynaecology Ward. Due the sensitive nature of EP it was vital that the right women were approached regarding the study. Women identified as having had an EP needed to be old enough to consent and able to understand and complete all parts of the study. Potential participants meeting the inclusion criteria displayed in Table 1 were identified using the hospital's patient database.

Table 1. Inclusion & Exclusion Criteria.

Inclusion	Exclusion
- Aged 18 and over. - Formal diagnosis of EP - Admitted to EPAU/gynaecology ward. - EP between Jan 2009 and Jan 2010.	- Not enough English skills to understand and complete the measures.

A total of 24 out of 109 questionnaires were completed and returned (22.01% response rate). Six incomplete questionnaire packs were returned. The highest

response was from women who had recent EPs (0-3months) with a response rate of 54.16% which is higher than the overall mean response rate. Reasons for non-participation were not followed up, however some women expressed completing the questionnaires would be distressing. One woman felt unable to participate as questionnaires were received close to the due date of the pregnancy had it reached full term. Table 2 displays the number of women approached to take part in the study by length of time since EP and number of responses.

Table 2. Number of Questionnaires Sent & Response Rate by length of time since EP by month

Length of Time Since EP	**Number Sent**	**Number Returned**	**Return Rate For Month (%)**
12 months	16	0	0.0
11 months	5	1	20.0
10 months	7	1	14.3
9 months	8	1	12.5
8 months	13	2	15.4
7 months	6	0	0.0
6 months	4	3	75.0
5 months	9	0	0.0
4 months	16	3	18.8
3 months	11	4	36.4
2 months	2	1	50.0
1 months	6	6	100.0
0 months	5	2	40.0
Totals	109	24	Total Response Rate – 22.01%

Measures

- The Impact of Events Scale - Revised ([IES-R] Weiss & Marmar, 1997) - A subjective measure of distress following a stressful event. It has three subscales – Intrusions, Hyper-arousal and Avoidance. There is good internal consistency regarding the subscales. This measure has good content and construct validity (Weiss & Marmar, 1997). Several studies have used the IES-R in studies following pregnancy loss (Horowitz, 1979). A score of 50 is recommended to identify significant levels of PTSD symptoms (Creamer, Bell & Faulkes, 2003).

- Hospital Anxiety & Depression Scale ([HADS] Zigmund & Snaith, 1983). A self-screening measure of anxiety and depression. Basic psychometric properties of the HADS are considered good in terms of factor structure, intercorrelation, homogeneity, and internal consistency (Mykletun et al, 2001). As a result of there being several measures to complete in this study and due to the sensitive nature of EP the HADS was chosen as it allows a quick and accessible measure of two dimensions of distress. This measure has also been used in several pregnancy studies (Jomeen & Martin, 2004). A score of 0-7 (normal), 8-10 (mild), 11- 14 (moderate), 15 – 21 (severe).

- Perinatal Grief Scale - short form (PGS [Potvin, Lasker & Toedter, 1988]). A shortened 33-item version of the original 104-item scale consisting of three subscales – Active Grief, Difficulty Coping and Despair. Found to be valid in miscarriage, EP and stillbirth (Lasker & Toedter, 1988). Zisook, Devaul & Click (1982) suggested a score of 90 or above as indicative of psychiatric morbidity.

- Multidimensional Health Locus of Control (LOC) Scale - form C (MHLC [Wallston, 2007]). An 18-item measure of LOC regarding health conditions. Confirmatory factor analysis revealed this measure has potential clinical research value within early pregnancy (Jomeen & Martin, 2005). Made up of four subscales – Internal, Chance, Others and Doctors. All subscales have a possible range of 6 – 36 except for the Doctors subscale which has a range of 3 – 18. All subscales are independent of each other and there is no such thing as a total MHLC score. A high score on a particular subscale is considered indicative of LOC.

- Background & Demographic Questionnaire – The researcher gained permission to adapt a questionnaire used in research by The Ectopic Pregnancy Trust (www.ectopic.org.uk) to collate information regarding women's medical and obstetric history. It included space to write a subjective account of EP. For a copy of all measures see appendix 6.

Procedure

Ethical approval was granted by the Local Ethics Committee and consent was gained from the NHS Research and Development Department of the participating Trust (see Appendix 4 for REC documentation). Potential participants were approached by post with a letter written by the nurse on behalf of the principal researcher (Appendix 7), and a participant information sheet (Appendix 8). They also received the measures, a consent form (Appendix 9) and a stamped addressed envelope. If a woman wished to participate, they completed the questionnaires and returned them in the envelope provided. Posters and leaflets were also displayed in hospital waiting rooms with details of the study. This aimed to offer a direct 'opt – in' process for participation.

Results were entered into a database and analysed. Written accounts were transcribed for analysis.

Analysis

Data were entered into SPSS version 17. Scores were analysed using recommended scale cut – offs. Not all measures enable overall scores and therefore subscale scores were used. As participant numbers were low, extensive statistical analysis could not be conducted. However, descriptive statistics, Spearman's non - parametric correlations and Mann Whitney tests were used. When conducting multiple statistical tests, in this case correlations, there is an increased likelihood of finding a significant result when one does not exist (Type I error). It is possible to conduct post-hoc tests which accounts for multiple testing procedures by adjusting p - values to reduce the likelihood of type I errors. However, these can increase the likelihood of Type II errors (not finding a significant result when one really does exist). Post - hoc analysis was not carried out for this study due to it being small and exploratory. With small studies, more attention is paid to the size of the differences or the correlations rather than to the p-values; in order to decide whether it is worthwhile conducting further investigations and larger studies in the topic area.

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Transcribed responses from the Background & Demographic Questionnaire were analysed using thematic analysis (TA) which aims to identify and explore themes across a data-set. Themes were identified inductively using the method by Braun & Clarke (2006 [Appendix 10]). Meetings were held with research and field supervisors to discuss themes and check credibility of interpretations. The researcher explored data further by producing client profiles and two example cases are presented.

Results

Description of Sample

Tables 3 and 4 display characteristics of the sample. Participants were White/British with a mean age of 31.17 years (SD = 6.28). The mean number of months since EP was 5.32 (SD = 4.03). Women experienced a mean of 2.71 symptoms which occurred at a mean gestational age of 6.57 weeks (SD = 1.90).

Table 3. Age & Pregnancy Factors

Characteristic	**N**	**Minimum**	**Maximum**	**Mean**	**Standard Deviation**
Age	24	21	41	31.17	6.3
Number of Months Since EP	24	1	12	5.32	4.0
* Associated risk factors	22	1	2	1.25	0.4
Number of Symptoms	24	1	6	2.71	1.7
Gestational age at onset of symptoms	23	2	12	6.57	1.9

* Associated risk factors amongst others included pelvic inflammatory disease, chlamydia, previous termination or caesarean and taking the mini pill.

Table 4. Medical & Obstetric History

Characteristic		Frequency (%)
Previous Pregnancies	Previous EP	2 (8.3)
	Miscarriage	5 (20.8)
	Termination	5 (20.8)
	Live Births	10 (41.6)
Sexual Health	STI	3 (12.5)
Fertility Treatment	IVF	3 (12.5)
Knowledge of pregnancy	Suspected was Pregnant	19 (79.2)
Symptoms	Bleeding	20 (83.3)
	Pain	18 (75.0)
	Collapse	2 (8.3)
	Ruptured Tube	9 (37.5)
Treatment	Involved In Treatment Choice	17 (70.8)
	Treatment Type – Methotrexate	7 (29.2)
	Treatment Type – Surgery	17 (70.8)
	Tube Removed	17 (70.8)

When asked about future pregnancy, 25% of women reported feeling too scared to try again and 8.3% reported that they did not want another pregnancy with one woman adding she had been sterilised (See table 5).

Table 5. Future Pregnancy

Future Pregnancy	Number of Participants	Percentage
Too soon following EP	1	4.2
Don't want another pregnancy	2	8.3
Too scared to try again	6	25.0
Having difficulty conceiving	3	12.5
Further miscarriage	1	4.2
Needs fertility treatment	3	12.5
Pregnant again	5	20.8
Did not respond	3	12.5

Levels of Psychological Distress

Table 6. Mean Levels of Distress

Scale		**Minimum Score**	**Maximum Score**	**Mean**	**Standard Deviation**	**Number Scoring in Clinical Range (%)**
Impact of Events Scale		1	81	40.0	21.0	8.8 (37.5)
Hospital Anxiety & Depression Scale	Depression	2	18	6.8	4.9	9.9 (41.6)
	Anxiety	0	16	8.6	4.4	13 (54.1)
Perinatal Grief Scale		37	142	91.1	31.9	13 (54.1)

See Table 6 for summary of scores. The mean overall IES score was 40.0 and is below the specified cut-off of 50, suggesting participants were not suffering significant levels of PTSD. However, 37.5% of women scored above 50 on this scale. The mean

anxiety score was 8.63 indicating 'mild' levels of anxiety. However, 54.2% of women scored eight or above on this scale. The mean depression score was 6.75 suggesting women were not depressed. However, 41.6% of women scored eight or above. The mean PGS score was 91.1, suggesting levels of grief indicative of psychological morbidity with 54.16% of women scoring high enough to be considered clinical cases.

Relationship between Levels of Distress

Table 7 displays correlations between scores on the measures and their significance. Scores on all measures were significantly related.

Table 7. Correlations between Participants' Scores on the Measures

	IES	PGS	Anxiety (HADS)	Depression (HADS)
IES		.81*	.79*	.66*
PGS	.81*		.66*	.66*
Anxiety	.79*	.66*		.60*
Depression	.66*	.66*	.60*	

* Significant at the $p<0.01$ level

Factors Associated with Psychological Distress

Table 8 Displays scores on the LOC measure. Women scored highest on 'Internal' and 'Chance' subscales. There was no significant relationship between LOC and scores on the IES, anxiety and grief measures. However, there was a significant negative correlation between the 'chance' subscale and depression scores ($r(22) = -.541$, $p<0.01$).

Table 8. Summary of LOC Subscale Scores

LOC Measure Category	N	Possible Range in Scores	Minimum Score	Maximum Score	Mean	Standard Deviation
Internal	22	6-36	6	25	16.36	5.62
Doctors	22	3-18	3	22	12.91	5.23
Chance	22	6-36	7	24	15.09	5.35
Others	22	3-18	3	24	9.32	4.76

Correlations were used to explore relationships between age, number of months since EP, number of symptoms, gestational age at development of symptoms, LOC and scores on the measures (see table 9). Age and number of months since EP were not related to increased levels of distress. There was a significant negative correlation between number of months since EP and scores on the depression subscale ($r(22) = -.518$, $p<0.05$). There was a significant relationship between number of symptoms and the anxiety subscale ($r(22) = .416$, $p<0.05$) and PGS scores ($r(22) = .436$, $p<0.05$). There was a significant negative correlation between gestational age at development of symptoms and depression ($r(22) = -.52$, $p<0.05$).

Table 9. Correlations for Factors Associated with Psychological Distress

Factor	IES	PGS	Anxiety	Depression
Age	-.047	.01	-.02	.12
No. Months since EP	-.087	-.15	.09	-.52*
No. Symptoms	.347	.44*	.42*	.27
Gestational age at onset of symptoms	-.119	.01	.09	-.52*
Internal (LOC)	.190	.42	.06	.28
Chance (LOC)	-.261	-.19	-.08	-.54**
Doctors (LOC)	.251	.29	.29	.34
Others (LOC)	.157	.19	.09	.36

* Significant at the $p<0.05$ level

** Significant at the $p<0.01$ level

Mann Whitney tests were used to identify differences in scores on the measures for participants who already had children and those who did not, those involved in treatment choice and those who were not, those treated with Methotrexate and those treated through surgery, those with a ruptured or removed tube and those without and those who stated they would benefit from support agencies and those who would not. There were no significant differences identified between factors associated with psychological distress and scores on the measures. It was not possible to conduct analysis regarding the following factors – pain, bleeding, miscarriage, termination, previous EP, collapse, STI, knowledge of EP, those given adequate information and whether participants suspected they were pregnant or not and scores on the measures. However, analysis identified women who would benefit from support agencies reported higher levels of depression ($M = 8.8$, $SD = 4.4$) than those who felt they would not ($M = 4.5$, $SD = 0.5$, $U = 29$ $p<.05$). A table summarising these findings is available in appendix 13.

Analysis of Written Responses to Open – Ended Question

Thematic analysis was conducted to identify themes in participants written responses. All participants responded to the open – ended question. Responses ranged from a few sentences to three or four pages. All the women's data was used in analysis. Five themes were identified and are presented below alongside illustrative quotations.

Theme 1: Physical symptoms & pain

Participants described EP as a painful experience and focussed on symptoms and medical procedures involved in the treatment of EP.

'A week of blood tests was tough…..the hardest was the bleed.' (P1)

Participants described how the physical side of EP can take over from the emotional part.

'I felt so bad physically; I didn't have time to think about how I felt emotionally.' (P12)

Alongside this, participants described the seriousness of physical symptoms and how these are not acknowledged by others.

'I do get panicky on a night, laid in bed when I remember the pain I was in that night. It is still so vivid in my mind.' (P20)

'*I found that people think of the baby and don't realise your ill.'* (P3)

'*People think I should get over it already, it's not so easy tho.*' (P7)

One participant even described the scar from surgery as continuing to affect her:

'I felt…….scarred physically- as it would be a constant reminder.' (P16)

Theme 2: Changed Relationships

Participants described EP as changing relationships, some describing improved relationships:

'…these experiences have changed me and my husband as a couple. We are very strong and the love for him is immense.' (P18)

And others described relationships changing in less positive ways.

'I find myself snapping at my partner when I get home.' (P3)

A common theme within women's responses was a feeling of letting others down as a result of difficulties conceiving following the EP. Participant 16 describes this:

'I sometimes think I should leave my boyfriend so he can have the family, naturally he deserves.'

Theme 3: Adjustment & Appraisal

How women appraise EP appears to affect emotional response. Participants report changed personality factors and reduced daily functioning. Two participants were unable to work due to depression resulting from their EP.

'It's ruined my life…….I'm not the person I used to be.' (P7)

There is a focus on feelings of sadness, anger and confusion.

'I don't know why I had an ectopic pregnancy … Some things you just can't rationalise.'(P16)

Participants described feelings of guilt and self-blame. Participant 23 described an intense experience: *'I felt like a murderer…… I felt horrible and worthless…. I still do and I'll never forgive myself for killing my beautiful child.'*

Some participants described how due to the nature of EP, they experience a range of emotions but that are not always able to fully experience an emotion as a situation can change quickly.

'I didn't really have time for it to sink in that I was pregnant because just as suddenly there was no baby.' (P20)

However one woman described how this helped her in some way.

'I had no chance to 'bond' with the idea [of being pregnant] & therefore didn't feel too much of a loss for the pregnancy.' (P14)

Some women described how emotions can be heightened when further significant events occur following an EP.

'……not long after [the EP] I received more bad news and I just felt like I'd lost the plot.' (P10)

Finally, some women described feeling as though they have not yet felt the full emotional effect of the EP and worry how this is going to affect them.

'I am scared that I haven't yet been hit by things emotionally. It has also crossed my mind that there is something wrong with me for not really getting upset/affected emotionally.' (P8)

Theme 4: Changed Meaning of Pregnancy

Women reported a preoccupation with future pregnancy; namely worry EP will occur again, the effects on their fertility and a desire to become pregnant again.

'We are trying again, but at the back of my mind I am scared it might happen again.' (P12)

'My overwhelming feeling now is that I'm a mother without a child. I want to be a mum + I just can't wait to try again.' (P8)

A number of participants successfully conceived following their EP and described feeling this helped with difficult emotions associated with their loss.

'I think if I hadn't got caught [pregnant] so quickly I would be more emotional + depressed about the loss and craving to be pregnant. But I am very happy and believe "what's meant to be is meant to be.' (P24)

Participants described a process of 'pregnant but not really pregnant.' Women treated with Methotrexate are classed as pregnant until hormone levels decrease and indicate the pregnancy is over.

'*Its hard 4 weeks into it I'm still classed as being pregnant. Until I get negative tests from hospital.'* (P3)

Finally participants described how EP resulted in difficulty thinking about pregnancies especially around anniversaries. Contact with pregnant others is described as a painful reminder of their loss.

'I don't know how I'll feel on the date the baby would be due. That scares me a bit.' (P8)

'..my sister is pregnant she's a month behind what I would have been with my 1st and I can't be around her…..it's the worst time of my life.' (P7)

Theme 5 – Hospital Care

Participants described how staff taking time to acknowledge feelings, answer questions and be empathetic and sympathetic aid in emotional recovery.

'The last doctor I saw was lovely he told me answers to all my questions I wish I had seen him 1st.' (P1)

However, there was a feeling of disappointment with hospital care and professionals.

'……it became harder emotionally every time I went [to hospital].....The hospital left me waiting for hours leaving me more time to worry about what might happen to me.' (P4)

Part of the disappointment with hospital care was associated with a lack of information both during and post treatment.

'At [hospital] we felt messed about and kept in the dark about what was happening and often sat in a waiting room for several hours without any information.' (P6)

'Post operatively my care was good but the day I would have been discharged home no information was given to me…….I was disappointed with how I did get treated by some professionals on [the ward] as I thought care could have been better.' (P17)

Case Studies

Two cases are presented. One is an example of a participant scoring above cut – off for all measures and the other is an example of a participant scoring well below cut – off for all measures.

Participant 5 (P5) – High Levels of Psychological Distress

P5 was aged 21 and completed the questionnaires three months after EP. She had no associated risk factors and no previous pregnancies. She was unaware she was pregnant until development of symptoms at four weeks; EP was not diagnosed until eight weeks. This participant suffered several symptoms including abdominal pain, vaginal bleeding and feeling faint. Her fallopian tube ruptured and was surgically removed. Her written response was short and in bullet points but reveals several themes. Regarding the theme '*changed meaning of pregnancy'* she expressed a fear EP will reoccur and feeling scared to conceive again. She reported finding it hard to be around pregnant others and babies. In terms of the theme of '*adjustment and appraisal',* this participant reported self – blame including a statement that simply said, '*It's my fault*.' She described feeling guilty, as though she let her baby down. She

reported struggling with thoughts about what the child would have looked like. She experienced *'changed relationships'* as she felt closer to her partner than before. She scored evenly on the Internal and Doctors category of the LOC.

Table 10. Scores on measures for P5

Measure	Subscale	Score
Impact of Events Scale	Overall Score	81
	Intrusions	30
	Avoidance	29
	Hyper-arousal	22
HADS	Anxiety	18
	Depression	11
Perinatal Grief Scale	Overall Score	128
	Active Grief	50
	Difficulty Coping	41
	Despair	37

Participant 24 (P24) – Low Levels of Psychological Distress

Table 11. Scores on measures for P24

Measure	Subscale	Score
Impact of Events Scale	Overall Score	12
	Intrusions	9
	Avoidance	3
	Hyper-arousal	0
HADS	Anxiety	2
	Depression	0
Perinatal Grief Scale	Overall Score	45
	Active Grief	18
	Difficulty Coping	15
	Despair	12

P24 was 29 and completed the questionnaires six months after her EP. She reported one live birth delivered by caesarean section. She had a termination and used the Intrauterine Contraceptive Device. She suspected she was pregnant and experienced one symptom (abdominal pain) at six weeks into the pregnancy. Her tube ruptured and was surgically removed. Two themes were identified in her written response – *'Adjustment and Appraisal'* and *'Changed Meaning of Pregnancy'.* The pregnancy was unplanned and she reports experiencing several emotions from joy at the discovery of the pregnancy to sadness at being told she could not proceed with it. She expressed concern regarding future fertility. Initially looking at this case, one might assume that this woman would be experiencing levels of distress, particularly as a number of features are consistent with factors associated with psychological morbidity (see

appendix 14 – Epistemological statement regarding assumptions made in research). However, she reported being pregnant at the time of completion of the questionnaires and believed she would have struggled more emotionally if this was not the case. She believed this allowed her to feel '*what is meant to be is meant to be*.' She scored highest on the chance category of the LOC measure.

Discussion

Although overall there were low levels of trauma and depression in this population and mean anxiety scores fell into the 'mild' range, closer inspection of data highlights that many women were experiencing high and persistent levels of distress, particularly grief. This indicates that levels of psychological distress are not universally high. Variance in women's responses is something that current research has recognised and is beginning to explore (Callander et al, 2007). Findings from this study regarding levels of distress will be discussed in relation to existing literature on pregnancy loss.

Approximately 40% of women in this study scored within the clinical range on depression scales and two women reported feeling too depressed to return to work. Klier (2000) reported that during the first six months after pregnancy loss, women are at increased risk of developing a depressive disorder. Defrain et al (1996) found that 11.45% of women in their study considered suicide as a result of depression following their pregnancy loss and 1.8% actually attempted to take their own life. In the current study, there was a negative relationship between number of months since EP and levels of depression, suggesting that over time, symptoms of depression decreased. It is unclear what contributed to this; however, written responses indicated that levels of distress were influenced by outcomes of future pregnancies. Brier (2008) reported women's anxieties remain focussed on pregnancy related issues and appear to only fully remit when a subsequent pregnancy has a positive outcome. Therefore, as several

women in this study had conceived again, feelings of depression may have reduced. Experiencing an EP appears to impact considerably on women's future perceptions of pregnancy.

Anxiety levels were higher than depression with over 50% of women in this study scoring high enough to be considered clinical cases. This is high compared to other pregnancy loss studies. Geller et al (2001) compared 229 women with a matched community cohort of 230 women and found 15.7% of women who miscarried were suffering from an anxiety disorder compared to 10.9% of women in the community. PTSD is considered to be an anxiety disorder. Slade (1994) proposed that early pregnancy loss could be conceptualised as a traumatic life event, given the considerable pain and blood loss associated with it. However, just over 30% of women in the current study reported significant levels of trauma. This is low in comparison to findings of a review by Brier (2004) which reported PTSD symptoms in 77% of 1,370 women who had experienced a miscarriage. However, this was at four months post loss and it is unclear to what extent symptoms decreased over time.

Women's written responses consistently described symptoms similar to those experienced in PTSD such as flashbacks, hyper-arousal and avoidance. Women described fearing EP will happen again. Swanson et al (2007) found that women desire to become pregnant again but dread putting themselves in a position where pregnancy loss may reoccur. This coincides with the theme, '*Physical Symptoms & Pain'*, which describes the seriousness of EP and highlights women's difficulty coming to terms with their experiences. Physical consequences of EP set it apart from other forms of pregnancy loss as they are severe and potentially fatal. Several participants described avoiding reminders of EP due to the memories of pain associated with it.

Interestingly, trauma scores were significantly correlated with grief scores. Several studies have related such findings to the Lazarus Emotions and Adaptations Paradigm (1991). This model suggests people make sense of events based on what is at stake for them. Findings from this study suggest there are several aspects perceived as being at threat following EP, including physical health, fertility, and relationships. When an individual perceives much to be at stake, they are likely to suffer symptoms associated with trauma (Swanson, 2007) including hyper-arousal to further threats and avoidance (Engelhard, 2001). However, in relation to grief, a person is thought to heal more successfully when they reflect on their experience and allow themselves to mourn their loss (Brier, 2008). It is possible that trauma symptoms are preventing the grieving process from occurring, resulting in longer-term heightened levels of distress.

Overall grief scores were indicative of psychological morbidity. Cote – Aresnault and Dombeck (2001) found that following early pregnancy loss, women feel confused about what was lost but 75% of women still considered they lost more than a pregnancy. This appeared to be the case with women in this study who described losing 'a baby.' However women appeared to be mourning more than the loss of their child. Some described feeling as though they had lost a part of themselves and their femininity when their fallopian tube was removed. Alongside losses, women encountered physical and relationship changes. There were some women struggling to conceive leaving them feeling like *'a mother without a child.'* These women may mourn the loss of the 'mother role' in which they are highly invested and for which they are struggling to find an alternative. These changes alongside the loss may have contributed to the high levels grief in this study.

Alongside exploring levels of distress following EP, this study also aimed to examine what factors may relate to such distress, specifically LOC and medical and

obstetric history. This is in line with existing research which has begun exploring the effect of varying factors on distress following pregnancy loss. However, Defrain et al (1996) reported that variance could not be accounted for by such factors and this appeared to be the case in this study. It should be noted that as a result of a small sample size it was not possible to conduct some analyses affecting the generalisability of findings. Despite this, the data highlights some interesting findings.

Women treated with Methotrexate described a difficulty being classed as pregnant until hormone levels decreased and indicated the end of the pregnancy. Women adjust emotionally but also their bodies have to adapt to no longer being pregnant. Swanson et al (2007) suggest that some elements of distress may be hormonal. Such hormonal changes take place over a prolonged period during Methotrexate treatment which may heighten distress levels. There appears to be a paradoxical message for women in which the pregnancy is unhealthy and is ending but their body remains in a state consistent with a continuing pregnancy. This may be difficult for women to accommodate and their comments support this. Services should consider the language used in this situation and consider if there are ways in which women can be helped to process this stage of pregnancy loss.

Women may benefit from information regarding the treatment in order to fully understand it and what it entails. Staff members should aim to be aware of women's emotional reactions and acknowledge the potentially complicated psychological process they are experiencing. Women reported benefiting from staff who were sympathetic to their loss. Nikcevic (2000) reported that the terminology the doctors use in relation to the pregnancy loss was important for women's emotional responses. For example, asking the parents if they would like the loss to be referred to as an EP or a baby. Alongside this, staff should be sensitive to the level of information shared with women.

Some women might prefer to discuss the treatment and the hormone levels each time and others to only be told that they will need to return for another appointment. Finally, parents may benefit from debriefing following the treatment and given a space to discuss their experiences.

In a study regarding attachment and pregnancy loss, Robinson (1999) suggested that once a woman knows she is pregnant, an attachment forms immediately. In the current study 79% of women suspected they were pregnant and therefore one might assume that as a group these women would suffer high levels of distress as they begin to form an attachment with their child. These expectations of parenthood contribute to feelings of guilt and failure often associated with depression (Letherby, 1993). Interestingly, a negative relationship existed between gestational age at the onset of symptoms and levels of depression. It is unclear why this occurred however qualitative data highlighted that not all women have difficulty with the loss of the child but instead struggle with feelings of guilt for being concerned about their own health. Gross and Pattisson (2007) discuss how currently women are viewed as a 'vessel' for the child and are made to feel that their health and feelings are second to the child's.

Related to the above, women described feeling angry towards others for not realising how ill they were. In the theme *changed relationships,'* many women described a strengthening of relationships, however some described difficulties. Social support has been found to be important in women's emotional recovery, particularly when others recognise and validate feelings (Abboud & Liamputtong, 2005). Therefore gestational age may not be associated with levels of depression as there may be a more complicated process occurring not solely focussed on the lost child.

Feelings of self – blame and guilt may affect how women attribute control over the cause of their loss and may be reflected in women's LOC scores. Women scored highest on the 'internal' subscale and interestingly the 'chance' subscale; these are contradictory categories and indicate that there is no clear pattern regarding LOC and levels of distress. Previous research has noted an internal LOC is related to a difficulty adjusting to loss and higher levels of psychological distress (Maker & Ogden, 2003). Women with higher chance scores reported lower levels of depression and future pregnancy appeared extremely important in this. Further pregnancy may allow women to feel able to overcome feelings of personal responsibility for the loss and failure about their bodies.

Implications for Healthcare

Two cases were presented for discussion, an example of a high and a low scoring participant. There were similarities and differences between these cases and although comparable themes emerged, it is evident that individual circumstances affect psychological outcome. Several studies have identified varying levels of distress and have attempted to account for this by investigating the influence of certain factors and contexts in women's lives. These studies have often concluded that a pregnancy loss is in itself stressful and each woman's case should be considered on an individual basis (Walker & Davidson, 2001). Findings from this study indicate that a number of symptoms experienced during EP can result in heightened levels of distress; therefore it is it important for staff to recognise this risk.

Participants were an entirely White British sample recruited from one hospital which inevitably affects the generalisability of findings to other populations and settings. However, this study's biggest limitation was the low recruitment rate. Other studies on pregnancy loss have encountered difficulties with recruitment and suggest

women are reluctant to take part in research as it may increase psychological distress (Nikcevic, 2000). It may be possible however, that women who did not take part are more distressed than those who did. Staff should be aware of women who do not express a need for support. Lasker and Toedter (1991) found that women who appear to be coping or seem withdrawn may be experiencing the most disturbed reactions.

Qualitative data highlighted the significant impact good experiences of hospital care can have on women's emotional recovery, but also highlighted a high level of disappointment. There should be a focus on providing appropriate care and support for women following EP. Half of the participants reported that they would have benefited from support agencies following EP and these women also reported higher levels of depression, indicating such women are in need of support. It was not clear what kind or level of support these women would require; therefore it would be beneficial for future research to explore this. The highest response was from women who had recent EP's (0-3 months) indicating this may be a good time for hospitals services to provide women with effective links to support services.

Finally, it is important to explore how staff working with this population can be supported. Dealing with high distress on a daily basis can result in emotional exhaustion which is damaging for both parties (Fothergill et al, 2004). Hence it is important for professionals to be informed by psychological theory on how best to understand and work with women following EP. Alongside this, future work should focus on the recruitment of this population in research. Findings suggest women suffer psychological difficulty following EP and their distress appears to differ in several ways to women following miscarriage. Therefore there is enough evidence to warrant this population being considered as a separate group. In order to further understand this group more information is required and therefore women need to participate in research.

Therefore understanding reasons for non-participation will inform future research designs and recruitment strategies.

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TOTAL WORD COUNT FOR EMPIRICAL PAPER – 6,144

TOTAL WORD COUNT FOR COMPLETE THESIS – 11, 339

Part Three.

Appendices

Appendix 1 – Notes or Guidelines for Authors for Systematic Literature Review

Health Psychology Review

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Instructions for Authors

Introduction

Submission of a paper to ***Health Psychology Review*** will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of the editor and publisher.

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Submission process

Manuscripts must be submitted by one of the authors of the manuscript. The submitting author is responsible for the article during the submission and peer review process.

To facilitate the review process ***Health Psychology Review*** accepts only online submissions. All submissions should be made online at ***Health Psychology Review***'s

ScholarOne Manuscripts site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Preparation of manuscripts

Currently, ***Health Psychology Review*** can only accept manuscripts written in English. Manuscripts should be double-spaced and should be prepared in accordance with the format and style specified in the Publication Manual of the American Psychological Association (APA), Sixth Edition. Pages should be numbered consecutively and organized as follows:

The Title Page (p. 1) should contain the article title, authors' names and affiliations. It should also include an author note with authors' full affiliations and the address for manuscript correspondence (including e-mail, address and telephone and fax numbers). In accordance with the APA Publication Manual (6th Ed.). No information that would indicate authors' identity or affiliation should be contained in the manuscript itself, all such information should be included on the title page only.

The Abstract (p. 2) must be a single paragraph that summarizes the main findings of the paper in fewer than 200 words. After the abstract a list of up to six keywords that will be useful for indexing or searching should be included.

Manuscript length

There is no formal word limit for manuscripts. Submissions should, however, be as long as necessary and authors of submissions of excessive length which do not covey ideas and points succinctly and concisely will be asked to truncate their manuscript. We also draw authors' attention to the Health Psychology Review online repository of supplemental materials that provides a permanently accessible resource of materials that are too long for the print version of the journal (e.g., oversized tables, intervention protocols, questionnaires etc.) but to which authors of articles appearing in Health Psychology Review wish readers to have access.

Style guidelines

The manuscript should follow the guidelines of the APA Publication Manual, Sixth Edition.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Figures should be in a finished form suitable for publication and should be numbered consecutively with Arabic numbers in order of appearance in the text.

Tables should be numbered consecutively with Arabic numbers in order of appearance in the text. Type each table double-spaced on a separate page, with a short descriptive title typed directly above and with essential footnotes below.

Competing interests

A competing interest exists when your interpretation or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors should disclose all financial and non-financial competing interests.

Authors are required to complete a declaration of competing interests and submit it together with the manuscript. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'. Please consider the following questions:

Financial competing interests

- In the past five years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? Is such an organization financing this manuscript? If so, please specify.
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- Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.
- Do you have any other financial competing interests? If so, please specify.

If you are unsure as to whether you, or one of your co-authors, has a competing interest please discuss it with the editorial office.

Authors' contributions

All authors are expected to have made substantive intellectual contributions to, and to have been involved in drafting or revising the manuscript. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship. With the submission of a manuscript, it is assumed that all authors have read and approved the final manuscript.

Acknowledgements

All contributors who do not meet the above criteria for authorship, should be listed in an acknowledgements section in accordance with the APA guidelines. The acknowledgements should be contained on the title page of the manuscript as making acknowledgements available to reviewers will compromise the masked peer-review process. Examples of those who might be acknowledged include those who provided general, technical, or writing assistance. Acknowledgement of funding/grants is also included in this section.

Proofs

The manuscript will be edited according to the style of the journal, and PDF proofs will be e-mailed to the corresponding author for final review. To avoid delay in publication, only necessary changes should be made, and corrections should be returned promptly.

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Upon acceptance of an article, authors will be asked to transfer copyright to Taylor & Francis. This transfer will ensure the widest possible dissemination of information. A letter will be sent to the corresponding author confirming receipt of the manuscript. A form facilitating transfer of copyright will be provided after acceptance.

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Appendix 2 – Reflective Statement

Reflective Statement

The research process has been interesting and challenging. There were times when things appeared straight forward and others that seemed difficult and caused me anxiety and frustration. However, as a result of carrying out this research, I have come to the conclusion that such difficulties are an important part of the research process that inform and strengthen the employed rationale and methodology. Having to reconsider ideas and make changes enhanced my understanding of the topic area and the context of research. This reflective statement has been written to record my learning throughout the process of planning and carrying out a large – scale research project. It will hopefully highlight ways in which certain things could have been done differently or more effectively and therefore inform future researchers in their study designs.

The forming of an idea

Having a wide interest in psychology I was initially unsure which area I would like to write a thesis on. Whilst on an adult primary care placement I saw a client who had experienced a traumatic birth. It appeared to have really affected her and her experience touched me. It sparked an interest in the effect of pregnancy on women's mental health. I then attended presentations at the university in which staff discussed their research interests and I began to think about what I would like to do. I had been particularly interested in a presentation on Ectopic pregnancy. As I had not heard of it before I decided to investigate it further. When I began learning more about this form of pregnancy loss and became aware of its severity, I was shocked that there was so little written about the impact on women and their families. I decided I would like to conduct research in this area, but as existing literature was so limited, I felt unsure where to begin. I spoke with my research supervisor who recommended I spoke with a consultant from an emergency gynaecology ward. He helped me to form some ideas

and stated that he would be interested in learning more about women's experiences of ectopic pregnancy and how we might identify which women may be vulnerable to experiencing heightened levels of distress.

As literature on ectopic pregnancy was limited I began reading about issues related to other forms of pregnancy loss such as miscarriage. After reading a study by Maker and Ogden (2003) I became aware that women can suffer very high levels of distress after pregnancy loss, nearly half of their participants scored high enough on validated measures to be considered clinical cases. I noticed that many studies in this area were written by or contributed towards by two American Psychologists named Judith Lasker and Lori Toedter. I emailed them to discuss ideas and issues found in their research. I received an email back containing a copy of their longitudinal study entitled, 'The Impact of Ectopic Pregnancy: A 16 Year Follow – Up Study.' This study raised my awareness of the serious and continued impact ectopic pregnancy can have on a woman. I felt that women's experiences of pregnancy loss as a whole were not well addressed, but I especially felt that aspects of ectopic pregnancy differentiated it from other forms of loss and it should be investigated separately. It was quite daunting to form an idea and make sure that my research would contribute something worthwhile to the literature base.

Designing a Study

I was initially interested in the prevalence of distress in this group of women and planned to use quantitative methods. I felt that as this population of women had not been studied in detail it would be important to establish to what extent they experience psychological distress. After further discussion with research and field supervisors, it was felt that it would be beneficial to explore to what extent certain factors identified in the literature as affecting women following a miscarriage also contribute to distress

following ectopic pregnancy. It was anticipated that this may help identify women who would benefit from support.

Whist investigating ectopic pregnancy I became aware of The Ectopic Pregnancy Trust. I contacted the organisation who also carries out research. They informed that a high number of women contacted them every year for support. They granted me permission to use their research questionnaire designed to gather background and demographic information which I planned to adapt in order to gather information relevant to my research ideas. The questionnaire also included a page for women to record a written account of their ectopic pregnancy and I thought this may be of use in adding richness to any data I collected (www.ectopic.org.uk). As I was interested in looking at a number of aspects of women's experiences I began thinking about the measures I might use. The Hospital Anxiety and Depression Scale (Zigmund & Snaith, 1983) was used as it is a short measure and collates information regarding two areas of mental health. It has also been used in several pregnancy loss studies and has been validated for use in early pregnancy (Jomeen & Martin, 2004). The Impact of Events Scale (Weiss & Marmar, 1997) was chosen as a short way of measuring symptoms of trauma. This measure has also been used in other pregnancy loss studies. Also through my reading of the literature, I noticed that several pregnancy loss studies had used the Perinatal Grief Scale (Potvin, Lasker & Toedter, 1988). This is a validated measure of grief following pregnancy loss. Form C from the Multidimensional Health Locus of Control Scales (Wallston, 2009) was used as it can be tailored specifically for the condition under investigation.

Initially I was unsure how I would analyse women's written responses but the options were to conduct content analysis or conduct thematic analysis. At this point I was unsure how much women would write and whether there would be enough to

conduct thematic analysis. During this stage of my research, I had to really consider what it would be like to experience and ectopic pregnancy and how I could make participation in the research as easy as possible. I had to think about how to tailor the research both to the aims of the research but also to the population under investigation.

Liaison with Early Pregnancy & Emergency Gynaecology Services

As part of the process of learning about the population of women I wanted to recruit and how best to design my study, I met with a Practice Development Nurse on a number of occasions. Having been involved with research before, and working on a daily basis with these women her input was invaluable. During these meetings I was able to begin to build relationships with relevant staff members such as the nurses on the wards. I was able to spend time on the wards and gain an idea about what it is like for women in these settings and understand the process women go through in the diagnosis and treatment of ectopic pregnancy.

I also attended a consultants meeting and presented my research. This was extremely daunting but was useful as the consultants asked questions and gave advice about the design of my study so that I could better develop it. Liaison with the service was important as it allowed me to make the recruitment stage as easy as possible without adding extra pressures to an already busy staff group. Additionally, staff needed to be aware of my research and what it entailed in case women encountered any difficulties during participation.

Ethics approval

I found the process of gaining ethical approval for my study very difficult. Having never sought such approval before I was at times confused about what form I needed to complete and who it needed to be sent to. It was also a very long process and

caused a considerable delay in my study getting started. My academic supervisor was unable to attend the LREC meeting and therefore I attended alone. I felt confident that I had covered all possible ethical concerns and put things in place to account for them. It was however still anxiety provoking to enter a room full of people who were there to ask questions about your study. The panel's main concern was regarding the identification of high levels of distress and how this issue will be dealt with. Despite my nerves, I was able to answer all of their questions and my study was awarded approval on the premise that I made a few small amendments. Once these had been made, full ethical approval was granted and my study could go ahead.

At a later stage, I had to make an application to LREC for permission to amend my research design as I was having difficulty with recruitment. The amendments were approved.

Recruitment

Once ethical approval was granted, I met with the Practice Development Nurse who took me onto the ward where I put posters and leaflets around the ward. During this meeting, I met with nursing staff and informed them that I had approval for my study and recruitment could start as soon as possible. The nurses appeared on board with my research and I felt positive that I would be able to get a good sample size. However, I experienced some disappointment regarding participant numbers. Ethically, a nurse needed to approach a woman for me and ask their permission for me to approach them. Due to the high demand on nurses they often forgot or women were discharged before anybody had a chance to discuss my research with them. I also found that a number of women expressed that they were too distressed at that time to take part. The recruitment strategy took a lot of time and effort and was not having much success.

I had to reconsider it as following several months, only six women had agreed to take part and only four women had completed and returned the questionnaire packs.

After discussion with my supervisors and nursing staff, we decided to change the recruitment strategy. Women were now to be recruited from the hospital patient database. This meant that I had access to more women to participate in my study but meant that I had to change the design of my study. I had planned to recruit women following their discharge from hospital and then follow them up at three months post discharge. This longitudinal design would have allowed some insight into how distress is experienced over time. However, it was anticipated that recruiting women from the database who had had an ectopic pregnancy within the last year would allow between group comparisons. I felt more positive about recruitment after this as the database contained lots of women's names. Despite this amendment, I was still only able to recruit 24 women. Other studies, such as that by Nikcevic and Nicolaides (2000) have reported difficulty recruiting women following pregnancy loss. I find myself still wondering why this is the case. Women who take part in studies often report that they would like more help and support but do not participate in research in order to improve understanding about how best to help. It did not appear to me that women did not take part in my research because they were not distressed. I came to this conclusion as several women telephoned the hospital after receiving the questionnaire packs and expressed very strong responses and opinions to my research. One woman expressed that the questionnaires had been received to close to her due date had the pregnancy been healthy. This might suggest that she is experiencing difficulty following her ectopic pregnancy and participating in research close to such an important anniversary would have been too much.

The difficulty with this recruitment strategy is that one is reliant on the information from the database being correct. There were occasions where women expressed feeling angry that their address details were incorrect, their names were incorrectly spelt and so on. Additionally, it became apparent that some women were classified in the hospital system as having had an ectopic pregnancy but this was not the diagnosis they had been given verbally. Some women were told they had a pregnancy in an unknown location and were therefore shocked to receive the questionnaire packs on ectopic pregnancy. Following this, myself and the Practice Development Nurse had to search the database for details of the diagnosis they had been given. This added an extra strain on recruitment and I was very grateful to the nurse for giving up her time to help with this. As it was not always clear what diagnosis women had been given, it was decided not to send questionnaire packs. Therefore it is possible that I lost some potential participants as a result of this.

The recruitment stage posed the greatest challenge in the whole research process. It highlighted that a research design may seem plausible on paper but when carried out in real life does not always go to plan. I think if anybody was to do a similar study in the future they need to take time to think about this stage. I was disappointed that despite my efforts and continued amendments only 24 women completed questionnaire packs, but I am grateful to the women who did take part.

Data Collection

Following the amendments to the study, it became a postal study. Therefore, data collection involved posting out questionnaire packs and waiting for completed questionnaires to be returned. Following the difficulties with recruitment, it was a relief to feel as though data was beginning to be collected. However, I became very anxious

as time went on and I was only receiving small amounts of returned questionnaires. As the study was anonymous, it was not possible to follow up potential participants, or ask them why they had chosen not to take part. At this point, I began to recognise the benefits of using more than one hospital site to recruit from. If I had more time I may have gone back to LREC and sought permission to collect data from other hospital sites. Due to low participation rates, future research should concentrate on following up non-participation and should consider recruiting from several sites to increase numbers.

Analysis of data

Due to the low sample size it was not possible to carry out extensive statistical analysis. I met with the department's statistician to discuss analysis options as I wanted to use my data in the best possible way. The statistician reported that I would only be able to carry out descriptive statistics and non-parametric tests. I was concerned that I would not have enough data to show anything. I began looking in more detail at women's written responses. I transcribed them for analysis and I noticed that many women had demonstrated a real honestly in their responses and had written relatively long accounts. It was decided that it would be possible to conduct thematic analysis on the data. The study therefore had a mixed design with quantitative and qualitative elements.

Transcribing the women's accounts helped me to become familiar with their responses. I enjoyed this aspect of the research as I was genuinely touched by women's responses. It spurred me on to ensure I did the best I could with the data they had provided. I was astounded by the number of potential themes I identified from women's responses. I found it difficult to condense themes together and ensure that all important aspects were covered by a themes title. My academic and research

supervisors also read the women's responses. This was extremely helpful in checking credibility of interpretations and themes. This process encouraged me to think about my relationship with the data and to appreciate the importance of getting outsiders ideas and reflections.

Writing the empirical paper

I initially held concerns about writing my empirical paper. Writing in a concise and scientific way is an acquired skill and something I have at times struggled with. The restriction of a word limit was difficult particularly considering the mixed methodology in my research. However, having the experience of writing an article ready for publication has been extremely useful and is an important skill to learn. Concise writing is something Psychologists use on a daily basis. It is important to learn how to communicate findings in a useful and concise way to ensure that important information is read and understood by others.

Systematic literature review

Having to conduct a systematic literature review was initially daunting as I had never carried out this form of review before. I had searched the literature at an early stage in order to form ideas and design this research; however the systematic literature review was conducted at a later stage due to the aforementioned difficulties in recruitment for my empirical paper. On reflection, I wish I had realised how much work this literature review would be and had started it earlier. However, although it was challenging I feel that the systematic literature review provides a routine and structured way of reporting issues raised in the literature.

Supervision

Supervision has been extremely important throughout the research process. It allowed me access to advice and guidance throughout each stage of research. More importantly, supervision allowed me time and space to reflect on my personal experiences both of the research process as a whole and my responses to participants and their responses. I was surprised about how passionate I became about this topic area, especially when one considers I am a young woman who has never had any pregnancies. Supervision allowed discussion of issues surrounding ectopic pregnancy. I realised that I was unaware of what ectopic pregnancy was before I embarked on this research process and I wonder how many other people do not realise what an ectopic pregnancy entails. I have always been aware that a loss of any kind, including a pregnancy loss, is a difficult experience but I was not aware of the potential seriousness of ectopic pregnancy and that it is still a leading cause of maternal death.

Overall reflections

The research process was challenging in a number of ways, yet also very rewarding. I feel I have learnt a lot about myself along the way. I realise that I have the ability to accept that things do not always go to plan, and although this can at times make me anxious, I was surprised by my ability to deal with these anxieties and balance all the demands on me as a trainee clinical psychologist.

Statistics have never been one of my strengths and I was initially concerned about conducting a quantitative study but was aware of the importance of statistical significance in studies. However, the research process resulted in a mixed method design. I feel this was appropriate considering the difficulties I entailed during recruitment. Quantitative methods allowed me to establish levels of distress within the

participant group, and although it was not possible to carry out all analyses I was able to explore the affects of some factors on levels of distress. Qualitative methods allowed a more in-depth exploration of women's experiences. The discovery of themes allows a detailed description of what it is like for some women to experience this form of pregnancy loss.

Something that stood out from this research was women's experiences of the physical symptoms of ectopic pregnancy. Symptoms can be potentially fatal but women described feeling guilty for worrying about their own health. When thinking historically, a pregnancy was considered successful if the woman survived. It was considered even more successful if the baby also survived. However this appears to have changed and the message appears to be that the baby is more important. Gross and Pattison (2007) described this process. They suggest that once pregnant a woman becomes a 'vessel' for the child and her health and needs from that point on come second. This encouraged me to think of the experience of pregnancy as a whole for women. I realised that pregnancy is a natural event that is considered wonderful by many people. However, pregnancy for some women can be extremely difficult, and becoming a mother actually entails a lot of changes and losses.

I discovered that research takes a great deal of time and this highlighted the importance of good planning, groundwork and making important links with services. As a result of the difficulties experienced during the recruitment stage I have learnt that access to a high number of potential participants does not guarantee that there will be a high number of participants willing to take part. Flexibility and willingness to alter the design so it is tailored to the population is extremely important. Overall, I am pleased with my research. My empirical study achieved what it set out to do - explore women's

experiences of ectopic pregnancy, and after conducting my systematic literature review I feel there is a place for my study in the current literature base.

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Appendix 3 – Notes for Guidelines for Authors for Empirical Paper

British Journal of Health Psychology (BJHP)

Notes for Contributors

The aim of the **British Journal of Health Psychology** is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although *the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length* **(see email at the end of Author Guidelines***).*

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via our online peer review system. The Journal operates a policy of anonymous peer review. **Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper.**

5. Manuscript requirement

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, and Conclusions. Review articles should use these headings: Purpose, Methods, Results, and Conclusions. Please see the document below for further details:

 British Journal of Health Psychology - Structured Abstracts Information

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

6. Publication ethics

All submissions should follow the ethical submission guidelines outlined the documents below:

Ethical Publishing Principles – A Guideline for Authors

Code of Ethics and Conduct (2006)

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Copyright

On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form. To find out more, please see our Copyright Information for Authors.

Email regarding word count

From: Rachel H Whitehead [mailto:R.Whitehead@2004.hull.ac.uk]

To: Journals External

Subject: Enquiry

Dear whom ever it may concern.

I have written a paper entitled 'An Exploratory Study of Women's Responses to Ectopic Pregnancy.' My difficulty is that the research used a mixed design and there are two case studies presented for discussion. This means my word count is about a thousand words over the 5000 word count. I read that you would consider taking longer manuscripts if they are concise and extra words are necessary to the paper.

Can you please help me with this issue?

Rachel Whitehead

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To: Rachel H Whitehead

Subject: RE: Enquiry

Dear Rachel,

It would be easiest if you submit the manuscript for consideration, with the explanation below for the extended word count, and then the editors will be able to read the paper and decide whether they'd be happy to extend the normal word limit. If you have any problems using our submission system, please do not hesitate to contact me.

Best wishes,

Hannah Wakley

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48 Princess Road East

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Appendix 4 – Ethical Approval

NHS
National Research Ethics Service
South Humber Research Ethics Committee
Room FC27
Corision House
Trust Headquarters
Willerby Hill Business Park
Willerby
HULL
HU10 6ED

Telephone: 01482 389157
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01 September 2009

Miss Rachel Whitehead
Trainee Clinical Psychologist
Humberside NHS Mental Health Teaching Trust
The Univeristy of Hull
Cottingham Road
Hull
HU6 7RX

Dear Miss Whitehead

Study Title: **Prevalence Of, and Factors Relating to the Development of Psychological Distress In Women Following Ectopic Pregnancy**
REC reference number: **09/H1305/43**
Protocol number: **Version 2**

Thank you for your letter of 17 August 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Reminder letter	Version 1	02 July 2009
CV - Supervisor - Lesley Glover	Version 1	02 April 2009
Participant Consent Form	Version 1	27 March 2009
GP/Consultant Information Sheets	Version 2	19 June 2009
Letter of invitation to participant	Version 3	05 May 2009
Questionnaire: Non validated	Version 2	05 May 2009
Questionnaire: Validated	Version 1	
Summary/Synopsis	Version 3	27 April 2009
Protocol	Version 2	05 May 2009
Investigator CV	Version 1	02 April 2009
REC application	Version 2.2	06 July 2009
Participant Information Sheet	Version 4	17 August 2009
Advertisement	Version 4	17 August 2009
Response to Request for Further Information	Version 1	17 August 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports

- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1305/43	Please quote this number on all correspondence

Yours sincerely

pp K. Waltham

Dr Ian G Woollands
Chair – South Humber REC

Email: karen.waltham@humber.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR1 for CTIMPs, SL- AR2 for other studies]*

Copy to: *Mr Stephen Walker*
[R&D office for NHS care organisation at lead site]

Appendix 5 – Research Questions & Hypotheses

Research Questions and Hypotheses

1. What levels of psychological distress exist in this population?

2. How do levels of psychological distress differ depending on length of time since EP?

Experimental Hypothesis – There will be a high level of psychological distress in this participant group. Levels of anxiety, depression, and PTSD will be higher in women who have had recent EP's (0 – 4 months). However, those women reporting symptoms after 5 – 12 months will have specific factors in their medical and obstetric history, which have contributed to the maintenance of symptoms.

3. To what extent does this participant group experience a grief reaction following their EP?

Hypothesis - The amount of women scoring highly on the Perinatal Grief Scale will decrease but women still experiencing a grief reaction from 5 – 12 months will have specific factors in their medical and obstetric history, which have contributed to maintenance of symptoms.

4. Is a woman's medical and obstetric history associated with levels of psychological distress following EP?

Definition – The term medical and obstetric history is used to encompass a woman's past medical conditions and complaints and her previous childbearing history.

Hypothesis - There will be a relationship between the medical and obstetric history and women's scores on the measures.

5. Is a woman's Locus of Control regarding her condition associated with levels of distress?

Hypothesis - There will be a relationship between women's scores on the Locus of Control measure regarding her condition and levels of psychological distress. Women who cope by externalising cause will have lower levels of distress in comparison to those who internalise blame.

6. What are women's subjective experiences regarding their EP?

Hypothesis – although every woman's experience will be different, common themes will emerge from participants written responses.

Appendix 6 – Standardised Measures

IMPACT OF EVENT SCALE-REVISED

Instructions: The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you *during the past 7 days* with respect to the incident in question. How much were you distressed or bothered by these difficulties?

		Not at all	A little bit	Moderate-ly	Quite a bit	Extreme-ly
I1	Any reminder brought back feelings about it.	0	1	2	3	4
I2	I had trouble staying asleep.	0	1	2	3	4
I3	Other things kept making me think about it.	0	1	2	3	4
H4	I felt irritable and angry.	0	1	2	3	4
A5	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
I6	I thought about it when I didn't mean to.	0	1	2	3	4
A7	I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
A8	I stayed away from reminders about it.	0	1	2	3	4
I9	Pictures about it popped into my mind.	0	1	2	3	4
H10	I was jumpy and easily startled.	0	1	2	3	4
A11	I tried not to think about it.	0	1	2	3	4

A12	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
A13	My feelings about it were kind of numb.	0	1	2	3	4
I14	I found myself acting or feeling like I was back at that time.	0	1	2	3	4
H15	I had trouble falling asleep.	0	1	2	3	4
I16	I had waves of strong feelings about it.	0	1	2	3	4
A17	I tried to remove it from my memory.	0	1	2	3	4
H18	I had trouble concentrating.	0	1	2	3	4
H19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
I20	I had dreams about it.	0	1	2	3	4
H21	I felt watchful and on guard.	0	1	2	3	4
A22	I tried not to talk about it.	0	1	2	3	4

PERINATAL GRIEF SCALE

PRESENT THOUGHTS AND FEELINGS ABOUT YOUR LOSS

Each of the items is a statement of thoughts and feelings which some people have concerning a loss such as yours. There are no right or wrong responses to these statements. For each item, circle the number which best indicated the extent to which you agree or disagree with it at the present time. If you are not certain, use the "neither" category. Please try to use this category only when you truly have no opinion.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I feel depressed.	1	2	3	4	5
2. I find it hard to get along with certain people.	1	2	3	4	5
3. I feel empty inside.	1	2	3	4	5
4. I can't keep up with my normal activities.	1	2	3	4	5
5. I feel a need to talk about the baby.	1	2	3	4	5
6. I am grieving for the baby.	1	2	3	4	5
7. I am frightened.	1	2	3	4	5
8. I have considered suicide since the loss.	1	2	3	4	5

9. I take medicine for my nerves.	1	2	3	4	5
10. I very much miss the baby.	1	2	3	4	5
11. I feel I have adjusted well to the loss.	1	2	3	4	5
12. It is painful to recall memories of the loss.	1	2	3	4	5
13. I get upset when I think about the baby.	1	2	3	4	5
14. I cry when I think about him/her.	1	2	3	4	5
15. I feel guilty when I think about the baby.	1	2	3	4	5
16. I feel physically ill when I think about the baby.	1	2	3	4	5
17. I feel unprotected in a dangerous world since he/she died.	1	2	3	4	5
18. I try to laugh, but nothing seems funny anymore.	1	2	3	4	5

19. Time passes so slowly since the baby died.	1	2	3	4	5
20. The best part of me died with the baby.	1	2	3	4	5
21. I have let people down since the baby died.	1	2	3	4	5
22. I feel worthless since he/she died.	1	2	3	4	5
23. I blame myself for the baby's death.	1	2	3	4	5
24. I get cross at my friends and relatives more than I should.	1	2	3	4	5
25. Sometimes I feel like I need a professional counsellor to help me get my life back together again.	1	2	3	4	5
26. I feel as though I'm just existing and not really living since he/she died.	1	2	3	4	5
27. I feel so lonely since he/she died.	1	2	3	4	5

28. I feel somewhat apart and remote, even among friends.	1	2	3	4	5
29. It's safer not to love.	1	2	3	4	5
30. I find it difficult to make decisions since the baby died.	1	2	3	4	5
31. I worry about what my future will be like.	1	2	3	4	5
32. Being a bereaved parent means being a "Second-Class Citizen".	1	2	3	4	5
33. It feels great to be alive.	1	2	3	4	5

Multi – Dimensional Health Locus of Control - Form C

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale that ranges from strongly disagree (1) to strongly agree (6). For each item circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher the number you circle. The more you disagree with a statement, the lower the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE **(SD)** 2=MODERATELY DISAGREE **(MD)** 3=SLIGHTLY DISAGREE **(D)**	4=SLIGHTLY AGREE **(A)** 5=MODERATELY AGREE **(MA)** 6=STRONGLY AGREE **(SA)**

		SD	MD	D	A	MA	SA
1	If my condition worsens, it is my own behaviour, which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be?	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing that affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

Research Questionnaire

The Ectopic Pregnancy Trust

Personal Details

Name -
Date of Birth –
Ethnic Origin: (not place of birth but the ethnic group to which you belong).

Have you suffered from or received treatment for any of the following conditions prior to your 1st Ectopic Pregnancy? (Please tick)

- ❑ **Abdominal Surgery**
- ❑ **Caesarean Section**
- ❑ **Appendicitis**
- ❑ **Termination**
- ❑ **Miscarriage**
- ❑ **Chlamydia**
- ❑ **Pelvic Infection**
- ❑ **Endometriosis**
- ❑ **Had a coil (UCD)**
- ❑ **Used the Mini Pill**
- ❑ **Tubal Surgery**
- ❑ **Fertility Treatment**
- ❑ **D & C**
- ❑ **Sterilisation.**

Previous Pregnancies

How many pregnancies have you had?

Type of Pregnancy	**Number**
Live Births	
Miscarriage	
Ectopics	
Still Birth	
Termination	

Experiences of Your 1st **Ectopic Pregnancy**

The following questions are about your experience of Ectopic pregnancy.

Before your 1st Ectopic pregnancy did you know what Ectopic pregnancy was? YES / NO

What symptoms did you have when a health care professional first saw you? (Please tick)

Abdominal pain		Vaginal bleeding	
Bowel Problems		Feeling Faint	
Vomiting		Pain in Shoulder	
Feeling Unwell		Fainting	
Late period		To report being pregnant	
To Have a Scan Due To Previous Ectopic		Scan following IVF or other fertility Treatment	
Sudden Collapse		Other (please give details)	

Did you know or suspect you were pregnant? YES / NO

Did you have a pregnancy test? YES / NO

Did anyone suspect it was an Ectopic pregnancy? (I.e. you / partner / health care professional?) YES / NO

How many weeks into your pregnancy did your symptoms appear? …….

How many weeks pregnant were you when your Ectopic was diagnosed? ……

Were you tested for sexually transmitted infections? YES / NO

Who did you first report to when your symptoms first appeared? …….

How many times were you seen before Ectopic pregnancy was diagnosed and you were admitted to the Early Pregnancy Unit?

……..

After Diagnosis

Once diagnosed do you feel Ectopic pregnancy was fully explained to you? YES / NO
Do you feel you were given adequate information whether it was verbal or written? YES / NO
Were you involved in the treatment choice? YES / NO

What treatment did you / are you receiving? (Please tick)

Don't Know		Removal of Tube	
Surgery		Medical Treatment To Keep Tube	
Keyhole Surgery		Methotrexate	
Abdominal Incision		Wait and See If Ectopic Settles	

Did your Tube Rupture? YES / NO
Do you feel you were given an adequate explanation of treatment? YES / NO

After Treatment

Were you informed of the future risks of Ectopic Pregnancy? YES / NO

Were you given any information or contacts about local or national support groups or agencies? YES / NO

Do you feel you would benefit from support from agencies? YES / NO

If YES what kind of support do you feel you would benefit from? (Please tick)

Written		Support Group	
Internet		Counselling	
Verbal		Further referral to mental health services	

Future Pregnancy

Please read all the options and tick the one(s) that apply to you.

I don't want another pregnancy my family is complete		I have conceived naturally since my Ectopic	
I'm too scared to try again		I have had a child since my Ectopic pregnancy	
I'm having difficulty conceiving		I have had a further miscarriage since my Ectopic pregnancy	
It feels too soon after my Ectopic pregnancy		I have needed fertility treatment such as IVF	

Have you suffered any physical problems that you did not have before your Ectopic pregnancy?

……

How Has The Ectopic Pregnancy Affected Your Life?

Please write a short account of your Ectopic pregnancy. Please consider how the Ectopic pregnancy may have changed your life, emotions and affected you relationships. Also consider how you felt following your Ectopic pregnancy and how you feel about it now.

HAD Scale

Number: Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick one box only in each section

1 *I feel tense or 'wound up':*
- Most of the time ☐
- A lot of the time ☐
- Time to time, Occasionally ☐
- Not at all ☐

2 *I still enjoy the things I used to enjoy:*
- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

3 *I get a sort of frightened feeling as if something awful is about to happen:*
- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

4 *I can laugh and see the funny side of things:*
- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

5 *Worrying thoughts go through my mind:*
- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

6 *I feel cheerful:*
- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

7 *I can sit at ease and feel relaxed:*
- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

8 *I feel as if I am slowed down:*
- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

9 *I get a sort of frightened feeling like 'butterflies' in the stomach:*
- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

10 *I have lost interest in my appearance:*
- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

11 *I feel restless as if I have to be on the move:*
- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

12 *I look forward with enjoyment to things:*
- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

13 *I get sudden feelings of panic:*
- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

14 *I can enjoy a good book or radio or TV programme:*
- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

Appendix 7 – Nurse Letter

Dear ……

As you may be aware, there is a research study being carried out within the Gynaecology Department at Women & Children's Hospital, at the Hull Royal Infirmary. The research is looking into women's experiences of **Ectopic Pregnancy**. There is very little written or known about how to support women during this difficult time. It is hoped that the information gathered from this study will help us to understand women better and through doing so be able to help them better in the future. We understand that this may have been an extremely difficult time for you. However, we would **really appreciate if you take part in this study.** It may not help you directly, but the information and comments you provide will be valuable in helping women in the future.

The study requires you to complete a questionnaire pack - included with this letter. The pack will take no longer than an hour to complete. Once completed, please return the questionnaires in the stamped addressed envelope provided. Participation is completely anonymous.

If you encounter any difficulty whilst completing these questionnaires, please do not hesitate to contact myself on (01482) 382750, or the researcher Rachel Whitehead on (01482) 464117. Finally, if you feel as though you are not coping well emotionally please contact your GP for advice.

Many thanks for your time and we hope that you will take part in this study,

Elizabeth Morris
Practice Development Nurse- Gynaecology

On behalf of Rachel Whitehead
Trainee Clinical Psychologist

Appendix 8 - Participant Information Sheet

Participant Information - Prevalence Of, and Factors Relating To, the Development of Psychological Distress in Women Following Ectopic Pregnancy

We would like to invite you take part in a research study. Before you make a decision, you need to understand why the research is being done and what it involves. Feel free to talk to the hospital staff about the research if you wish. Take time to decide whether or not you would like to take part.

Part 1 -What is the purpose of this study?

We do not know much about the psychological effects of Ectopic pregnancy. The purpose of this study is to help us understand how Ectopic pregnancy and events from you reproductive history affect you emotionally. The term 'psychological distress' in this study is used to mean symptoms of depression, anxiety, trauma and grief.

Why have I been invited to take part in this study?

If you have received this information sheet along with a letter through the post then you will have had an Ectopic pregnancy within the last year. We understand that this is difficult for you and therefore your participation in this study is highly valued.

What will I need to do if I take part?

A questionnaire pack is included with this information sheet. If you are willing to take part then please complete the full questionnaire pack and return it in the stamped addressed envelope provided. The questionnaires are very simple to complete. Many only require a tick or circle answer. Once you have sent the questionnaire back, your participation in the study is over.

Are there any disadvantages to taking part?

We appreciate that this may be an extremely difficult time for you. The study requires you to think about your experiences in order to complete the questionnaires, which might feel quite hard.

Are there any advantages to taking part?

Although this study may not help you personally, your views will help us gain a better understanding of women's experiences following Ectopic pregnancy and might help towards our service provision for women in the future. Some people also find filling out the questionnaires a welcome distraction.

Will my participation be kept confidential and what if there is a problem?

We will follow ethical and legal practice and all information about you will be handled in confidence. All information from you will be confidential and no names will be attached to specific questionnaires. Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2. **If the information in Part 1 has interested you, please read Part 2.**

Part 2

What happens if I no longer want to participate?

Questionnaires are confidential and no names are attached to them. Therefore, it would be difficult to determine which questionnaires belong to you. If you have provided the researcher with your contact details in order to receive feedback regarding the results of the study and change your mind about this, your details will be safely discarded.

Complaints

If you have any concerns about the study, you should ask to speak to the researcher (The University of Hull, Department of Clinical Psychology – 01482 464117). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital.

Confidentiality

Any information you contribute to the study will be confidential. The information you provide will be confidential. All information will be collected and stored securely. Names or any identifiable details will not be kept or stored. Only the researcher and other authorised persons (research supervisor) will have access to the data. Once the study is over the data will kept for approximately 5 years.

If you find that you are experiencing any difficulty during your participation in this study you are advised to visit your GP.

Results

The results of this study will be reported as an academic doctorate degree. If you would like, feedback and results can be shared with you.

This study has been reviewed by a Research Ethics Committee to protect your safety and rights. If you have any queries regarding the study you can contact the researcher, Rachel Whitehead (Trainee Clinical Psychologist at The University of Hull) on 01482 464117. You might also find it useful to visit The Ectopic Pregnancy Trust website for information and support regarding Ectopic pregnancy along with other existing research studies - www.ectopic.org.uk.

Appendix 9 – Consent Form

Center Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project:

Prevalence Of, and Factors Relating To, the Development of Psychological Distress in Women Following Ectopic Pregnancy.

Name of Researcher: **Rachel Whitehead** (Trainee Clinical Psychologist).

1. I confirm that I have read and understand the information sheet - Version 1 27th March 2009. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I agree to my GP being informed of my participation in the study.

4. I agree to take part in the above study.

Please Print Name (BLOCK CAPITALS) ……

Participant Signature ……

When completed, 1 for patient, 1 for researcher site file and 1 (original) to be kept in medical notes.

Appendix 10 – Thematic Analysis Method

This method of thematic analysis by Virginia Braun & Victoria Clarke in the paper - Using thematic analysis in psychology, was adapted for use in this study.

Phase 1- Familiarising yourself with your data – Transcribing data, reading and re-reading the data, noting down initial ideas.

Phase 2 - Generating initial codes – Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.

Phase 3 - Searching for themes – Collating codes into potential themes, gathering all data relevant to each potential theme.

Phase 4 – Reviewing themes – Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis.

Phase 5 – Defining and naming themes – Ongoing analysis to refine the specifics of each theme, and overall story the analysis tells, generating clear definitions and names for each theme.

Phase 6 – Producing the report – The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Appendix 11 – Qualitative Analysis

Theme	Description / Definition
Theme 1 – Physical Symptoms & Pain	Encapsulates the medical procedures encountered during diagnosis and treatment of EP. Also, includes descriptions of pain and symptoms. Women describe a lack of recognition from others regarding the seriousness of the condition.
Theme 2 – Changed Relationships	Includes both the positive and negative impact EP can have on relationships and the impact of social ignorance.
Theme 3 – Adjustment & Appraisal	Theme depicting how a woman's adjustment to the EP may depend on her appraisal of it. Includes a description of intense emotions experienced and processes involved with these emotions.
Theme 4 – Changed Meaning of Pregnancy	A theme capturing several aspects of changed meaning of pregnancy. Includes a fear of EP occurring again, a preoccupation with future conception, further pregnancy and a difficulty being around pregnant others. This theme also describes the experience of women treated with Methotrexate for which the loss of the pregnancy can be prolonged.
Theme 5 – Hospital Care	Describes women's experiences of hospital care. Includes both negative and positive experiences and how these impact on emotional recovery. Describes a lack of information and how this affected them.

Appendix 12 – Quantitative Analysis

SPSS Output

Age

	N	Minimum	Maximum	Mean	Std. Deviation
Age	24	21	41	31.17	6.281
Valid N (list wise)	24				

Number of Symptoms

	N	Minimum	Maximum	Mean	Std. Deviation
Number of Symptoms	24	1	6	2.71	1.732
Valid N (list wise)	24				

Gestational Age at Onset of Symptoms

	N	Minimum	Maximum	Mean	Std. Deviation
Gestational Age at Onset	23	2	12	6.57	1.903
Valid N (list wise)	23				

Number of Months since EP

	N	Minimum	Maximum	Mean	Std. Deviation
Number Of Months Since EP	22	1	12	5.32	4.028
Valid N (list wise)	22				

Associated Risk Factors

	N	Minimum	Maximum	Mean	Std. Deviation
Associated risk factors	24	1	2	1.25	.442
Valid N (list wise)	24				

Mean Levels of Psychological Distress

	N	Minimum	Maximum	Mean	Std. Deviation
Overall IES	24	1	81	40.04	21.035
Avoidance	24	0	29	13.92	6.769
Intrusions	24	1	31	15.79	9.362
Hyper-arousal	24	0	22	8.96	6.140
Anxiety	24	2	18	8.63	4.915
Depression	24	0	16	6.75	4.436
Overall PGS	24	37	142	91.08	31.941
Active Grief	24	11	52	34.58	12.434
Difficulty Coping	24	13	54	29.75	11.566
Despair	24	12	43	26.75	9.643
Valid N (list wise)	24				

Mean LOC

	N	Minimum	Maximum	Mean	Std. Deviation
Internal	22	6	25	16.36	5.619
Doctors	22	3	22	12.91	5.227
Chance	22	7	24	15.09	5.353
Others	22	3	24	9.32	4.755
Valid N (list wise)	22				

Spearman's rho Correlations between Levels of Psychological Distress

		IES	Anxiety	Depression	PGS
IES	Correlation Coefficient	1.000	.791**	.660**	.813**
	Sig. (2-tailed)	.	.000	.000	.000
	N	24	24	24	24
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**
	Sig. (2-tailed)	.000	.	.002	.001
	N	24	24	24	24
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**
	Sig. (2-tailed)	.000	.002	.	.000
	N	24	24	24	24
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000
	Sig. (2-tailed)	.000	.001	.000	.
	N	24	24	24	24

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Spearman's rho Correlations for Age and Scores on the Measure

		IES	Anxiety	Depression	PGS	Age
IES	Correlation Coefficient	1.000	.791**	.660**	.813**	-.047
	Sig. (2-tailed)	.	.000	.000	.000	.826
	N	24	24	24	24	24
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**	-.024
	Sig. (2-tailed)	.000	.	.002	.001	.910
	N	24	24	24	24	24
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**	.122
	Sig. (2-tailed)	.000	.002	.	.000	.572
	N	24	24	24	24	24
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000	.008
	Sig. (2-tailed)	.000	.001	.000	.	.972
	N	24	24	24	24	24
Age	Correlation Coefficient	-.047	-.024	.122	.008	1.000
	Sig. (2-tailed)	.826	.910	.572	.972	.
	N	24	24	24	24	24

**. Correlation is significant at the 0.01 level (2-tailed).

Spearman's rho Correlations for Length of Time since EP and Levels of Distress

		IES	Anxiety	Depression	PGS	Months
IES	Correlation Coefficient	1.000	.791**	.660**	.813**	-.087
	Sig. (2-tailed)	.	.000	.000	.000	.700
	N	24	24	24	24	22
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**	.090
	Sig. (2-tailed)	.000	.	.002	.001	.689
	N	24	24	24	24	22
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**	-.518*
	Sig. (2-tailed)	.000	.002	.	.000	.014
	N	24	24	24	24	22
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000	-.151
	Sig. (2-tailed)	.000	.001	.000	.	.501
	N	24	24	24	24	22
Months	Correlation Coefficient	-.087	.090	-.518*	-.151	1.000
	Sig. (2-tailed)	.700	.689	.014	.501	.
	N	22	22	22	22	22

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Spearman's rho Correlations for Number of Symptoms and Levels of Distress

		IES	Anxiety	Depression	PGS	Symptoms
IES	Correlation Coefficient	1.000	.791**	.660**	.813**	.347
	Sig. (2-tailed)	.	.000	.000	.000	.097
	N	24	24	24	24	24
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**	.416*
	Sig. (2-tailed)	.000	.	.002	.001	.043
	N	24	24	24	24	24
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**	.274
	Sig. (2-tailed)	.000	.002	.	.000	.195
	N	24	24	24	24	24
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000	.436*
	Sig. (2-tailed)	.000	.001	.000	.	.033
	N	24	24	24	24	24
Symptoms	Correlation Coefficient	.347	.416*	.274	.436*	1.000
	Sig. (2-tailed)	.097	.043	.195	.033	.
	N	24	24	24	24	24

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Spearman's rho Correlations for Gestational Age at Onset of Symptoms and Levels of Distress

		IES	Anxiety	Depression	PGS	Gestational Age
IES	Correlation Coefficient	1.000	.791**	.660**	.813**	-.119
	Sig. (2-tailed)	.	.000	.000	.000	.589
	N	24	24	24	24	23
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**	-.015
	Sig. (2-tailed)	.000	.	.002	.001	.944
	N	24	24	24	24	23
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**	-.111
	Sig. (2-tailed)	.000	.002	.	.000	.614
	N	24	24	24	24	23
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000	.011
	Sig. (2-tailed)	.000	.001	.000	.	.960
	N	24	24	24	24	23
Gestational Age	Correlation Coefficient	-.119	-.015	-.111	.011	1.000
	Sig. (2-tailed)	.589	.944	.614	.960	.
	N	23	23	23	23	23

**. Correlation is significant at the 0.01 level (2-tailed).

Spearman's rho Correlations for LOC and Levels of Psychological Distress

		IES	Anxiety	Depression	PGS	Internal	Doctors	Chance	Others
IES	Correlation Coefficient	1.000	.791**	.660**	.813**	.190	.251	-.261	.157
	Sig. (2-tailed)	.	.000	.000	.000	.397	.259	.242	.485
Anxiety	Correlation Coefficient	.791**	1.000	.603**	.656**	.056	.287	-.075	.087
	Sig. (2-tailed)	.000	.	.002	.001	.804	.195	.742	.699
Depression	Correlation Coefficient	.660**	.603**	1.000	.663**	.278	.340	-.541**	.361
	Sig. (2-tailed)	.000	.002	.	.000	.210	.122	.009	.099
PGS	Correlation Coefficient	.813**	.656**	.663**	1.000	.415	.289	-.190	.185
	Sig. (2-tailed)	.000	.001	.000	.	.055	.191	.397	.410
Internal	Correlation Coefficient	.190	.056	.278	.415	1.000	.478*	.128	.135
	Sig. (2-tailed)	.397	.804	.210	.055	.	.024	.571	.549
Doctors	Correlation Coefficient	.251	.287	.340	.289	.478*	1.000	-.046	.214
	Sig. (2-tailed)	.259	.195	.122	.191	.024	.	.837	.339
Chance	Correlation Coefficient	-.261	-.075	-.541**	-.190	.128	-.046	1.000	.086
	Sig. (2-tailed)	.242	.742	.009	.397	.571	.837	.	.703
Others	Correlation Coefficient	.157	.087	.361	.185	.135	.214	.086	1.000
	Sig. (2-tailed)	.485	.699	.099	.410	.549	.339	.703	.

**. Correlation is significant at the 0.01 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed).

Appendix 13 - Mann Whitney Tests

Table 10. Mann – Whitney Results for factors associated with distress and scores on measures.

Factor & Measure	**Mean'Yes'**	**Mean 'No'**	**U value & Significance**
Already Have Children	10	14	-
IES	12.90	12.21	66 ns
Anxiety (HADS	13.25	11.96	62.5 ns
Depression (HADS)	13.45	11.82	60.5 ns
PGS	13.30	11.93	62 ns
Involved in Treatment Choice	17	6	-
IES	12.59	10.33	41 ns
Anxiety (HADS)	13.12	8.83	40 ns
Depression (HADS)	12.62	10.25	40.5 ns
PGS	12.82	9.67	32 ns
Treatment Type	17 – surgery	7 - Methotrexate	-
IES	12.50	12.50	59.5 ns
Anxiety (HADS)	11.68	14.50	45.5 ns
Depression (HADS)	11.88	14.00	49 ns
PGS	13.18	10.86	48 ns
Ruptured Tube	9	15	-
IES	11.28	13.23	56.5 ns
Anxiety (HADS)	11.72	12.97	60.5 ns
Depression (HADS)	11.11	13.33	55 ns
PGS	13.27	13.27	56 ns
Tube Removed	17	7	-
IES	12.50	12.50	59.5 ns
Anxiety (HADS)	11.68	14.50	45.5 ns
Depression (HADS)	11.88	14.00	49 ns
PGS	13.18	10.86	48 ns
Benefit from Support Agencies	12	11	-
IES	14.04	9.77	41 ns
Anxiety (HADS)	13.38	10.50	49.5 ns
Depression (HADS)	15.08	8.64	29 p = 0.02
PGS	13.58	10.27	47 ns

Appendix 14 – Epistemological Statement

Epistemological Statement

Presently, a number of psychologists are leaning more towards a scientific stance, focussing on fact, truth and reason and would describe themselves as 'scientific practitioners.' However, in the past, psychology has leaned more towards philosophy, abstract concepts and reflection. The direction psychology takes is often dependent on 'current happenings' e.g. cultural beliefs and social stances. Currently policies, procedures and guidelines driving psychology recommend evidence based practice deriving from empirical research findings, and use outcome measures to establish effectiveness of treatment and practice. It even appears that the reflective process has been affected by the scientific stance in that it is used as a method of improving outcomes as oppose to discussion of deeper meanings and exploration on the experiences of the practitioner and participant/client.

In my six years experience of psychology (three years undergraduate study and three years post graduate training), I have developed a view of psychology as a means of understanding, exploring, and allowing for individual differences. I have often concluded that there is not a 'one size fits all' option or clear definitive answers. As part of the reflective process for my study, I began to think about the nature and process of research, the assumptions we make as professionals and the scientific study of psychological concepts. This was not to question the value of research in psychology but rather to think about what is being researcher and how.

My experience of research and discussions with others regarding the conclusions of my study and how I arrived at them encouraged me to think from an epistemological position. Research usually aims to test existing theory, develop and test hypotheses in order to further our knowledge. I initially set out on my research journey with no

assumptions regarding early pregnancy loss or whether distress existed following an ectopic pregnancy. Additionally, the research and literature base is limited with little theories and ideas currently existing. Therefore, in order to research this area I had to make assumptions about this area in that it requires exploration and that distress exists following such a loss. I made this assumption based on my own knowledge of loss and existing theories relating to this. I approached this research topic from a critical realism point of view in that 'primary qualities' exist which are shared realities. For example, a ball is round – and nobody could really argue that it is a triangle. Taking this into account I took the view that an ectopic pregnancy occurs and will have some effect on an individual. Secondary qualities are subjective to an individual and therefore what kind of effect the ectopic pregnancy has is variable between individuals and therefore I wanted to explore this further.

Alongside this, I had to make the assumption that distress can be defined, tested and measured. Many techniques are used to test such assumptions including experiments, controlled trials, interviews and in the case of this study questionnaires. Again, we make the assumption that the tools we use are valid and reliable enough to universally measure others distress and capture their experiences. This is interesting considering my earlier ideas of psychology as exploration of unique experiences and accounting for individual differences. Thinking in this way highlights the need to reflect on the research process and what we are assuming and why to ensure as much as possible that the topic area is being approached from an objective stance.

I had initially set out only to explore women's reactions to ectopic pregnancy with no assumptions about prevalence of distress following this type of pregnancy loss. During the research process there seemed to be an assumption that I should establish 'whether distress exists' following ectopic pregnancy so that I can then further explore

the issues relating to this, therefore quantitative measures were included in an attempt to establish the level of distress within this population. Thinking in this way is important as it allows identification of how such assumptions arise during the research process and how they then influence other aspects of it along the way.

Quantitative measurement required distress to exist as a definable variable which is recordable in a way that is reliable and valid. Reliability and validity are determined statistically and through subjective and objective opinion. This allowed certain data to be collated, which was hopefully the information I had intended to collect, but it does not incorporate individual difference. A concept identified in this research was a process of complicated grief in which was not always sadness regarding the loss of a child but rather grief regarding the loss of a fallopian tube signifying a reduced chance of future conception, a loss of femininity and a sense that their bodies had let them down somehow. This was not and is no way identifiable from the quantitative measures that were included in the study. This highlights how research can sometimes enrich our knowledge base but can also limit it.

Qualitative methods were incorporated in attempt to account for the limitations of quantitative measures. Such methods of accessing each participant's inner reality and gaining an insight into their unique experiences is again based on an assumption; the assumption that as people we can comprehend, access and express our most inner thoughts and feelings. With regards to the current study, there is also the assumption that if people can access thoughts and feelings that they could then communicate their experiences in writing in such a way that would allow another (such as a researcher) to summarise, define and categorise them for ease of understanding. It seems reasonable to suggest that something will inevitably be lost during this process and allows much room for bias. Some women wrote more than others when giving their subjective

account of EP which might result from some women being better equip than others to express their full experience, and therefore such qualitative methods are limited by an individual's ability to share beliefs and experiences.

Finally, assumptions made early on the research process will inevitably effect interpretation which is often done from the view of the researcher and includes existing assumptions and theories. On reflection, I notice that I set out with little or no assumptions of my research area and ended up analysing data for levels of distress and creating themes in order to categorise women's written responses. Research as a whole is an interesting process and I have found it useful to think about it from this epistemological angle. Assumptions create something to build from but the danger is that ideas become 'real.' It has felt important for me to acknowledge the assumptions I made during the research process and the limitations which may have arose during my attempt to explore and report women's experiences of ectopic pregnancy. Thinking in this way ensures that any conclusions drawn from my research findings are less likely to suffer from researcher bias and that there is not over confidence in results. Findings of mine and any study for that matter where should be left open to further study, exploration and interpretation.