Support Following Miscarriage

Alice Elfer

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University College London
I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Alice Elfer

Date: 20 September 2017
Overview

One in four pregnancies ends in miscarriage; it is the most common type of pregnancy loss. It can be a devastating and traumatic experience, yet often it goes unrecognised and unspoken about. This thesis, presented in three parts, looks at formal and informal sources of support for women in the aftermath of miscarriage.

Part I is a literature review of the effectiveness of psychological interventions for women following miscarriage. Thirteen studies met inclusion criteria. Interventions evaluated included CBT, IPT, nurse/midwife led sessions, and psychological debriefing. Nine of the studies found improvement in symptoms following intervention. There was no evidence of differential effectiveness for interventions of different theoretical underpinnings.

Part II presents the findings of a qualitative study of women’s experiences of social support following miscarriage. Thirteen women took part in semi-structured interviews which were analysed using Braun and Clark’s (2006) method of thematic analysis, yielding 10 themes. Women encountered a number of barriers to talking about miscarriage e.g. its physical nature and being surrounded by other pregnant women. They experienced both unsupportive interactions (e.g. dismissive remarks, encouragement to move on) and supportive interactions (e.g. validation and permission to talk). The findings are discussed with reference to the literature on grief, trauma and social support.

Part III is a critical appraisal of the process of conducting the research presented in Part II. It focuses on three main areas: personal reflexivity; epistemological reflexivity; and broader reflections on miscarriage as a taboo subject.
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The completion of this project and my clinical training would not have been possible without the love and care of my family, particularly my husband, Luke. You have lived through each high and low with me and always believed I could do it.

Most importantly, I would like to thank the women who participated in this study. This thesis is dedicated to you: your courage, openness and determination to help others has been truly inspiring.
Part I: Literature Review

Psychological Interventions for Women Following Miscarriage
Abstract

Aims: Miscarriage can be a devastating and traumatic experience for women, one which increases the risk of psychological morbidity in the months that follow. This review aimed to evaluate the effectiveness of psychological interventions designed to reduce these psychological sequelae.

Methods: A systematic search for relevant studies was conducted via the electronic databases PsychInfo, MedLine, CINAHL and the Cochrane Library, citation searching and manual searches of bibliographies. The methodological quality of studies was assessed using the Effective Public Health Practice Project Quality Assessment Tool.

Results: 13 papers met the inclusion criteria. They comprised four CBT interventions, five nursing/midwife interventions, three IPT interventions and one psychological debriefing intervention. Ten studies used a randomized controlled trial design and three were uncontrolled. Overall, study quality was mixed; while study design was an area of strength, areas of weakness included selection bias, blinding and drop-out. Nine of the studies found improvement in symptoms following intervention. There was no evidence of differential effectiveness for interventions of different theoretical underpinnings. For the RCTs there was a median Cohen’s $d$ of 0.18; for the uncontrolled studies the median $d$ was 0.69.

Conclusions: The findings provide preliminary evidence that intervention following miscarriage can benefit women. While symptoms improve naturally over time intervention can hasten and improve resolution of symptoms. However, further research is needed to replicate and expand on these findings.
Introduction

Miscarriage is a common experience: roughly one in five confirmed pregnancies end in miscarriage (Simmons, Singh, Maconochie, Doyle & Green, 2006). In the UK it is defined as early pregnancy loss before 24 weeks gestation (NHS Choices, 2015) and occurs before any legal recognition of life - that is, when a pregnancy is lost there is no official record that that life had ever existed.

It is widely acknowledged that grief responses following miscarriage are common and can be similar in intensity to other significant losses (Brier, 2008). There are, however, few sociocultural norms in place to mark the life or death of a foetus before 20 weeks, leading some researchers to refer to miscarriage as a type of ‘disenfranchised grief’ which is not openly acknowledged or publicly grieved (Doka, 1999, p. 38).

Bennett et al. (2012) summarise a number of factors which make the experience of miscarriage particularly difficult: the physical process, which can include rapid hospitalisation and surgery; having to explain to others who may or may not know about the pregnancy; uncertainty of cause leading to self-blame and guilt; and the particular nature of grieving “what could have been” rather than “what was” (Bennett et al., 2012, p. 162). Consistent with this, there is a substantial literature documenting the increased risk of psychological morbidity following miscarriage. Several reviews have highlighted the broad range of psychological consequences that such a loss can have, including depression (Klier, Geller & Ritsher, 2002), anxiety (Brier, 2004), and Posttraumatic Stress Disorder (Diamond & Diamond, 2016).
The six months immediately following the miscarriage is the period of highest risk for psychological distress. Compared to the general population, women have been found to have higher levels of depression (Klier et al., 2002) and anxiety (Cumming et al., 2007; Prettyman, Cordle & Cook 1993), including increased risk of episodes of obsessive-compulsive disorders and Posttraumatic Stress Disorder (Brier, 2004). Cumming et al. (2007) found that, for some women, symptoms persisted at 13 months and reached levels of clinical significance; this was particularly the case with anxiety.

These symptoms have been differentially understood according to two distinct theoretical conceptualisations: grief and trauma. Studies showing high levels of depression have been used to support the grief perspective, while high levels of anxiety have lent support to the trauma perspective (Stratton, 2008). More recently, a third conceptualisation of traumatic or complicated grief has been suggested (Kersting & Wagner, 2012; Klier et al., 2002); distinct from normal grief, depression and trauma, traumatic grief is characterised by yearning for the deceased and feeling stunned by the loss (Priegerson et al., 1999).

Various interventions, drawing on these theories, have been developed, typically taking the form of either bereavement counselling (Brier, 2008; Diamond & Diamond, 2016) or follow-up focused on the physical aspects of miscarriage (Conway, 1995). The former are based on the grief literature while the latter tend to take a medical approach focusing on the physical trauma and anxiety about future pregnancies. However, in the UK, the provision of these interventions is inconsistent and very few women actually receive support (Nikčević, Tunkel & Nicolaides, 1998; RCOG, 2006).
Several studies have explored women’s experiences of post-miscarriage care: both what was found to be helpful and unhelpful. They have found repeated complaints of lack of sensitivity, empathy and information (Rowlands & Lee, 2010; Simmons et al., 2006). Consistent with this, studies exploring what women would want from services have found that validation, emotional support and adequate information were reported to be most important (Corbett-Owen & Kruger, 2001; Séjourné, Callahan and Chabrol, 2010a). Several studies have found that a majority of women express a wish for psychological therapy following their miscarriage (Musters et al., 2013; Nikčević et al., 1998; Séjourné et al., 2010a). It should be noted, however, that while this wish was expressed, only a small number of women pursued it once offered (Séjourné et al., 2010a). A number of theories have been proposed to explain the reason for this inconsistency: natural recovery means that women no longer need support; or the experience was so traumatic that women do not feel able to revisit it (Séjourné et al., 2010b). Engelhard (2004), in support of the former, suggests that not all women need intervention following miscarriage and that, instead, careful assessment, empathy and signposting are key, with intervention reserved only for those at risk of psychological morbidity.

**Previous Reviews**

There is limited rigorous research evaluating the effectiveness of interventions aimed at providing support to women following miscarriage. Two reviews have been conducted (Murphy, Lipp & Powell, 2012; Stratton & Lloyd, 2008).

Stratton and Lloyd (2008) conducted a narrative review of studies pertaining to evaluation of hospital-based support (both medical and psychosocial) following
miscarriage. Their inclusion criteria included all types of evaluation: anecdotal feedback; uncontrolled studies; and randomized controlled trials (RCTs). They discuss five studies: three nurse-led interventions focusing on bereavement care (one of which was a protocol for nursing care, both practical and emotional); one psychologist-led intervention for trauma; and one service evaluation of a follow-up clinic run jointly by an obstetrician and a psychologist. They concluded that there was insufficient evidence to draw conclusions regarding effectiveness and suggested that further research is needed.

A Cochrane review by Murphy, Lipp and Powell (2012) evaluated six RCTs of psychological follow-up care for women experiencing miscarriage. Although the interventions varied in length and who they were provided by, they mainly consisted of “sessions using recognised counselling techniques” (Murphy et al., 2012, p. 12). The outcomes measured were diverse, including grief, anxiety and depression as well as emotional disturbance, self-esteem and isolation. Comparing studies according to the number of sessions provided, they found no evidence in favour of one session of counselling. There was some evidence to suggest the effectiveness of three sessions of counselling; however this was discounted by Murphy et al. (2012) as the effect was found on a measure developed by the study author rather than on any standardised measures. While the methodological rigour of this Cochrane review is valued for providing clear, explicit findings, the restriction to RCTs means a number of studies using other designs were excluded which might provide important insights into intervention effectiveness or at least areas for future research.
Based on such a sparse literature, NICE guidelines (2012) concluded that the only consistent evidence is for the need to provide adequate information regarding available services, including counselling, support groups and helplines.

A number of factors make it difficult to draw conclusions from these reviews about psychological care for women following miscarriage. Firstly, the definition of miscarriage varies internationally and therefore so do the inclusion criteria used by studies: from pre-12 weeks gestation (Nice Guidelines, 2012), pre-20 weeks gestation (Stratton & Lloyd, 2008) to pre-23 weeks gestation (Murphy et al., 2012). Furthermore the definition of stillbirth also varies and often overlaps with definitions of miscarriage, with some defining loss after 20 weeks as a stillbirth (Diamond & Diamond, 2016). There is mixed evidence as to the relationship between gestational stage and intensity of loss. Some studies have suggested that length of gestation correlates with strength of attachment and therefore grief response (Klier, Geller & Ritsher, 2002). Others, however, have suggested that there is no relationship between these variables particularly within the first and second trimesters (Slade, 1994). It is therefore unclear whether these differing definitions of miscarriage might affect findings about the effectiveness of interventions.

Secondly, interventions in the reviews were heterogeneous in nature and rarely clearly defined by their theoretical underpinnings. This, coupled with the paucity of studies, makes it difficult to draw comparisons or conclusions about differential effectiveness.
Aims of the Current Review

The current review aimed to specifically explore the effectiveness of psychological interventions, defined as talking therapies or counselling focusing on the psychological (rather than medical) sequelae of miscarriage. Interventions were also categorised according to their theoretical underpinnings in order to enable exploration of differential effectiveness. Given that the Cochrane review (Murphy et al., 2012) identified only six RCTs, the methodological criteria for inclusion was broadened to include both controlled and uncontrolled designs. An additional aim of this review was to evaluate the methodological quality of included studies in order to highlight areas for future research.

Method

Inclusion and Exclusion Criteria

Studies were included in the review according to the following criteria:

Participants. Women (over the age of 18 years) experiencing miscarriage. Due to the differences in definition of miscarriage, studies were included if they used the term ‘miscarriage’ or ‘spontaneous abortion’ regardless of gestation. Studies were excluded if they focused on the following: ‘stillbirth’, ‘neonatal death’ (death in the first month of life) or abortion due to foetal abnormality. A number of studies included participants experiencing different types of loss throughout the perinatal period. Where it was possible to identify the percentage of participants experiencing miscarriage and this percentage was greater than 50% these studies were included in the review. Studies which involved the partner were included, but those which focused on the broader family were excluded.
**Intervention.** Any type of psychological intervention, i.e., talking therapy, including counselling, aimed at reducing psychological therapy distress following miscarriage. The intervention could be delivered individually or in a group format, face-to-face or over the telephone; interventions delivered via the internet were included if they involved interaction between the participant and health professional (i.e. not computerised therapy). No restriction was placed on the number of sessions provided. The intervention could be conducted by any health professional; peer support interventions and studies of nursing care protocols were excluded. A number of interventions have been designed to support women through the process of subsequent pregnancies after a previous miscarriage (Bailey et al., 2015; Ockhuijsen, 2015). These interventions were also excluded because the new pregnancy tended to be a key focus of the work.

**Study Design.** Randomized controlled trials, non-randomized and uncontrolled designs (i.e. pretest-posttest cohort design) were all included. Small-N designs and case studies were included only if there were two measurement points (i.e., pre- and post-intervention) and they used statistical methods to analyse the findings.

**Outcome.** At least one quantitative measure of psychological distress (e.g., grief, anxiety, depression) must have been used to evaluate the outcome of the intervention, for example the Perinatal Grief Scale (Potvin et al., 1989) or the Hospital Anxiety and Depression Scale (Zigmund & Snaith, 1983).

**Search Strategy**

Studies were identified via four electronic databases: PsychInfo, CINAHL Medline and the Cochrane Library. Additional studies were identified through citation
searches of key studies including an existing review of follow-up care for miscarriage (Murphy et al., 2012).

Table 1 lists the search terms used. These were generated through examining the search terms used in a previous review (Murphy et al., 2012) and by examination of the keywords and subject headings of key studies. These terms were divided into three clusters which provided a framework for the search: (1) terms describing miscarriage; (2) terms referring to the psychological consequences of miscarriage; (3) terms describing a range of psychological interventions. The term ‘Spontaneous Abortion’ was searched as a Subject Heading and Keyword, while the other terms were searched only as keywords. The three groups of terms were entered separately and combined with AND in the final search.

The search covered studies published within a 20 year period (January 1996 to August 2016). Only papers published in peer-reviewed journals and in English were considered for inclusion.

**Study Selection**

Figure 1 details the process of selection and exclusion. A number of papers were excluded as they reported literature reviews, anecdotal evidence of women’s experiences or case studies. Other reasons for exclusion included the age of parent or type of perinatal loss; the type of intervention (e.g., nursing care protocols or changes to service level structures); and lack of quantitative outcome data. If uncertainty arose as to whether or not a study should be included, two other researchers were consulted. This resulted in 13 studies for inclusion in the review.
**Data Extraction**

For these 13 studies key data were extracted. This included details of the intervention (e.g., theoretical orientation, number of sessions, medium of delivery, intervention facilitator); study design (e.g., sample size, participant characteristics, type of control group); outcome measures; and details of the analysis and results.

**Table 1. Search Terms**

<table>
<thead>
<tr>
<th>Cluster</th>
<th>Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miscarriage</td>
<td>Miscarr* OR spontaneous abortion OR pregnancy loss* OR perinatal loss OR perinatal death OR loss adj5 pregnancy</td>
</tr>
<tr>
<td>Psychological Consequences of Miscarriage</td>
<td>Grief or Griev* OR Bereav* OR Mental health OR Depression OR Anxiety OR Post?traumatic stress OR Psychological Morbidity OR Psychological well?being</td>
</tr>
<tr>
<td>Interventions</td>
<td>Intervention* OR Therap* OR Psychotherap* OR ?therapy OR Counselling OR Cognitive Behavio?ral OR Cognitive-Behavio?ral OR CBT OR IPT</td>
</tr>
</tbody>
</table>
Figure 1. Study Selection Flow Chart

701 studies identified from initial search

- 243 from PsychInfo
- 211 from MedLine and
- 245 from CINAHL
- 2 from Cochrane Library

98 duplicates removed

564 studies excluded

Primary reasons for exclusion:
- Medical interventions
- Psychological sequelae but no intervention
- Qualitative methods only

603 studies screened by titles and abstracts

39 studies full text screened in terms of inclusion and exclusion criteria

28 studies excluded

Primary reasons for exclusion:
- Literature reviews, book chapters, anecdotal evidence or unpublished theses (16)
- Participants: undefined combination of miscarriage, late loss of pregnancy (still birth, neonatal loss) or loss due to fetal abnormality (4)
- Intervention: nursing care interventions or service level change (3)
- Design: lack of pre or post outcome measures (1)
- Outcome: qualitative results only (3)
- Analysis: lack of statistical measures (1)

11 studies met the inclusion criteria

13 studies included in the review

2 studies included from Murphy, Lipp and Powel (2012) review


Assessment of Methodological Quality

The quality of the studies included in the review was evaluated using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool (Jackson & Waters, 2005; Thomas, Ciliska, Dobbins & Micucci, 2004). The tool assesses the quality of a study in six domains: selection bias, study design, confounding variables, blinding, data collection methods and participant withdrawal and dropout.

This tool was selected because it can be used to evaluate a wide range of study designs including both randomized controlled trials and uncontrolled studies (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012). It has also been judged to be suitable for systematic reviews of effectiveness (Deeks et al., 2003) and has been reported to have construct and content validity (Jackson & Waters, 2005; Thomas, Ciliska, Dobbins & Micucci, 2004).

Two modifications were made to the tool to ensure systematic rating of the studies included in this review (Coughtrey & Pistrang, 2017). For the domain of study design, in order to clarify the distinction between non-randomised controlled designs and uncontrolled designs, the former were rated as moderate and the latter as weak. For the domain of withdrawals and drop-outs, studies were rated as strong if they carried out an intent-to-treat analysis and attrition was less than 33%.

Each study was double rated according to these six domains by the lead researcher and a second researcher. The rate of agreement was generally high with disagreement only occurring three times; when this occurred the rating was discussed and resolved according to the Quality Assessment Tool Dictionary and where necessary a third researcher was consulted.
**Synthesis**

Following the quality appraisal a synthesis of the studies was carried out focusing on study design, sample characteristics, the nature of the intervention, any commonalities across the interventions, therapist characteristics, outcome measures and reported outcomes. Outcomes were considered in terms of statistically significant change, effect size and clinical significance.

**Results**

**Overview of Results**

The characteristics of the 13 studies are summarised in Table 2. The studies are organised according to the type of intervention: four cognitive behavioural interventions; five nursing or midwife counselling interventions; three interpersonal therapy interventions; and one psychological debriefing intervention. Studies varied in the method of communication; ten were conducted face-to-face; two were conducted over the telephone; and one was conducted via email.

Ten studies were randomised controlled trials (RCTs) and three were uncontrolled studies. The studies were conducted in the UK, USA, Germany, France, Sweden, China and Japan. There was some overlap between studies included in this review and prior reviews; five studies were also included by Murphy et al. (2012); and three were also included by Stratton et al. (2008).
### Table 2. Characteristics of included studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kersting et al., 2011 (Germany)</td>
<td>RCT – wait list control</td>
<td>N = 83 Mean Age 34.3</td>
<td>2x weekly email contact for 5 weeks</td>
<td>‘Therapist’</td>
<td>IES ICG BSI</td>
<td>Grief, PTSD and overall mental health improved over time in both groups. Greater improvement over time for the intervention group compared to the wait list control.</td>
</tr>
<tr>
<td>Nakano et al., 2013 (Japan)</td>
<td>Uncontrolled</td>
<td>N=14 Mean Age 32.3</td>
<td>50min weekly CBT ≤ 16 sessions Mean No. Sessions = 8.9 (SD 4.6)</td>
<td>Psychiatrist</td>
<td>K6 BDI-II STAI-s</td>
<td>Depression and anxiety improved.</td>
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</tbody>
</table>
### Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
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<tbody>
<tr>
<td><strong>Cognitive Behavioural Interventions cont.</strong></td>
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<tr>
<td>Nikčević et al., 2007</td>
<td>RCT – no treatment + alternative treatment controls</td>
<td>N=127 Mean Age 34.9</td>
<td>1 x 50min session cognitive therapy + 20min medical follow-up</td>
<td>Psychologist</td>
<td>HADS TGI Study specific questionnaire</td>
<td>Anxiety, depression, grief and self-blame improved over time in both groups. Greater improvement of grief, self-blame and worry scores over time in the intervention group. Greater decrease in anxiety for those having any type of follow up compared to those with no follow up.</td>
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<tr>
<td>(UK)</td>
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<tr>
<td>Séjourné et al., 2010</td>
<td>RCT – waitlist control</td>
<td>N=134 Mean Age 31.82</td>
<td>1 x 20-90min session (mean 37min)</td>
<td>Psychologist</td>
<td>HADS IES-R</td>
<td>At 3 weeks post-intervention women in the intervention group had lower scores for anxiety, depression and PTSD compared to the wait list control. Anxiety, depression and PTSD reduced over time for both groups.</td>
</tr>
<tr>
<td>(France)</td>
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</table>
Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
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<tbody>
<tr>
<td><strong>Midwife/ Nurse Counselling Interventions</strong></td>
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<tr>
<td>Adolfsson et al., 2006 (Sweden)</td>
<td>RCT – usual care control</td>
<td>N=88 Mean age 31.3</td>
<td>1x 60min session 21-28 days post miscarriage</td>
<td>Midwife</td>
<td>PGS</td>
<td>No differences in grief scores between groups.</td>
</tr>
<tr>
<td></td>
<td>Follow-up: 3m</td>
<td>Miscarriage (pre-13wks)</td>
<td></td>
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<tr>
<td>Kong et al., 2014 (China)</td>
<td>RCT – usual care control</td>
<td>N=214 Mean age not provided</td>
<td>1 x 60min supportive counselling + 1 x 30 min telephone counselling 2wks post miscarriage</td>
<td>Midwife Counsellor</td>
<td>BDI GHQ-12</td>
<td>Overall mental health and symptoms of depression improved over time in both groups. For women with higher baseline scores, there was greater improvement in the treatment group compared to the control.</td>
</tr>
<tr>
<td></td>
<td>Follow-up: 6wks 3m 6m</td>
<td>Miscarriage (pre-24wks)</td>
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</table>
Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Midwife/ Nurse Counselling Interventions continued</td>
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<tr>
<td>Rowsell et al., 2010 (UK)</td>
<td>Uncontrolled</td>
<td>N=52 Mean Age 31.9</td>
<td>1-2hr session 6wk post miscarriage + 30min consultation 2m post miscarriage</td>
<td>Midwife Counsellor and Medical consultant</td>
<td>HADS IES The Coping Schedule</td>
<td>Anxiety, depression and PTSD improved over time. Reduction in IES avoidance and avoidant coping following the intervention.</td>
</tr>
<tr>
<td></td>
<td>Follow-up: mean 6.7wks after intervention</td>
<td>Recurrent Miscarriage (pre 28wks, mean gestation 9wks, range 5-17wks)</td>
<td></td>
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</tr>
<tr>
<td>Swanson 1999 (USA)</td>
<td>RCT- no intervention control + delayed measurement control</td>
<td>N=185 Mean Age 32.5</td>
<td>3x 1 hour counselling sessions</td>
<td>Principal Researcher or Nurse</td>
<td>10-item Rosenberg scale POMS IMS</td>
<td>Improvement for both groups over a year. Lower scores for anger, depression, overall emotional disturbance at one year for treated women compared to controls. Greater decrease in personal significance scores between 4m and 1year for treated women compared to controls. Greater decrease in devastating events score for women in the treated, delayed measurement group.</td>
</tr>
<tr>
<td></td>
<td>Follow-up: 1yr after enrolment</td>
<td>Miscarriage (pre-20wks)</td>
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</tbody>
</table>
## Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Midwife/ Nurse Counselling Interventions continued</strong></td>
<td></td>
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</tr>
<tr>
<td>Swanson et al., 2009 (USA)</td>
<td>RCT – 3 interventions + no intervention control</td>
<td>N=341 couples (682 individuals) Mean Age: 33.2</td>
<td>(1) 3x1 hour counselling sessions (2) 3 videos (3) 1x 60min counselling session + 3 videos</td>
<td>‘Counsellor’</td>
<td>CES-D</td>
<td>Depression resolved faster in condition (1) compared to (2), (3) or no intervention control. Grief scores reduced faster in condition (1) compared to (2), (3) or no intervention control.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Miscarriage (pre-21wks) Follow-up: 13m post miscarriage</td>
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<tr>
<td><strong>Interpersonal Interventions</strong></td>
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</tr>
<tr>
<td>Johnson et al., 2006 (USA)</td>
<td>RCT – usual care control</td>
<td>N = 50 Mean age 30.3 50% Miscarriage (4-19wks gestation)</td>
<td>14 sessions Group IPT for Major Depression.</td>
<td>Psychiatric Nurse, Psychiatrist, Psychologists</td>
<td>HRSD MSPSS SAS DAS PBGS ICG</td>
<td>Grief and depression improved over time in both groups. Faster improvement in PTSD scores for the IPT group. Decrease in social role impairment in the IPT group.</td>
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<td></td>
<td></td>
<td></td>
<td>Effect Sizes: MSPSS 0.27 SAS 0.26 PBGS grief 0.33</td>
</tr>
</tbody>
</table>
Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Interventions continued</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Neugebauer et al., 2006 (USA)</td>
<td>RCT – usual care control</td>
<td>N=19</td>
<td>6 30min IPC telephone sessions.</td>
<td>Psychiatric Social Worker (not IPT trained, IPT certified Psychotherapists)</td>
<td>HAM-D-17</td>
<td>Depression improved in both groups.</td>
</tr>
<tr>
<td></td>
<td>Follow up: None ITT analysis</td>
<td>Mean Age 29.7</td>
<td></td>
<td></td>
<td></td>
<td>Greater improvement in symptoms in the IPC group compared to the control.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Miscarriage (pre-28wks, mean gestation at loss 12wks)</td>
<td></td>
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<tr>
<td>Neugebauer et al., 2007 (USA)</td>
<td>Uncontrolled</td>
<td>N = 17</td>
<td>6 telephone sessions of IPC</td>
<td>IPT trained Clinical Psychologist</td>
<td>CES-D</td>
<td>Depression improved at follow-up</td>
</tr>
<tr>
<td></td>
<td>Follow-up: None ITT analysis</td>
<td>Mean age 32.5</td>
<td></td>
<td></td>
<td></td>
<td>Effect Size</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Miscarriage (pre-28wks)</td>
<td></td>
<td></td>
<td></td>
<td>ITT sample 0.66</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>Completer sample 1.14</td>
</tr>
</tbody>
</table>
Table 2. Characteristics of included studies cont.

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Participants</th>
<th>Intervention</th>
<th>Delivered by</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lee et al., 1996</td>
<td>RCT- no intervention control</td>
<td>N=39</td>
<td>1 x 60min psychological debriefing session 2wks post miscarriage</td>
<td>Psychologist</td>
<td>HADS, IES, RMQ, Perceptions of Care questionnaire</td>
<td>Anxiety, depression and PTSD decreased over time for both groups. Fewer women met the clinical cut off scores for intrusion and avoidance at follow-up.</td>
</tr>
<tr>
<td>UK</td>
<td>Follow-up: 4m post miscarriage</td>
<td>Miscarriage (6-19wks)</td>
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</tbody>
</table>

Note. BSI (Brief Symptom Inventory), CES-D (Centre for Epidemiological studies-Depression), DAS (Dyadic Adjustment Scale), GRE (Grief Related Emotions), GHQ-12 (General Health Questionnaire), HADS (Hospital Anxiety and Depression Scale), HRSD (Hamilton Rating Scale for Depression), ICG (Inventory of Complicated Grief), IES (Impact of Event Scale), IES-R (Impact of Events Scale-Revised), IMS (Impact of Miscarriage Scale), MGI (Miscarriage Grief Inventory), MSPSS (Multi-dimensional Scale for Perceived Social Support), PBGS (Perinatal Bereavement Grief Scale), PG (Pure Grief), PGS (Perinatal Grief Scale), POMS (Profile of Mood States), RMQ (Reactions to Miscarriage Questionnaire), SAS (Social Adjustment Scale), STAI-s (State-Trait Anxiety Inventory-state), TGI (Texas Grief Inventory).
Quality Appraisal of Included Studies

The EPHPP quality ratings are shown in Table 3. For the domain of selection bias the quality ratings were mixed. Eight studies had strong recruitment methods, asking every woman entering clinics during a designated time period to participate. Six of these also had good enrolment and were therefore given an overall rating of strong; the remaining two studies had poor uptake following recruitment and were therefore rated as moderate. The other five studies recruited participants via pamphlets and posters making it hard to ascertain the audience they were reaching. Despite this, four of the five had good enrolment and were rated as moderate; the remaining study had poor enrolment so was rated as weak.

The quality of study design was also mixed. Ten studies reported having a control group and randomly allocating to groups. Of these, seven described the randomization process and were rated as strong; three did not describe the method of randomization and were rated as moderate. The remaining three studies were uncontrolled and rated as weak.

The domain of confounding factors was applicable for the 10 studies that used a control group. Of these, eight identified and adequately controlled for confounders and were rated as strong. The other two studies were rated as weak. Lee, Slade and Lygo (1996) identified a difference between groups in the percentage of participants with children but did not report any attempt to control for this. Johnson et al. (2016) reported attempts to stratify groups according to type of loss but did not provide details of the presence or absence of any other confounders.
### Table 3. Quality Assessment of Reviewed Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Selection Bias</th>
<th>Study Design</th>
<th>Confounders</th>
<th>Blinding</th>
<th>Data Collection Method</th>
<th>Withdrawals and Drop-outs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolfsson et al. 2006</td>
<td>Strong</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Moderate</td>
</tr>
<tr>
<td>Johnson et al., 2016</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Moderate</td>
<td>Strong</td>
<td>Moderate</td>
</tr>
<tr>
<td>Kersting et al., 2011</td>
<td>Moderate</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Strong</td>
</tr>
<tr>
<td>Kong et al., 2014</td>
<td>Moderate</td>
<td>Strong</td>
<td>Strong</td>
<td>Moderate</td>
<td>Strong</td>
<td>Strong</td>
</tr>
<tr>
<td>Lee et al., 1996</td>
<td>Strong</td>
<td>Moderate</td>
<td>Weak</td>
<td>Weak</td>
<td>Strong</td>
<td>Moderate</td>
</tr>
<tr>
<td>Nakano et al., 2013</td>
<td>Moderate</td>
<td>Weak</td>
<td>n/a</td>
<td>n/a</td>
<td>Strong</td>
<td>Weak</td>
</tr>
<tr>
<td>Neugebauer et al., 2006</td>
<td>Strong</td>
<td>Moderate</td>
<td>Strong</td>
<td>Moderate</td>
<td>Strong</td>
<td>Strong</td>
</tr>
<tr>
<td>Neugebauer et al., 2007</td>
<td>Weak</td>
<td>Weak</td>
<td>n/a</td>
<td>n/a</td>
<td>Strong</td>
<td>Moderate</td>
</tr>
<tr>
<td>Nikčević et al., 2007</td>
<td>Strong</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Strong</td>
</tr>
<tr>
<td>Rowsell et al., 2001</td>
<td>Strong</td>
<td>Weak</td>
<td>n/a</td>
<td>n/a</td>
<td>Strong</td>
<td>Weak</td>
</tr>
<tr>
<td>Séjourné et al., 2010</td>
<td>Strong</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Weak</td>
</tr>
<tr>
<td>Swanson 1999</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Moderate</td>
</tr>
<tr>
<td>Swanson et al., 2009</td>
<td>Moderate</td>
<td>Strong</td>
<td>Strong</td>
<td>Weak</td>
<td>Strong</td>
<td>Strong</td>
</tr>
</tbody>
</table>
Blinding was an area of general weakness across all studies: of the 10 studies where this domain was applicable, seven were rated as weak. Participants in all studies were aware of the intervention and outcome measures were generally self-report. Only three studies (Johnson et al., 2016; Kong et al., 2014; Neugebauer et al., 2006) reported any attempt to use blinded outcome assessors.

The domain of data collection was an area of strength across studies. All studies used well-known, reliable and valid outcome measures.

The domain of withdrawals and dropouts was mixed. Seven studies presented clear information regarding retention throughout the study; the remaining six lacked detail. Two were rated as strong (Nikčević et al., 2007; Swanson et al., 2009) because they had a dropout rate less than 20%. Three studies were also rated as strong because they both reported drop-out rates of less than 25% and also performed an ITT analysis (Kersting et al., 2011; Kong et al., 2014; Neugebauer et al., 2006). Five studies were rated at moderate because they reported drop-out rates between 20-40%. This included Neugebauer et al. (2007) who reported a 47% drop-out during the intervention stage but did perform an intent-to-treat analysis. Three studies were rated as weak because the drop-out exceeded 40% (Rowsell et al., 2001; Séjourné et al., 2010) or they failed to provide sufficient information regarding retention through the programme (Nakano et al., 2013).

**Study Design**

Of the 13 studies, ten were randomized controlled trials (RCT); the remaining three were uncontrolled. Five of the RCTs compared their intervention to a no intervention control group; two used a waitlist control group and three used a treatment-as-usual control group. The latter included a standard midwife visit (Adolfsson et al., 2006), a ‘Coping with Depression’ group (Johnson et al., 2016)
and “whatever care women sought on their own initiative… and does not necessarily involve treatment per se” (Neugebauer et al., 2006, p. 1301).

All studies compared participants’ scores pre- and post-intervention. Additionally the 10 controlled studies also had a follow-up period: for six of these it was between three and 12 months post intervention; for three follow-up was determined by the time elapsed since the miscarriage: Nikčević et al (2007) conducted their intervention at five weeks post miscarriage and follow-up at 16 weeks post miscarriage; Swanson et al. (2009) began their intervention within three months of the miscarriage with follow-up at 13 months post miscarriage; Kong et al. (2014) conducted their intervention on the day of hospital attendance and follow-up at three and six months post-miscarriage. For the remaining one study follow-up was set at nine weeks post-enrolment, with the intervention lasting from three to six weeks (Neugebauer et al., 2006). Two of the three uncontrolled studies had no follow-up period; the third, Rowsell et al. (2010) gave follow-up questionnaires to participants on average 6.7 weeks post intervention.

**Sample Characteristics**

The majority of participants across studies were reported to be well educated, employed and living with a stable partner. This is with the exception of Neugebauer et al. (2006) where 25% did not complete secondary education. The majority of studies focused on women only, with the exception of Swanson et al. (2009) who explored an intervention for couples, and Johnson et al. (2016) who allowed partner participation for three out of 12 sessions. The age of participants was fairly consistent across studies with the mean ranging from 29.3 years to 34.9 years.

Nine of the studies reported that approximately 50% of participants had at least one child, one study excluded women with children (Nakano et al., 2013) and
the other three did not report this statistic (Adolfsson et al., 2006; Kong et al., 2014; Neugebauer et al., 2006). There was similar variation in the number of women who had experienced prior miscarriages: two studies (Nakano et al., 2013; Rowsell et al., 2001) focused on women experiencing recurrent miscarriage (two or more consecutive miscarriages), while two studies excluded women who had experienced a previous miscarriage (Lee et al., 1996; Nikčević et al., 2007). The remaining eight studies did not consistently report statistics on the percentage of participants experiencing previous miscarriages, but where this was reported it ranged from 23-32%.

Studies differed in the definition of miscarriage: nine studies defined it as varying between pre-13 weeks gestation and pre-28 weeks gestation; four studies did not present information regarding their definition at all (Kersting et al., 2011; Nakano et al., 2013; Rowsell et al., 2001; Séjourné et al., 2010). Six studies additionally reported means for the gestation at the time of the miscarriage; this ranged from 9 weeks to 12 weeks (Adolfsson et al., 2006; Lee et al., 1996; Neugebauer et al., 2006; Rowsell et al., 2001; Séjourné et al., 2010; Swanson, 1999).

A further difference across studies was the time between miscarriage and study enrolment. For example, Séjourné et al. (2010) and Kong et al. (2014) met women on the day of their surgical procedure while Kersting et al. (2011) reported that the time since miscarriage ranged between 1-144 months (mean 15.4 months).

**Nature of the Intervention**

The types of intervention delivered varied broadly but can be divided into four distinct categories: Cognitive-Behavioural Interventions; Midwife/Nursing Care Interventions; Interpersonal Therapy Interventions; and Psychological Debriefing. The majority of studies involved face-to-face sessions except five; two were
conducted over the phone (Neugebauer et al., 2006; Neugebauer et al., 2007); one involved communication via email (Kersting et al., 2011); and two involved a mixture of face-to-face and video contact (Swanson et al., 2009) or telephone contact (Kong et al., 2014).

**Cognitive Behavioural Interventions.** Four studies evaluated interventions based on cognitive behavioural principles. The number of sessions provided varied from one (Nikčević et al., 2007; Séjourné et al., 2010) to up to 16 (with a mean of 8.9, Nakano et al., 2013). Session length was roughly 50 minutes for all the interventions except Séjourné et al. (2010) for which the intervention lasted between 20-90 minutes.

Despite this, the content of the interventions was quite similar: a description of the loss and individual responses to it; cognitive restructuring; and problem resolution, including how to talk to others. Two studies also incorporated medical information (Séjourné et al., 2010) or a medical review with a consultant (Nikčević et al., 2007).

Kersting et al. (2011) conducted their intervention via email; participants were given a total of 10 writing assignments (two per week) relating to confrontation, cognitive restructuring and social sharing. Each assignments lasted 45 minutes and on completion was emailed to the therapist who provided individual written feedback.

**Midwife/Nurse Counselling Interventions.** Five studies examined interventions led by midwife counsellors or nurses. All of these interventions, with the exception of Kong et al. (2014), offered attendance to the partner as well as the woman; however only Swanson (2009) focused explicitly on both partners’
experience, while the others made it clear that the focus was exclusively the woman.

Three of the interventions were based on Swanson’s theory of caring (Adolfsson et al., 2006; Swanson, 1999; Swanson et al., 2009); the two remaining studies (Kong et al., 2014; Rowsell et al., 2001) did not explicitly state their theoretical underpinnings.

Swanson (1999) offered participants three 1-hour sessions at 1, 5 and 11 weeks post enrolment. These sessions focused on three topics: ‘coming to know and considering what has been lost and possibly gained’; ‘going public and sharing the loss’; and ‘getting through it and trying again’. Adolfsson et al.’s (2006) covered the same topics, condensed into a single 60-minute session. Swanson (2009) compared several different interventions: the first, ‘Nurse Caring’, consisted of the same intervention offered by Swanson (1999); the second, ‘Self Caring’, consisted of three 18 minute videos to be watched at home focusing on self and partner caring, understanding the experience and reflective writing; the third, ‘Combined Caring’, combined these two interventions offering one face-to-face session with the Nurse Counsellor followed by the video intervention.

Rowsell et al. (2001) evaluated one face-to-face session lasting 1-2 hours. This focused on the woman talking openly about the miscarriage experience and her responses to it and the midwife providing information about miscarriage and offering tests to determine the cause. This intervention was followed by a further 30 minute appointment with the Midwife Counsellor and a Consultant Obstetrician to receive test results and plan for future pregnancies. Kong et al. (2014) provided a similar intervention: one 60 minute face-to-face session of ‘supportive counselling’ (listening, encouraging hope, providing information and advice) on the day of
attendance at hospital, followed by a further 30 minute session over the phone, two weeks later.

**Interpersonal Therapy Interventions.** There were three interpersonal therapy interventions: Johnson et al. (2016) evaluated Interpersonal Psychotherapy (IPT) adapted for Perinatal Loss, and Neugebauer et al. (2006; 2007) evaluated Interpersonal Counselling (IPC) adapted for miscarriage. Both IPT and IPC assume that depressive symptoms develop and are maintained through interpersonal patterns (Neugebauer et al., 2007). Treatment thus focuses on improving communication, changing relationship expectations and utilizing social support (Johnson et al., 2016). IPC is a variant of IPT, designed for those in distress but not clinically depressed.

The Johnson et al. (2016) intervention involved 12 group sessions as well as a pre- and post- group individual session. The group sessions focused on four topics: ‘the emotions of grief’, ‘understanding what happened’, ‘grieving with others’, ‘holding the memory and moving forward’. These were repeated in three cycles in order to “begin work on each issue”, “assess progress”, and “address any remaining issues” (Johnson et al., 2016, p.847). A supportive other was invited to a maximum of 3 out of 12 sessions.

The IPC interventions (Neugebauer et al., 2006; 2007) were similar in nature involving individual telephone sessions based on the original IPC manual, miscarriage literature and bereavement literature. Neugebauer et al.’s (2006) intervention consisted of up to six 30-minute weekly sessions, with the majority having no more than three sessions; Neugebauer et al. (2007) did not provide details of the sessions provided but reported that participants had an average of 3.2 sessions.
Psychological Debriefing Interventions. Only one study employed a Psychological Debriefing approach. Lee et al. (1996) adapted their method from Dyregrov (1989) and Mitchell (1983) who both describe psychological debriefing following disaster. Lee et al. (1996) evaluated a one-hour session of psychological debriefing approximately two weeks post miscarriage. The session consisted of six phases: an introductory phase (explaining the study and session structure); the fact phase (discussing the experience of miscarriage); the feeling phase (describing emotional response the miscarriage); the symptom phase (describing any changes since the miscarriage); the teaching phase (validation of symptoms and coping methods, education about stress response); and a re-entry phase (answering questions, agreeing a plan for the future and disengagement). The session was conducted face-to-face at the participant’s own home.

Therapist Characteristics

Ten of the studies provided clear information about the therapist(s) facilitating the intervention. For the remaining three studies, the professional orientation or qualification of the therapist was unclear (Kersting et al., 2011; Swanson 1999; Swanson et al., 2009). Four of the interventions were conducted by psychologists (Lee et al., 1996; Neugebauer et al., 2007; Nikčević et al., 2007; Séjourné et al., 2010); three were delivered by nurses or midwives (Adolfsson et al., 2006; Kong et al., 2014; Rowsell et al., 2001); one was delivered by a CBT trained psychiatrist (Nakano et al., 2013); one was conducted by a combination of psychologists, psychiatrists and psychiatric nurses (Johnson et al., 2016); and one by a combination of a psychiatric social worker and two IPT-certified psychotherapists (Neugebauer et al., 2006).
**Target of Intervention**

The aim of the interventions varied across studies. Three studies explicitly stated that depression was the target of their intervention: subsyndromal depression (Neugebauer et al., 2006; Neugebauer et al. 2007) and major depression (Johnson et al., 2016). All three of these studies used the Structured Clinical Interview for DSM-IIIR (SCID) to determine psychiatric exclusionary criteria. Two further studies also used the SCID to determine psychiatric exclusionary criteria (major psychiatric disorders or substance dependency) but the targets of their interventions were less specific: depression and anxiety (Nakano et al., 2013); PTSD, grief, depression and overall mental health (Kersting et al., 2011). The remaining eight studies did not have any psychiatric exclusionary criteria and the target of intervention varied. One study aimed to target depression and grief (Swanson et al., 2009) and one to improve symptoms of grief exclusively (Adolfsson et al., 2006). Six studies were aimed at broadly ‘benefitting’ women (Séjourné et al., 2010, p.289), improving ‘emotional-wellbeing’ (Kong et al., 2014; Swanson, 1999, p.288), ‘distress’ (Nikčević et al., 2007, p. 283, and ‘adaptation’ (Lee et al., 1996, p.47; Rowsell et al., 2001, p.33).

**Outcome Measures**

All studies used at least one reliable and valid self-report outcome measure, which was an inclusion criterion for the review. One study also used the Longitudinal Interval Follow-up Examination (LIFE; Keller et al., 1987) interview to assess the time to recovery (Johnson et al., 2016). A range of measures were used to assess change in different areas. Table 4 shows the outcome measures used as well as the different psychological sequelae targeted by the interventions.
<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Used by</th>
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<tbody>
<tr>
<td>Depression</td>
<td>HADS (5)</td>
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<tr>
<td></td>
<td>CES-D (2)</td>
</tr>
<tr>
<td></td>
<td>HRSD (1)</td>
</tr>
<tr>
<td></td>
<td>BSI (1)</td>
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<td></td>
<td>POMS (1)</td>
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<td>K6 (1)</td>
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<td></td>
<td>BDI (1)</td>
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<tr>
<td></td>
<td>GHQ-17 (1)</td>
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<tr>
<td></td>
<td>Johnson et al., 2016</td>
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<tr>
<td></td>
<td>Kersting et al., 2011</td>
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<td></td>
<td>Kong et al., 2014</td>
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<td>Lee et al., 1996</td>
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<td>Nakano et al., 2013</td>
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<td>Neugebauer et al., 2006</td>
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<td></td>
<td>Neugebauer et al., 2007</td>
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<td></td>
<td>Nikčević et al., 2007</td>
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<td></td>
<td>Rowsell et al., 2001</td>
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<td>Séjourné et al., 2010</td>
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<td>Swanson, 1999</td>
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<td>Swanson et al., 2009</td>
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<tr>
<td>Anxiety</td>
<td>HADS (4)</td>
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<td>K6 (1)</td>
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<td>STAI (1)</td>
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<td>Kersting et al., 2011</td>
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<td>Kong et al., 2014</td>
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<td>Lee et al., 1996</td>
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<td>Swanson, 1999</td>
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<td>Swanson et al., 2009</td>
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<tr>
<td>Grief</td>
<td>ICG (2)</td>
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<td>TGI (2)</td>
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<td>PBGS (1)</td>
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<td>PGS (1)</td>
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<td></td>
<td>MGI</td>
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<td></td>
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<td>Johnson et al., 2016</td>
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<td>Kersting et al., 2011</td>
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<td>Nikčević et al., 2007</td>
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<td></td>
<td>Swanson et al., 2009</td>
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<tr>
<td>Trauma</td>
<td>IES (3)</td>
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<tr>
<td></td>
<td>IES-R (1)</td>
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<tr>
<td></td>
<td>Kersting et al., 2011</td>
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<td></td>
<td>Lee et al., 1996</td>
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<td>Rowsell et al., 2001</td>
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<td></td>
<td>Séjourné et al., 2010</td>
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<tr>
<td>Impact of Miscarriage</td>
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<td>RMQ (1)</td>
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<td>Study specific questionnaires (2)</td>
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<td>Social Support and</td>
<td>MSPSS (1)</td>
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<tr>
<td>Adjustment</td>
<td>SAS (1)</td>
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<td></td>
<td>DAS (1)</td>
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<tr>
<td>Coping</td>
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<tr>
<td>Self-Esteem</td>
<td>Rosenberg Self-Esteem Scale (1)</td>
</tr>
<tr>
<td>Care</td>
<td>Perceptions of Care Questionnaire (1)</td>
</tr>
</tbody>
</table>

*Note: (N), number of studies using this measure*
Outcomes

Statistically significant change. All 10 RCTs reported a reduction in symptoms over time in both treatment and control groups but only six of these found a greater reduction for the treatment group relative to the control group. These six involved comparison to a no-treatment control (Swanson 1999; Swanson et al., 2009; Nikčević et al., 2007), a wait-list control (Kersting et al., 2011), a treatment-as-usual control (Neugebauer et al., 2006), and an alternative active treatment control (Johnson et al., 2016; Swanson et al., 2009). Each of these studies had a follow-up at which the differences in reduction of symptoms were maintained; however this period varied in length from three weeks (Neugebauer et al., 2006) to 13 months (Swanson et al., 2009). Only three had a follow-up period greater than six months (Johnson et al., 2016; Swanson 1999; Swanson et al., 2009).

Two RCTs found inconsistent advantages of the intervention. Kong et al. (2014) found that of women with higher baseline scores, those in the counselling group showed greater improvement compared to the control group, otherwise there were no differences between groups; Séjourné et al. (2010) found improvement in the treatment group at three weeks but by 10 weeks the intervention and wait-list group had equivalent outcomes.

The remaining two RCTs reported no difference in symptomatology compared to a no-treatment control (Lee et al., 1996) and a treatment-as-usual control (Adolfsson et al., 2006). Both of these interventions offered a one-hour intervention within the first month of miscarriage.

The three uncontrolled studies (Nakano et al., 2013; Neugebauer et al., 2007; Rowsell et al., 2001) all found changes in symptomatology from pre-to post-
intervention. However Rowsell et al. (2001) found that, other than for the domain of
IES-avoidance, this change occurred prior to the start of the intervention.

There was little evidence of differential effectiveness for interventions with
different theoretical underpinnings. All three interpersonal therapy interventions
found significant change; however one had no control group and no follow-up
(Neugebauer et al., 2007) and one had a follow-up of only 3-6 weeks (Neugebauer et
al., 2006). Two out of four CBT interventions (Kersting et al., 2011; Nikčević et al.,
2007) found change maintained at 3-4 months follow-up; (the remaining two found
change but this was either not maintained (Séjourné et al., 2010) or there was no
follow-up (Nakano et al., 2013). Two out of five nursing interventions (Swanson,
1999; Swanson et al., 2009) found change maintained at 12-13 months follow-up
and one found improvement but only for women with high baseline scores (Kong et
al., 2014); of the remaining two, one found a change but only on one domain
(Rowsell et al., 2010) and the other found no change (Adolfsson et al., 2006). The
only study of a debriefing intervention (Lee et al., 1996) found no significant change.

**Effect Sizes.** Table 5 shows the effect sizes for the primary outcome
measures. Effect sizes were reported in three studies; for seven studies, effect sizes
were calculated by the author based on the information provided. For Nikčević et al.
(2007) effect sizes were calculated between the intervention group and the no-
intervention control group at four month follow-up. For Swanson (1999) effect size
was calculated between the intervention and control groups (regardless of
measurement condition: early versus delayed) at one year follow-up. Three studies
(Adolfsson et al., 2006; Kong et al., 2014; Swanson et al., 2009) did not provide
sufficient information to calculate the effect size.
## Table 5. Effect Sizes

<table>
<thead>
<tr>
<th>Author</th>
<th>Outcome</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolfsson et al. (2006)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Johnson et al. (2016)</td>
<td>HRSD, BDI, ICG,</td>
<td>0.12, -0.04,</td>
</tr>
<tr>
<td></td>
<td>PBGS, MSPSS, SAS</td>
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</tr>
<tr>
<td></td>
<td>DAS</td>
<td>0.26, 0.00</td>
</tr>
<tr>
<td>Kersting et al. (2011)</td>
<td>ITT analysis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>IES</td>
<td>0.56</td>
</tr>
<tr>
<td></td>
<td>ICG</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td>BSI sum</td>
<td>0.46</td>
</tr>
<tr>
<td></td>
<td>BSI depression</td>
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</tr>
<tr>
<td></td>
<td>subscale</td>
<td></td>
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<tr>
<td></td>
<td>Completer Sample</td>
<td></td>
</tr>
<tr>
<td></td>
<td>IES</td>
<td>0.86</td>
</tr>
<tr>
<td></td>
<td>ICG</td>
<td>0.71</td>
</tr>
<tr>
<td></td>
<td>BSI sum</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>BSI depression</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td>subscale</td>
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<tr>
<td>Kong et al. (2014)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lee et al. (1996)</td>
<td>HADS anxiety,</td>
<td>0.11</td>
</tr>
<tr>
<td></td>
<td>HADS depression</td>
<td>0.27</td>
</tr>
<tr>
<td></td>
<td>IES Intrusion</td>
<td>0.42</td>
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<tr>
<td></td>
<td>IES Avoidance</td>
<td>0.18</td>
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<tr>
<td>Nakano et al. (2013)</td>
<td>BDI, STAI-s</td>
<td>1.27, 1.25</td>
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<tr>
<td>(pre-post effect size)</td>
<td></td>
<td></td>
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<tr>
<td>Neugebauer et al. (2006)</td>
<td>ITT analysis</td>
<td></td>
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<tr>
<td></td>
<td>CES-D</td>
<td>0.15</td>
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<td>CES-D</td>
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<td>(pre-post effect size)</td>
<td>CES-D</td>
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<td>Completer Sample</td>
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<td>CES-D</td>
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Table 5. Effect Sizes cont.

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<thead>
<tr>
<th>Author</th>
<th>Outcome</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nikčević et al. (2007) c</td>
<td>HADS anxiety</td>
<td>0.18</td>
</tr>
<tr>
<td>(between intervention group</td>
<td>HADS depression</td>
<td>0.00</td>
</tr>
<tr>
<td>and no intervention control</td>
<td>TGI</td>
<td>0.08</td>
</tr>
<tr>
<td>group at 4m)</td>
<td>Self-Blame</td>
<td>0.24</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>0.16</td>
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<tr>
<td>Rowsell et al. (2001) c</td>
<td>HADS anxiety</td>
<td>0.33</td>
</tr>
<tr>
<td>(pre-post effect size)</td>
<td>HADS depression</td>
<td>0.31</td>
</tr>
<tr>
<td></td>
<td>IES Intrusion</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td>IES Avoidance</td>
<td>0.69</td>
</tr>
<tr>
<td>Séjourné et al. (2010) c</td>
<td>HADS anxiety</td>
<td>0.33</td>
</tr>
<tr>
<td></td>
<td>HADS depression</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td>IES-R</td>
<td>0.04</td>
</tr>
<tr>
<td>Swanson (1999) c</td>
<td>POMS overall emotional</td>
<td>0.17</td>
</tr>
<tr>
<td>(between intervention group</td>
<td>disturbance</td>
<td></td>
</tr>
<tr>
<td>and control group at 1 year)</td>
<td>POMS depression</td>
<td>0.25</td>
</tr>
<tr>
<td></td>
<td>POMS anger</td>
<td>0.19</td>
</tr>
<tr>
<td></td>
<td>IMS personal significance</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>IMS devastating event</td>
<td>0.05</td>
</tr>
<tr>
<td>Swanson et al. (2009) a</td>
<td>-</td>
<td>-</td>
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</table>

Note. a unable to calculate effect size; b effect size reported in the paper; c effect size calculated by the present author

For the seven RCTs where effect size could be explored, Cohen’s d ranged from -0.04 to 0.86, with a median of 0.18. According to Cohen (1988) this is a small effect size. For the three uncontrolled studies Cohen’s d ranged from 0.31 to 1.27, with a median of 0.69, which would be considered a medium effect size.

**Clinically Significant Change.** None of the studies reported their findings in terms of reliable and clinically significant change. One study reported their findings according to the reliable change index (Jacobson & Truax, 1991): Kersting et al. (2011) found that the treatment group had a higher percentage of participants showing reliable change compared to the wait-list control group on measures of
trauma (82% and 42% respectively), depression (70% and 31%), grief (67% and 39%) and overall mental health (70% and 39%) in the per-protocol analysis. However they did not report the percentage of participants who had clinically recovered, i.e. had scores below the clinical cut-off for diagnosis.

Three studies reported change in clinical significance from pre- to post-intervention: Lee et al. (1996), Nikčević et al. (2007) and Rowsell et al. (2001) all reported a reduction in the percentage of cases reaching the clinical cut-off for anxiety and depression and for IES-intrusion and IES-avoidance (Lee et al. 1996).

Discussion

This review examined 13 studies of psychological interventions for women following miscarriage. These comprised four CBT interventions; five nurse/midwife counselling interventions; three IPT/IPC interventions; and one psychological debriefing intervention. The interventions and design varied in a number of areas: definition of miscarriage; length of intervention; timing of intervention; and follow-up period. Of particular importance, interventions varied in the target of the intervention, and often, multiple different outcomes were assessed. There was little evidence of differential effectiveness for interventions with different theoretical underpinnings.

All studies found improvement over time. Ten studies suggested that the observed improvements were attributable to the intervention: eight RCTs (Johnson et al., 2016; Kersting et al., 2011; Kong et al., 2014; Neugebauer et al., 2006; Nikčević et al., 200; Séjourné et al., 2010; Swanson, 1999; Swanson et al., 2009) and two uncontrolled studies (Nakano et al., 2013; Neugebauer et al., 2007).

The six RCTs using a waitlist, no intervention, or treatment-as-usual control showed that, while symptoms gradually improved over time in both groups, the
intervention seemed to hasten or increase this improvement. The remaining two RCTs (Johnson et al. 2016; Swanson et al. 2009) compared their intervention to alternative treatment controls and their results seem to show the differential effectiveness of particular interventions for different symptoms. Swanson et al. (2009) found that the Nurse Caring intervention was effective for women’s depression but the Nurse Caring and Self-Caring interventions were equally effective for symptoms of grief. Johnson et al. (2016) found that the IPT intervention was particularly effective in reducing symptoms of PTSD and improving social functioning, while the Coping with Depression control was equally effective at reducing depressive symptoms.

Furthermore, Kong et al. (2014) found that their intervention improved recovery compared to the control group, but only in a subgroup analysis of women with high baseline scores. This adds to the evidence suggesting that interventions should be tailored to specific symptomatology.

The length of follow-up varied with only two studies collecting outcomes beyond 6 months (Swanson, 1999; Swanson et al. 2009). Séjourné et al. (2010) found that the observed improvement in participants at 3 weeks had become equivalent to the control by 10 weeks, suggesting the importance of long-term follow-up for both treated and control groups in order to evaluate the efficacy of interventions.

Two of the uncontrolled studies (Nakano et al., 2013; Neugebauer et al., 2007) found improvements in symptomatology pre- to post intervention. However, it is possible that this reflects the finding of all the other studies in this review that symptoms naturally improve over time. The third uncontrolled study (Rowsell et al., 2001) found that the significant improvement in symptoms occurred between time 1
and 2, before the start of the intervention. This is consistent with prior research that bereaved individuals improve naturally over time without intervention (Schut & Stroebe, 2011, for review).

Consistent with previous reviews, it remains hard to draw any overall conclusions about the effectiveness of interventions following miscarriage. This is predominately due to the heterogeneity of the studies included. The inclusion criteria were deliberately broad in order to capture all relevant studies; however, this still only yielded a small number of studies, all of which varied in a number of areas. Variation in the definition of miscarriage, intervention timing and follow-up were areas which made it particularly difficult to draw comparisons across studies.

A broader difficulty within this field of research is establishing exactly what is being ‘treated’. This is consistent with differences in the way researchers have attempted to understand the psychological responses to miscarriage: as grief (Brier, 2008) (and when does grief turn into depression or complex grief?) or trauma (Lee & Slade, 2996). Five studies used the SCID to assess participants prior to study entry and outlined inclusion and exclusion criteria based on the severity of symptoms. The remaining seven had no such criteria and interventions were instead targeted at improving symptoms in a number of different areas or wellbeing in general. This may have had implications for the conclusions that could be drawn from the studies; Kong et al. (2014) suggest that the lack of beneficial effect for women with very low levels of distress at baseline, may have diluted the evidence of overall therapeutic effect.

Furthermore, a wide range of outcome measures were used which made it difficult to compare improvements. Future interventions may be better placed targeting specific symptoms rather than trying to address miscarriage per se.
Study Quality and Methodological Considerations

The quality of studies included in this review was very mixed when rated according to the EPHPP tool. An area of general strength was study design: the majority of studies included a control group and used randomization processes to allocate participants. As grief was a potential outcome to be monitored, the use of a control group to show natural recovery is particularly important. Most studies appropriately controlled for confounding variables and all studies used well-validated and reliable outcome measures.

Areas of weakness included selection bias, with only half the studies using strong recruitment methods. Studies that advertised via pamphlets and posters may have attracted a self-selecting participant group, which, in a relatively new area of research, makes it difficult to draw conclusions about the usefulness of interventions for a broader population. Blinding was an area of general weakness with only one study employing blind assessors. Finally, only half the studies reported participant retention clearly and the majority of studies were rated moderate or weak because of high dropout rates.

Several other important methodological issues, not covered by the EPHPP tool, need to be considered. Firstly, there was great variability in the way miscarriage was defined (varying from pre-13 weeks to pre-28 weeks gestation) and often the definition was not given at all. Moreover, some studies included women experiencing much later pregnancy loss and stillbirth. The obstetric history of participants also varied with several studies focusing on recurrent miscarriage (Nakano et al., 2013; Rowsell et al., 2001) and others excluded women who experienced recurrent miscarriage (Nikčević et al., 2007; Lee et al., 1996). Furthermore the time between miscarriage and study entry varied from one day
(Séjourné et al., 2010) to 144 months (Kersting et al., 2011). This heterogeneity makes it hard to draw conclusions about the effectiveness of interventions for ‘miscarriage’.

Secondly, the EPHPP tool does not differentiate between self-report measures and assessor rated outcomes. The studies in this review almost exclusively relied on self-report measures; standardised interviews might have given a more objective measure of change.

Finally, eight studies had either no follow-up period or follow-up was less than six months. Given that research suggests the six months following miscarriage is the period of highest risk (Klier et al., 2002; Brier, 2004) and that symptoms of anxiety, depression and grief can remain elevated for up to 12 months (Cumming et al., 2007), a longer period of follow-up should be incorporated in future research in order to fully evaluate the efficacy of interventions. The differing lengths of follow-up coupled with the variation in time elapsed since the miscarriage occurred made it near impossible to assess the change in symptoms during this critical 12 months.

**Clinical Implications and Future Research**

Every study in this review found that symptoms improved over time even without intervention. This lends support to the notion of time as a natural healer following miscarriage. However, there is also preliminary support for the hypothesis that psychological interventions following miscarriage can hasten recovery and, for some symptoms, improve recovery. Further research in this area is therefore warranted.

Dropout rates in the studies included in this review were high; however, qualitative studies suggest that women want support following miscarriage (Séjourné et al., 2010a; Simmons et al., 2006). This is consistent with previous research which
has found that, despite requesting support, uptake is often low (Séjourné et al., 2010a). It is unclear why this might be; perhaps support is no longer needed due to natural recovery or, as Séjourné et al. (2010b) suggest, it could be that women, having waited for an intervention, are unwilling to revisit traumatic experiences. This is supported by the finding that women who drop out often have higher baseline scores (Kong et al., 2014; Séjourné et al., 2010b). It would be helpful for future research to explore the reason for dropout in more detail in order to avoid any iatrogenic effects as well as to ensure that interventions are financially viable.

Related to this, further research regarding the timing of intervention is also required. Should interventions be offered immediately or delayed? Taking a bereavement perspective, delaying the intervention would allow for the natural resolution of grief (Schut, 2010); however, taking a trauma perspective, intervention should be offered much more quickly (Dyregov, 1989). The studies reviewed here offer no further clarification on this issue, with no differential effectiveness evident for immediate or delayed intervention. Lee et al. (1996) suggest that early assessment might be key to establishing what type of support might be warranted and when. They suggest that intervention without adequate assessment might do more harm than good in contradicting women’s own coping skills. Support for this comes from Kong et al.’s (2014) finding that their intervention was only effective for those women with higher baseline scores. If women were assessed following a miscarriage, could intervention type and timing be tailored to specific presentations rather than to the miscarriage experience as a whole? Johnson et al. (2016) and Neugebauer et al. (2007) were the only two studies that targeted a particular symptom (depression) with an intervention designed for that purpose (IPT/IPC). Further research is needed, but Johnson et al.’s (2016) findings suggest that their
Intervention was as good as an existing depression treatment and received higher satisfaction ratings by participants.

Future research would also benefit from some methodological improvements: clarification of sample and terminology (what type of pregnancy loss is being studied and how is this defined); the routine use of appropriate control groups; the use of blind assessors at study entry and follow-up, rather than only self-report measures; the use of similar outcome measures to allow for comparison across studies; and extended follow-up for both intervention and control groups.

Conclusions

The findings of this review suggest that intervention following miscarriage can be of benefit to women. While symptoms improve naturally over time for the majority of women, intervention seems able to improve and/or hasten the resolution of grief, depression, anxiety, trauma, anger and self-blame, particularly for women with higher baseline scores. However, the review has also raised questions regarding the way in which the consequences of miscarriage are conceptualised and consequently what treatment is appropriate and when it should be provided. Further research is needed to explore these important questions. Of particular interest is the effectiveness of early assessment and the provision of interventions adapted for miscarriage and designed to target specific psychological sequelae, such as IPT for depression or psychological debriefing for trauma.
References


Murphy, F., Lipp, A., & Powles, D. (2012). Follow-up for improving psychological well-being for women after a miscarriage. *Cochrane Database of Systematic Reviews, (3).*


Part II: Empirical Paper

Women’s experiences of support following miscarriage: ‘Navigating the awkwardness’
Abstract

**Aims:** Previous research has suggested that silence surrounds the experience of miscarriage and that many women feel it remains a taboo subject. Despite recognition of this difficulty, there is little detail regarding the nature of supportive or unsupportive interactions following miscarriage. This study aimed to explore women’s experiences of social support following miscarriage.

**Method:** Semi-structured interviews were undertaken with 13 women who had experienced a first-trimester miscarriage. The interviews were analysed using Braun and Clark’s (2006) method of thematic analysis.

**Results:** The analysis yielded 10 themes which were organised into two domains: (1) barriers to talking about miscarriage and (2) supportive and unsupportive interactions. Barriers included both internal and external factors, such as beliefs about miscarriage and not wanting to burden others. Opportunities to talk openly were rare; interactions were often experienced as awkward or difficult. However, when women felt understood and validated this had a profound emotional impact; similar others were particularly able to provide this type of support.

**Conclusions:** The findings are consistent with previous research suggesting there is often a silence surrounding miscarriage. They also confirm that social support following miscarriage is highly valued. There is a potential role for professionals and the voluntary sector to offer support and guidance to women and their families on how to navigate these difficult conversations.
Introduction

Miscarriage has repeatedly been described as a ‘silent’ topic, something which is dealt with behind closed doors (Bansen & Stevens, 1992; Layne, 1990; Rowlands & Lee, 2010). In the UK there are no sociocultural norms in place to mark the life or death of a foetus pre 20 weeks and as such it has been described as a type of ‘disenfranchised grief’ which is not openly acknowledged or publicly grieved (Doka, 1999). Advice to newly expectant parents is often to wait to share the news of pregnancy until the 12th week when the risk of miscarriage is much reduced. While it is suggested that this secrecy is to guard against raised hopes or the potential difficulty of having to share the loss of the pregnancy, it also means that many of those in one’s usual support network are unaware that a life had existed before it was lost. Practices around early pregnancy do, however, vary cross-culturally, often incorporating a more public ritual following loss (Layne, 1990); it is unclear what impact this has on parental wellbeing.

The isolation experienced by couples after miscarriage has recently been described by Mark Zuckerberg (Founder of Facebook) in a high profile open letter about his and his wife’s experience (Zuckerberg, 2015). He comments on the loneliness which they felt as a consequence of the silence and secrecy surrounding their miscarriage and contrasted this to the benefits of sharing the experience, which generated hope and understanding. His letter prompted a wide response from media in the UK particularly, with similar reports that miscarriage remains a taboo topic (Freeman, 2017; Pritchard, 2015; Whitehouse, 2015; Williams, 2015). Consistent with these reports, the UK organisation Mumsnet (2014) found that only 23% of women had spoken to friends about their experience.
Social Support

While support provided by professionals is important, after a difficult event such as miscarriage informal support from family and friends may also be crucial. Research into the use of informal (e.g. friends, family, peer support groups) versus formal (e.g. professional counselling or therapy) sources of support shows that in times of need individuals first seek out members of their immediate social network (Barker, Pistrang, Shapiro & Shaw, 1990), typically accessing formal support only if problems persist or escalate. There is a large body of evidence indicating that social support is associated with better physical and mental health (Cohen & Wills, 1985; Coyne, Ellard & Smith, 1990).

Cohen (2004) suggests three variables of social relationships which influence health outcomes: social support, social integration and negative interactions. Social support is the material and emotional resources that are available to the individual. It has been broadly categorised according to its functional components: emotional, informational, and instrumental. Cohen (2004) suggests that these types of support influence health outcomes by providing a buffer to the impact of stressful events; the belief that others will be able to provide resources in times of need, may make individuals feel more able to cope and therefore generate less emotional arousal. This is supported by the finding that perceived social support is more strongly related to wellbeing than received social support (Prati & Pietrantoni, 2010).

Social integration refers to the degree to which individuals are engaged in a range of social roles and relationships. Cohen (2004) suggests that this has a main effect on wellbeing by increasing self-worth and positive identity. Cohen posits that this could be as a result of access to multiple sources of information and resources, but also exposure to ‘role concepts’ (p. 678) which help guide an individual as to
how to behave. Meeting these expectations reinforces self-worth and identity. Social integration or contact with similar others may be particularly important during periods of loss, illness or adversity. The value of peer support programmes, in which similar others provide informal support from a position of personal experience, has been well documented for physical health problems (e.g. Hoey, Ieropoli, White, & Jefford, 2008) and for its value in supporting women following pregnancy loss (e.g. Gold, Boggs, Mugisha, & Palladino, 2011; Klein, Cumming, Lee, Alexander & Bolsover, 2012). Consistent with Cohen’s suggestion, advice and guidance from those with similar experiences is highly valued (Pistrang, Jay, Gessler & Barker, 2012). Furthermore the presence of similar others has been linked to increased self-esteem and mood amongst those with concealable stigmatized identities (Frable, Platt & Hoey, 1998).

Negative interactions, in contrast, can be a source of stress which not only impacts upon psychological wellbeing but also increases the risk of susceptibility to illness (Cohen, 2004; Cohen et al., 1998). Indeed, negative interactions have been found to be more strongly predictive of mood and wellbeing than supportive interactions (Newsom, Rook, Nishishiba, Sorkin, & Mahan, 2005; Rook, 2001), leading some researchers to suggest that the nature of such interactions should be a focus of research (Coyne et al., 1990).

**Social-Cognitive Processing Model**

The social-cognitive processing model (Lepore, 2001) posits that recovery from a traumatic experience is facilitated by talking. It suggests that social support reduces distress by aiding the cognitive processing of events, for example by enabling consolidation of current information, providing new perspectives and
information about the event and increasing a sense of control over emotional responses.

‘Social constraints’, however, might hinder or impede this process. Critical remarks, a reluctance to listen, avoidance of the topic or simply a lack of availability, have been conceptualised by Lepore and Revenson (2007) as social constraints which reduce the possibility to talk and receive support. They suggest that this contributes to continued distress by preventing cognitive processing and by undermining feelings of trust, acceptance and security.

A lack of social support following trauma has been found to be a risk factor for the development of posttraumatic stress disorder (PTSD) (Brewin, Andrews & Valentine, 2000). Friends and family appear to be particularly significant in shaping posttraumatic cognitions which moderate PTSD symptoms (Woodward, Eddinger, Henschel, Dodson, Tran, & Beck, 2015). In particular, greater social constraints have been associated with greater PTSD symptoms (Belsher, Ruzek, Bongar & Cordova, 2012).

The social-cognitive processing model has also been helpfully applied to understanding recovery from bereavement. Social sharing following a bereavement has been shown to aid the search for meaning and understanding of what has happened (Pennebaker, Zech & Rime, 2001). Kreicsbergs, Lannen, Onelov and Wolfe (2007) found that sharing one’s grief with others was one of the strongest predictors of grief resolution. Conversely, consistent with the social-cognitive processing model, social constraints have been associated with greater depressive symptoms and stress following bereavement (Juth, Smyth, Carey & Lepore, 2015; Lepore, Silver, Wortman & Wayment, 1996).
Social Support as an Interactional Process

Much of the social support literature has conceptualised social support merely as something given and received rather than as an interactional process. The lack of detail regarding the interpersonal processes that constitute support is a major limitation of the field, with researchers and theorists (e.g. Barker & Pistrang, 2002) calling for more of a focus on the features of supportive and unsupportive interactions, that is, what actually occurs that is felt to be helpful.

Coyne et al. (1990) have theorised that ‘dilemmas of helping’ occur in interactions where one person is attempting to support another. They highlight that supporters (particularly close others) have their own needs, such as managing their own distress about the situation; they are thus confronted with a dilemma of how to continue to provide support while also meeting their own needs. Coyne et al. (1990) have argued that in order to understand whether support is effective, we need to explore how individuals within a network negotiate these ‘dilemmas of helping’. This is perhaps particularly the case with bereavement, which is said to create a ‘social network crisis’, with the loss of a loved one often rendering a whole network of individuals less able to support each other (Vachon & Stylianos, 1988).

Furthermore, Lehman, Ellard and Wortman (1986) have suggested that the supporter can often be so upset by seeing the bereaved in distress that any prior knowledge or strategies they had about coping with bereavement and ways of being supportive are replaced by (unhelpful) attempts to make that person feel better.

It is possible that when a supporter’s own needs are great, interactions are less successful because it is difficult to be empathic towards the other. The most helpful interactions have been found to be characterised by high empathy (e.g. Harris, Pistrang & Barker, 2006; Pistrang, Piciotto & Barker, 2001); that is being
able to understand the other’s experience. This is consistent with evidence which suggests that empathy is a key element in the success of peer support interactions (Pistrang et al., 2012). Importantly, Pistrang et al. (2001) found that it was not necessarily the accuracy of the supporter’s understanding, but their tentative attempts to understand, which were found to be helpful.

Social Support following Miscarriage

There is currently limited research into women’s experiences of social support following miscarriage. There is some quantitative data, mainly from questionnaire studies providing some statistics about how likely women are to talk to different groups of people, with figures suggesting that the majority of women do talk to their partners, friends and other relatives (Conway, 1995; Conway & Russell, 2000; Séjourné, Callahan & Chabrol, 2010). However the lack of detail in these studies provides no understanding as to the particular nature of these conversations; their content, breadth and how supportive they are felt to be.

Several other studies have taken a qualitative approach, using interview methods. One key theme arising across these studies is that women want to talk but often feel there is a ‘hush’ surrounding the experience (Bansen & Stevens, 1992, Rowlands & Lee, 2010). This appears inconsistent with the findings from the quantitative studies above. One explanation for this might be the lack of detail provided in quantitative studies of support; one might perceive support to be available but at the same time experience a number of social constraints on that support (Juth et al., 2015).

Qualitative studies have also indicated that when support is received, these interactions are felt to be ‘pivotal in shaping the entire miscarriage experience’ (Rowlands & Lee, 2010, p. 283), with some negative interactions experienced as
unsupportive, hurtful and invalidating (Bansen & Stevens, 1992, Rowlands & Lee, 2010). However, these studies look very broadly at women’s experience of miscarriage and the factors which influence their ability to cope, focusing mainly on the provision of professional support; they cover social support as just one aspect of this (Bansen & Stevens, 1992; Rajan & Oakley, 1993; Rowlands & Lee, 2010). More detailed exploration of support processes is needed.

**Current Study**

While research and theory both point to the importance of social support in the aftermath of miscarriage, there is little detailed understanding of what facilitates or hinders talking and the nature of supportive or unsupportive interactions. This study aimed to examine this in detail: what encourages women to talk to others and what prevents them, and how they experience others’ reactions. As in other areas of social support research, a richer understanding of these interpersonal processes following a miscarriage is needed.

The study used a qualitative methodological approach (specifically, semi-structured interviews). Qualitative approaches are particularly suitable for studying complex psychological processes because they focus on personal meanings and can produce accounts rich in detail (Pistrang & Barker, 2012). Furthermore, qualitative methods are useful for studying under-researched areas as they allow an exploratory approach (Barker, Pistrang & Elliott, 2016).

The study was informed by the theoretical literature on social support. Drawing on the conceptualisation of social support as an interactional process, the study aimed to obtain detailed accounts of helpful and unhelpful interactions, including any social constraints which influenced conversations. The study focused
on interactions within women’s natural support networks, i.e. informal sources of support such as friends and family, rather than support from healthcare professionals.

The study addressed the following research question: What are women’s experiences of talking (or not talking) about their miscarriage? More specifically, what facilitates or hinders talking, and what kinds of interactions are experienced as supportive or unsupportive?

Method

Ethics

The study received ethical approval from the University College London Research Ethics Committee in February 2016 (Appendix A; this approval was for an amendment to a larger programme of research). All participants were provided with a written information sheet (Appendix B) and given the opportunity to ask questions about the study before agreeing to participate. Participants gave written, informed consent prior to participation (Appendix C).

Setting

The study was advertised via The Miscarriage Association and Mumsnet. The Miscarriage Association is a national charity in England and Wales which provides support and information to those experiencing miscarriage and promotes best practice in medical care. Mumsnet is a UK based parenting forum and website with over 12 million unique users each month. The study advertisement (Appendix D) was placed on the Miscarriage Association Facebook page which at the time had just under 15,000 followers and on the Mumsnet Research Forum. The advertisement was placed twice: once in April 2016 and once in January 2017. Participants were asked to respond via email or through the comments section of the
advertisement; they were subsequently telephoned by the researcher to screen for the study eligibility criteria.

Participants

Eligibility Criteria. To be eligible to participate women were required to:

(1) Have experienced a first trimester miscarriage (pre-13 weeks gestation). This time frame was chosen in order to focus on the process of accessing and receiving support when others are unlikely to have been aware of the pregnancy.

(2) Have had the miscarriage more than three months ago and within the last 18 months. The minimum of 3 months was to guard against women being interviewed while emotionally vulnerable in the immediate months following the miscarriage. The maximum of 18 months was to ensure relatively ‘live’ memories of their experiences.

(3) Be 21 years of age or older

(4) Speak fluent English

(5) Live in Greater London or be willing to travel for the purpose of the interview.

Recruitment. The recruitment process is outlined in Figure 1. No responses were received from the Mumsnet advertisement. Of the 66 women who responded to the Miscarriage Association advertisement between April 2016 and January 2017, 36 did not meet the inclusion criteria, with the main reason being locality (28 women lived outside of London, or the UK). Other reasons for exclusion were: the miscarriage occurring more than 18 months ago; loss of a pregnancy beyond the first trimester; and one women who had experienced a surrogate miscarriage (this woman was excluded because of the additional confounding factors involved with this type of
66 women responded to advert

36 did not match the inclusion criteria
Reasons:
- Living outside of London or the UK (28)
- Longer than 18 months ago (4)
- Loss of pregnancy post 12 weeks (3)
- Surrogate miscarriage (1)

30 women contacted to participate

14 did not respond
Participants were contacted within a week of their response to the advert. 10 did not respond further. Four were asked to wait 3 months before the interview, but did not respond to later contact.

3 withdrew prior to interview
Reasons:
- Beginning IVF (1)
- Miscarried again 2 days before interview (1)
- Too busy (1)

13 interviewed
pregnancy). Of the 30 women who were eligible, 14 did not respond to email or telephone contact following their initial contact and three withdrew prior to taking part in the interview. This left a sample size of 13 women (46% of eligible respondents).

**Participant Characteristics.** The characteristics of the 13 participants are shown in Table 1. Ages ranged from 31 to 41 years ($M = 35.15$, $SD = 2.67$). The majority of participants were White British ($N=11$, 85%); the remaining two were Black African and White European. The level of education was high, with the majority (69%) having completed degree level qualifications. All participants were either married or in long-term relationships. The majority (69%) had between one and two children; the remainder had no children. The number of miscarriages experienced ranged from one to four ($median = 2$) and the time since the most recent miscarriage was between three and 16 months ($M = 7.69$ months, $SD = 3.86$ months).

**Semi-Structured Interview**

A semi-structured interview schedule was developed for the study (Appendix E). Prior to developing the schedule the researcher met with an ‘expert-by-experience’ (a woman who had experienced three miscarriages within the last two years) in order to gain some initial understanding of salient issues in 1) disclosing a miscarriage and 2) responses from others. Once an initial schedule was developed, the same expert-by-experience reviewed the questions to ensure they were relevant and appropriate. She suggested that for women who have experienced multiple miscarriages, each should be explored individually because often the experience and decision making process for each were very different. The schedule started with broad open questions about the context of the pregnancy: how the participant found out, who was told and how she and others felt about the pregnancy. Questions then followed according to four main areas: (1) Initial disclosure about the miscarriage, including who was told, what was told and how this was done; (2)
Helpful/supportive interactions, including how individuals responded and the impact of this; (3) Unsupportive interactions; and (4) Not talking, exploring whether there was anyone who was not told or particular aspects of the miscarriage which were not spoken about.

Questions were used to elicit detail about these interactions and to establish any impact of the interaction on the relationship. Participants were also explicitly asked if they would have liked anything to be different about the support they received.

Interviews were often highly emotive and in many instances were the first opportunity women had had to tell their story in depth. The interview schedule was therefore used flexibly, allowing for ideas raised by the participant to be fully explored as well as allowing for pauses and changes of direction as appropriate. A highly empathic

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Education</th>
<th>Children</th>
<th>Number of Miscarriages</th>
<th>Time since last Miscarriage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>33</td>
<td>A Level</td>
<td>2</td>
<td>4</td>
<td>16m</td>
</tr>
<tr>
<td>2</td>
<td>36</td>
<td>Post-Grad</td>
<td>0</td>
<td>1</td>
<td>10m</td>
</tr>
<tr>
<td>3</td>
<td>31</td>
<td>Doctorate</td>
<td>0</td>
<td>1</td>
<td>5m</td>
</tr>
<tr>
<td>4</td>
<td>37</td>
<td>Masters</td>
<td>1</td>
<td>4</td>
<td>8m</td>
</tr>
<tr>
<td>5</td>
<td>33</td>
<td>Post-Grad</td>
<td>0</td>
<td>2</td>
<td>6m</td>
</tr>
<tr>
<td>6</td>
<td>36</td>
<td>Degree</td>
<td>1</td>
<td>1</td>
<td>9m</td>
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<tr>
<td>7</td>
<td>34</td>
<td>A Level</td>
<td>1</td>
<td>1</td>
<td>4m</td>
</tr>
<tr>
<td>8</td>
<td>41</td>
<td>Degree</td>
<td>1</td>
<td>2</td>
<td>12m</td>
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<tr>
<td>9</td>
<td>34</td>
<td>A Level</td>
<td>1</td>
<td>3</td>
<td>3m</td>
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<tr>
<td>10</td>
<td>35</td>
<td>Degree</td>
<td>1</td>
<td>2</td>
<td>4m</td>
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<tr>
<td>11</td>
<td>34</td>
<td>GCSE</td>
<td>0</td>
<td>2</td>
<td>8m</td>
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<tr>
<td>12</td>
<td>34</td>
<td>Post-Grad</td>
<td>1</td>
<td>3</td>
<td>4m</td>
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<tr>
<td>13</td>
<td>39</td>
<td>Post-Grad</td>
<td>1</td>
<td>2</td>
<td>11m</td>
</tr>
</tbody>
</table>
stance felt important: allowing the woman’s story to unfold, usually chronologically, with
the interviewer taking an approach of attentive listening and empathic questioning
(Josselson, 2013). Nonetheless, the interviewer ensured each area of the interview
schedule was covered.

Each interview lasted approximately 90 minutes and was audio recorded with the participant’s permission. Interviews were transcribed using Express Scribe Software and all identifying information was removed. All interviews were conducted face-to-face, either at University College London, in participants’ own homes or in three cases in cafés. The location of the interview was decided by the participant, unless their home was outside of London, in which case participants were requested to travel to University premises.

**Qualitative Data Analysis**

Braun and Clarke’s (2006) method of thematic analysis was used to analyse the data. Thematic analysis is a way of systematically examining the data to identify common themes or patterns (Willig, 2013; Fereday & Muir-Cochrane, 2006) and organising them into broad themes while also capturing detail (Barker & Pistrang, 2012). Thematic analysis is not explicitly linked to a theoretical or epistemological position (Braun & Clark, 2006); it has therefore been suggested that thematic analysis has ‘theoretical flexibility’ (Willig, 2013). Braun and Clarke (2006) suggest that thematic analysis is commonly used but poorly demarcated and they therefore outline a number of clear steps to allow it to be used in a more rigorous manner. They outline six stages, which were followed in the present study. Although these are presented chronologically below, the analysis was an iterative process.

Firstly, the researcher familiarized herself with the data, transcribing the interviews and beginning to identify meaning by annotating the transcripts, sticking closely to participants’ own words. Secondly, initial codes were generated for the main ideas
expressed; this was done within each interview and then compared across interviews by creating summary sheets for each interview (see example summary sheet in Appendix F). The third step involved collating codes into broader themes (see Appendix G for an example). In the fourth step, these broad themes (each with constituent sub-themes) were reviewed with the supervisors of this project to check if they were grounded in the data and if alternative ways of labelling and organising the data might be more appropriate. The fifth step was to refine the definition of, and label for, each theme and sub-theme; where possible, verbatim phrases from participants were used for theme and sub-theme labels. Finally, the themes were organised into two domains and written up with data extracts to support each sub-theme.

**Credibility Checks.** Credibility checks were undertaken in accordance with good practice guidelines for the production of qualitative research (Barker & Pistrang, 2005). Firstly, a consensus approach was adopted; the researcher and the supervisors of this project (two experienced qualitative researchers) read and coded excerpts of interviews which were then discussed and compared for differences in understanding. The researcher and supervisors also discussed different ways of grouping codes into the most salient themes and sub-themes before a consensus on the final framework was reached.

Secondly, respondent validation was used to ensure that interpretations of the data were accurate. Following each interview a summary of the main themes was emailed to the participant for her to comment on accuracy (See Appendix H for the letter of invitation to participants). At the time of writing summaries had been sent to all participants and three responses received. All of these women stated they agreed with the way their interview had been represented and had nothing further to add.
**Researcher Perspective**

I am a 30 year old White British woman and I conducted this research in my second and third years of the Clinical Psychology Doctoral training. I have no children. I have had no personal experience of miscarriage but a number of family members have. The family narrative is that these losses were significant, to be remembered and talked about. I have also worked therapeutically with women who had sought support for their grief, anxiety and depression following a miscarriage. As a therapist, I hold the belief that talking is important and helpful.

During data collection and analysis I attempted to ‘bracket’ (Fischer, 2009) these views in order to remain open to different experiences, opinions and ideas. I also used a research journal and supervision to reflect on how this personal perspective might lead to ‘co-construction’ of the narrative (Josselson, 2013).

**Results**

The analysis generated 10 themes, which were organised into two domains (Table 2). The first relates to the barriers which prevented women from talking about their miscarriage with those around them. The second relates to the interactions that participants did have with others: what happened and what was felt to be supportive or unsupportive. Before presenting the themes, some contextual information regarding participants’ miscarriage experiences is provided.

**Overview and Context**

The experience of early pregnancy and the physical process of miscarriage, while not the focus of the results, provides an important backdrop to the interactions that participants had with those around them.

The early weeks of pregnancy were, for all participants, filled with cautious excitement. While aware of the possibility of miscarriage and the tradition to not disclose
pregnancy before 12 weeks gestation, participants reflected that they could not help but be full of hope that they would have a child.

Table 2: Themes and sub-themes

<table>
<thead>
<tr>
<th>Domain</th>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Barriers to talking about miscarriage</td>
<td>1.1 ‘It’s only a miscarriage’</td>
<td>Miscarriages are common ‘It’s just a bunch of cells’</td>
</tr>
<tr>
<td></td>
<td>1.2 ‘It’s really hard reliving it’</td>
<td>‘Untelling’ I don’t want them to see me cry Fearing what people might say</td>
</tr>
<tr>
<td></td>
<td>1.3 ‘It’s about women’s bits’</td>
<td>Horrific details of the miscarriage ‘It’s quite private’</td>
</tr>
<tr>
<td></td>
<td>1.4 ‘I didn’t want to burden them’</td>
<td>They’ve been through it too Getting on others’ nerves It’s too awkward</td>
</tr>
<tr>
<td></td>
<td>1.5 ‘All my friends are pregnant’</td>
<td>A painful reminder Friends withdraw too I don’t want to worry her</td>
</tr>
<tr>
<td>2. Supportive and unsupportive interactions</td>
<td>2.1 ‘Navigating the awkwardness’</td>
<td>I know you know, but who’s going to bring it up? I need to know I can talk Wait for me to want to talk Will you be able to cope with it?</td>
</tr>
<tr>
<td></td>
<td>2.2 ‘Glossing over it’</td>
<td>‘At least…’ Generic responses</td>
</tr>
<tr>
<td></td>
<td>2.3 ‘Talk, but not too much’</td>
<td>Others don’t want me to be sad Moving on I don’t want to be the ‘Miscarriage Girl’</td>
</tr>
<tr>
<td></td>
<td>2.4 ‘Be what you need to be’</td>
<td>Recognising the loss Permission to talk Feeling understood</td>
</tr>
<tr>
<td></td>
<td>2.5 ‘Kindred Spirits’</td>
<td>Validation I’m not alone Turning something negative into something positive</td>
</tr>
</tbody>
</table>
Having a miscarriage was not only a shocking and devastating loss, but a physically traumatic experience. The exact process of miscarrying varied for each participant; for five of the 13 women the miscarriage began naturally at home (or in one case at work), while others had the miscarriage confirmed and opted for surgical (seven women) or medical (one woman) management. All women said they were unprepared for the physical effects and were very shocked and frightened by the pain, blood loss and/or sudden admission to hospital.

The interactions women had with healthcare professionals during and after their miscarriage were felt to be extremely important. Often these were insufficiently supportive, with brief appointments, inadequate facilities and in several cases very insensitive comments. On the rare occasion when professionals were felt to be supportive, it was their recognition of the significance of the loss that was especially important; simple comments such as ‘I am very sorry for your loss’ (P6) were extremely meaningful. In addition to this, participants often noted actions which shielded them from other pregnant patients (e.g. providing facilities which separated them from pregnant women in the clinic; encouraging pregnant women to put their scan photos away before going into the waiting room) which they felt demonstrated that professionals truly cared.

**Domain 1: Barriers to talking about miscarriage**

Although every participant had talked to someone about their miscarriage, the amount they talked about it and how much detail they provided was influenced by a number of factors. This included personal barriers – participants’ own beliefs about miscarriage, how distressing it was to relive the experience and a wish to protect others – as well as external barriers, such as others’ beliefs and experiences.
Theme 1.1: ‘It’s only a miscarriage’

Participants’ beliefs (and the beliefs of those around them) about early pregnancy and miscarriage were important in influencing how able they felt to talk about their loss. This included beliefs that the foetus is not a ‘real’ child before 12 weeks and that miscarriage is a common experience. These beliefs often made it difficult for women to openly express their feelings about the miscarriage.

Several participants suggested that the prevalence of miscarriage made them think of it as less important, even to feel grateful that it was an early miscarriage rather than a later pregnancy loss, and as something that they should just cope with because others must do.

*It almost seemed like a rite of passage – oh that’s that bit that you have to go through before you get a baby, you have to go through a miscarriage, oh it’s so common.* (P5)

*I guess at the time I thought, well it’s only a miscarriage...loads of people have miscarriages, I’m supposed to just get on with it and just go to work.* (P8)

Furthermore, before their own miscarriage, women had rarely heard others talk about it; this, coupled with knowing its frequency, suggested that it was not something to be discussed openly.

*There’s definitely still a culture of it’s something you deal with silently behind closed doors, like I’ve never heard of anyone at work saying I need to take a couple of days off because I’ve had a miscarriage.* (P2)

The frequency of miscarriage led to a certain amount of caution and secrecy in the first 12 weeks of the pregnancy. Several participants described being aware of the ‘unwritten rule’ not to tell people about the pregnancy until 12 weeks. Some felt this implied that a miscarriage should not be talked about.
Always since I’ve been younger everyone always said “oh you must never tell anyone you are pregnant until 12 weeks”. It’s like well why? “Oh well you might miscarry”…and it’s almost as if people are like well you wouldn’t want anyone to know that you had miscarried… (P1)

Although most participants described feeling very attached to the baby from the moment they knew they were pregnant, they felt that other people often did not see it as a baby at all.

Because for most people it’s not a baby yet, it’s just a bunch of cells, but it’s amazing how quickly in here, it’s a baby. (P8)

She [mother] had the same reaction that she had towards my previous ones [miscarriages], which is that oh you know it wasn’t meant to be, it wasn’t a real baby yet. (P4)

Participants talked about having thought about what the future would be like with their baby; often these thoughts were not shared but kept privately between themselves and their partner. When the pregnancy was lost, they felt that all of these hopes were lost too and that others were unable to relate to this. The perception that other people did not view the loss as the loss of a child, often had the impact of participants doubting their way of grieving and limiting the way in which they shared with others. Several women talked about wondering if the level of grief they experienced was abnormal.

I said [to partner] I wanted to do a little funeral or something like that but it just felt like a conflict of is that too much? People don’t really do that, the baby was only tiny. So we decided to do something just us. I think the message from everybody from society, from doctors and even from family is like you can’t - it’s not a properly developed human. So if you do something like that it would be a bit mad or maybe it would be perceived that we are not coping with the grief appropriately and we’re over the top, like we should just get over it. So I was worried about how that would be perceived by other people and questioning that for myself, thinking am I doing it wrong? (P3)
Theme 1.2: ‘It’s really hard reliving it’

Despite at times minimising the significance of the loss, all participants described feeling shocked and devastated by the miscarriage. Most reported that they were so upset by their loss that talking about it was often very difficult. In the initial aftermath most participants felt this was almost impossible and consequently friends and family were informed either via the partner or in a brief text message.

I gave him a list and said you gotta tell these people, I just couldn’t. And it’s also dealing with the reaction you know, people don’t know what to say most of the time. (P4)

The process of telling others was described as ‘untelling’ by several participants; Participant 4 said this was part of the language used amongst women who had experienced miscarriage and was the process of telling all those who knew about the pregnancy about the miscarriage. All participants said that although it was important to let family know what had happened, the process of telling them was difficult. This was partly because, as Participant 9 highlighted, they felt they needed to be ready to deal with people’s reactions and often this was not the case soon after the miscarriage. Moreover, telling others what had happened was difficult because each time it meant reliving the experience.

It [telling others] was really hard, probably one of the hardest things we’ve ever had to do. You know, go around reliving that same story over and over again. It was just, you know, so you’ve gone through the horrible experience and then you’ve got to tell everyone... (P9)

The way in which Participant 9 described the process of ‘untelling’ also suggests that while reliving the experience was difficult, it was also very painful to be ‘unravelling’ the story of her pregnancy: It’s like unravelling it…what was once there isn’t any more. (P9)
Several participants described being conscious of repeatedly crying in front of others (including their partners) and therefore often cutting conversations short or avoiding being with people at difficult moments so as not to become upset in their presence.

*I was crying a lot and so I had this [medical] appointment and I told him [husband] I didn’t want him to come because I didn’t want him to see me like that anymore.* (P1)

Furthermore, several participants described how they became quite cautious about talking about the miscarriage with others because they felt fearful that someone might say something offensive or belittling of their loss.

*I am worried that they [others] would say something that I would perceive as being disrespectful towards the pregnancy or the baby itself...so I think partially it’s me trying hard not to have my experience spoiled by all of this medical statistical discourse that goes with it.* (P3)

**Theme 1.3: ‘It’s about women’s bits’**

For most participants, aspects of the miscarriage felt too horrific and too personal to share with others. The physical nature of the miscarriage in some cases was very traumatic, involving rapid hospitalisation, heavy blood loss and having to dispose of the foetus themselves.

*It was 10 weeks and it was in my hand and I’ve got that visual in my mind and it had a little umbilical cord and everything... it was horrible. And then I just flushed it down the toilet.* (P1)

*I knew that my mum was already attached to the baby ... maybe I thought it’s gonna somehow ruin the experience for her .... the baby is now somewhere in the toilet and that is an awful thing...I couldn’t really have that conversation with my mum, I think it would be too horrific for her to hear.* (P3)

This had not been something participants were prepared for, often only being advised by professionals that the miscarriage would be like a heavy period. Women described feeling quite lonely at these particularly difficult moments, at a loss as to what to
do and not feeling able to talk to others about it. Several participants reflected that not talking about this physical aspect perpetuated the cycle of not knowing about miscarriage.

*I had no clue about the physical effects, I didn’t realise it would be so physically awful...I was bleeding for about 7 weeks and people just don’t realise...I talked to some people but not many because it’s quite gory really.* (P10)

There was also a sense that the experience of miscarriage overlapped with other ‘private’ (P1) parts of life such as menstruation and sex, which participants often did not want to talk about or felt that it would be inappropriate to do so.

*All the things I’m talking to you about, you know, my period and I bled and this that and the other, they are all quite private things aren’t they.* (P1)

Several participants said that the bleeding following the miscarriage and the return to normal menstruation were extremely painful – both physically and emotionally (each period serving as a reminder of the loss). However most participants felt that periods were not something that you could talk about, particularly with men.

*We’re talking about vaginas and women’s bits and bleeding and kind of periods and for [husband’s] dad and my dad that is just something they don’t do.* (P3)

Furthermore, disclosing the miscarriage at work often seemed to be particularly difficult. Several participants described wanting to keep their work and private life separate but that the miscarriage made this difficult: one participant miscarried at work and all participants needed to request time off. Some felt uncomfortable explaining what was happening because it involved such personal information.

*I felt a bit embarrassed telling them [manager] why I wasn’t coming to work...it’s like a taboo no one really wants to acknowledge it...I think it’s probably the physical nature of it I mean women are basically having periods every month and you’re not really supposed to talk about it are you...pregnancy as well is a bit the same you were sort of expected to withdraw from respectful life so I think there is a bit of a hangover from all that ...*(P8)
Sharing information about the miscarriage seemed to invite questions regarding when the couple might try again for a baby, an aspect of life that women felt should remain private. Participant 1 reflected that she wished she had not spoken to her mother about her first two miscarriages because of the difficult conversations it prompted later:

*I probably wouldn’t have told my mum about the first two because of her pressing me... not pressuring me but just going on and on asking “are you pregnant yet?” When I had those scans she [the sonographer] was like “right so you’ve got to do it on Thursday” so on Thursday my mum text me saying “remember you’ve got to do it tonight”. You know, inappropriate!*(P1)

A further consequence of miscarriage being so intrinsically linked to the woman’s body was that in some cases friends and family associated the cause of the miscarriage with the woman’s physical health. Participants expressed that they knew this was not the case, but felt very upset by these comments feeling that it suggested they were to blame for what had happened. For two participants it prevented any further discussion about the miscarriage or future pregnancies.

*People give their views in why they think it might have happened...that is a no-go area. Don’t go there... people would like “but you’re really stressed at work, maybe that’s what caused it”... like it’s my fault that’s what it feels like....they would go on to my shitty list pretty fast.*(P4)

*My mother-in-law’s first comment [to disclosure of miscarriage] was “well you were drinking when we went out for [father-in-law’s] birthday”...that was the first thing she said... so again that connotation that it’s your fault.* (P12)

**Theme 1.4: ‘I didn’t want to burden them’**

Participants were acutely aware of the impact that talking about their miscarriage might have on their friends and family. They often described fearing that talking too frequently or in too much detail might upset, annoy or unsettle those around them.
Consequently it was common for participants to limit these conversations despite the recipient often being explicitly willing to listen.

An important cause of these worries was a recognition that the sense of loss they felt was also felt by their family, particularly their partner and parents.

*She [mother] said “you can talk to me anytime about it”, but I also kind of feel like she’s been through it as well and so if I talked to her about it I didn’t want to upset her either.* (P7)

There was also a recognition in some cases that the announcement of the pregnancy had bought happiness and hope to family members (particularly parents) and now this was being taken away.

*I found myself having thoughts of oh maybe she’s [mother-in-law] excited about the grandchild, and now not having that and being made redundant and older age contributed to that, so I can’t take, not take responsibility, but I felt that maybe if the baby was here she wouldn’t be feeling as low.* (P3)

*The worst thing about having a miscarriage and telling people is you feel like, even though your heart’s broken, you’re breaking so many other people’s hearts, you know. Because they’re so happy for you and then to tell them that.* (P11)

As well as wanting to protect others, some participants highlighted how difficult it was for them to see others upset when they too were feeling sad and in need of comfort.

*I sent a [text] message to my mum and she just sent me these crying faces like about 50 of them...I thought she was really selfish and I just thought, I don’t want to hear about your tears, I have just lost my baby.* (P3)

*It just felt a bit difficult with her [mother] because I felt that I would then be comforting her rather than the other way around.* (P13)
A further reason for participants feeling reluctant to talk was a sense that it might begin to get boring or tiresome, particularly if the other person did not feel as upset or was dealing with it in a different way. They described feeling that they were saying the same things over and over again, and reported a sense of guilt about this.

*With my husband, I mean he’s excellent, you know we’re best friends but I just felt I didn’t want to burden him with my emotions…. I was glad that he wasn’t devastated but also I kind of felt like I didn’t want to talk about it too much to him because I felt like it might be getting on his nerves.* (P1)

Participants frequently described feeling aware that the topic might make others (particularly friends or colleagues) feel awkward or uncomfortable. While this did not always stop them from talking, they often decided to talk about it in a different way or at a different time. For example, several participants said that they used social media as a way to share information in a less confronting way. For one woman this took the form of a blog about her experiences:

*I think the ability to write a blog allows you to be a bit more honest because you don’t have to look at people or face them, you can just write it and people can react to it if they want to or they can ignore it if they want to, you’re not forcing a reaction.* (P5)

In a similar way Participant 8 felt that breaking the news via a text message rather than face to face, was easier and less embarrassing for the other person.

*If people sort of come bounding up to you and they’re like “How are you? How’s it going?” And you’re like “Actually I lost the baby”, it’s like they would feel so embarrassed and you know you are going to make them feel so bad. So with some people I didn’t even tell them if that happened I’d just be like “yeah fine” and then later on I’d just message them and say “Look actually” because at the time it just felt too awkward.* (P8)

**Theme 1.5: ‘All my friends are pregnant’**
A prominent theme across interviews was the excruciating experience of being surrounded by other women having babies. During hospital admission for the miscarriage, participants were often literally surrounded by pregnant women (e.g. Early Pregnancy Units were situated within the maternity wards). Moreover, due to age, many members of participants’ social networks were also expecting or giving birth around the same time. Participants described how difficult this situation was and that often it felt too painful to be near the pregnant woman.

‘I just thought, I can’t be near her. I can’t look at her. I can’t talk to her. I just can’t deal with that. It was so hard.’ (P10)

The progress of the other’s pregnancy was felt to be a vivid reminder of what had been lost.

Everything that they go through, every milestone, of course I thought that would have been my baby shower, my 20 week scan you know...and then of course he’s born... it’s just so close, it’s so raw. (P11)

It was horrible, horrible, every milestone, every time I saw her she was more pregnant, it just reminded me of what I lost...literally they would have been born within a week of each other so it was the mirror...everything was the same the whole way along. (P12)

Several participants described struggling to have their first child while friends or family members succeeded with apparent ease. For others, the pain was in seeing other parents give birth to second and third children, while desperately hoping for a sibling for their first child. This juxtaposition was described as particularly difficult when the other woman was a valued friend or relative; the feelings of jealousy and anger contrasted with feelings of love and excitement for them.

I have suffered with severe jealousy during this journey and I have hated myself for it...jealous of your lovely friends who you really care about and wouldn’t wish any of this on... you meet people who don’t have any problems and they just sail through everything and you think that’s not fair! (P1)
Participants also had a sense that often the other expectant parent (both mothers and fathers) withdrew from the relationship too: perhaps out of guilt about their pregnancy or uncertainty about how to manage the situation, not knowing what to say or how to broach the subject. In some cases this meant the loss of key members of their support network.

*My brother kind of fell off the radar... he didn’t know what to say...I sensed that he was feeling guilty about his family set up and how things had gone for them. When I talked to my mum she said he was worried about rubbing our faces in it.* (P5)

Additionally, several participants talked about feeling protective of the friends or family members who were pregnant: they were concerned that talking about their miscarriage would cause the other woman to worry about their own pregnancy, or that their sadness might ‘bring her down’ (P13). Several participants reflected that they felt guilty for sharing their experience and often tried to hold back on how much they talked about the miscarriage with these women. Nevertheless there was a recognition that the pregnant woman was also losing a member of her support network.

*I felt so awful telling my [pregnant] sister that I had lost it, partly because you know she hadn’t made it to the 12 weeks yet and she was almost there, I didn’t want to scare her. And also I think she was finding the whole [pregnancy] a bit overwhelming and I think it was nice for her to have me to talk to, we were sort of going through it together. I felt like I was just pulling all that away from her. My sister’s probably the person I tell most to and she was the one I couldn’t really talk to about it.* (P8)

**Domain 2: Supportive and Unsupportive Interactions**

The process of talking was often a complicated negotiation and women frequently felt they did not get the right type of support. However, when appropriate support was given it had a powerful impact. The themes in this category describe how women talked, the responses others gave, and what was important about these interactions.
Theme 2.1: ‘Navigating the awkwardness’

Most participants reported that other people were first told about the miscarriage soon after it had happened, in a very brief format such as a text message. This was usually done by the husband or partner due to the extent of the woman’s emotional distress and physical discomfort. This, however, seemed to create a situation in which many members of participants’ social networks knew about the miscarriage but no one was sure about whether to bring it up. Participant 7 reflected that she held back from asking a friend about her own miscarriage because she was unsure how the friend was dealing with it and whether she would want to talk. Other participants had a similar sense of why others did not raise the subject.

*I’ve never had a face-to-face conversation with any of them [managers] about it…it just makes you feel a bit awkward...you know that they know and they know that I know but we haven’t bought it up.* (P8)

*I always find it hard when people know what you’ve been through and then avoid talking to you about it but I guess that’s because they don’t want to upset you by bringing it up.* (P9)

Participant 5 reflected on this process in relation to her brother, who had a baby soon after her miscarriage. She described how difficult it was that he was not in contact but also recognised that perhaps he needed to know it was ok to talk.

*The lack of contact after the second [miscarriage] left me angry and the longer it went on the angrier I got and although logically I could have skyped him it almost became a kind of principle thing, like well I am the one who’s gone through a really hard time so I’m not gonna contact him...but then I thought maybe he’s waiting for a sign from me that I want to talk.* (P5)

Women felt that there need not have been this awkwardness about who should start the conversation; they suggested that all they wanted was to know that it was ok to talk, that others were willing to listen and that they were being thought of.
I think it’s just someone sort of saying that they are happy to talk to you about it. I think my mum saying that you know if you want to talk about it, that really helps because then I know I’ve got that option if I want to. (P7)

One of my best friends every so often she will just send a message saying how are you? And I know what she means by that. That’s it. I don’t need any more than that. (P10)

Participants suggested that the drive to talk fluctuated from day to day and sometimes it felt too difficult. If the option to talk was clear, women said that they could talk when they felt ready, at a time when they felt able to manage the conversation.

Only I know when I am feeling a bit rubbish, so then I suppose that’s why it probably is better that I broach the subject rather than people talking to me because I know the point when I want to discuss it. (P7)

Participant 3 described how this had been the case with some of her friends, allowing her not only to talk to them, but also giving her and her husband the ‘strength’ to cope with it themselves.

I think it gave us a strength and allowed us to deal with [the miscarriage] the way we needed to really… it was like “We are here for you in the background feeling really sad for you but you reach out, you have the control, if you need it we are here for you, but we are not going to be too intrusive.” (P3)

Another important aspect of this ‘navigating the awkwardness’ was a feeling that one party – either the person disclosing or the recipient – needed to be able to cope with the emotion which came with it. For example, Participant 4 described disclosing to a colleague who found the conversation very awkward; she felt she was the one who then needed to ‘navigate’ this and move the conversation on. She went on to say that there were times when her ‘emotional resources’ were too low to do this and at these times she felt as though she too would ‘crumble’.
He [colleague] nearly crumbled on the floor and he kind of got all embarrassed. So I thought obviously that is not something you are comfortable talking about, I am, but let’s move on. But then again it all had to be down to me to navigate the awkwardness. (P4)

Similarly, Participant 13 had the sense that her grandmother would not know how to deal with the situation if she began to cry. Consequently it felt uncomfortable to have a conversation about the miscarriage because of the uncertainty about how it would progress.

I’m thinking, okay you’re sorry, that’s great. Where do we go from here? Apart from me bawling my eyes out… she [grandmother] wouldn’t know, she’d never understand it. (P13)

Participant 13 contrasted this to the response of a colleague who did not feel uncomfortable when she became upset and responded in a comforting and helpful way.

I got a bit upset and she [colleague] immediately whisked me away and gave me a great big hug and that’s all it took… just that hug can make a huge difference. (P13)

Theme 2.2: ‘Glossing over it’

When talking about their miscarriage, participants often felt that others ‘glossed over it’ (P2). A number of different types of responses left them feeling that people did not fully appreciate the personal experience of loss. A commonly reported response was to try and highlight the positive aspects of the situation, with nearly every participant describing ‘at least’ responses:

People quite often say “Well at least you’ve got one”. It’s kind of like, don’t worry about it, you’ve got one…but every single miscarriage is a loss, is a bereavement. (P6)

After my second miscarriage someone said to me “Well at least you can get pregnant”…to me that phrase is worthless because yeah I could get pregnant another 10 times and still not have a baby… it’s just worthless it doesn’t bring me any sort of comfort. (P5)

Participants often felt very hurt by these responses, which they perceived as minimising or dismissing their loss.
That word, “at least”, it winds me up...it takes away from it... it’s missing the sentiment, the journey. (P11)

“It wasn’t meant to be” or “better now than later on”... it does hurt because you know, as much as you know things weren’t meant to be, you still want them to be... (P9)

Several participants described ‘generic’ (P13) or general responses from others which gave them the impression that the person had not really thought about them at all.

I don’t know if they’re [family] thinking of me too much, I think they’re just kinda being quite general... it’s like look at me, remember me, you know this is probably on my mind every single day. You know that I want to talk because I’m a talker so don’t just say it will be alright. (P6)

I remember being quite surprised by my mother-in-law’s text... it was very generic...I do remember that. But at no fault of her own, it was just obviously not knowing what to say, it was just very much like, sorry to hear the news, thinking of you... I do remember thinking is that all you’ve got to say? (P13)

Most participants said that they knew these comments were not made out of malice; consequently they typically would not challenge these statements but would just grit their teeth and say thank you. Some participants said that they appreciated the effort made in attempting to say something helpful, compared to those who said nothing at all.

*Just saying something is more important than anything.* (P4)

They’ve tried to reach out and say what they think will be comforting and it is an uncomfortable subject and I have friends who I am not in contact with anymore because they didn’t reach out to me at all. (P5)

Others felt that the comments were often an attempt to fill an awkward silence; they would have preferred people to just acknowledge that there was nothing that they could say.
It just feels like empty words like someone is filling the silence. I think that is where some of the weird comments come from when it is quiet and they don’t know what to say, when sometimes silence is enough or just a hand on the shoulder. (P1)

I just realised that people were just clutching at straws trying to say anything... it’s like don’t stress yourself out trying to find words for something you don’t really have words for. (P11)

Theme 2.3: ‘Talk, but not too much’

An important question which arose for many participants was how much they could or should talk about their miscarriage. This was influenced by the way others responded to them; direct and indirect comments, as well as what went unsaid, gave women the impression that they should curtail talking.

Some participants felt that family members did not want to see them so upset and consequently tried to encourage them to stop thinking about it and instead focus on other things.

[Mother said] “Make sure you don’t talk about it in too much detail because I don’t want you to then be sad the whole Saturday” and I said “Mum, if I am going to be sad then maybe that’s what my body and soul needs, maybe I need to talk to someone and be sad and then move on”, but she is still like “talk about it a bit then but not too much.” (P3)

Participants also said they got the impression that people expected them to move on from it more quickly than they were. In some cases this was communicated very directly: Participant 5 described how her neighbour expected her to move on from her grief when this neighbour announced her own pregnancy.

My neighbour turned round and said “Well I’ve been speaking to other people who have had miscarriages and she [participant] should just suck it up and be happy for us”. (P5)

For other participants, indirect comments gave them the impression that others were moving on more quickly
My mother-in-law phoned a few days ago and said “I’ve just been to a fete and bought a baby blanket, shall I bring it down with me when I come?” I said “erm no”...so she said “oh so you’re not pregnant again then?” (P7)

Most commonly, participants felt that the fact that people stopped asking gave the message that they too should stop talking about it.

It feels like it’s [the miscarriage] been happening for quite a while now. We lost the first baby back in July. So, you know, people stop asking how are you? (P9)

Some women said this led them to question the way they wanted to talk about the loss, thinking that maybe they were ‘doing it wrong’ (P3).

I have been one to talk about it a bit more. I thought, god am I dealing with it a completely different way to everybody else? Am I a bit strange that I want to talk about it and be open? (P7)

However, most participants recognised that actually the grief continued for some time. Particular events such as the expected due date of the baby or the start of her period each month were often stark reminders of the loss, prompting a resurgence of grief. For some, grief was unexpectedly triggered many months later. Very rarely were others aware of these triggers.

It’s very normal to feel like this months, years, whatever, down the line. I think, you know, you can read about everything, you know, but I haven’t really seen that much or heard that much about that side of it – that it’s ok to feel like that no matter how long it takes down the line. I think that’s something I’ve not really heard much about. (P13)

Participants also described immediate limits to the amount they were able to talk, in particular, others asking how they were but then quickly changing the subject. This gave participants the impression that either they did not really want to know the details of what had happened or that they did not really think it was something important enough to discuss.
He [friend] said “Oh that’s a bit rubbish isn’t it?” And then that conversation moved on. So I think it was just a bit dismissed you know. (P9)

She [friend] definitely didn’t want to know about it… you can just tell she just sort of changed the subject... I remember it came up in conversation once and um it was very quickly batted away and yeah I think you just pick up very quickly from people whether they want to talk about it or not. (P8)

It was rare that participants were given the opportunity to talk about the miscarriage in its entirety; often the research interview was the first time that they felt they had had the opportunity to reflect on their whole ‘story’ (P4), including the journey they had made in recovery. Where it was possible to do this, participants reported that it was extremely validating.

*That I can go to work now, and I don’t talk all the time about miscarriages, but I can go to work knowing that people understand that part of my experience is this [miscarriages]. I feel like I’m being myself more than going in and feeling like I have this dirty secret about losing pregnancies.* (P4)

*I think I wanted to capture the whole process and I was really glad that you [the interviewer] have asked me about what was going on in my life before the pregnancy… I was a bit worried it was only going to be about the four or five days of utter hell rather than the whole process so it was important for you to hear the whole [story].* (P3)

Several participants did however, say that they perhaps thought about the miscarriage too much and did not want it to define or consume their lives.

*I didn’t really want it to be constantly like oh it’s the miscarriage girl who is constantly putting depressing things about miscarriage online…sometimes you can feel like miscarriage just takes up every sort of waking moment’* (P5).

*I don’t want to let this define me I don’t want to be pitied I don’t want people to say “Oh you know [Participant name], this happened to her, isn’t that sad”.* (P1)
Ultimately, women said that moving on or talking less about the miscarriage was ok so long as this could be directed by them.

*She [mother-in-law] was like “Oh I’m so sorry to hear that, oh well at least it worked this time so you know you can conceive” sort of look forward which is absolutely our approach but I suppose you kind of want to be the one in the driving seat of when you want to do that.* (P2)

**Theme 2.4: ‘Be what you need to be’**

In contrast to some of the awkward or dismissive responses, women talked about the most supportive interactions being those in which they felt people were able to connect to their sense of loss and recognise that something significant had occurred.

*He [dad] said “I’m really sorry” and I said “It’s fine” and he said “It’s not fine”. He was the first person to say, actually it’s not fine (crying).* (P6)

*The fact that my boss saw it as a bereavement and it is recorded as a bereavement, that meant a huge amount actually.* (P4)

It was not only recognition of the loss which was important, but responses which were felt to accurately reflect how the woman was feeling. Several participants described conversations in which a friend or relative had tentatively stated how they thought the woman might be feeling. It was particularly helpful when difficult emotions, such as jealousy or anger, were named and accepted. Talking in this transparent way allowed women to feel that they too could be open and honest.

*My friend said the most amazing thing to me after I miscarried, saying “You just have to allow yourself to be what you need to be now...if you need to cry for two weeks do it, if you need to scream, if you need to be a bitch to everybody, because this is your body and your baby.”* (P 3)
In contrast, participants also described interactions in which friends or relatives recognised that the loss was significant but their response to it was a bit ‘too much’. This again left participants feeling misunderstood and isolated.

*My sister is quite sweet, she bought me a plant, a hyacinth, and she was like “I bought you this and I thought it could represent your babies”...I was just a bit like thanks... it didn’t touch me the way she wanted it to but I just pretended it did.* (P1)

*Everyone thought I needed to rest...I thought I need to go back to work and everyone’s like oh no it’s too soon.* (P11)

Being given permission to talk and feeling understood was particularly important when the other person was expecting a baby. This allowed the relationship to be sustained and in some cases this person became a great source of support.

*Because she’d [friend] been more open about it [her pregnancy] and I knew that she was there if I needed to talk to her and that she would understand if I didn’t want to go round and see her and the baby... that really helped because it took the barriers down and I did go round and see her and I spent a lot of time with her.* (P7)

*My cousin was brilliant... he sent me a text message to let me know his daughter had been born saying “I’d really love you to come round and see her when you feel comfortable and I understand you might find it difficult”. And I think I responded to say “I do want to come round but I don’t want to make you feel uncomfortable if I get upset”. And he responded “If you cry you cry, it’s not going to bother us, and we understand if you arrive and 10 minutes later you want to leave. We won’t take offence.” That meant a lot... that he could empathise with what we’ve been through... we saw them every week.* (P5)

These open conversations also led to new perspectives on the loss: several participants described how others were able to give them ‘creative’ (P3) ways to think about the miscarriage, which bought a sense of hope.

*They [husband and his friend] had quite a different way of thinking about it which helped me too. So they see it as the baby had a choice to stay in this world or not to stay and for some reason the baby didn’t but who are we to tell the baby what choices he can make and that made me feel really nice.* (P3)
I did speak to one lady who had had a miscarriage and had another baby and something she said really stuck in my mind was ok if that hadn’t happened if I didn’t have that miscarriage this little boy wouldn’t be here and that is a real comfort to think well hopefully that will be me. (P7)

Furthermore, participants were able to reflect on some of the positive consequences of the process. Importantly, for most women the experience of support highlighted to them the strength of particular relationships as well as the building of others.

The message I took from that was just how much your friends love you and how much they.... they feel what you feel and how through the toughest time in your life they can be there for you...and you can look at that [miscarriage] in a negative way or you can think oh the baby allowed us to realise just how much people love and care for you. (P3)

As horrible as this situation is loads of wonderful things come from it and you learn wonderful things about people and the kindness of people. (P12)

Probably the worst two years of our marriage, you know, we've only been married four years this year. It's been the worst two years of our marriage, but we're still together for it...we're stronger than ever. (P11)

Theme 2.5: ‘Kindred spirits’

All participants felt very strongly that unless others had experienced miscarriage it was very hard for them to fully understand what it had been like. This lack of personal experience was perceived as a barrier to providing support.

I think that is what the problem is with miscarriage... unless you've been through it it’s just so hard to understand...everyone knows what it’s like to lose someone they love because everyone goes through that...but why would you think of that for miscarriage because you may never go through that. (P6)

Several participants went further to say that although those who had similar experiences could empathise to a degree, they also felt that any differences, such as experience of recurrent miscarriage, meant that this was limited. For example, Participant 9
talked about feeling quite isolated after her third miscarriage, because no one within her network had experienced more than one miscarriage.

My friend has had one loss and it’s been, you know, well she’ll come around here and we’ll have a good cry and, you know, it’s fine, but I have felt there has been that sort of gap that no one else has been through what we’ve been through...there’s a certain amount of empathy that friends who haven’t experienced it can offer, but there is something more that comes from finding someone that’s had the same number of miscarriages... (P9).

The sense of isolation participants felt when they did not know anyone with similar experiences was contrasted with powerful feelings of connectedness and understanding when they found such women.

With this group of ladies [online forum], there is no guilt, it’s like everything and anything goes. You can say it again and again and again and feel angry and be there in the middle of the night. If I wake up...in the first couple of months after [the miscarriage] I didn’t sleep very well and I would be awake at four in the morning really sad, if I posted a message somebody would be there...they get it...with them I feel there is a kindred spirits kind of thing. (P4)

As participant 9 highlighted, what was important about these interactions was the sense of acceptance and validation. Through the exchange of stories, participants highlighted that they came to realise their feelings were very common and they reflected how reassuring it was to hear that others too felt grief, jealousy and hopelessness.

I had a conversation with a friend who had a miscarriage at the similar time to me and that was a turning point for me because it made me feel a lot better. I mean, it’s horrible that she is going through it, but that we are both feeling the same way...that’s really reassuring. (P7)

Nearly all participants also talked about wanting to use their experiences to help others in a similar position. Many stated that this was the reason for taking part in the research and through doing so they felt they were turning a ‘negative’ into a ‘positive’.
I have managed to do something positive with something awful. Help other people maybe. (P1)

That would be hugely positive just to help one person not have that shock and fear if I could stop someone going through that. (P12)

Several women described feeling a lack of control through the miscarriage process; they related this to not being able to stop the process from happening and not having an answer as to why it had happened. Through talking to others, sharing information and feeling like they were helping others, there was a sense of regaining some control.

I do these wellbeing talks at work...I find them quite empowering...even though what I talk about is the miscarriages, it’s sort of applicable to other things. It’s about resilience, connection, about relationships and the kind of strength that you get from being able to talk to people. (P4)

Discussion

This study explored women’s experiences of support following miscarriage, including what hindered or facilitated talking and, when conversations did occur, what made them feel supportive or unsupportive. Overall, the findings are consistent with previous research, which suggests that there is a silence surrounding miscarriage and that support from friends and family is often lacking both in its availability (Conway, 1995) and appropriateness (Rowlands & Lee, 2010). There were a number of themes regarding the barriers to talking, including both internal and external barriers. Additionally, themes reflected the complex nature of interactions that took place. Adequate and appropriate support was rare, but when it was available, it had a profound emotional impact.

Participants described a number of barriers to talking which have been widely recognised within the social support literature as ‘social constraints’ that limit an individual’s opportunity for talking (Lepore et al., 1996; Lepore & Revenson, 2007). This
included minimizing comments, such as ‘at least you can get pregnant’, changing the subject and negative comments which made women reluctant to continue talking. Moreover, women also described several barriers which appear particularly important to the topic of miscarriage.

Firstly, participants’ accounts support the idea that miscarriage is a type of disenfranchised grief (Doka, 1999) and that this acted as both an internal and external barrier to talking. Women reflected that they personally held beliefs that miscarriage was common and therefore just something to be endured; several participants said that they felt they should be back at work soon after. In addition, women felt that the dismissive responses they received from others gave the impression that to grieve would be ‘mad’ and that instead they should move on more quickly than they felt inclined to.

Secondly, the physical nature of miscarriage acted as a barrier to talking. Women suggested that miscarriage is particularly difficult to talk about because of its occurrence within their own body and its association with genitalia and menstruation. Participants recognised both a personal reluctance to share intimate details and a belief that others (particularly men and colleagues) would not want to hear about the more graphic physical details, including blood loss and surgical management or disposal of the foetus. Previous research regarding women’s experience of gynaecological cancers similarly found that participants felt embarrassed talking about some of the physical consequences (Pistrang et al., 2012). This is consistent with research which suggests that menstruation is a social taboo (Johnston-Robledo & Chrisler, 2013) and that in seeking support for pregnancy loss the internet is highly valued because anonymity is preserved (Geller, 2012).

Thirdly, the interviews highlighted the difficulty of being around other pregnant women during and after their own miscarriage. This represented a social constraint on a
number of levels: participants withdrawing from the relationship because it painfully reminded them of their own loss, and pregnant women withdrawing because of a sense of guilt and awkwardness. The concept of ‘a social network crisis’ suggested by Vachon and Stylianos (1988) in the context of bereavement can be helpfully applied here. They suggest that multiple members of a social network are usually affected by a death and that consequently a vacuum of support is created. A similar effect is apparent following miscarriage, with the immediate social network (e.g. partner, parents) feeling bereaved. The present research extends this idea to suggest that the loss may also affect the broader social network, particularly those who are pregnant; while perhaps not directly grieving the loss, other pregnant women may have feelings of guilt, fear and awkwardness that can reduce capacity for support within the network. In this situation, ‘dilemmas of helping’ (Coyne et al., 1990) seem prominent; both the woman who has had a miscarriage and the woman who is pregnant are preoccupied by their own needs and both lose a member of their support network.

Furthermore, even when talking was possible, it seemed to be inhibited by awkwardness. Women’s descriptions of interactions highlighted what they felt was a mutual avoidance of the subject, with neither party wanting to upset the other or make them feel uncomfortable. Prior research has similarly described couples’ struggle to work out how to be supportive (Harris et al., 2006) and furthermore has suggested that even when people know how to be supportive, anxiety or discomfort may get in the way of providing this (Lehman et al., 1986). Anxiety or a focus on one’s own needs seems to prevent effective attunement with the other.

In contrast, empathy and acceptance seemed to be key factors in determining helpful responses. Participants described the most supportive interactions as those which included recognition of their loss, tentative expressions of understanding, permission to
feel a certain way or expressions of similar experience. Such features have previously been identified as essential to empathic communication (Pistrang et al., 2001). The opposite - dismissive comments or assumptions about feelings - left participants feeling isolated and misunderstood.

Consistent with prior research, it seemed that what was important to women was the perceived availability of support (Prati & Pietrantoni, 2010); that is, knowing support was there should they want it. Previous studies of social support following pregnancy loss have intimated that physical presence (‘being there’) is important to women (Van, 2012). However, participants in the present study suggested that emotional availability - another person who is holding the woman in mind - was enough for them to feel supported. Moreover, many participants felt that it was actually better if they were in control of when and how to talk, rather than others asking them. Transparent dialogue about how to navigate the process of talking and what the woman needed, allowed for support which more accurately met the woman’s needs and encouraged further talking. A similar process applied to continuing conversations long after the miscarriage had occurred; women often felt distressed by those who encouraged them to move on before they felt ready, whereas those who felt support continued did not necessarily carry on talking but felt reassured and validated by its availability.

Talking to similar others – that is, other women who had experienced miscarriage – was highlighted as particularly valuable. Nearly every participant described a powerful sense of relief and acceptance that came from meeting other women who could really understand their loss. Moreover, participants highlighted the importance of finding women who had not only experienced pregnancy loss, but who had experienced a similar loss to their own. For example, those who had experienced recurrent miscarriage expressed an acute feeling of difference between themselves and those who had only had one
miscarriage. The importance of similar others is well documented in the literature on social support: they may be perceived as less judgemental (Lehman et al., 1986) and in a more legitimate position to offer advice and guidance (Pistrang et al., 2012). Furthermore, contact with similar others has been found to improve mood and self-esteem for those with a concealable stigmatized identity (Frable et al., 1998). Consistent with this, participants in the present study said that contact with similar others led to them feeling understood and validated, even empowered by the sense of collective knowledge and experience. As a consequence, several women described feeling more able to incorporate the miscarriage as a part of their narrative and to use their experience to help others. Several participants wrote blogs, contributed to forums or even gave talks about their experiences. Indeed, for most participants the reason for taking part in the research was to help others. In being able to openly share their story, participants reflected that they often gained new perspectives on it or recognised how far they had come on their journey.

Limitations

This study has several limitations. Most importantly, it is worth considering the nature of the sample, which although of adequate size for qualitative research (Willig, 2013), was a convenience sample which is unlikely to be representative of the wider population. There was a lack of diversity within the sample in terms of level of education and cultural background. Perceptions of miscarriage as well as practices following miscarriage vary across cultures, so it is difficult to say whether the experiences of women in this study would generalise to other populations. Furthermore, Pennebaker et al. (2001) suggest that in bereavement research in particular it is difficult to get a truly representative sample. They suggest that it is possible that those who seek to participate in research are those who have not yet had the opportunity to work through their emotions. This is supported by the recruitment process in the current study: women often contacted the
researcher in the early weeks following miscarriage (despite the advertisement stating the minimum three months inclusion criteria) expressing a strong need to talk about their experiences. When the researcher contacted these women after the three-month time period, quite a few did not take up the offer to participate; it is possible they no longer felt the need to talk about their experiences.

The findings of this study are also limited by the reliance on retrospective accounts of interactions from the perspective of one individual. It has been argued that it is difficult to fully appreciate the complexity and detail of supportive interactions using this method and that research should also attempt to study live interactions between individuals (Pistrang, et al., 2001).

**Research and Clinical Implications**

There are a number of implications for future research. This study demonstrates the complexity of social interactions which cannot fully be captured through the use of quantitative measures (Coyne et al., 1990). The perspective and needs of both the recipient and provider of support should be considered. Therefore, future research should aim to: (1) interview the provider of support in order to further understand their experience; (2) examine different sources of support in detail, as different issues are salient for different groups of supporters, e.g. partners, parents, friends or colleagues; and (3) study live interactions between recipient and supporter. Barker and Pistrang (2002) suggest that social support researchers can learn from psychotherapy researchers who have analysed real conversations (i.e. in psychotherapy sessions) in order to understand helpful and unhelpful interactional processes. For example, the Couples Helping Exercise has been used to explore how one member of a couple attempts to help the other (Pistrang et al., 2001). Such a paradigm might also enable further insight into both parties’ experience of these conversations.
There are also a number of important clinical implications. Firstly, it is clear that there is a need for further education on the psychological impact of miscarriage. However, the present study also suggests that there is a role for education around talking about miscarriage, both in terms of how to best elicit appropriate support and how to respond in a way which is most supportive.

Secondly, the plethora of social constraints on talking about miscarriage could inhibit cognitive processing of traumatic events (Lepore, 2001). Women might not all need psychological intervention, nor would this necessarily be effective (Murphy, Lipp & Powels, 2012), but this study suggests that more discussion and understanding of the psychological impact of miscarriage could have a positive impact on women’s wellbeing following miscarriage. Clinicians potentially have a role in acknowledging the importance of social support and helping women and their families to access and make use of it. This could include spending time with women to think about who to talk to and how to talk. Most women in the current study reported that they got no information from clinicians about available support; therefore it could also be beneficial to provide information and/or referral to local services when women attend hospital. For example the Miscarriage Association provides face-to-face peer support groups (https://www.miscarriageassociation.org.uk/how-we-help/support-groups/) as well as a number of online services https://www.miscarriageassociation.org.uk/how-we-help/online-support/. They also produce a range of leaflets which could be made available to women attending clinics.

Finally, women in this study often described a sense of disenfranchised grief. This potentially has negative effects on the ability of the bereaved woman to make sense of the loss and find meaning (Pennbaker et al., 2001). The ‘continued bonds’ theory of grieving (Silverman & Klass, 1996) suggests that an important part of the resolution of grief is
through developing continued bonds with the deceased. This may be particularly difficult with miscarriage, given the short lifespan and its often private nature. Therefore, it may be important to think about how memories and experiences of pregnancy could be shared or memorialised in some way in order to support women and their families to develop these continued bonds. This potentially has implications for advice on the sharing of the pregnancy before 12 weeks; had women shared the news of the pregnancy with key members of their network, perhaps it would have been more possible to develop continued bonds after the miscarriage. The eagerness of women to participate in this study and to help others by sharing their experience may be one way in which women were making sense of their loss, finding meaning and developing a continued bond with their unborn child.
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Part III: Critical Appraisal
This critical appraisal is a reflection on the process of conducting the piece of research presented in Part II. When conducting qualitative research it is particularly important to reflect on the impact of the researcher on each stage of the study; Berger (2015) argues passionately that, rather than seeing knowledge as objectively acquired, one must “understand the role of the self in the creation of knowledge” (p. 220). Furthermore, the interaction between researcher and participant and the relationship they develop affects the construction of the data: “a different relationship will unfold a different story” (Finlay, 2002, p. 531).

A distinction can be made between two forms of reflexivity. Personal reflexivity is the practice of reflecting on how one’s own values, beliefs and experiences have shaped the research, as well as how the research has affected the researcher; and epistemological reflexivity is the practice of reflecting on how the research question and methods have influenced the research and our understanding of the data (Willig, 2013). Below, I will firstly engage in personal reflexivity to explore the impact I have had on the research, as well as the impact of the research on me as an individual and as a trainee clinician-researcher. Secondly, I will use epistemological reflexivity to reflect on the way in which the interview process might have shaped the findings. Finally, I will present some broader reflections on the nature of miscarriage as a taboo subject.

**Personal Reflexivity**

Engaging in this process of reflection allows for the ‘bracketing’ of one’s personal perspectives (Finlay, 2008; Fisher, 2009): recognising and setting them aside in order to remain open to the possibility that the data will be different to one’s own expectations (Starks & Trinidad, 2007). However to entirely bracket one’s beliefs is near impossible and instead the approach has been likened to a ‘dance’ by Finlay (2008), who suggests there is a tension between bracketing one’s beliefs and using them as a source of insight.
It is also important to consider the degree to which the researcher is an insider or outsider: an insider in some way belonging to the group being studied, allowing perhaps for greater rapport and depth of coverage; an outsider holding a more detached position, enabling genuine curiosity and protecting against false assumptions (Berger, 2015; Dwyer & Buckle, 2009).

In light of this, I will reflect on a number of important aspects of my personal position and experience which might have impacted on the research: (1) being a female researcher; (2) being an insider-outsider in terms of miscarriage; and (3) being a trainee clinical psychologist. Following this, I will reflect on how the research affected me personally, and how it might have affected the participants.

Firstly, gender was a key aspect of the study and therefore my gender as a researcher is important to reflect on. As a woman, I was an insider in this research: the research interview a conversation between two women. One of the ideas raised by participants was that it often felt particularly difficult to talk to men about the miscarriage, largely because of its physical nature and connotation to menstruation. Therefore, I am sure my insider position as a woman made it much easier to talk about ‘embarrassing’ topics such as bleeding. My similar experience of the secrecy surrounding menstruation meant that there was a shared understanding and perhaps a greater rapport (Berger, 2015). However, I wonder what different questions a male researcher might have asked? I noticed at times that I slipped into a position of ‘knowing’ from personal experience that it is difficult to talk to men about women’s physical health. Had I been a man, an outsider, might it have been possible to take a more curious stance about the experience of talking about the physical aspects of miscarriage? When there are greater similarities between researcher and participant it is possible for both parties to assume understanding and similarity and overlook difference (Berger 2015; Finlay 2008).
In contrast, I held more of an outsider position in relation to the miscarriage experience. I have never personally experienced a miscarriage, nor do I have any children. However, as might be expected from the prevalence of miscarriage, I know a number of people who have experienced miscarriage. Nonetheless, it is not something that I, or others, have talked very openly about. In my professional role as a clinician, I have worked with a number of women experiencing different types of pregnancy loss. It was the experience of working with these deeply bereaved women which prompted me to conduct this research. Many of these clients had not shared their loss with those around them and felt a distinct lack of support. In this context, I felt very strongly that had their loss been recognised and grieved by others it would have made a significant difference to their psychological wellbeing. So, when beginning this research I appreciated both the difficulty of offering support as well as a desperate wish for support.

My training as a clinical psychologist means that I hold the assumption that talking about difficult experiences is helpful and that individuals often want and need support, be it formal or informal, to process these difficult experiences. This contributed to my assumption that women would want and need the support of others following their miscarriage.

It was important to ‘bracket’ these beliefs during the process of interviewing. Before beginning this project, I spent some time challenging my assumptions: I was open to the possibility that some women may not have been as distressed as the clients I worked with: and I realised that many women might not have felt the need to talk about it.

As part of the process of personal reflexivity it is also important to reflect on how the research has impacted upon the researcher personally as well as how it might have impacted upon participants. It has been suggested that this is particularly important for
such emotive topics as grief and loss research (Rowling, 1999). The potential negative impact of the interviews was carefully considered in terms of ethics; however, it is also important to consider the potential benefits and value of engaging in such a process (Josselson, 2013).

As a clinician-researcher I often struggled with keeping my researcher hat on rather than slipping into clinician mode, with the urge to want to help participants in some way (Thompson & Russo, 2012). The particular position of listening to someone’s story but not intervening felt quite unusual; as a clinician or even as a friend one’s focus is always – how can I help this person? However, as a researcher one’s main concern is – what can I learn from this person? How can I get inside this person’s experience so I can understand? Often this is actually what people want: they do not want advice or guidance but want to be heard (Rogers, 1975). However, this can be a hard position to maintain as the listener. I have been very affected by this process of trying to just be with someone in their distress, to listen to it and really understand it. It has been a hugely valuable experience not just in my role as a researcher but also as a clinician and an individual. This process is only possible with the support of good supervision and reflective spaces (Lowes & Gill, 2006).

Throughout the process I also felt a strong drive to ensure the research was taken forward in a meaningful way. I am sure this was, in part, my own hopes for a successful project, but I also felt that this was strongly driven by participants; during the interviews many asked questions about what would be done with the findings and commented that they hoped it would make a difference to others. These questions are obviously understandable when participants are investing their emotion, energy and time into a project, but I also wonder (as I mentioned in Part II), if this research was a way of ensuring the lost baby’s life had meant something.
This has had a profound effect on my beliefs about the value of research and the importance of considering from the beginning such questions as: How can I make this research meaningful to the researched group? How can the knowledge gained be effectively disseminated to both academics, clinicians and wider society?

It is also important to ensure that the research is a broadly helpful experience for participants (Josselson, 2013). It is hard to know exactly how each woman found the interviews but I think for many it was a helpful experience. Several participants reflected, during the interview, on becoming aware of their own strength and resilience, as well as realising the importance of particular members of their support networks. In the context of often not having the space to talk openly about their miscarriage, the interview also provided an opportunity in which women were able to talk freely, without judgement. One of the concerns of participants was that in talking they would be burdening those around them, so the interview was also unique in that this would not be a concern, instead involving a specific request to talk in detail, from a position of knowledge and expertise. Rowling (1999) suggests that participants perhaps feel more comfortable to disclose in the context of research compared to a therapy session because the research puts them in the powerful position of being knowledgeable rather than in need of help. In this sense the interview is often a ‘quasi-therapeutic activity’ (Lowes & Gill, 2006, p. 592).

**Epistemological reflexivity**

Epistemological reflexivity encourages reflection on the scientific assumptions that have been made and the procedures used during the course of the research, and how these might have impacted upon our understanding of the data (Willig, 2013). In this case, it requires reflection on the research literature on miscarriage and how the process of the interviews might have shaped the findings.
Assumptions

From the beginning of this project I was informed by the existing research literature on miscarriage. This suggests that miscarriage is distressing to women and their families (Brier, 2004; Brier, 2008; Diamond & Diamond, 2016; Klier, Geller & Ritsher, 2002) and that the majority of women want that distress to be known about and acknowledged by those around them (Conway & Russell, 2000; Rowlands & Lee, 2010). This project assumed these findings to be a broadly accurate representation of women’s experiences and aimed to focus specifically on gaining a better understanding of the nature of supportive and unsupportive interactions. This assumption does, however, shape the data and it is likely that the sample represented a group of women for whom the miscarriage was particularly significant.

The existing literature acknowledges a lack of focus on the man’s perspective of miscarriage (Murphy, 1998; Pudifoot & Johnson, 1997). The decision, in this study and in previous ones, to explore women’s experiences of miscarriage but not men’s perhaps positions miscarriage, from the beginning, as something intrinsic to the woman. Furthermore, in the current study, the nature of the interviews as a conversation between two women, again continues the social narrative that miscarriage is only discussed amongst women. If the research had addressed both men’s and women’s experiences of support following miscarriage I wonder if it might have prompted a different conversation.

Setting up the interview

In beginning each interview, I wanted to establish a relationship which privileged the experience of the participant and allowed me to be in the position of curiosity rather than expertise. I tried to achieve this in a number of ways.

Firstly, at the beginning of the interview I was transparent with participants about my areas of experience and interest as well as gaps in my understanding. I was also explicit
that what was most important to me was to hear about the experience of miscarriage from their perspective. This meant the interviews began from a collaborative standpoint. Collaboration has been suggested to be particularly important in feminist research (Campbell & Wasco, 2000; Oakley, 1981), but reflecting now I wonder if it was also key in establishing rapport with participants who had experienced a lack of control during their miscarriage.

Secondly, I paid attention to the location of the interview as a factor which might influence power relations (Elwood & Martin, 2000). Participants were given the choice of where they wanted to meet, with the guidance that it should offer enough privacy but essentially wherever they would feel most comfortable. The majority of women wanted me to come to their house, three wanted to meet in a café and two chose to come to the university. This variation allows for some reflection on how the location affected the interviews. When interviewing women in their own homes, I felt that they were much more in control of the process; they ‘hosted’ the occasion and dictated the atmosphere, e.g. choosing to sit at the kitchen table or on the sofa. Moreover, afterwards, I reflected that because of this general ambience of their hosting, I perhaps took their lead more in the interview. This contrasted to the interviews which I ‘hosted’ at the university; these felt more formal, the rooms very suggestive of the power and knowledge attached to my academic position. The women had travelled to see me, putting me further in a position of power. I tried to counter this in interviews by expressing gratitude for travelling, offering reimbursement for their travel costs, providing refreshments and ensuring the rooms were as comfortable as possible. The interviews conducted in a café, while probably least appropriate for private, emotive conversations, offered a neutral territory, aiding the development of a mutual task. I think I felt more constrained asking particular questions
and I noted that at more private moments both voices became more hushed and the language used more insinuating.

**Interview style**

Empathy, the act of understanding and appreciating another’s experience (see Gair, 2012, for an overview of the term), parallels the insider-outsider debate about what level of engagement with the issues being studied is appropriate or useful. The dilemma of the level of empathic attitude is thoughtfully explored by Rowling (1999), who reflects on the use of empathy in qualitative interviews about the experience of bereavement. She weighs up the concerns of either being too ‘in’ the research, overwhelmed by the emotionality of the content and unable to sufficiently contain and explore participants’ narratives, versus appearing too detached and cold. She suggests employing ‘empathic distance’, which balances empathy with a curious approach: ‘being alongside and with someone, rather than in or out’ (Rowling, 1999, p. 179).

This same dilemma arose for me during this study; a highly empathic attitude seemed important for such a sensitive topic. Participants often said that they had not told their story to anyone in its entirety and it very much felt like this is what they hoped for in the research interview. This was particularly the case with descriptions of the physical experience which had often been kept very private. I had not initially planned to explore this area, however it seemed very important for me to hear the chronology and detail of what had happened. As such, I used my interview schedule flexibly as a way of developing a balance between empathy and detached curiosity.

I think this dilemma had additional complexity because the research was an assessed piece of work for a doctoral qualification. The difficulty thus involved balancing my own needs to get enough information for a good thesis as well as the participants’ needs to talk to someone about their experience.
Broader Reflections

During the process of this research I have also reflected more broadly on the subject area and have grappled with understanding why miscarriage is so hard to talk about. Below, I will use my experience of talking to women about their miscarriages to try to understand why talking in general is so difficult. I will also reflect on some broader cultural and political dimensions which might influence conversations.

The role of anxiety

In my conversations around this piece of research I have noticed in myself a reluctance to mention miscarriage. Within the interviews itself there was of course specific permission to talk about the miscarriage and therefore a frank and open discussion was possible. However, in follow-up emails, telephone calls or casual conversations about the research with friends, I noticed that I felt some anxiety and approached the subject cautiously. I found myself worrying about asking participants about their current pregnancy for fear that they might have miscarried again and in asking about it I would upset them. I noticed that I felt guilty for telling female friends about some of the awful experiences of miscarriage, worried I would scare them. I particularly noticed a complete avoidance of the topic with anyone who was currently pregnant. At the beginning of the project I debated having current pregnancy as an exclusion criterion. These types of fears are commonly noted in the literature on miscarriage but, despite my awareness, I could not help but be affected. The anxiety caused by talking about pregnancy loss is great, mostly driven by a fear of upsetting the woman, but maybe also a fear that if it is spoken about it becomes more real and thus more dangerous.

This anxiety was contrasted with my experience of the interviews which were actually not as upsetting as I thought they would be. This may have been the result of finding a way to ‘be with’ rather than ‘in’ the experience (Rowling, 1999), but I also
wondered if it represented a deficiency in my ability to empathise. The inability of others to understand the experience was so often reported by participants I wondered if I too was subject to this failing. I wonder if the intangible nature of a pregnancy to anyone but the woman makes it difficult to connect to and therefore to empathise? This may be particularly the case for someone who has never been pregnant.

A feminist perspective

The presence of the woman’s body in conversations about miscarriage was also highlighted in the interviews. Participants described how private some aspects of the miscarriage felt. It is possible that failure to empathise is also a recognition of this private boundary of the body. However it is also important to consider how this very personal aspect of miscarriage can lead to a discourse of shame and blame. The feminist literature is important here; Cosgrove (2004) suggests that the terminology of pregnancy loss medicalizes the process and undermines the lived experience of loss. She argues that it minimises the experience (the surgical management procedure is known as an ‘evacuation of the retained products of conception’) and places responsibility for the loss on the woman. As one participant in the current research suggested:

*I think the word miscarriage gives all the responsibility to me... in my head it sounds like carrying a beautiful glass vase or something really precious and then tripping over and spilling it everywhere* (P3)

However, there has been relatively little written about miscarriage from a feminist perspective; it has been suggested that it is a difficult topic for feminists who have argued for the rights to abortion and reproductive control (Layne, 1990; 2003). Layne (2003) suggests that this lack of feminist commentary has only perpetuated the silence and shame around miscarriage and that instead feminists should play a role in a new women-centred discourse of pregnancy loss.
Lack of Ritual

During the process of conducting the research I was also struck by the lack of socially sanctioned rituals which are available to families following miscarriage. Many participants tried to find ways to memorialise their loss, but often this was set against a backdrop of questioning whether or not this was a bit ‘mad’. Rando (1985) provides a review of the number of ways in which ritual aids bereavement. Two are of particular interest to the understanding of the silence following miscarriage. Firstly, she suggests that rituals provide a structure which not only aids individuals in making sense of their loss but gives them something to physically do. Secondly, she suggests that this structure facilitates the participation of other group members and allows for social interaction. I wonder if the lack of ritual and guidance, leaves people uncertain about how to comment on the loss or come together to support the family, instead leaving a silent abyss.

Cultural practices to commemorate pregnancy loss vary across the world; for example Mizuko Kuyō is the Japanese ritual to mourn the unborn dead (Harrison, 1995) which has become increasingly popular in the United States (Wilson, 2009). It would be helpful to conduct further research on the nature of social support cross-culturally to understand whether a more public discourse would help women and their families feel understood and supported through their grief.

Concluding Thoughts

Within the context of a currently overstretched and underfunded National Health Service, this research has also prompted important reflections regarding how we as clinicians make use of and strengthen clients' personal support networks. Part I of this thesis highlights that not all women experiencing miscarriage will want or benefit from psychological interventions. Part II, however, suggests the great value of supportive interactions within one’s social network. There is therefore an important dual role for
clinicians: to contribute to a different social discourse around miscarriage and to make conversations about social support central to our interventions.
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Appendix A: Ethical Approval from the UCL Ethics Committee
The below is a copy of the email confirming the ethics amendment approval for study this study (CEHP2015530)

From: King, John  
Sent: 02 February 2016 14:21  
To: Pistrang, Nancy; AcadServ.Ethics  
Subject: Ethics Amendment Approval Pistrang CEHP2015530  
Attachments: Ethics Amendment3 Pistrang CEHP2015530.zip

Dear Nancy,

I have reviewed your recent application for an amendment for your ethics approval, and I am happy to approve it. Please keep this email, to which I have attached the documents for archiving with the REC.

Best Wishes,

John

---

Dr John King  
Senior Lecturer, Research Department of Clinical, Educational and Health Psychology  
& Institute of Cognitive Neuroscience  
Division of Psychology and Language Sciences  
University College London  
1-19 Torrington Place  
London WC1E 7HB  
UK

Tel: +44 (0)20 7679 5993 (internal 45993)  
Email: john.king@ucl.ac.uk  
Web: https://iris.ucl.ac.uk/research/personal?upi=JAK1N44

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Appendix B: Participant Information Sheet
Women’s Experiences of Support Following Miscarriage

Information Sheet for Participants

We would like to invite you to take part in this research project. You should only take part if you want to. Before you decide whether you want to take part it is important for you to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information.

We are interested in whether or not women talk about their miscarriage to those around them, for example, to their partner, friends, family or a support group. We are also interested in women’s accounts of how people respond to them, including both helpful and unhelpful things that people have said. We’d like to hear a range of experiences, including when women have told no-one.

Who is being invited to take part?

We are inviting women (over the age of 21) to participate if they have had a first trimester miscarriage in the last two years but more than three months ago.

Do I have to take part?

It is up to you to decide whether to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you do decide to take part you are still free to withdraw at any time and can do so without giving a reason. Withdrawing from the study has no consequences for any support you may be receiving.

What will I be asked to do?

If you decide to take part we will ask you to meet with a researcher to discuss your experiences of talking (or not talking) about your miscarriage. The interview will be audio-recorded so that we have an accurate record of what was said. The meeting will last about an hour and a half, and will either take place at UCL or somewhere that you choose. Women who take part will be given a £10 voucher as a token of our appreciation.

What will happen to the information that is collected?

The recordings of the interview will be transcribed (written up). We will then delete the recordings. The transcriptions will be made anonymous; names and any identifying information will be removed so that you cannot be identified.
All written information will be stored securely and will be destroyed five years after the study has ended. All data will be collected and stored in accordance with the Data Protection Act 1998. If for any reason you decide to withdraw from the study, all information you provided will be deleted.

Everything that you tell us will be kept confidential; only the research team will have access to what has been said. The only time confidentiality would be broken is if we became concerned that you or another person were at risk of serious harm. If we did need to tell someone else then, where possible, we would discuss this with you first and it would be managed as sensitively as possible.

Once the project is over, the results will be written up as part of a postgraduate thesis and may be submitted for publication in an academic journal. Reports will not reveal the identity of anyone who took part. An anonymous summary of the findings will be given to those who took part in the project and will be sent to any participating organisations.

**Are there any risks of taking part?**

It is possible that the interview might touch on areas that are distressing. If this were to happen, the researcher will be able to talk this through with you and discuss any support you might need, and you will have the option of stopping the interview.

**What are the possible benefits of taking part?**

Participants in previous similar studies have reported that the process of talking to a researcher can be interesting and helpful. We hope that the information we obtain from this study will improve our understanding of women’s experience of miscarriage and the type of support they need.

**Further information and contact details:**

If you have any questions about this study, please contact the researchers:

Alice Elfer, Clinical Psychology Trainee alice.elfer.14@ucl.ac.uk
Nancy Pistrang, Professor of Clinical Psychology n.pistrang@ucl.ac.uk
Chris Barker, Professor of Clinical Psychology c.barker@ucl.ac.uk

Research Department of Clinical, Educational and Health Psychology
University College London
Gower St
London WC1E 6BT
Telephone: 020 7679 5962

**Thank you for considering taking part in this study.**

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair

Project ID No: CEHP/2015/530

You will be given a copy of this information sheet to keep.
Appendix C: Consent Form
Informed Consent Form for Research Participants

Please complete this form after you have read the Information Sheet and listened to an explanation about the research.

Title of Project: Women’s Experiences of Support Following Miscarriage

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair
Project ID No: CEHP/2015/530

You will be given a copy of this Consent Form to keep.

Participant’s Statement
I ………………………………………………………………………………………………………………
Agree that:

- I have read the Information Sheet and the project has been explained to me orally;
- I have had the opportunity to ask questions and discuss the study;
- I have received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury;
- My interview will be audio-recorded and I consent to use of this material as part of the project.

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as confidential and handled in accordance with the provisions of the Data Protection Act 1998.

I agree to take part in this study.

Signed: Date:

Investigator’s Statement
I ………………………………………………………………………………………………………………
Confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:
Appendix D: Study Advertisement
Women’s Experiences of Support Following Miscarriage
Research Participants Needed

Have you recently had a miscarriage? What was your experience of talking (or not talking) about it to others?

I am a Trainee Clinical Psychologist at University College London and I am undertaking some research looking at women’s experience of support following a miscarriage.

I am interested in whether or not women talk about their miscarriage to those around them, for example, to their partner, friends, family or a support group. I am also interested in women’s accounts of how people respond to them, including both helpful and unhelpful things that people have said. I’d like to hear about a range of experiences, including when women have told no-one.

We are inviting women (over the age of 21) to participate if they have had a first trimester miscarriage in the last two years but more than three months ago.

If you decide to take part I will ask you to meet with me to discuss your experiences of receiving support. The meeting will last about an hour and a half, and will either take place at UCL or somewhere of your choice.

If you are interested in participating in the study or would like further information, please contact me:

Alice Elfer, Clinical Psychology Trainee <alice.elfer.14@ucl.ac.uk>

Research Department of Clinical, Educational and Health Psychology
University College London
Gower St
London WC1E 6BT
Telephone: 020 7679 5962

Thank you for considering taking part in this study.

This study has been approved by the Research Department of Clinical, Educational and Health Psychology Ethics Chair
Project ID No: CEHP/2015/530
Appendix E: Semi-Structured Interview Schedule
In this study we are interested in finding out about women’s experience of support following a miscarriage. I have some questions I would like to ask but these are just as a guide, I would really like to hear about your personal experience and what you feel was important at this time. I understand that this may bring up some strong feelings for you, so please take your time and let me know if you would like to stop.

1. **Background/Context**
   Can you tell me a bit about your experience of having a miscarriage, whatever you feel comfortable telling me?
   Was this your first miscarriage? (If more than one I discuss with participant which would be most appropriate to talk about or ask questions about each if significantly different)
   How long ago did it happen?
   Who knew that you were pregnant?
   Prompt to uncover possible reasons why person did or did not disclose their pregnancy
   How many weeks pregnant were you when you miscarried?
   Prompt: to uncover the meaning of this for the person

2. **Telling Others**
   Did you tell anyone that you miscarried?
   At what point did you tell them and how?
   What did you tell them?
   What made you want to tell (or not) them?
   What were you hoping for in telling [name]?
   (If not mentioned follow up with regards to partner, family, and friends)

3. **Helpful/Supportive Interactions – ask participant to think of one or more examples of the most helpful interactions and take each one in turn.**
   How did you tell [name]?
   What did you tell [name]? /What did you actually say?
   How did [name] respond?
   How did you feel when [name] did/said that?
   How did you respond when [name] did/said that?
In what way was the conversation helpful/supportive?
What was it about what [name] said or how [name] said it?
What difference did it make to you?
Did it make any difference to your relationship with [name]?
Is there anything you held back from saying?
Did [name’s] reaction have any influence on who else you decided to tell or on how you talked about it?

4. Unsupportive Interactions - ask participant to think of one or more examples of the most unhelpful interactions and take each one in turn.
   How did you tell [name]?
   What did you tell [name]? What did you actually say?
   How did [name] respond?
   How did you feel when [name] did/said that?
   How did you respond when [name] did/said that?
   In what way was the conversation unhelpful/unsupported?
   What was it about what [name] said or how [name] said it?
   What did it mean to you?
   What difference did it make to you?
   Did it make any difference to your relationship with [name]?
   What is your understanding of why [name] responded like that?
   How would you have liked them to respond/What would have been helpful?
   Did [name’s] reaction have any influence on who else you decided to tell or on how you talked about it?

5. Not talking
   What influenced your decision not to talk to anyone?
   Is there anything that would have made a difference to that decision?
   Were there people that you would have liked to talk to that you didn’t?
   Has anyone ever spoken to you about something similar? How did you experience that?
   What do you think it would have been like if you had spoken to someone?
   Did you have other ways of coping with your miscarriage?
6. **Closing the interview**

Is there anything I haven’t asked about that you think is important?

Looking back now, what would you recommend to women experiencing a miscarriage?

How was it to talk about these experiences?

Do you have any questions or concerns about what we have discussed or the study?

**General Probe questions:**

How did that affect you?

What did you think about that?

How did you feel?

What was that like for you?

What made you feel that way?

What did you do?

How did you react?

How did you manage?

What were other people doing?

What was the best/worst thing about that?

What about that affected you most?

What did that mean for you?

What was important about that for you?

What makes that stand out in your memory?

Can you tell me more?

Can you give me an example?
Appendix F: Process of thematic analysis: example of an individual summary sheet
Participant 3 Summary Sheet

**Caution around the pregnancy in case something goes wrong**
Being told not to get too attached, too excited – supervisor. Pg. 5
‘Wait with your love’ pg. 6
The early days aren’t important – no medical care before 12 weeks pg. 8
Better not tell in case something goes wrong – following the rule blindly p29

**Responsibility for the wellbeing of the pregnancy/Blame for miscarriage?**
You should do X Y Z while pregnant – the media. Pg. 8
Terminology: ‘miscarriage’ sounds like blaming woman p35

**Why people are told about miscarriage?**
For support at work – supervisor
For support specifically for husband from friend – pg.27 – talk, cry, think creatively p.28
Building positive memories

**Enablers to talking**
Someone who had experienced it
Supervisor had a miscarriage – the only one who understood pg. 12
Being a bit ‘selfish’ doing it the way I wanted to do it – needed to talk p24
Messages saying we’re here for you, but you have control – tell us if you need us p45

**Barriers to talking**
Too horrific;
Family don’t want to hear about physical details. Pg. 11
Might be too ‘horrific’ (pg. 12) might ‘ruin the experience’ (pg. 11)
Feel bad for upsetting people
Not making others upset pg. 14, 18, 24
People might think we’re a bit mad, not coping appropriately if we do a funeral. Pg. 15
Making mother cry, I let people down
Worry about what people will say
Fear of people being disrespectful and ruining the experience p41
It’s quite private?
Mums did the asking, not dads – talking about women’s bits, periods, vagina’s etc. just something they don’t do. p22
Telling people at work - they know only a little about personal life and then something very sensitive
Timing of talking
Needing time as a couple alone first p20

**Going through it with Husband**
Being in it together
Both experiencing emotional pain p13
Caring focused on woman. Felt worried about him. Hard to be there for him, p27
Closer relationship p.14, 27 – he made me feel brave and courageous p.26

**Talking to others who are invested in the pregnancy**
Mother – difficult because she is already attached pg.11
Mother-in-law – looking forward to being grandparent p18
A sense of responsibility, letting people down, a baby would have bought happiness p18
**Pace of moving on**
People want you to move on quickly, get back to being happy p24, 25

**People’s responses**

**Unhelpful**
Mother’s tears – ‘selfish’ 17
Father-in-law not really knowing what to say being awkward pg.23

**Helpful**
Friend: ‘Be what you need to be now’ (p.19) vs Mother: ‘talk about it but not too much - talking might make you more sad’
Be what you need to be now – Friend. Permission to: scream, bitch, cry pg. 19,
Husband/Friend - think creatively about loss, different perspectives p.28
I’m sorry for your loss – miscarriage association p33 written response, go back to it
Honesty from friend – do you feel X – gave permission for feelings about friend’s pregnancy p46

**Non-verbal responses**
Hug from father in law – pg. 22

**Outcomes**

**Positive**
Closer with husband pg. 14, 27
Talking as healing p.25
Husband closer with friend p28
Building positive memories throughout the pregnancy p31
Realised how much people love and care p43
Others support provided strength to couple to deal with it together p.45
Talking openly enabled people to support appropriately p46

**Negative**
Don’t continue to talk about it – with father-in-law after awkward response pg. 23
Appendix G: Process of thematic analysis: illustration of initial notes, codes and themes
Extract of interview with P7

P: you want to keep busy but then also you don’t want to forget there’s that balance. I think that’s the mistake I made to begin with I did that to begin with and I couldn’t deal with it I probably at the beginning of [month] I had a bit of a relapse I felt really rubbish really erm I’ve come out at the other side of that now

I: Why do you think you were wanting to keep busy?

P: just sort of lots of distractions really I had to [describes job] but also I think people make you feel maybe not intentionally, but people make you feel like you should just get on with it.

I: In things that they say?

P: I think people don’t know how to react to it yeah so people don’t talk about it with you because they think it will upset you so then you think well then I should just carry on because you know

I: Because they are not talking about it you feel that you should just get on with things?
P: And I know they don’t mean it in a mean way but it would have been nice if months down the line there had been someone to say are you ok do you need to talk about it? Or even your GP to send you a letter saying this happened are you ok do you need any further follow up or anything

I: That would have made a difference?

P: Yeah I think so because while I know there are places to go to talk to someone just to have someone to give you that push

I: a bit of a push to talk

P: yeah would you like to or not. I think when I got to [month] I was like hang on a minute all this time has passed, I am thinking about it every day and time is moving on. I had my 20 week scan date coming up because they send that out in one go so I knew the date when that was supposed to be erm so then you reach dates like that

I: what are those dates like?

P: Time passing

I: Reminders… that would have been

P: Certain dates are reminders of the loss.

I: A painful reminder
**P:** That day at was really difficult  

**I:** Did anyone knew about that?  

**P:** No nobody remembered it. I mentioned it to my sister a day or two later. She finds it difficult but she is really good she is just like yeah but you’ll have another one its fine. Which is fine but she doesn’t know how to talk about it as well and she is thinking about having kids so that’s hard for her because she’s probably got that worry in the back of her mind god is it going to happen to me. Nobody remembered. Dismissing the loss. Talking about miscarriage makes other women worry – will it happen to me? Sister feels worried – will it happen to me? Thinking about what could have been. Glossing over it/’at least…’ I don’t want to worry her.
Appendix H: Respondent Validation: letter of invitation
Dear ……..

Back in ……date…… we met for a research interview regarding your experiences of support following your miscarriage. You may remember me mentioning at the time that I would write to you with a summary of what we spoke about. Attached to this email is that summary, reflecting what I understood to be the most important points.

It would be really helpful if you would let me know how accurate you feel the summary is and if there is anything that I have missed which you feel was important to you at this time. If there is anything which you have thought about since our meeting please feel free to add that too.

It is of course entirely up to you if you want to respond or not. If you would like to, please respond to the questions below via email. Alternatively you are welcome to call on the number below if you would like to discuss anything in person.

Either way I would like to take this opportunity to thank you once again for giving up your time to be involved in the project.

Best Wishes,

Alice

1. How accurately do you feel the summary reflects the main things you said in our conversation?
2. Is there anything that I have missed out?
3. Is there anything you would like to add?
4. Any other comments about the summary, the interview or the research generally