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The Provision of Psychosocial Support in Early Pregnancy Assessment Services in Australia

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Abstract

Background

Miscarriage is a common event estimated to affect up to one in four confirmed pregnancies and can result in significant psychological morbidity. Appropriate psychosocial support at the time of a miscarriage can lead to better psychological outcomes in the months or years following a loss. Early Pregnancy Assessment Services (EPASs) are typically dedicated outpatient clinics in public hospitals designed to manage patients with pain and/or bleeding in early pregnancy and are considered the "gold standard" for miscarriage care. Despite some best-practice recommendations outlining the psychosocial support EPASs should offer, very little is known about what they provide.

Aim

The aim of this study was to explore the provision of psychosocial support in Early Pregnancy Assessment Services in Australia.

Method

A mixed method approach utilising audit, field notes and semi-structured interviews was conducted to acquire information on clinic structure and operation, and the provision of psychosocial support. Thirty-one key-informants were recruited from 13 EPASs and two miscarriage support organisations across Australia. Interviews were audio-recorded, transcribed, and thematically analysed.

Results

Findings demonstrated considerable variability in how EPASs functioned in Australia, and therefore the provision of psychosocial support. Results were presented in three categories: psychosocial support currently provided, psychosocial support considered ideal by participants, and barriers to changing psychosocial support. Considerable variation in the structure and function of services were observed, such as staffing arrangements, physical location of service, and availability of ultrasonography. However, most participants described the emotional support provided by EPAS staff similarly, noting the importance of acknowledging and validating patients' feelings, guilt mitigation, and providing individualised care. Referrals for additional psychological support were rarely reported, however many participants discussed the importance of utilising General Practitioners for follow-up and

ongoing support. Common barriers to providing ideal psychosocial support was reported and primarily centred around limitations on time and resources, resulting in the physical care of patients taking priority over psychological care. Despite these restrictions, all EPAS staff demonstrated a clear and strong commitment to providing best possible patient care within their own clinical setting and acknowledged the need for improved psychosocial support.

Conclusions

This study provides the first exploration of Australian EPASs' provision of psychosocial support. It has demonstrated that health care professionals working in EPASs are dedicated to providing the best possible care to their patients within their clinical setting. Time and funding restrictions were considered major barriers to providing improved psychosocial support. More research into where psychosocial support is best offered is needed to improve patient experience and lower psychological morbidity following miscarriage.

Declaration of Originality

This is to certify that:

- The thesis comprises only my original work towards the degree of Master of Philosophy (Medicine) except where indicated in the preface,
- Due acknowledgement has been made in the text to all other material used,
- The thesis is less than 50,000 words in length, exclusive of tables, maps, bibliographies and appendices

Signed:

Date: 2nd October 2019

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Table of Contents

List of Tables and Figures

Tables

Figures

List of Acronyms

COREQ	Consolidated Criteria for Reporting Qualitative research
D&C	Dilation and curettage
DGP	Department of General Practice
ED	Emergency Department
EPAP	Early Pregnancy Assessment Protocol
EPASs	Early Pregnancy Assessment Services
EPL	Early Pregnancy Loss
EPPs	Early Pregnancy Problems
GP	General Practitioner
HEAG	Human Ethics Advisory Committee
NHMRC	National Health and Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
O&G	Obstetrician Gynaecologist
PLS	Plain Language Statement
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Sands	Miscarriage, Stillbirth And Newborn Death Support
UK	United Kingdom
US	United States

Chapter 1: Introduction

1.1 Overview

Early pregnancy loss (EPL) is a common, yet distressing event for many women. This study explores the psychosocial support available following miscarriage, in particular exploring the provision of psychosocial support in Early Pregnancy Assessment Services (EPASs) in Australia. Early Pregnancy Assessment Services, which are designed as one stop centres for management of EPL, will be introduced and their role in delivering psychosocial support will be explored. This introduction will provide the background and context for the study. The research question and objectives are outlined, and the significance of this research discussed. Finally, an overview of this thesis is provided.

A psychosocial approach can be defined as one which considers the context of both psychological factors and the social environment as possible influences on the physical and mental health and wellbeing of an individual (1). For the purpose of this thesis, psychosocial support is considered the provision of psychological and social resources, in addition to biological or physical medical management.

1.2 Early Pregnancy Problems

In Australia, miscarriage (or spontaneous abortion) is defined as a pregnancy loss before 20 weeks of gestation (2). At or after 20 weeks a pregnancy loss is considered a stillbirth. This definition varies slightly between countries, for example in the United Kingdom (UK), miscarriage is defined as a pregnancy loss up to 24 weeks gestation, and a loss at or after 24 weeks gestation is defined as a still birth (3).

It is estimated that EPL occurs in approximately 20-25% of confirmed pregnancies (4-7). From this, it can be extrapolated that in Australia, 285 miscarriages occur every day, affecting 104,000 couples a year (6, 7). However, it is difficult to accurately measure this rate, which is likely to be under-reported, as EPL often occurs before women are even aware they are pregnant and they often assume it to be a heavy or late period.

Early pregnancy problems (EPPs) refer to pregnancy complications such as pain and/or vaginal bleeding in the first 20 weeks of gestation. Women experiencing EPPs are usually in a stable condition and present to their General Practitioner (GP) or Emergency Department (ED) with

concerns for the viability of their pregnancy (8). Common outcomes of EPPs include threatened or actual miscarriage, and ectopic pregnancy (5). Miscarriage and other forms of EPL are outlined in Table 1.

Table 1: Definitions of types of early pregnancy loss in Australia (4, 9)

Name	**Definition**
Threatened Miscarriage	Pain and/or bleeding which may/may not be followed by miscarriage
Inevitable Miscarriage	More severe pain and/or bleeding resulting in loss of pregnancy
Complete Miscarriage	Miscarriage where all pregnancy tissue has been passed
Incomplete Miscarriage	Miscarriage where some pregnancy tissue remains in uterus
Missed Miscarriage	Fetus is non-viable, but remains in uterus
Recurrent Miscarriage	Three or more consecutive miscarriages
Ectopic Pregnancy	Embryo implants outside the uterus, commonly in the fallopian tubes
Molar Pregnancy	Abnormal pregnancy development, either partial: non-viable fetus develops, or complete: no fetus development
Blighted Ovum	Embryonic sac develops without embryo (anembryonic pregnancy)
Pregnancy of Unknown Location	A pregnancy test is positive, but no pregnancy is visible on an ultrasound scan

The cause of miscarriage is often unknown, but it has been estimated that approximately 40-50% occur due to chromosomal anomalies resulting in pregnancy loss in the first trimester (10, 11). Other risks factors include alcohol and drug use, tobacco inhalation, maternal age, obesity and a history of previous miscarriage (10). As miscarriage largely occurs due to chromosomal development issues, only very rarely is a treatable cause found (12). Unfortunately, once a miscarriage has begun there is no medical intervention that can stop it from continuing (13). Therefore, treatment instead focuses on managing miscarriage to avoid heavy bleeding, infection, and to reduce pain.

These issues often require dedicated and trained gynaecological sonographers for appropriate diagnosis, in addition to compassionate and sensitive care from all healthcare professionals involved. The three main miscarriage management options: expectant or conservative management, medical management, and surgical management, are summarised in Table 2

below. The choice of management option is dependent upon the individual woman's medical condition, as well as her personal preference where possible.

Table 2: Miscarriage management options (14)

Management option	**Summary**
Expectant or conservative management	No active treatment administered, with the aim to see if the miscarriage completes naturally
Medical management	Pharmaceutical intervention using typically misoprostol, or in combination with mifepristone, either vaginally or orally to expedite miscarriage process
Surgical management	Surgical intervention typically through a dilation and curettage (D&C) to empty uterus. This process is often used to avoid additional pain, bleeding or prolonging the process

1.3 Psychological impact

The high frequency of miscarriage means that it is often considered a routine, and consequently trivial event, which is easily managed medically. However, whilst physically miscarriage can be easily managed, the reality is that psychologically it often results in significant morbidity. Women's feelings towards experiencing a miscarriage are variable and often dependent upon their individual circumstances and beliefs. Women's reactions may range from relief if they were feeling unsure or ambivalent towards the pregnancy through to utter devastation. However, feeling of distress, grief, sadness, self-blame, anger, isolation and guilt are all common (15-17). While experiences and reactions can vary considerably, substantial evidence exists to show that for many women miscarriage represents a bereavement (18).

Research has shown up to half of all women who experience miscarriage suffer some psychological morbidity in the following weeks, months, or even years (19). For a considerable number of women, the distress is so significant it fulfils the criteria for clinical levels of psychiatric illnesses such as anxiety, depression and post-traumatic stress disorder (17, 19-22). Studies have shown 10-50% of women experience some form of major depressive disorder and 20-40% experience heightened anxiety symptoms (19). For approximately 40% of women, the intensity and duration of this grief has been described as similar to perinatal death, with

psychiatric symptoms persisting for up to 6-12 months following a miscarriage (19). In a recent UK study, 25% of women were found to likely to meet the criteria for post-traumatic stress disorder (PTSD) one month after miscarriage, 32% for anxiety, and 16% for depression. The number for PTSD rose to 38% at three months after the loss (17).

Another common misconception about miscarriage is that women do not form strong attachments to the foetus in the early stages of pregnancy. However, research shows no correlation between length of gestation or other obstetric factors, and the level of psychological distress women experience at the time of a miscarriage (15, 23-27). Not only can miscarriage result in psychological sequelae at the time of miscarriage, but it often also adversely affects future pregnancies due to heightened levels of anxiety and fear during subsequent pregnancies (28, 29).

Although most women experience some form of psychological morbidity following a miscarriage, studies have shown that there are common predisposing risk factors for increased psychological distress. These include a history of psychiatric illness, no living chidren, a lack of knowledge about miscarriage, and ambivalence towards the pregnancy (19, 20, 26). Another commonly reported risk factor is a lack of social support (18-20), which will be discussed further under the next sub-heading 'Social support'.

1.4 Social support

Given the significant impact miscariage can have on women's psychological health, a strong support network is crucial. Unfortunately, at a societal level, this is all too often lacking, and women are met with a wall a silence surrounding miscarriage. This occurs for many reasons including: because it is an 'unseen' loss with no physical person to grieve and therefore is not recognised as a genuine loss: because there is no legal recognition of the loss in birth or death certification, and there are no socially embedded rites or rituals to commemorate the loss (30-33).

In addition, silence around miscarriage often occurs because many women feel they have to hide their pregnancies until the '12 week mark' (33). This societal practice presumably exists as the risk of pregnancy loss is significantly heightened in the first trimester (33). This custom may act to protect a woman from having to disclose the news of a pregnancy loss to those whom she may not want to know. However, this logic fails when a woman seeks support for bereavement at the time of a miscarriage, if her wider support network was unaware of the

pregnancy. Unfortunately, this silence often adds to the feelings of loneliness and isolation experienced by many women after a miscarriage and can exacerbate psychological morbidity (33).

As previously mentioned, studies have consistently shown that a major predisposing risk factor to psychological morbidity following miscarriage is a lack of social support (18, 19). Lee and Slade's 1996 review of the literature on miscarriage as a traumatic event showed that a number of studies had found that a lack of support from friends, partners, and families contributed to the risk of increased psychological disress (18). Similarly, Stratton and Lloyd's literature review in 2008 presented similar findings, showing this risk factor has consistently been reported (34). Positive support experiences from both social networks and health care providers at the time of a miscarriage, can buffer the loss and lead to better psychosocial outcomes (34, 35).

At the time of a miscarriage, women's central support figure is primarily their partner (36-38). Although there is limited research on partners' experience of miscarriage, a recent Australian study found that male partners often feel that they have to take the 'supporter' role and remain strong and stoic at the time so as not to burden their partner further with their grief. Men commonly reported their grief and loss as a father was often overlooked and unacknowledged by healthcare professionals and within their social networks (39). Due to this percieved pressure to take on a support role, in addition to other factors such as differing levels of grief experienced, miscarriage can cause significant relationship strain, distance and reduced sexual intimacy (24, 29, 40, 41). Collins, Riggs and Due's 2014 study which interviewed women about their adult relationships following a pregnancy loss explored the often heterogeneous nature of experiencing a pregnancy loss. The study found that for many women, the strain of a pregnancy loss resulted in feelings of emotional isolation in the relationship with the partner. Conversely, for a smaller number of participants, the experience of a pregnancy loss was seen as a bonding experience which strengthened the relationship and resulted in a deeper and more meaningful connection (24).

Relationship strain due to miscarriage is not limited to just intimate relationships, but can affect relationships with friends and family also. This often occurs when those affected by miscarriage feel there is lack of understanding or acknowledgement of their loss by their support networks. Families and friends may not validate the miscarriage as a loss or allow the women to grieve fully (18, 24, 32, 37, 42, 43). It has been frequently reported that despite best intentions, friends and family often do not know what to say at the time of miscarriage, which

is interpreted as a lack of care, adding to the concept of miscarriage as a disenfranchised grief (24, 33). Studies have also shown that many women who experience miscarriage commonly struggle with friends or family members who may be heavily pregnant or have young children, increasing tension in these relationships and at times resulting in the breakdown of family relationships (24, 37, 42).

1.5 Management of Early Pregnancy Problems in Australia

In Australia, there are two main options for maternity care: public and private. If a woman chooses to use the private system, her pregnancy will be managed by her private obstetrician. In the public system, her care will be managed by different midwives and obstetricians through visits to outpatient clinics at her local hospital. Another common option is shared-care, where a women's chosen GP and a local hospital work together to care for her pregnancy needs.

When a woman experiences EPPs, her experience is unfortunately likely to differ depending on whether she is a public or private patient. When experiencing EPPs in the private system, she will likely be seen promptly by her private obstetrician. As a private patient, she will have continuity of care, seeing the same obstetrician throughout the course of her pregnancy. Studies have found that women in the private healthcare system tend to have higher levels of satisfaction with their miscarriage care compared to women in the public system (23, 44).

In the public system, women's care at the time of miscarriage is likely to be quite different and current management can be inconsistent and often insufficient (44, 45). Many women do not have their first antenatal appointment until the 12-week scan and consequently, when EPPs occur they have not been connected in with a pregnancy care provider. In the public system, EPPs are traditionally managed by GPs or in hospital EDs, with gestations over 20 weeks managed in labour or delivery suites (45). A 2002 study of Victorian GPs found that 77% of GPs surveyed referred non-viable pregnancies on, to either ED, or to an EPAS (46). EPASs will be discussed in more detail under the next sub-heading 'Early Pregnancy Assessment Services'. Figure 1 provides an overview of the typical pathway a patient in the public system may expect when experiencing EPPs.

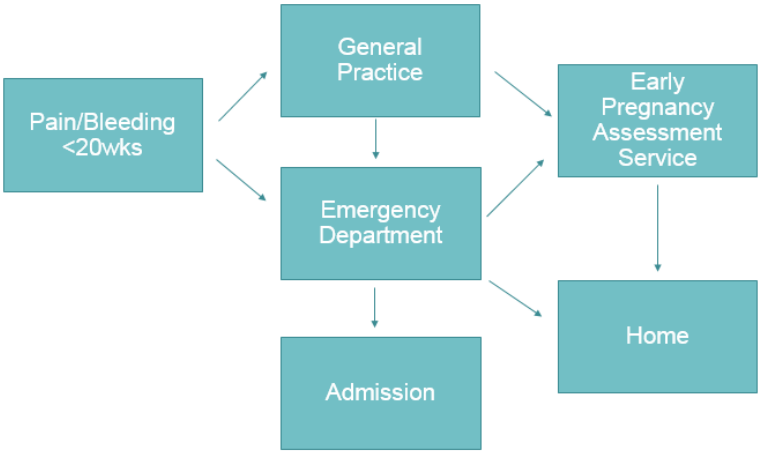

Figure 1: Typical pathway of care for public patient experiencing EPP

Unfortunately, ED management of EPP is often inappropriate due to long waiting times, unnecessary admissions, lack of appropriately trained sonographers and staff, and loss of continuity of care (45). This is partly due to miscarriage very rarely being a life-threatening condition, except in the rare case of an ectopic pregnancy (4). EPPs are typically a very low priority in ED as patients are hemodynamically stable, and therapeutic treatment will not prevent a miscarriage from occurring. Women will often spend hours in a waiting room before being seen by a doctor. Once seen they will either have their miscarriage confirmed and be sent home, referred to an EPAS, or very rarely be admitted. Continuity of care cannot be maintained and EDs rarely have access to specialised resources or appropriately trained staff (47). Studies have frequently found that ED management of miscarriage results in high complaint numbers, in addition to poor use of clinical resources and financial outcomes (45, 47, 48).

Some EDs utilise an Early Pregnancy Assessment Protocol (EPAP) to help address these issues by changing clinical behaviour to try and ensure patients are treated in a similar way to an EPAS. In a 2009 study, O'Rourke and Wood found that by introducing an EPAP, treatment time decreased, specialised care increased, and hospitals financially saved 63% per patient (49). While introducing an EPAP to ED may have its advantages in addressing aspects of care such as treatment time and hospital finances, little research has been undertaken to investigate how psychosocial support can be improved within these services.

The medicalised approach to miscarriage frequently ignores the significant psychological sequelae experienced by women (32). Literature has shown that health care providers play an

important role in shaping how women experience their miscarriage and the level of their associated psychological distress. Although some women are content with the level of care they receive, unfortunately, studies have repeatedly shown that women are often highly dissatisfied with the support care they receive from health professionals at the time of miscarriage, frequently citing issues including a lack of empathy, compassion and sensitivity from staff, use of medicalised terminology, a lack of follow-up or referral to support services and a focus on their physical and not emotional needs (31, 32, 34, 37, 50-54). One recent Australian study (2018) interviewed 15 women about their perceived support by healthcare professionals following a miscarriage, and found that women's distress was exacerbated following negative experiences with health care providers (37). Issues raised by these women included a lack of follow-up, information provision, emotional support, and transparency, as well as insensitive terminology use and a dismissive attitude (37).

There appears to be a disconnect between what women want from their healthcare providers, and what clinicians are able to provide or consider their role to be. In a hospital-based Australia study, Evans et al (2002) surveyed 109 women who experienced miscarriage and 43 staff involved in miscarriage care about the psychological needs of women following miscarriage. The study found that 65% of women thought their hospital experience could be improved by factors such as a more considerate and sensitive attitude from staff. Although many staff agreed that the hospital experience could be improved, they thought this would best be achieved through the provision of counselling and an increase in staff numbers (15). Similar discrepancies were found in a recent Australian study (2018) exploring healthcare professionals' views and practices caring for women experiencing miscarriage (55). Clinicians in this study often did not consider themselves responsible for patients' emotional care following miscarriage due to time and resource limitations, desensitation to women's loss, and a need for self-protection (55).

1.6 Early Pregnancy Assessment Services

Early pregnancy assessment services are considered the 'gold standard' for EPP management and are described in best-practice guidelines (4). EPASs are typically a dedicated outpatient unit, often attached to an ED or gynaecology department, which treat women referred with EPPs from an ED or GP. They aim to overcome issues experienced by women in EDs by providing a specialised EPP centre, which offers comprehensive and streamlined management and treatment options (47, 56). EPASs were first described in the UK in 1991 and provide a

benchmark for the definitive management and continuity of care for women experiencing EPP (57).

Their introduction to the UK has resulted in an array of benefits to both patients and hospitals. Benefits commonly highlighted in the literature include reduced ED wait times, hospital admissions, surgical interventions and hospital expenditures due to appropriate and targeted care (47, 49, 56, 57). Other reported benefits include reduced length of stay in hospitals (47, 56), re-presentation rates (48, 58) and unnecessary pathology testing (56), earlier diagnosis (48, 58), and personalised management plans (59, 60). Although there is limited literature that focuses on women's experience of EPASs, it can be assumed that they also improve women's experience due to the provision of prompt diagnosis, treatment options, and in some cases bereavement counselling (4, 59).

Given the benefits of EPASs evident from their implementation in the UK, it would be reasonable to assume similar benefits may be evident in Australian EPASs.

1.7 EPASs in Australia

The non-universal and often insufficient management of EPPs in ED in Australia result in inconsistent and inequitable service, long wait times, inappropriate resource use, and often-dissatisfied patients due to a lack of clear diagnosis or management plan. This led to Condous' recommendation in 2008 to establish easily accessible and dedicated EPASs in all hospitals across Australia (45). Further recommendations from research and governing bodies that echoed this sentiment soon followed (45, 57, 59, 61).

Literature on EPASs in Australia is almost non-existent. Only one 2012 study by Crilly, Wendt and Beatson has been published on an Australian Early Pregnancy Assessment Clinic (59). An evaluation of the structure and process of the clinic found that it was ED-based, led by specifically trained nurses, offered a private area for patients, and provided information handouts. However, it did not offer extended opening hours or the option of sonography on-site. Recommendations of this study included extension of operational hours, "more regular, structured, consistent education" for staff, and further research evaluating other Australian EPASs.

Unlike the UK, there is no national database of EPASs in Australia (62), therefore it is difficult to know the exact number and location of services. Anecdotally it seems EPASs are sparse, vary widely in the services they offer and are largely centred in major city hospitals. A

superficial examination of hospital websites suggests most services have limited opening hours, and eligibility for entry varies between centres. Likewise, referral pathways for women differ; some services require a referral from a GP, others have an entry pathway exclusively through their ED, while a very limited number offer self-referral. Facilities for on-site, gynecologically trained sonographers and appropriate counselling services appear limited and sometimes non-existent.

Best-practice guidelines such as the National Institute for Health and Care Excellence (NICE) guidelines (4) endorsed by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), and guidelines produced by Queensland Health (63), have outlined what facilities and services EPASs should provide. However, to date there has been little published research examining the establishment or successes of Australian EPASs. This suggests Australia is lagging behind other developed countries in the introduction and standardisation of EPASs, and thus appropriate care for women who experience EPPs. While psychosocial support services are considered to be an essential element in some EPASs internationally, the extent to which this is available in Australia has never been explored.

Therefore, this thesis will explore the nature and provision of psychosocial support to women after a miscarriage, specifically in Australian EPASs.

1.8 Aim of the Study

This study aims to explore the psychosocial support offered in Early Pregnancy Assessment Services in Australia.

Objectives:

- To explore the psychosocial support best-practice guidelines recommend be offered to women who experience miscarriage
- To investigate the psychosocial support women want from healthcare providers at the time of a miscarriage
- To explore the provision of psychosocial support offered to women who experience miscarriage, both in EPASs and outside a clinical setting through support organisations.

1.9 Significance of research

There is substantial evidence that demonstrates EPL can result in significant psychological morbidity for women, and that many women are unhappy with the emotional care they receive at the time of miscarriage. However, there is very little research on women's psychological support needs at the time of miscarriage in Australia. EPASs were introduced to Australia as best-practice for EPL, yet to date almost no research has been conducted on them, and there is no evidence of the provision of psychosocial support in EPASs. This study will provide previously unreported information through summarising the current recommendations by experts and guidelines for psychosocial support following miscarriage. It will also examine what psychosocial support is currently available in Australia, both in the healthcare system and more broadly.

This research is the first Australian study to investigate the provision of psychosocial support in EPASs. It will examine if current psychosocial provision in EPASs meets the recommendations outlined in best-practice guidelines. This will provide essential baseline information about Australian EPASs, will contribute to the overall understanding of the current miscarriage experience in Australia, and will highlight potential improvements required for Australian miscarriage care. Results will also offer a much needed foundation for the creation or revision of psychosocial support guidelines for Australian EPASs.

Findings will also directly benefit participating EPASs, as results will be fed back to participants to offer information on how services compare across the country. Results will highlight what aspects of care work best for particular services, and potential areas for improvement seen across all EPASs.

The direction of future research will be informed by explicitly demonstrating what supports are currently offered in EPASs, and what may be lacking. Findings from this study have the potential to be used to demonstrate to government or funding bodies the need to increase resources into this underfunded area of healthcare.

Ultimately, this study aims to improve the quality of care provided to women who experience miscarriage in Australian EPASs.

1.10 Thesis overview

This chapter has outlined the need for and current limited provision of psychosocial support following EPL. It has provided the rationale for this research and described the aim of the

study. Chapter Two details findings of the literature review and justifies the need for this research through three literature review research questions:

Part 1: What are best-practice guidelines regarding the provision of psychosocial support to women who experience miscarriage?

Part 2: What psychosocial support do women want from healthcare providers when experiencing a miscarriage?

Part 3: What psychosocial support is currently offered to women who experience miscarriage in Australia?

Chapter three details the methodological framework and methods used to conduct this study. Chapter Four details findings of the study, which are then explored further in the discussion in Chapter five. Conclusions to the study are described in Chapter Six.

Chapter 2: Literature review

2.1 Introduction

This chapter provides a review and analysis of current knowledge about psychosocial support following miscarriage from both published and grey literature. It is presented in three parts to determine what is written in the literature about the three research questions:

Part 1: What best-practice guidelines exist regarding the provision of psychosocial support to women who experience miscarriage?

Part 2: What psychosocial support do women want from health care providers when experiencing a miscarriage?

Part 3: What psychosocial support is currently offered to women who experience miscarriage in Australia?

Findings in relation to each question will be summarised and explored under its subheading. Gaps in the literature will then be outlined, and the justification for the research undertaken for this thesis will be provided.

All searches conducted to answer these three questions were based on PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (64). Three databases; Medine (OVID), PsycINFO (OVID) and CINAHL, were chosen to cover suitable fields of research. Medline is a leading database of medical research, including nursing and allied health research published worldwide and PsycINFO is a comprehensive database of all fields of psychology. These two databases allowed utilisation of the user-friendly OVID interface, which offers detailed searches using the 'Advance Search' option and mapping to MeSH terms for more comprehensive searches. CINAHL is the Cumulative Index to Nursing and Allied Health Literature, which contains broad content from a range of nursing specialities. It was chosen due to the usefulness of identifying qualitative literature and the importance of nurses and midwives in miscarriage care. Boolean operators 'OR' and 'AND' were utilised, and terms were searched using the 'Map Term to Subject Heading' (MeSH) operator. Searches were limited to English language only, human studies, and study publication date was restricted to include only guidelines published from 2000.

2.2 Part 1: What best practice guidelines exist regarding the provision of psychosocial support to women who experience miscarriage?

The term 'guideline' is used in many different contexts and therefore has varying definitions. For the purpose of this thesis, the National Health and Medical Research Council (NHMRC)'s definition will be used, which states:

"Clinical practice guidelines are evidence based statements that include recommendations intended to optimise patient care and assist health care practitioners to make decisions about appropriate health care for specific clinical circumstances" (65).

NHMRC clinical practice guidelines must meet a rigorous standard to be approved. These include being developed by a multidisciplinary team, include a transparent declaration of potential conflicts, undergo a process of public consultation, and incorporate a plan for dissemination and implementation (66) Guidelines which have been designed by medical professional organisations for the purpose of patient care will therefore be included here. However, other kinds of recommendations for support will not be included. For example, Miscarriage, Stillbirth And Newborn Death Support, or Sands Australia, is a not-for-profit organisation that supports families whose baby has died through miscarriage, stillbirth or newborn death. Sands Australia recently released a document titled 'Australian Principals of Bereavement care' (67), which is the first comprehensive document which explicitly lists psychosocial recommendations for pregnancy loss. They list 10 key principals which include aspects of care such as recognition of parenthood, acknowledging grief is individual, awareness of burials, cremations and funerals, and health professionals' access to self-care. However, it should be noted that these suggestions relate to miscarriage, stillbirth and newborn death, and therefore may not be entirely appropriate for miscarriage alone. Similarly, as they cannot be confirmed to be entirely based on the best-available scientific evidence and produced in a systematic methodology, they cannot be considered as guidelines.

Searches of the chosen databases were conducted to screen for any relevant clinical practice guidelines, and the search strategy utilised in all three searches were identical. Title search: ("practice guideline*" OR "clinical guideline*") AND key words: (miscarr* OR "pregnancy loss" OR "spontaneous abortion" OR ectopic).

PsycINFO provided no results, Medline provided 18 articles, and CINAHL provided 2 results. However, after title and abstract screening was undertaken, none were found to be relevant to miscarriage within the Australian healthcare system.

A search of NHMRC's 'Australian Clinical Practice Guidelines' was undertaken. It is possible to conduct a search either through the 'guideline portal' or the 'guideline register', and the former was selected to broaden the potential scope of results. 'Guideline portal' includes NHMRC guidelines, evidence-based guidelines not approved by NHMRC, and guidelines developed by Australian guidelines developers (68). Searches using the terms 'miscarriage' and 'pregnancy loss' produced no results. A search using the term 'pregnancy' found 13 guidelines, however all were specific to a topic unrelated to miscarriage, and none included anything about miscarriage or pregnancy loss.

This search strategy is summarised here in Figure 2.

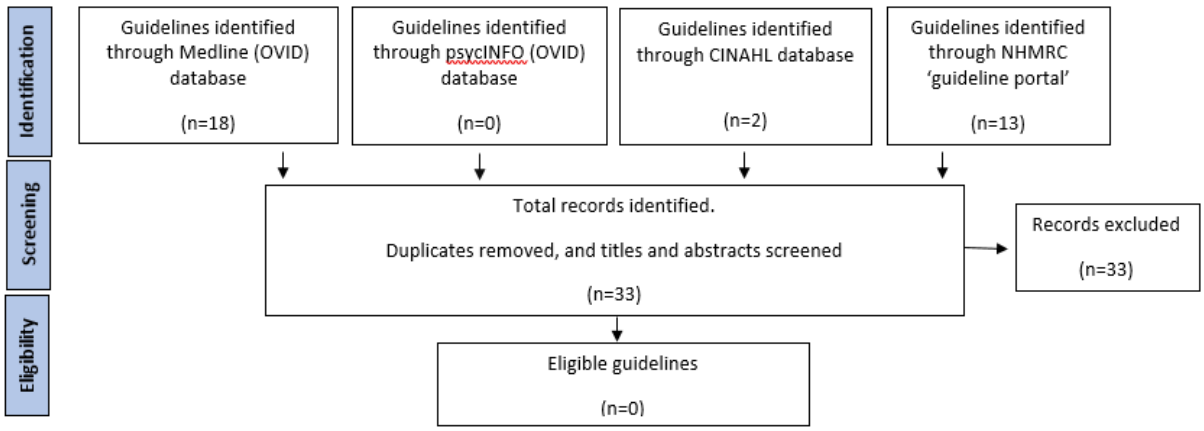

Figure 2: Part 1 literature search flowchart based on PRISMA (64)

Online searches of The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and state governments were also conducted.

Currently in Australia, there are no specific national guidelines for psychosocial support following a miscarriage or early pregnancy loss. RANZCOG was found to endorse the UK's National Health Service (NHS)'s NICE guidelines titled 'Ectopic pregnancy and miscarriage: Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage' (4). These guidelines primarily address physical management of EPPs; however, they do include some aspects of psychosocial support. These are primarily addressed under the

subheading ‘support and information giving’ and include suggestions such as providing patient information and support in a sensitive manner, training for healthcare professionals in sensitive communication and breaking bad news, offering a 24-hour contact telephone number, and offering information on where to access support and counselling services.

Using the state and territory government health websites, it was possible to locate a range of guidelines or recommendations. Queensland Health have their own specific clinical guidelines titled ‘Early Pregnancy Loss’ (63), while NSW Government Health have a policy directive (not a guideline) titled ‘Maternity - Management of Early Pregnancy Complications’ (69). They both contain a specific section for psychosocial support. South Australia Health also have their own perinatal practice guideline titled ‘Perinatal Loss’ (70), which does not have a specific psychosocial section, but does include suggestions for psychosocial support under different and more specific subheadings. A summary of the suggestions for psychosocial support from these government documents is summarised in Table 3 below.

Western Australia’s Department of Health have clinical practice guidelines titled ‘Perinatal Loss’ and ‘Miscarriage’. However, ‘Perinatal Loss’ did not discuss any pregnancy loss before 20 weeks, and ‘Miscarriage’ is a restricted area guideline which is password protected and therefore could not be accessed and is only available ‘internally’. Victoria, Tasmania, Northern Territory, and Australian Capital Territory did not have any relevant clinical guidelines, and instead only referred to those mentioned above.

T*able 3: Comparison of psychosocial recommendations*

Psychosocial recommendations	**NICE guidelines**	**QLD Health**	**NSW Health**	**SA Health**
Location: Consultation and treatment in a private area away from the maternity ward	✓	✓	✓	
Communication: Offer/facilitate the presence of support person		✓		
Ensure both parents are present at discussions		✓		✓
Provide written and verbal information		✓	✓	✓
Breaking bad news: Staff to be trained in sensitive communication	✓	✓		
Inform of diagnosis in timely manner	✓	✓		✓
Reassure woman it wasn't her fault (when appropriate)		✓		
Allow parents to see absence of heartbeat on ultrasound		✓		✓
Prepare parents for what their baby may look like (when appropriate)		✓		✓
Counselling or bereavement services: Counsel women on potential to experience grief, depression or anxiety		✓	✓	
Assess for psychological risk and refer to mental health services	✓	✓	✓	
Provide information about accessing psychological support	✓	✓	✓	✓
Inform of option of free counselling service (Medicare)		✓		
Memory making: Offer ultrasound results in writing or photo		✓		✓
Early Pregnancy Loss certificate		✓		✓
Memorials		✓		✓
Other		✓		✓
When options declined, provide option for mementos in sealed envelope for future access		✓		✓
Disposal: Inform parents that they can make their own decisions				✓
Provide parents with all options available		✓	✓	✓
Advise parents that cremation is not always possible <17 weeks		✓		✓

Queensland Health provides the most comprehensive clinical practice guidelines on this topic, with five pages dedicated to psychological support. Topics covered by in this section include context and experience of an EPL, communication with parents, supportive care, creating memories, and psychological morbidity. They also include an addition section addressing sensitive management of fetal tissues/remains.

2.3 Part 2: What psychosocial support do women want from healthcare providers when experiencing a miscarriage?

The literature search to address this question was conducted and a flowchart outlining the search strategy is shown in Figure 3. The following key search terms and Boolean operators were used to conduct the search: title search: (miscarr* OR "pregnancy loss" OR "spontaneous abortion") AND title search: (experience* OR perspective* OR perception* OR impact* OR affect* OR view* OR psyc*) AND Key word search: (support* OR care OR treatment* OR manag*).

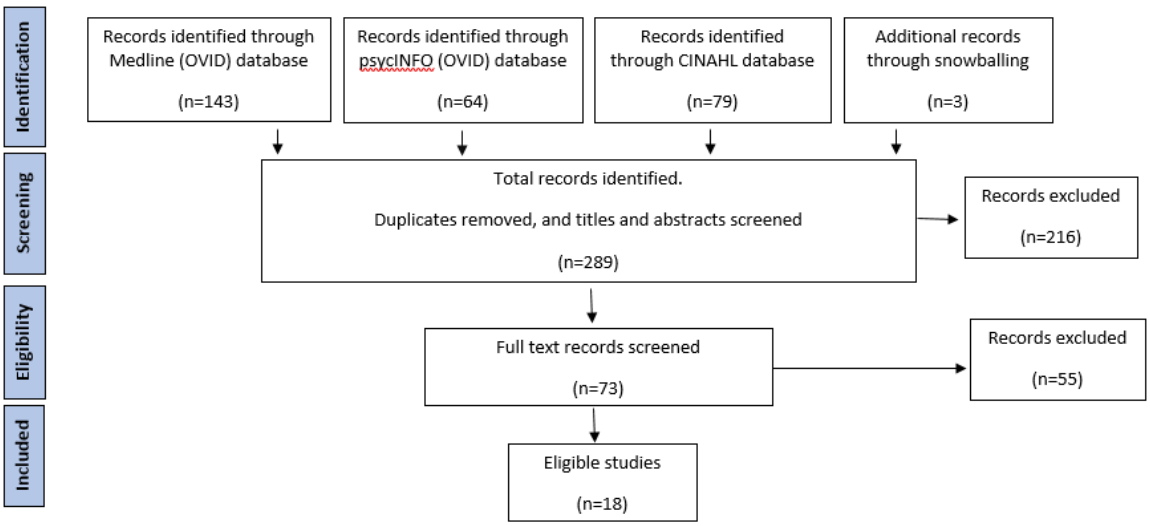

Figure 3: Part 2 literature search flowchart based on PRISMA (64)

The search of all three databases, with the addition of three articles found through snowballing generated a total of 289 results. After duplicates were removed and titles and abstracts were screened for suitability, 72 articles remained. The full text of these 72 articles

was analysed and eligibility determined based on a set of inclusion and exclusion criteria shown in Table 4.

Table 4: Part 2 inclusion and exclusion criteria

Inclusion	Exclusion
Articles published after January 2000 with an accessible full-text and in English	Articles published prior to 2000 or in language other than English
Peer-reviewed articles	Theses, dissertations, conference papers, book chapters or non-peer-reviewed papers
Studies focusing on women's experience of support from healthcare professionals following miscarriage	Studies evaluating the implementation of an intervention, targeting a specific participant group such as partners, young people, or specific ethnicity, studies conducted in countries with healthcare systems significantly different to Australia, studies exploring social support or physical care rather than psychosocial support

After eligibility criteria were considered a final 18 studies were included in this review; 13 studies were qualitative, one was quantitative, one was mixed-methods and three were reviews of the relevant literature. All studies explored women's experiences of miscarriage and the support they received from their healthcare providers. The most common qualitative method of data collection was semi-structured interviews: four were conducted Australia (37, 44, 71, 72), two in the United States (73, 74), two in the United Kingdom (54, 75), one in Ireland (76), and one in Canada (77). The number of interviews conducted in each study ranged from six to 22. One Australian qualitative study utilised in-depth interviews with three women (78). A UK study qualitatively analysed open-ended responses from a national survey of 172 women (79), and another study used phone follow-up surveys to qualitatively evaluate women's experience of miscarriage in an Australian public hospital (80). Only one Australian study took a mixed-method approach by surveying 109 patients and asking both open and closed questions (15). The final three articles were literature reviews providing an exploration of previously published research on what women want from healthcare providers following miscarriage (34, 53, 81).

The following five key themes were evident in the literature:

1. Women's desire for a focus on their emotional as well as physical needs;
2. A perceived lack of empathy and recognition of their loss;

3. Health professionals' use of insensitive and medicalised language;
4. A lack of information provision regarding cause, physical symptoms, and subsequent pregnancies;
5. A lack of follow-up care.

Reports of women feeling that healthcare providers **focused on treating their physical health and overlooking their emotional needs** was seen in most studies (34, 37, 44, 53, 71, 73, 77-79, 81). Many women felt alone and wanted more emotional support from doctors and nurses, with one participant noting that the hospital environment felt "*unsupportive and cold*" (73). Another woman summarised her feelings about the lack of sufficient emotional care offered to her, "*I just remember feeling really upset and I was in tears, but there wasn't any support in terms of anyone wanting to talk to me about what had just happened, more emotionally. But it was more, 'Are you okay? Are you in pain? Here's some painkillers. Have something to eat and drink and then you can go home'*" (71). This focus on the physical condition alone and inattention of emotional needs was aptly summarised in a free-text response from a national women's health survey, "*I was treated as though I just had a medical condition, rather than any recognition of the loss I had suffered*" (79).

A perceived lack of empathy, compassion, and acknowledgement of loss from health care providers was reported in almost all studies (15, 34, 37, 44, 53, 71-76, 78-81). A common theme was women's desire for staff to recognise their miscarriage experience and to be provided permission to grieve their loss. Similarly, a lack of much desired reassurance was also reported in many studies. In-depth interviews with three women who experienced a recent miscarriage found that they felt healthcare providers did not care or appreciate what they were experiencing, demonstrated by their staying distant and not listening to them (78). This notion was also echoed in findings from a survey of 109 Australian women, where 38% felt that the opportunity for them to express their feelings was poor to fair (15). When describing the perceived lack of compassion from hospital staff, one woman explained that she was "*treated like you're having your wisdom teeth out or something*" (44). Upset by this apparent apathy for her miscarriage experience, one participant requested staff "*stop viewing it as just a process and realise that, whether it's a women's first miscarriage or her fifth, it is still a loss*" (79).

The use of insensitive or medicalised terminology was also voiced in the literature as an unsatisfactory aspect of care (34, 53, 71, 76, 79). Women described the language used by some healthcare providers, particularly sonographers, as not only confusing, but also

insensitive and clinical. In a recent Australian study, one participant described her experience of learning of her pregnancy loss "*The sonographer started scanning and he's going 'oh, well, yeah you're pregnant but no it doesn't look like there is much there' ... And he said 'do you want to be pregnant?' and it's like, I said yes, and he said 'well there's not much there*'" (71). Other studies have shown that women are unhappy with the use of medical terms such as 'spontaneous abortion', 'products of conception' and 'foetus' when describing their loss. The same woman who described her experience with the sonographer also noted that "*they termed it as 'you've retained product', which is a saying I cannot stand, it's odious*" (71). This notion is also voiced in the free-text responses to a national online survey, "*my miscarriage was a 'missed abortion' type. I hate this term for a wanted baby*" (79).

A complaint that was reported in every study included in this review was that women wanted to be **provided more information about their miscarriage**. Women voiced that they felt information about their condition was being kept from them and that healthcare providers failed to provide a clear explanation about what was happening to them As one woman stated, "*they didn't tell me anything and they were really scaring me*" (73). Another woman in the same study even described not being informed of what her treatment would involve, "*they gave me paperwork, but they didn't explain to me what it meant*" (73). Many studies have found that women want more explanation and reasons for their miscarriage, as demonstrated by Evans et al.'s 2002 Australian survey which found that only 42% of women felt satisfied with the reason or explanation given by staff for their miscarriage (15). However, it should be noted that often a clear medical explanation cannot be provided, and in approximately half of miscarriage cases the exact cause is unknown (82). Women also wanted information about what to expect, such as information about physical symptoms, length of recovery, and subsequent pregnancies. A free text response from a 2006 UK survey by Simmons et al aptly summaries a personal experience with inadequate information provision, "*It would have been valuable to have received information about what could happen and what to do, as I was at home when I lost the baby and it was an extremely distressing experience*" (79). Harvey et al's 2001 phenomenological Australian study also found that when women didn't receive adequate information at the time of miscarriage, they felt it hindered their recovery due to not knowing what to expect, leading to feelings of disempowerment and loss of control (78).

The final theme common to the literature found was women's **desire for better follow-up care from the healthcare providers** (15, 37, 53, 54, 71, 73, 79-81, 83). A reported lack of follow-up of physical symptoms, emotional well-being, as well as lack of referrals to miscarriage support services often left women feeling alone in their recovery. A US qualitative study exploring

patients experiences of miscarriage management in an emergency room described the lack of direction from staff offered to one woman, "*I didn't like the fact that they just… discharged me and I'm like, 'so, what's next? What do I do? Should I lay down? Should I stay laying down or is there something I could do?' I didn't know anything*" (73). A number of studies which included women who were treated in a special EPAS clinics did not report the same lack of follow-up regarding physical health (37, 44, 75), and instead focused on inadequate emotional follow-up. A participant from Due et al's 2018 study appreciated receiving a follow-up call, but suggested an earlier call would have been more beneficial, "*I thought it would have been terrific if … someone I had spoken to during this process called me earlier just to say, 'Darl, how are you going?' Cos the entire burden of making sure Abby was okay was on my mum … thank God she is still around*" (71). Similarly, women valued the provision of resources such as brochures and contact details for miscarriage support organisations like as Sands, and often benefited from utilising them, "*I attended the Sands meeting last week. It was good to know that what I was thinking was normal*" (80).

It is evident from this review that there is consistency in the literature about the support wanted by women, and the support women feel is lacking from healthcare providers. Yet, there is very limited research exploring the efficiency of implementing support interventions to address these issues. One literature review found evidence to suggest higher levels of satisfaction with healthcare providers improves emotional adjustment following miscarriage (34). However, much of the research to date on potential interventions has been unclear and the findings are contradictory (34, 51, 84). An example of this contradiction can be seen in research which aimed to address the finding that women wanted improved follow-up care. Intervention studies found the uptake of the offer of follow-up was poor (34), with little evidence to suggest it improved patients' psychological morbidity (22, 34, 84). Similar discrepancies may exist between patient and clinicians' perspectives on who is responsible for the provision of emotional support. One recent Australian pilot study found many health professionals did not consider themselves responsible for patients' emotional care following miscarriage due to limitations of time and resources, compassion fatigue and a need for self-protection (55). More research is needed to clarify what types of support from healthcare providers would be most beneficial to women who experience miscarriage and they types of support healthcare providers can offer.

2.4 Part 3: What psychosocial support is currently offered to women who experience miscarriage in Australia?

Given the unique environment of the Australian healthcare system, only findings from Australia are included in this section of the literature review. An initial exploration of support services which function independently from the public healthcare system was first undertaken. These were largely known by the research team and relevant networks before this search, and the remainder were identified through snowballing from relevant organisations' literature and online information. A description of available services can be seen in Table 5 below. They typically offer psychosocial support to women experiencing early pregnancy loss through websites, phone hotlines and peer support groups. In addition, some of these services have been involved in training healthcare providers and in developing health promotion information. Most of these services are non-government organisations that run with limited funding from donations and fundraising. Very few focus primarily on supporting women and families after a miscarriage, as most encompass all forms of pregnancy loss, often focussing on stillbirth.

These support services are valuable resources for women feeling alone or wanting additional support following a miscarriage. Studies on online perinatal loss support groups have shown that peer support connects grieving women, creating a community and helping women bring meaning to their loss, consequently reducing feelings of isolation (85, 86). However, most are not co-designed with consumers, and many remain invisible to both healthcare providers and those seeking support (55, 87). For example, the only organisation listed that focuses solely on miscarriage is the newly established Pink Elephants Support Network. Yet, if a woman or her partner feel they need support and try to find it through a Google search of 'miscarriage support Australia', they would have to search through five pages of results before finding this organisation. Likewise, many organisations mentioned above are not connected to any recognised research group, and therefore are likely unable to undertake evidence-based research to guide and strengthen their services to ensure maximum benefit to those seeking support. Similarly, there appears to be limited awareness of these support groups by EPASs given that they operate in isolation of the public health system.

Table 5: Overview of psychosocial support services

Organisation	Location covered	Topic of focus	Phone line	Internet support in addition to information provision	Peer support groups	Support from a qualified HCP	Training for HCPs
SANDS	Nationally	Miscarriage, stillbirth and newborn death	24 hr by volunteers	Yes, live chat and email	Yes	No	Yes
Pregnancy Loss Australia	Nationally	Miscarriage, stillbirth and infant loss	No	No	No	No	No
Pregnancy, Birth and Baby	Nationally	Expecting parents and parents of children up to 5 years	7am-12am everyday	Yes – video call	No	Yes	No
Bears of Hope	Nationally, but primarily NSW & ACT	Miscarriage and stillbirth	Yes	Yes – email, Skype, and forum	Yes	Yes	Yes
The Pink Elephants Support Network	Nationally	Miscarriage	No	Yes – email	Yes	No	No
Red Nose Grief and Loss	Nationally	Miscarriage, stillbirth and loss of child	24 hr	Yes – live chat Mon-Fri 11am-7pm with volunteer	Yes	Yes	Yes
COPE	Nationally	Emotional and mental health in pre and postnatal periods	No	No	No	No	Yes
PANDA	Nationally	Anxiety and depression during pregnancy and 1st year of parenthood	Yes – 9am-7:30pm Mon-Fri	Yes – email, forums	Yes	Yes	Yes
The Compassionate Friends	Victoria	Grief support	Yes – 24 hrs	Yes – video chats	Yes	No	Yes
GriefLine	Nationally	Grief support	Yes – midday-3am everyday	Yes – online counselling	No	Yes	No
Australian Centre for Grief and Bereavement	Nationally, but primarily Victoria	Grief and bereavement	No	No	Yes	Yes	Yes

The provision of psychosocial support by healthcare providers was then explored through the following literature search. The search strategy was very similar to the search conducted in Part 2 of this literature review, and a flowchart outlining the method is shown in Figure 4. The following search terms and Boolean operators were used to conduct the search through key words: (miscarr* OR "pregnancy loss" OR "spontaneous abortion") AND (support* OR care OR treatment* OR manag*) AND (psychosocial OR "psycho social" OR "psycho-social" OR psychology* OR counsel* OR social) AND Australia*.

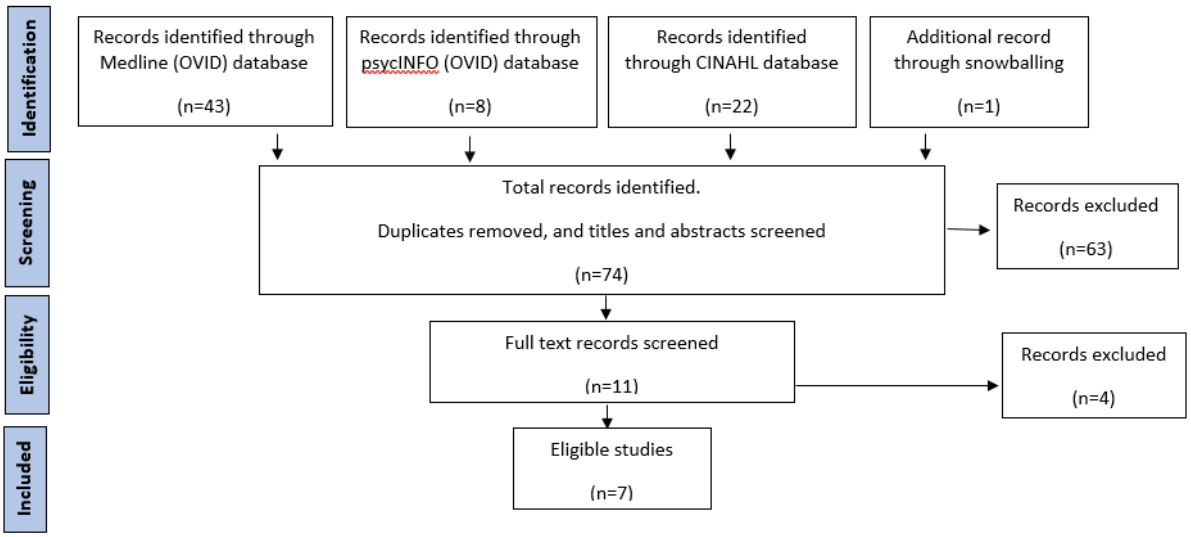

Figure 4: Part 3 literature search flowchart based on PRISMA (64)

The search found a total of 74 articles, and after duplicates were removed 54 remained. Titles and abstracts were then screened for suitability and 11 remained. The full texts of these papers were then analysed and considered based on eligibility criteria shown in Table 6, and seven articles were found to be relevant.

Table 6: Part 3 inclusion and exclusion criteria

Inclusion	Exclusion
Articles published after January 2000 with an accessible full-text, in English and based in **Australia**	Articles published prior to 2000, in language other than English, or based in a country other than Australia
Peer-reviewed articles	Theses, dissertations, conference papers, book chapters or non-peer-reviewed papers
Studies focusing on what support women received, or what support is available/offered to women following miscarriage	Studies evaluating the implementation of an intervention, targeting a specific participant group such as in vitro fertilisation (IVF) patients, studies exploring social support, or studies focusing on acupuncture use

Four of the seven final papers found in this search were also included in Part 2's literature search (15, 37, 53, 71). The following three studies focused solely on women and partner's experience of miscarriage care, and therefore add little to what was outlined in part 2 of the literature review (32, 37, 71). Bellhouse et al's 2019 qualitative study on 15 women's experience of miscarriage found that women perceived a lack of psychosocial support from their healthcare providers at the time of their miscarriage (37). Similarly, all 15 participants in Due et al's 2018 qualitative study exploring the healthcare provision following pregnancy loss reported negative interactions with their healthcare providers due to a lack of "emotion-focussed support" (71). Rowlands and Lee's 2010 qualitative study of 9 women found similar themes to those outlined in Part 2, such as a lack of information provided, reported use of insensitive comments, and perceived lack of empathy form staff (32). As all three studies focused on women's experience of psychosocial care following miscarriage, where they received care is not explicitly stated, and thus may have been an EPAS, an ED, or General Practice.

Geller, Psaros and Kornfield's 2010 literature review did include some studies with staff as participants, however no new themes or insights into the provision of psychosocial support was evident (53). One objective of their literature search was to determine what comprises "treatment as usual", and they found that this varied between studies and settings, so no conclusions can be drawn about 'typical psychosocial treatment'.

Edwards et al's 2018 qualitative study explored the experiences of three women, two male partners, and six registered nurses following miscarriage in a non-metropolitan ED (88). Findings were very similar to studies previously discussed on women's experiences of

miscarriage support from healthcare providers, especially in ED. However, this study also offered insight into nursing staff's views such as the restrictions to providing adequate psychosocial support. These included limited resources, a lack of specialised staff, limited funding, and lack of personal development opportunities which all impacted on patient care (88). These findings are mirrored in Jensen, Temple-Smith and Bilardi's 2018 qualitative paper exploring 12 health professionals' practices in supporting women following miscarriage (55). Participants included four GPs, four Obstetrician Gynaecologists, three midwives and one sonographer. Clinicians viewed their support role as primarily guilt alleviation and focused largely on their patients' physical health, relying on patients to express the need for any further support. Like Edwards' study, participants named limitations on time and resources as restricting their ability to provide psychosocial support, in addition to compassion fatigue and the need for self -protection (55).

Evans et al's 2002 mixed methods study explicitly explored 109 patients' and 43 staff members' views on hospital psychosocial care and found staff agreed that the hospital experience could be improved for women (15). Most staff surveyed were either unsure or agreed that the psychosocial needs of their patients were not adequately met, and 56-86% felt they did not have adequate time to listen and talk with patients. Reflecting Edward et al's study reported earlier, 65% of staff reported no professional training in caring for women experiencing miscarriage, and 80% reporting wanting to receive training (15).

Part 3 of this literature review explored the current provision of psychosocial support to women who experience miscarriage in Australia. Only four of the seven studies discussed included healthcare providers as participants (15, 53, 55, 88), and none explored EPASs specifically.

2.5 Discussion of literature

The findings of this review reveal a gap in the literature on the provision of psychosocial support in the Australian healthcare system. This literature review demonstrates the lack of evidence-based clinical guidelines on psychosocial support, a well-documented need to improve psychosocial support from patients' perspectives, and a lack of literature on the provision of such support by the healthcare system. No studies were found that explored what psychosocial support is offered in *Australian EPASs*, and very limited studies reported on what was offered by healthcare providers more generally. Most literature on EPASs focuses on hospital benefits of these clinics as discussed in the introduction, or on women's experience of

care. Given the increasing utilisation of EPASs in Australia for management of EPPs, this knowledge gap must be addressed to help improve women's miscarriage care and support.

2.6 Conclusion

This chapter explored what is known in the current literature on the psychosocial support following miscarriage, by examining the existence of professional guidelines on the topic, research on the support wanted by women following a miscarriage, existence of miscarriage support organisations, and research on the support provided by health professionals in Australia.

Findings highlight the need for explicit guidelines regarding psychosocial care for women who experience miscarriage. Studies have consistently shown that many women report unsatisfactory emotional care and support from healthcare professionals following miscarriage, yet the literature provides little evidence of research on the provision of such support from the providers' perspective in Australia, specifically from EPASs. The proposed study aimed to address this gap in knowledge by answering the following research question:

What psychosocial support is offered in Early Pregnancy Assessment Services in Australia?

The next chapter outlines the methods utilised to answer this question, and discusses the methodological framework, study design, and ethical considerations.

Chapter 3: Methods

3.1 Introduction

This chapter describes the methods employed to answer the research question, "What psychosocial support is offered in Early Pregnancy Assessment Services in Australia?" The methodological framework is discussed and justified, the research team and study design is outlined, the method of data analysis is described, and a statement of ethical consideration is provided.

This study has been reported in accordance with Consolidated Criteria for Reporting Qualitative research (COREQ) guidelines (89) (Appendix 6).

3.2 Methodological framework

Various methods of approach were considered prior to conducting this research. A primarily qualitative approach was chosen with some initial audit questions and field notes. This is explained in more detail under the subheading 'Study design'. Qualitative research methods are commonly employed in areas of research where little information about the topic is known (90). The primary goal of qualitative research is to develop concepts which help us to understand the meanings, experiences and views of the participants (91). This is achieved through the systematic collection and interpretation of verbal or visual data (92).

Due to the practical nature of this study, qualitative description was chosen as the most appropriate framework. As a contribution to theoretical knowledge was not a research aim, typical qualitative theoretical frameworks such as phenomenology, ethnography, and grounded theory were not considered appropriate. Qualitative description is a pragmatic rather than theory driven approach, suitable for research "aiming to gain firsthand knowledge of patients', relatives' or professionals' experiences with a particular topic" (93). Unlike many other qualitative frameworks, qualitative description is founded within existing knowledge and the experience of the research group (93) and is commonly used in healthcare research as it allows researchers to address questions of particular clinical interest or relevance. This method was particularly suited to this research as key informants' knowledge and views could be explored within the context of published best-practice guidelines and prior research on patients' experiences of miscarriage. Unlike other qualitative frameworks, qualitative

description does not aim to provide a theory based or interpretive analysis, rather it aims to provide a straight description of events or topics of investigation (94).

3.3 Research team and reflexivity

All interviews were conducted by LC (BSc (Hons)) or co-conducted with SRH (BSc). SRH was a 2018 Honours student in the Department of General Practice (DGP), whose research focused on the pathways into and common characteristics between EPASs in Victoria. Participants based in interstate EPASs or from miscarriage support organisations were interviewed by LC only. Both women received research and interview training during their study in the DGP, and neither had any prior relationship with participants. Participants were informed that this research project was being undertaken with an aim to better understand EPASs in Australia and their provision of psychosocial support.

Although the intention of this research was to interview participants objectively to explore EPASs and their provision of particular services, researcher bias should not be overlooked. The interviewer's personal perspective likely influenced the way interviews were conducted and data were interpreted (95). As a young woman with a keen interest in women's health issues, LC's innate perspective is one that is likely to focus on the patients' experience rather than the health care providers'. Similarly, a lack of clinical qualification or experience may have resulted in difficulty empathising with clinicians' perspectives or may have biased interpretation of clinician's responses. Although these personal characteristics ideally do not influence this research significantly, it is important to acknowledge the possibility of researcher bias and to recognise the lens through which this research is viewed.

3.4 Study design

To gain an understanding of what psychosocial support is offered in EPASs, semi-structured interviews were chosen as the main method of data collection. This was considered most appropriate as semi-structured interviews aim to "seek views on a focused topic or, with key informants, for background information or an institutional perspective" (92). In-depth interviews are used to understand an experience from a personal perspective (92), and therefore were not suited to the aims of this research study. Similarly, focus groups were not chosen as anonymity cannot be guaranteed, and staff from the same EPAS may have had differing perspectives on the service, presenting opportunity for conflict. In addition to semi-

structured interviews, some initial audit questions were utilised to collect basic information about the structure and fundamental function of the service. Likewise, field notes were taken to assist with process mapping, which was utilised to gain an increased understanding of what the typical patient journey may involve (96).

3.4.1 Participants

Participants invited to participate in this study were those considered 'key informants' who had previously, or who were currently involved in an EPAS. In addition, key informants currently involved in miscarriage support organisations were also included to gain perspectives from those who often support women following their EPAS care. Participants were ineligible if they were not located or practicing in Australia. Potential participants included all EPAS staff, such Obstetrician Gynaecologists (O&G) consultants and registrars (specialists and specialists in training, respectively), resident medical officers (doctors pre-specialist training), nurses, midwives, sonographers and pastoral care practitioners. People with varying roles within the same EPAS were invited to participate where possible to provide differing perspectives.

3.4.2 Recruitment

As Australia lacks any national database of EPASs, and information about specific EPASs services can be difficult to locate, it was expected that there could be some challenges with recruitment of participants. Therefore, to maximise recruitment, both purposive and convenience sampling were employed, with multiple strategies including utilising existing contacts, snowball sampling, and cold calling. The research team provided details of known contacts, who were then emailed an introductory invitation to participate by SRH or LC (Appendix 1). This introductory email included an overview of the research project, the plain language statement (PLS) (Appendix 2), consent form (Appendix 3), and contact details of the research team. After existing contacts were contacted, snowball sampling was utilised to assist with recruitment of additional participants. This method contributed a significant portion of participant recruitment given the lack of publicly available information about EPASs. Finally, cold calling was employed where other methods failed. Cold calling began with contacting the University of Melbourne's clinical hospitals and expanding to contacting interstate hospitals with known EPASs. The aim of this recruitment method was to recruit all University of Melbourne clinical hospitals, in addition to interstate comparisons, to reach data saturation.

Participants did not receive any reimbursement for participating due to financial limitations and some contention around the appropriateness of this technique (97). However, all participants were provided a summary of findings.

3.4.3 Data collection

The interview guide (Appendix 4) was developed and structured based on the psychosocial recommendations outlined in the Queensland Health Early Pregnancy Loss Clinical Guidelines (63), existing literature and the expertise of the research group. Questions were subjected to ongoing reflection and consideration and adapted accordingly as interviews progressed.

Participants were invited to participate in a semi-structured interview either face-to-face or via telephone. Prior to the interview, participants were required to read the PLS to ensure they were fully informed about what their involvement in study would entail, sign the consent form agreeing to participate and provide permission for the interview to be audio-recorded.

Before commencing the interview, each participant was asked a series of demographic questions about their gender, their role and time working in the service. Initial interview questions were audit-style to collect information about EPAS operation, such as opening hours, referral pathways, staffing arrangements, management options offered, and provision of counselling. Interviews then progressed to open-ended questions, which included best aspects of the service, service barriers and areas for improvement, and participant's view of psychosocial support. A brief tour of the service was provided in most hospitals and field notes were taken to better understand a typical patient journey.

Participants were not provided their transcripts for review due to time limitations of both the study team and participants. However, participants were provided feedback on summary findings of the study and were provided the opportunity to amend any information collected during the interview.

3.5 Methods of data analysis

Throughout the recruitment period the research team met on a weekly basis to discuss emerging themes and refine the interview schedule and sampling framework. The research team aimed to recruit participants from a variety of locations, professional positions and include both male and female participants. After 31 interviews were complete the research team met again to discuss the results and review the interview transcripts, and at this time it was decided that no further themes were arising from the data and saturation had been met.

All transcripts and field notes were transcribed verbatim by the student researchers or a transcribing company. Transcripts were de-identified and allocated a study number to protect participant and EPAS confidentiality. All transcripts and field notes were subject to content

analysis. Qualitative content analysis is the method of data analysis typically used in qualitative descriptive studies (94). This dynamic and reflective method accommodates new insights throughout the analysis process and is orientated towards summarising the information collected in data. Although most themes are induced from raw data, content analysis may also begin with a pre-existing coding framework which is then modified over the course of analysis (94).

Descriptive audit data were considered, and meaningful features chosen and collated into tables for comparison between services. These tables were supported and supplemented by field notes taken during process mapping.

To begin the content analysis process, interviews were first manually read to gain a preliminary understanding of emerging themes and to note any reflections or insights on interviews (93). A pre-existing coding framework was created from key interview prompts, and some broad themes were then deduced from data (94). Transcripts were then re-read, and noteworthy phrases or concepts were 'coded'. Commonly arising codes were then categorised into appropriate themes and extracted for further consideration. Transcripts were then imported into NVivo software to manage data and refine the coding frameworks. The research team gradually reached consensus on themes which held true across data. These themes were then examined with consideration of existing knowledge on EPASs and psychosocial support available to women who experience miscarriage. A selection of transcripts were read and cross-coded by members of the research team to minimise interpretation bias and ensure accuracy and consistency of analysis.

3.6 Ethical consideration

Ethics approval for this study was granted by the Human Ethics Advisory Group (HEAG) of the Department of General Practice at the University of Melbourne, Victoria, Australia, application number 1851563.3 on the 26 June 2018 (Appendix 5). The project was deemed "minimal risk" as the participants were key informants and the interview questions were of a non-sensitive nature.

There were no anticipated risks to participants, however a risk management strategy was implemented if participants became distressed at any point during the interview. Participation was voluntary, and the option of withdrawal at any time was reiterated at commencement of the interview.

In addition to university ethical clearance, some hospitals required this project to be subject to the hospital's own research governance committee for ethical approval.

3.7 Conclusion

The combination of qualitative and audit methods used in this study were identified to be the most suitable for exploring the provision of psychosocial support in EPASs. The next chapter will discuss the results of this study.

Chapter 4: Results

4.1 Introduction

This chapter presents the findings of data collected over 31 semi-structured interviews. Details of the recruitment process and its success are presented first, followed by demographic details of participants, and finally thematic results which arose from the interviews. Findings are presented in three broad categories in relation to the provision of psychosocial support; 1) Psychosocial support currently provided 2) Psychosocial support considered ideal by participants, and 3) Barriers to changing psychosocial support. Themes and subthemes have been identified within categories, and direct quotes from participants are used to describe these themes. Figure 5 provides an overview of themes within each three categories.

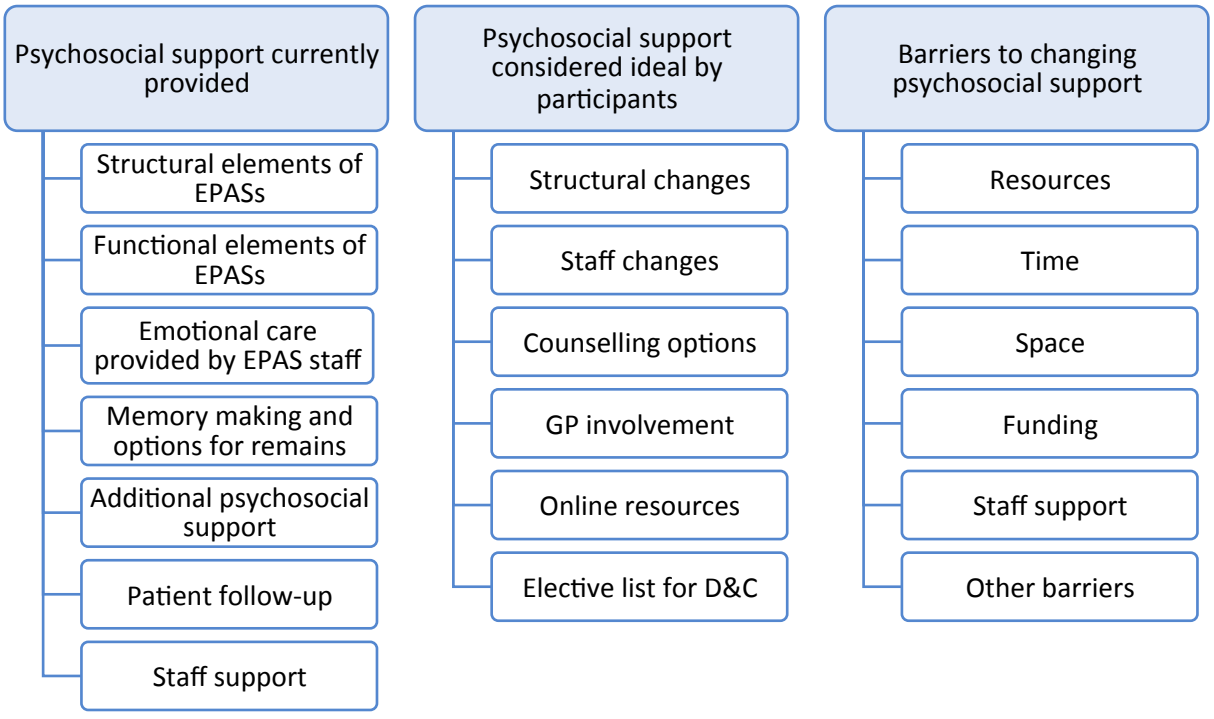

Figure 5: Diagram of three categories and main themes

Observational data collected from field notes is also presented in conjunction with these findings.

4.2 Recruitment

The study team contacted 56 people from 17 EPAS and two support services and recruited a total of 31 participants from 13 EPASs and two support services. This recruitment method utilised approximately 130 emails and 55 phone calls, and a detailed explanation of recruitment steps and numbers is shown in Figure 6.

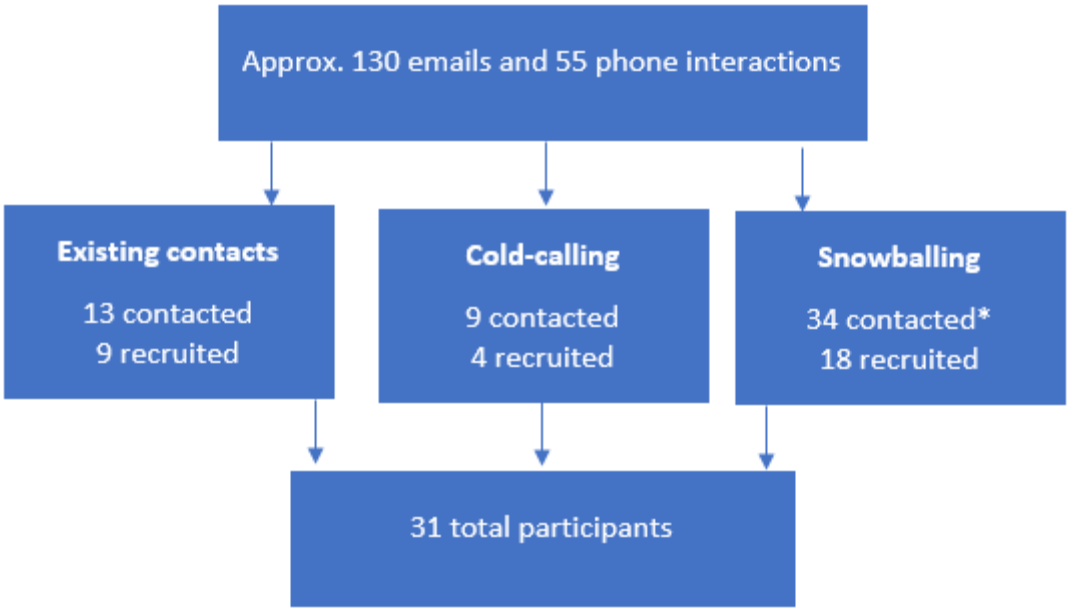

Figure 6: Recruitment flow chart

* Additional people were informed about this research without their details being provided to us. E.g. an advert was placed on a closed Facebook group, and others said they would distribute study information to their own networks.

There were a range of reasons for non-participation of people who were directly contacted, but not recruited (n=25), as outlined in Table 7.

Table 7: Reason for non-participation

Reason for non-participation	**Number (n=25)**
No response	11
Expressed interest, but lost to follow-up	4
Did not work in EPAS	4
Unavailable/uninterested	3
No EPAS in hospital	2
Required hospital ethical clearance	1

Interviews were conducted from the 9th June 2018 to 16th April 2019. Ten interviews were conducted over the phone and 21 interviews were conducted in-person. Of the 13 EPASs represented, all except one clinic was visited in-person. Details of the approximate locations and participant numbers from each EPAS are shown in Figure 7. Interviews ranged in duration from approximately 15 minutes to 1 hour and 20 minutes, with an average of 35 minutes. Interviews less than 25 minutes were all from services in which another staff member was/members were interviewed for longer. Several were from the same service and had limited time due to patient appointments.

Figure 7: Map of EPAS distribution

4.3 Participant demographics

Brief participant demographics were collected to ensure a range of views and professions were represented (Table 8). Twenty-eight participants worked in EPASs, while three worked outside of EPASs but within the field of miscarriage support. Three participants were male and 28 were female. Due to the large variety of qualifications and roles, many participants having multiple roles, and the need to ensure anonymity, the roles shown below in Table 2 have been grouped according to participants' position within the EPAS. It should be noted that often participants

fulfilled multiple roles, for example many clinic coordinators worked directly with patients as a nurse/midwife in addition to managing the service. To provide some level of context to quotes while also ensuring anonymity, participants have been further grouped as either 'clinical' or 'support'. 'Clinical' participants include doctors, nurses, midwives and sonographers. 'Support' participants include support organisation staff, pastoral care practitioners, counsellors and psychologists.

Table 8: Participant demographics

	Number (n=31)
Gender	
Male	3
Female	28
Role or position	
Clinic manager/coordinator	9
Nurse/midwife	6
Ob/Gyn consultant	4
Ob/Gyn registrar	3
Specialised GP	2
Pastoral care practitioner	2
Sonographer	1
Clinical psychologist	1
Bereavement counsellor	1
Miscarriage support organisation founder	2

4.4 Psychosocial support currently provided

This section provides details of the types of psychosocial support able or unable to be provided by all 13 EPASs. Audit data was collected and is presented in Tables 9 and 10. Qualitative data supported by participant quotes is presented in conjunction and below.

Table 9: Structural elements of EPASs

	EPAS 1	EPAS 2	EPAS 3	EPAS 4	EPAS 5	EPAS 6	EPAS 7	EPAS 8	EPAS 9	EPAS 10	EPAS 11	EPAS 12	EPAS 13
Location of EPAS	Antenatal clinic	Mixed ward	Antenatal clinic	Near ED	Outpatients clinic	Antenatal clinic	Near ED	Outpatients clinic	Antenatal clinic	Near fetal medicine clinic	Antenatal clinic	Fertility clinic	Pregnancy ED
Location of ultrasound	Radiology	In clinic	Radiology	In clinic	Radiology	Radiology	In clinic	Radiology	Radiology	Radiology	Radiology	Radiology	In clinic
Separate quiet room for distressed patients	No	No	No	Yes	No	No	Yes	No	No	Yes	No	Yes	No

Table 10: Functional elements of EPASs

	EPAS 1	EPAS 2	EPAS 3	EPAS 4	EPAS 5	EPAS 6	EPAS 7	EPAS 8	EPAS 9	EPAS 10	EPAS 11	EPAS 12	EPAS 13
Usual staffing	Registrar	Nurse, Sonographer, Registrar	Midwife, Resident	Midwife, Consultant or Specialised GP	Resident, Nurse	Resident or registrar	Nurse, Junior & Senior doctor	Midwife Specialised GP	Resident	Nurse/ Midwife, Sonographer, Resident	Midwife, Resident or registrar	Midwife, Registrar, Resident	Nurse/ Midwife, Sonographer, Resident, Registrar
Eligible gestation	<16wks*	≤16wks	≤12wks	<13wks*	<16wks	<13wks	<12wks	<20wks	≤12wks	≤12wks*	<20wks	<20wks	<20wks
Self-referral accepted	No	No	If returning patient	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes
Interpreters Available	Onsite & telephone	Limited onsite & telephone	Onsite & telephone	Onsite & telephone	Onsite & telephone	Onsite & telephone	Onsite & telephone	Limited onsite & telephone	Limited onsite & telephone	Telephone	Onsite & telephone	Telephone	Limited onsite & telephone
Patient literature**	Available, not routinely offered	Provided	Provided	Provided	Available*	Available*	Provided	Provided	Provided	Provided	Provided	Provided	Provided

Key: *unclear

**Patient literature included information leaflets/brochures about miscarriage, management options and at times support services

4.4.1 Structural elements of EPAS

Table 9 provides an overview of some structural elements of the EPASs which relate to the psychosocial elements of care.

Location of EPAS

Six services were physically located alongside antenatal or maternity services, and consequently shared a waiting room with obviously pregnant patients. Participants from these services voiced their dissatisfaction with this situation.

> *"It sits with general gynae[cology] and the antenatal clinic. That's something also I would like to look into. We need to move this space to somewhere else" – P15 (clinical)*
>
> *"Unfortunately, there's always antenatal clinic with every EPAS" – P4 (clinical)*
>
> *"I would like to point out that this room was right next to a maternity assessment room. I find it really sad that women who are experiencing a miscarriage have to share their waiting area with women who are coming on 20 weeks of pregnancy for assessment. […] It must be totally awful for these women to share their waiting area." – P16 (clinical)*

The remaining seven services were located in other wards or areas away from antenatal/maternity services, which was viewed as the most appropriate location to reduce the potential for additional patient distress.

> *"We've made sure that we separated ourselves from being close to all the pregnant women because it's not appropriate" – P3 (clinical)*
>
> *"We've put them in general outpatients because I don't want them sitting with a 38-week pregnancy, you know? So, we try to keep them out of maternity ward, and we try to keep them out of antenatal clinic" – P9 (clinical)*
>
> *"Obviously the women are not sitting with very obviously pregnant women" – P27 (clinical)*

Ultrasound facilities

Four services had the facilities to be able to routinely perform ultrasounds within the EPAS itself, and nine typically utilised the Radiology Department if scans were required. Some

services that could not routinely scan within the service had ultrasound machine onsite, however they did not have staff trained to perform scans working there regularly.

> *"We've got this one stop shop facility where we can basically see them, scan them, look after them and admit them if we need to" – P27 (clinical)*
>
> *"We do have the availability of an ultrasound machine in the clinic, but it's rarely done, and usually because the clinician is usually a more junior clinician" – P11 (clinical)*
>
> *"We send them across there [radiology] for formal ultrasounds. We don't do any bedside scanning in here"' – P14 (clinical)*

Quiet room

Four of the 13 services had a dedicated room separate from the clinical or consulting room available for patients and their families if they needed a quiet and private area. Three services noted that they had a room that could be used for this purpose if it was not already in use by others, and six did not have the space.

> *"This is the crying room basically. And so, people can come and see them here and they can sit here; we will bring them a cup of tea" - P12 (clinical)*
>
> *"We've always got somewhere to actually put a distressed couple, so they don't have to sit in the waiting area. We can actually find somewhere quiet for them" – P27 (clinical)*
>
> *"I said I wanted a crying room, but they didn't have anywhere to put it" – P30 (clinical)*
>
> *"That would be the toilet" – P5 (clinical)*
>
> *"There's no place for them to grieve. There's no place for them to sit." – P4 (clinical)*

4.4.2 Functional elements of EPASs

Table 10 shows the variance in EPAS function and services offered. In some cases, details of the audit data collected from different participants who were working at the same service, differed. Clarification was sought where possible, and those details which remained unclear have been denoted by an asterisk in Table 4.

Staffing

Services appeared to have a range of different staffing arrangements, however most were run by nurse or midwifery staff alongside a junior doctor. Experience levels of medical staff working in EPAS varied drastically and ranged from residents to consultants. Most services relied on nursing and midwifery staff, although some were run solely by medical staff. Likewise, three services had a sonographer available in clinic at some times. All services that were not run by senior doctors had access to advice from senior on-call doctors if needed.

> *"It's basically one midwife, there's one medical officer - sometimes a registrar, sometimes a senior RMO that is the doctor allocated for EPAS. They also cover some other areas as well" – P21 (clinical)*
>
> *"The clinical contact at a medical level is often reasonably junior with a level of escalation to senior, but we do it a bit differently here… we do mostly our own scans and we're mostly pretty senior" – P7 (clinical)*
>
> *"The resident may have a question, refer to the registrar, if the registrar's got issues, we'll refer to the consultant, so we've always got access to refer up." – P5 (clinical)*

Gestational limit

A variation in the gestational limit of patients eligible to be seen in EPAS was also noted. Some EPASs restricted access to their service to patients in the first trimester of pregnancy only, while others saw patients up to 20 weeks of gestation. Oftentimes the purported limit and what occurred in actual practice did not align, as staff would accept patients beyond the limit specified, if they had been referred to the service.

> *"Anything up to 16 weeks, but in fact they see people who are probably up to 20 weeks" – P2 (clinical)*
>
> *"Anything less than 12 weeks, however, GPs and ED tend to send them anything less than 20 weeks" – P4 (clinical)*

Typically, patients experiencing pain and/or bleeding before 20 weeks, but after the EPAS eligibility limit, were seen in ED and then managed in the maternity ward due to the need for additional medical support.

Self-referral

Five EPASs did not allow patients to self-refer or walk in to gain an appointment. Other services allowed self-referrals for returning patients, but self-referral was generally not the preferred entrance pathway.

> *"If there's someone who is known to us and all that sort of thing. So, women can self-refer when they already know about the place" – P8 (clinical)*
>
> *"They can but we prefer them to have a doctor's referral. We're actually just changing our referral process […] We're trying to move to a completely referral process" – P20 (clinical)*
>
> *"Sometimes we get them from emergency, GPs, some women, or a lot of women, know about the service so they self-refer as well. They can call to make an appointment" – P21 (clinical)*

Access to interpreters

Many services noted the difficulties in accessing an onsite interpreter, however all services had access to telephone interpreters. Some EPASs found the use of telephone interpreters adequate, while others thought it restricted their ability to communicate effectively and within their allocated time.

> *"Unfortunately, the majority of the time we use phone, which is really bad. Yeah, really, really bad" – P4 (clinical)*
>
> *"We try to get interpreters, but you know, at that time, you can't always get one, so we might use a phone interpreter. So sometimes you have to use more simple language" – P21 (clinical)*
>
> *"It's not ideal, but it's the best we've got" – P23 (clinical)*

Patient literature

All EPASs had patient literature such as leaflets and brochures available which provided information on management options for specific medical conditions. Most services also had some literature from pregnancy loss support services or had references to such services within

other literature. However, not all staff were knowledgeable about what was available, and only some services appeared to routinely offer this literature these to patients.

> *"We've got information sheets there for bleeding in early pregnancy that we give out to the women and then the management of miscarriage information sheet […] We have brochures on SIDS and pregnancy loss, so we can hand them out" – P6 (clinical)*
>
> *"All people who go through EPAS are given resources for Pink Elephants which has its free resources and the advisory peer advisory program they can be part of" – P26 (support)*
>
> *"At the moment there is no way for patients to access patient information pamphlets" – P4 (clinical)*
>
> *"I'm sure we do, but I haven't seen them" – P14 (clinical)*

4.4.3 Emotional care provided by EPAS staff

Despite no EPAS staff having any formal counselling experience, the interviews demonstrated that all staff showed a profound care for their patients and demonstrated their support for their patients' emotional, as well as physical needs.

> *"We do lots of counselling. Obviously, there's lots of talking and talking and talking and providing information and we can refer on if we need to" – P3 (clinical)*
>
> *"We are not counsellors. We are not trained really to professionally counsel them, but we should have some expertise in that area just because, as you can imagine, they are very emotional" – P24 (clinical)*

Support and respect

All staff spoke of the importance of listening to their patients and the need to empathise and understand their feelings. Following this, showing care, respect and supporting patients in their specific needs was emphasised.

> *"They need to be listened to. You need to understand their perspectives, and you have to show empathy and sympathy and support them through it" – P10 (clinical)*
>
> *"You just do so many things to not leave someone on their own. You do so many things to try and help someone have some feelings. You do so many things to make sure that*

they have the right information. […] You're thinking that by the end of that consult, you want that woman to feel that she's been listened to. By the end of that consult, you want to feel that somehow, you've said the things that are going to make her feel safe enough that she can have some feelings with you" – P8 (clinical)

"I think having someone who is caring at the forefront of the EPAS service is really important. And you know with that I guess having enough time for the woman to come through and to feel heard rather than it being a really rushed service where it's just churning through patients quickly. I think allowing enough time is really important" – P28 (clinical)

"I try to keep her in the loop of what they're [doctor and sonographer] talking about, because their language can be, I think for many people very tricky, so it's a bit concerning for them [the patient]. Trying to keep it nice and simple and explain what's happening, just so that she's got somebody there" - P3 (clinical)

Acknowledgment and validation

Acknowledging women's loss and validating feelings about their loss was discussed by almost all participants. This was often done at the beginning of consultations, especially as it was deemed necessary to allow patients to engage and listen to the necessary medical information and management options.

"I always offer my condolence, I always say 'I'm very sorry for your miscarriage', so I always acknowledge that to start with, which I think is very important thing to do." – P27 (clinical)

"It might be something that happens and its very common, and it does happen a lot, but it's still your pregnancy and your pregnancy loss is still really important. It will be a part of your life forever, but it's still important, you can't always brush it off" – P3 (clinical)

"Just sitting with them and listening. I think that's a validating their experience, not telling them that "oh, this happens to one in five. We'll get you another baby due". You know just sitting with them. And I suppose your physical presence shares with them, and the fact that we have a clinic, shares with them that they're not alone. That's one of the biggest things, and that we're here to listen to their loss." - P12 (clinical)

"I think it's very important for it to be communicated to women that this is a very significant loss. That it's not to be downplayed, that this is a time of grief" – P13 (clinical)

"Just validating their loss and the process is really important […] you can be as devastated at five weeks as you can be at 11 or 12 weeks. To say that to them, that it's still a loss whenever it happens" – P20 (clinical)

Guilt mitigation

Most participants discussed the need to reassure their patients that they were not responsible for their miscarriage. This included explaining more likely reasons for their pregnancy loss, and directly addressing potential thoughts women may have about how they could have caused their miscarriage. This was also discussed as something that needed to occur early in a consultation, to allow patients to consider other aspects of care.

> *"I always used to include something along the lines of 'you look for somebody to blame, and please try not to blame yourself' and a little sort of spiel that you get ready over the years of, you know, 'you might look back over the couple of weeks that have gone past and think was it that glass of wine I had? Was it the piece of soft cheese? Was it intercourse?' Quite a few things that are most common, and just try to sort of pre-empt them and say 'you didn't do anything wrong. You've done the very best you could and I'm so sorry'" – P17 (support)*

> *"I always tell them they couldn't have made this happen. And that's the most important thing that no matter what else they hear or don't hear. You did not do this. You cannot have done this even if you wanted to do it. People pay a lot of money to go to abortion clinics, you know. You have to make a big effort to end a pregnancy. Just running for the train or lifting some boxes or you know fighting with your partner. None of that is going to make you miscarry." – P23 (clinical)*

> *"The important thing is to tell them that it's not their fault, because a lot of times women blame themselves. […] They then cling to something that they've done which is completely, medically is completely not rational, but 'oh yeah I flew to Sydney like three weeks ago. Could that be the cause?' Or you know, 'I cleaned my house last week, could that be the cause?' You know the kind of thing, and it's just about sort of sitting there and saying 'no it's not the cause, not that's not the cause, it's none of those things'. Just explaining to them medically why it occurs, typically with errors in the cell division, so it's nothing that the mum did or didn't do, and that kind of thing. I think that's probably the biggest relief, and once the women hear that they are often a lot more relieved, and then you can often go forward with the discussion. […] Once you do that, the women are a lot more open to speaking about other things" – P14 (clinical)*

Language

Some participants discussed the language used when talking with patients about their pregnancy loss. All avoided using clinical terminology such as 'products of conception', or words they thought lacked care and sensitivity. Instead, participants spoke of mirroring the

language used by patients themselves and were sensitive to their patients' emotions and individual preferences.

> *"I often talk about the baby. I do use that word. I try to veer away from embryo" – P7 (clinical)*
>
> *"Lots of people use lots of different terminologies. In the end I kind of try to pick up a cue of what the patients want to refer to it as" – P16 (clinical)*
>
> *"I will refer to the foetus as the baby or the pregnancy. But sometimes you have to say the tissue comes out rather than the baby comes out just because it's all a bit raw and you're trying to make it easier. You're not discounting the fact that it was their pregnancy but yeah some of it is medical you will say they're trying to catch the pregnancy tissue as opposed to this could have been your baby, just to make it easier I guess" – P23 (clinical)*
>
> *"Some women are very okay. They want it very medical. And you can tell that that's the way they're going to cope. Other women are still holding their tummy and crying and talking about the baby, in which case you then talk about the baby. Yeah because some women don't want to hear the word baby. They just want to move past that and get on." – P23 (clinical)*

Individualised care

Most participants discussed the need to tailor their care to individual patients by recognising the broad range of perspectives, beliefs and feelings towards miscarriage. Likewise, empowering patients to make their own clinical decisions based on this individualised care was raised by some participants.

> *"I always ask how did you feel when you found out you were pregnant? How do you feel now? Because a chunk of people felt very ambivalent but decided they wanted to keep the pregnancy. They're often the ones who struggle with the miscarriage a lot more, psychologically. Well, everyone struggles for different reasons, but you know, there's a bunch who are struggling because they feel that their ambivalence was the cause" – P8 (clinical)*
>
> *"Some people are more emotionally invested in their pregnancies beforehand, and some people are like well it's just a way of life. So, being able to respect what their beliefs are, and being able to provide whatever they need" – P3 (clinical)*
>
> *"It's really important for me that patients are aware that for miscarriage it's a really varied experience and the way you conceptualize the pregnancy is different. And the*

way you feel it is different and the emotional impact might be different" – P26 (support)

"I think the biggest thing is to acknowledge their loss and to support them with that loss in whatever way they need and allowing them to actually manage their own miscarriage. […] Which is why we have those options of how they want to sort of look after it, and you know if I have ladies and they regularly ask me what would you do, what do you recommend? I don't recommend. This is entirely what you feel is the best way for you to look after your miscarriage because it's her miscarriage not mine. So it's giving them the power to decide what they want to do and to manage it in their way." – P27 (clinical)

Inability to provide emotional care

Despite the large majority of EPAS staff being able to offer emotional support to their patients, some participants discussed their inability to provide this support. This was often due to restrictions on time and experience, which will be outlined further in category three.

"We don't do this well at all. Okay firstly the time allocated is largely clinical. Really, we're trying to get a diagnosis, and the other slips, I'm sorry. Even I, who am keen on this, would very seldom hand out that after pregnancy loss leaflet that we have" – P13 (clinical)

"I think from a psychosocial component there's probably a bit of issue in that the doctors who actually working in it probably don't have a lot of experience or information for patients […] I remember being a resident during that and it's quite confronting […] I can't imagine that I was terribly supportive when I was trying to, you know, blunder my way through" – P28 *(clinical)*

4.4.4 Memory making and options for remains

Discussions regarding memory making opportunities and options for handling of remains was largely absent from EPASs.

Memory making

Participants noted that there are plenty of memory making options for later miscarriages, typically past 16 weeks, and include opportunities such as photographer, hand and foot prints, photo frames, clothing, memorial books, and teddy bears. However, these are managed on a ward rather than in EPAS.

"To be honest with you, like I said earlier about early miscarriages, that I think most doctors perceive it as almost a normal event… we don't consider it [memory making] a justifiable use of resources I think is what the problem is. We do that for later losses, so second trimester losses probably beyond 16 weeks" – P1 (clinical)

"Because it's less than 12 weeks we don't unfortunately" – P4 (clinical)

"Here in EPAS? No, that would be done on the ward" – P6 (clinical)

"No, not really. We do it for foetal deaths, anytime they've had a birth. So anytime basically from mid-second trimester on, but not for early pregnancy" – P14 (clinical)

Some participants stated that this was partly due to a lack of options for memory making or believed that women did not have a strong connection in the earlier stages of pregnancy.

"The problem with early miscarriages is there isn't really much to give them […] I mean you can give them photos of the dead baby on an ultrasound but that seems a bit heartless" - P1 (clinical)

I find earlier gestations people aren't as connecting to it as a baby, as what they are a little bit later" – P3 (clinical)

A few participants did speak of memory making opportunities they could or do offer, such as ultrasound photos, certificates of naming, and other mementoes. However, discussions of these options were often limited by a lack of time with patients.

"[I] always offer them the picture of the ultrasound" – P7 (clinical)

"Our pastoral care does a certificate of naming and we'll do a service for parents. So they'll do a naming ceremony and a certificate and something to take home in lieu of, because parents actually feel very strongly about not getting a birth certificate. They find it very insulting, and the more I talk to parents the more I understand their point. Because if the baby was 3 days older it would exist. Now it doesn't exist." – P9 (clinical)

"I might talk to them about how memory building can be done in their own way. In their own way when they go home, and I might talk about some ideas of things that they might want to do together, and with their family. So yeah, so that's it's not exclusively that you take these things home, it's something that they can do at any time along their journey, in their own way" – P18 (support)

Handling of remains

Similarly, discussions regarding options for handling of remains was also typically restricted to pregnancy losses managed outside of EPAS and was arranged by either the social work or pastoral care teams.

> *"In fact, the only time the social workers get involved is if people want to take remains after they've had a curette and the picking up the remains from pathology." – P13 (clinical)*
>
> *"Before 12 weeks I think baby remains are just not discussed at all […] After 12 weeks definitely, because you are expecting a fetus that is more formed" – P16 (clinical)*
>
> *"If the baby is over 14 weeks, then we would need to talk to them to let them know the options of care for their baby […] One of them is hospital-assisted cremation, hospital assisted burial" – P18 (support)*
>
> *"I have so much to talk about and that [discussion of fetus remains] just gets so involved […] the second trimester losses we talk about what happens with it" – P30 (clinical)*

Many participants were unaware of hospital policies around this, however some participants that knew did inform patients of options. This aspect of care was more noticeable in Catholic hospitals, and again stressed primarily for second trimester losses.

> *"I make it very clear to women that they are aware that if it is hospital disposal it will mean that we will not do anything with baby. I let that soak in, and you need to be very clear that we will not do anything with your baby. Your baby will be considered medical waste" –P5 (clinical)*
>
> *"The parents could then decide whether they want us as the hospital to dispose of the baby or whether they would like to do something. If they want to do something, we link in with a funeral parlour that gives them very cheap rates, very simple service, so that that's not a massive expense for them. Alternately the hospital pays them to do burials in group plots for all out under 20 weekers" – P9 (clinical)*
>
> *"If they want products of conception, we can get that organised, if they want to take that home to bury or do with as they will, for memories we can do that" – P20 (clinical)*
>
> *"Talks to them about how we care for the fetal remains cause it's a Catholic hospital we don't thrown it in medical waste, we've got a funeral director who collects all the babies under 20 weeks, cremates them together" – P30 (clinical)*

Few participants also noted some cultural groups requesting to take home the pregnancy tissue, which was something that could be arranged if requested by the patient but is not routinely offered or discussed.

> *"If they ask, because surprisingly even in early miscarriages some – I think maybe Islanders – they want to get the tissue back. I think it's a quite common part of their culture […] for the few that have asked, I have warned them that it may not look like much, it may look like a little blob, but if you're keen, I'm very happy to wrap it up for you to take. That's the most we can do" – P4 (clinical)*

4.4.5 Additional psychosocial support

Beyond individualised care in which staff did their utmost to provide emotional care through sensitivity, use of appropriate language, acknowledgement of the loss, and information provision, few EPASs referred women to hospital bereavement services such as pastoral care or social work for first trimester loss.

> *"Pregnancies over 14 weeks, then they refer them to bereavement midwives and it's just a multidisciplinary team that look after them. We have other services that we can refer them to" – P24 (clinical)*
>
> *"We don't really have any counselling services specific for this. […] If they've come in for like a second trimester, yeah, we've got the whole works in place, we've got protocols, we've got everything. But if first trimester it's just a bit lacking, not having any counselling" – P14 (clinical)*

Social work and pastoral care

Social workers were mentioned by most participants; however, they were not utilised routinely and often only in cases where EPAS staff believed there to be additional concerns or previous mental health struggles. Likewise, some participants also discussed pastoral care, however they were also largely limited to seeing patients experiencing second trimester loss. Two EPAS staff spoke of some challenges they had encountered with requesting help from a pastoral care practitioner regarding conflicting religious beliefs with patients. However, they were largely discussed in respect to the immense support they can offer patients most in need.

"Social work will get involved but not routinely" – P9 (clinical)

"Generally, we don't get social work involved too much because they'd be here all day and they just don't have the service for that, but occasionally if we have a woman who seems to be not coping with the whole scenario then we might call the social worker to come and see them" – P21 (clinical)

"Women who are really distraught or who have had mental health issues in their past, and you can see they're struggling […] There's always a social worker on-site during the clinic hours […] otherwise there's no other way, there's no specific counselling service for EPAS" – P4 (clinical)

"All the good work [pastoral care] does is normally for people with second trimester miscarriages or third trimester losses" – P8 (clinical)

"Pastoral care here, mainly - I think - help with like the second trimester ones that get admitted. Back in the old days when I first started, pastoral care was a lot better than they are. [Name retracted] is lovely, but she tends to throw a lot of God talk around, and that upsets some of the women. So, I stopped using pastoral care cause I kept getting complaints […] The only time I call them down here is if I've got someone that's really upset and sobbing, and I haven't got time to sit with them" – P30 (clinical)

Psychology

Like social work and pastoral care, referrals to a psychologist were very rare and typically only when a patient was deemed as psychologically at high risk. One EPAS was the exception, having a clinical psychologist located next to the clinic and available if needed.

"[Psychological services are] not typically [available] through EPAS. Oftentimes we will say, if we think that the woman is really at risk, there is a psych service that we can ring" – P14 (clinical)

"The best we can do is refer them onto an outpatient psych appointment" – P14 (clinical)

"Whenever they see someone who is distressed, or they feel would want some extra support they have been referred to see me and they book them in to see me and I'm generally able to see them from the next week" – P26 (support)

External supports

Some participants spoke of the difficulties with continuity of care with the above services, as these are generally inpatient services, and EPAS patients are generally considered as

outpatients. Therefore, some preferred to refer women to external organisations for continued community support.

> *"As far as counselling it's our social work or I give them the contact details for Sands, for Bears of Hope and for Red Nose. They've all got phone lines with supportive people" – P20 (clinical)*
>
> *"I have to say we give them the pamphlets from SIDS if they want it, but I guess it's really just us talking to them." – P23 (clinical)*
>
> *"We usually tell them about the other outside services that they can source if the need to as well." – P21 (clinical)*
>
> *"It's easier to refer them to [local support organisation] who will continue to follow them" – P3 (clinical)*

4.4.6 Patient follow-up

Patient follow-up procedures within EPAS varied drastically between both services and individual patients. However, one consistent finding was the use of GPs for many follow-up procedures.

EPAS follow-up

Only one EPAS had participants who spoke of follow-up being offered regularly in-person and involving psychological as well as physical care.

> *"It would be individualised, but on average they are offered fortnightly reviews until they're physically and emotionally fine and so that's usually just one extra appointment but for some women its more, and in terms of psychosocial if that's becoming more of an issue than the physical, well then they probably won't be seen in EPAS anymore they'll be seen in pastoral care or social work or perinatal mental health or something in another setting" – P7 (clinical)*

Typically, follow-up was discussed as occurring if a patient was managing their miscarriage through expectant or medical management. Phone follow-ups were reported to occur much more than in-person appointments and were focused heavily on physical health rather than emotional, and often involved just tracking levels of human chorionic gonadotrophin (bHCG), to ensure they had returned to pre-pregnancy levels. All discussions of follow-up related to the

management of the miscarriage at the time of miscarriage or the immediate few weeks following, and none looked at recovery in the longer term.

> *"Anyone that chooses medical management we follow them up 10 to 14 days later" – P20 (clinical)*
>
> *"There's a pretty strong focus on phone-based follow up. So, the nurse who runs the clinic will do a lot of follow up with women via phone. In terms of the sort of psychological component - I don't think there's much. It's usually follow-up of you know bHCGs down the track. And yeah that kind of thing, or checking on symptoms, rather than the sort of social side of things." – P28 (clinical)*
>
> *"We have a telephone follow up service for all the women who are being managed expectantly or medical management at home, and also anyone with any complexity, we'll follow them up the next week so that's a nurse clinic where they have a telephone clinic, if someone's going to theatre for a curette, unless there's a problem they're discharged to their GP because we don't have appointments, if we did follow ups for everybody, physical follow ups, we wouldn't be seeing any new patients" - P12 (clinical)*

Other participants noted that follow-ups generally were occurring less now, if at all, than they had previously, reporting a lack of funding or time as the cause. One participant noted that the emotional aspect of follow-up they previous provided is no longer able to be offered.

> *"With the D&C we used to bring them back a week later and debrief with them but now that's too much money as well so now we call them on the phone, which is fine, but it doesn't seem as personal" – P23 (clinical)*
>
> *"We don't do as many follow-up calls as we used to" – P30 (clinical)*
>
> *"But now down here, cause it's so busy, now we only follow-up people that are being managed" – P30 (clinical)*
>
> *"I used to follow up anyone who had a miscarriage, or any sort of pregnancy loss, I would ring a week later to see how they were going physically and emotionally […] if I got an inkling that they weren't really good, I'd say look, you really need to see your GP and get a referral to see a psychologist. It's covered by Medicare" – P30 (clinical)*

GP follow-up

Most participants utilised GPs for both physical and psychological follow-up. Physical follow-up was discussed when patients were not considered high-risk, and therefore could safely be

managed out of EPAS. A small number of participants noted issues with this, as they believed some GPs were not comfortable managing miscarriages, and therefore would refer back to ED or EPAS.

> "*We tell them go see your GP for a check-up in a week's time" – P30 (clinical)*
>
> *"If ED's happy that it's a complete miscarriage and they've advised the woman to go onto their GP for follow up, and so that just entails us giving the woman a phone call, checking that everything's okay and you know do you have an appointment with your GP in 5 days or something... and of course we try and encourage that if everything's normal because then it doesn't impact on our service as much" – P11 (clinical)*
>
> *"We make pretty good use of our GPs to follow up" – P9 (clinical)*
>
> *"You send them back to their GP and then you have this cycle where some GPs are uncomfortable managing them so they keep calling the gynae team" – P4 (clinical)*

More commonly, participants spoke of heavily relying on GPs to provide psychological follow-up and continued emotional support in the community setting, referring women to their GPs for care or onward referral. Although some participants directly suggested this option to patients, others assumed that women would see their GP if they felt they needed additional support.

> *"One of the big things that we talk about is accessing your GP and so forth for ongoing counselling and resources" – P5 (clinical)*
>
> *"For patients that are really grieving and really deeply struggling we have a list of counsellors and psychologists that are specifically trained in loss, this kind of loss, that they can follow up themselves through a GP referral" – P18 (support)*
>
> *"We'll say 'if you're struggling go see your GP'. That's one of the common ways we manage it" - P4 (clinical)*
>
> *"Often the best way for them is a GP management plan and counselling sessions through that. So, they'd have to see their GP anyway" – P8 (clinical)*
>
> *"I find that a lot of the women will go back and speak to their GPs, rather than come back" – P6 (clinical)*

Only few participants, however, mentioned routinely providing discharge summaries to GPs, and procedures varied drastically between services. Some services could not offer regular discharge summaries.

> *"If the patient is safe to be discharged then we do send them to a GP, but there's no phone calls. Usually the residents write the letter to the GP. It's not a consistent thing though" – P15 (clinical)*
>
> *"I don't think that GPs necessarily get any communication from EPAS […] because it's so busy sometimes" – P1 (clinical)*
>
> *"We give them something to take to their GP, a lot of people don't want GPs getting an automatic discharge summary, so we give it to the patient and they can take it, it's like a summary of what we've done" - P12 (clinical)*

Finally, some participants reflected that they knew nothing of what happens to patients once they leave EPAS.

> *"I'm faxing back to their GP and whether their GP rings up and says make an appointment, I want to talk to you about this or whether they go to see their GP, I don't know. We don't arrange anything" – P13 (clinical)*
>
> *"…you just say 'ok look on the websites, see how you go, see your GP, they can refer you to some kind of counselling service'. Now, is the GP aware of these services? I have no idea." – P16 (clinical)*

4.4.7 Staff support

The support available for hospital staff emerged as a theme that influenced the support that was able to be offered to EPAS patients. Staff support had two subthemes: training and psychological support.

Training

A small number of larger EPAS had educational opportunities for their staff, or staff had independently undergone training emotional support specific to early pregnancy loss. One educational program involved senior doctors supporting more junior doctors in how to best support their patients.

"The clinic is always training, like registrars in particular. So most of us have someone rostered to be with us. It's a very helpful place for them to learn both scanning and just approaches to consults and listening to people and stuff. Because often it's really nice for everyone just to see how other people who have been around for a lot longer just deal with all the difficult emotions. […] There's a whole bunch of words that are out that we have written into our guidelines so that all the residents know they'll get into trouble if they use the words 'missed abortion' or 'blighted ovum' or you know?" – P8 (clinical)

"I run in house stuff all the time but most of the people who've elected to do this have done their own training as well" - P12 (clinical)

"We've done one [online training course] on psychosocial support, how to talk to women, what to say, what not to say, that sort of thing" – P30 (clinical)

"We often have external services, you know people from SIDS and Sands and Bears of Hope and all of those people come in quite regularly" – P5 (clinical)

One participant spoke of the difficulties in arranging initial training for EPAS staff.

"We had to push very hard to have some tutorials, saying hang on, you send these patients to us, you can't just expect us to know what to do with them. Yeah, that was actually quite difficult in the first 6 months" – P13 (clinical)

Most participants said they had no support training specific for EPAS, and learnt their skills 'hands on' through experience and from colleagues.

"Just whatever they do as part of O&G, no training in EPAS […] we do have a few guidelines on our system but I don't think there's anything about EPAS or early pregnancy" – P15 (clinical)

"So, no real teaching, experience is what we're learning on." – P9 (clinical)

"We kind of train each other" – P23 (clinical)

"We haven't really done anything specifically related to this service. We just catch it off the doctors. We're sort of learning as we go, so yeah it's been a very big learning experience" – P3 (clinical)

Some participants discussed the issues with this structure for more junior staff.

> *"It's quite distressing for these patients and having done the clinic on my own a couple of times it's really hard for junior registrars to run it or even just be there for these patients […] Our registrars are not trained to deal with this. We don't have sufficient time to talk to the patient" – P4 (clinical)*
>
> *"…I mean you get used to it, but the residents are often left by themselves to counsel the women" – P14 (clinical)*

Psychological support

Few participants spoke of the emotional toll working in EPAS could take on them, stressing the distressing nature of working in pregnancy loss daily and their own need for emotional support.

> *"The biggest thing for all health care professionals is self care. Because you can't go into these places with people unless you've done a little bit of work on yourself, and we're all so busy that we don't. We preach self-care, but we don't do it" – P17 (support)*
>
> *"I just keep taking my happy pills. Don't take them and I don't cope […] The fact that every day you're spending the worst day of someone's life with them." – P30 (clinical)*

Most discussed the positive supports they had available to them, such as pastoral care or supportive colleagues, and one participant discussed a lack of support.

> *"They're very good at just passing by and checking on staff. So, that's very good, extremely good. There's one of the pastoral carers who is my favourite from a particular case that I just couldn't get over, and I just had to go and cry at [name retracted] and then it was a little better" – P7 (clinical)*
>
> *"I get a lot of great support […] even from the fertility nurses here as well because you know I have to deal with a lot of grief on a daily basis, you know and some days are a little bit more stressful than others, but I know I've got a good team of colleagues out there that can actually help out or just listen or support me if I'm having a particularly tough day" – P27 (clinical)*

Another participant was concerned about the emotional impact working in EPAS may have on junior staff.

> *"Sometimes I think our RMOs are out of their depth, so I'll get some feedback that the doctors seemed like they just wanted to finish the consultation… and then I think he probably did want to just get it over and done with you know. I've had RMOs whose wives were pregnant who found EPAS very hard to do and then I get some people who go 'it's just so emotional it wears you out'." – P9 (clinical)*

> *"I'm concerned about the emotional impact, because if I just have the wrong person there you know our female staff won't come and tell me that they're pregnant until they're 18 weeks or 20 weeks or whatever and if I inadvertently put them on 3 weeks of EPAS and they're dealing with miscarriage after miscarriage then they're going to be so demotivated" – P9 (clinical)*

4.5 Psychosocial support considered ideal by participants

All participants discussed their views on potential changes or improvements to their service, or for miscarriage care more generally.

4.5.1 Structural changes

Suggestions for structural changes to EPAS were most commonly reported, and included ideas regarding the physical size and location of the clinic, as well as the availability of ultrasound.

EPAS expansion

Most participants working in EPAS discussed the need to expand the service they were currently delivering in terms of clinic hours, physical space and consultation time, to meet the needs of patients, noting the service was often over capacity.

> *"I think more spots, so you know more clinics. We could probably increase to another clinic a week. it would be good to have a Friday afternoon clinic – P12 (clinical)*

> *"It's not a very big room. We have medical students nearly all the time in term time, it's a bit crowded so you know, a bigger room – P13 (clinical)*

> *"We do also need to expand the service because they probably need a little bit more you know, psychological support as well. Which, I mean I'm sure that's given by the clinician, but it is only one person and I guess they're often time poor" – P11 (clinical)*

Away from antenatal

Of the six EPAS that were physically located in or near antenatal services, all had participants who stated their desire to be moved to a location away from other pregnant patients. Quotes regarding this dissatisfaction are also outlined in subheading '4.4.1 Structural elements of EPASs'.

> *"It is quite frustrating that we're not able to offer the gold standard, so ideally we would not be located in our antenatal clinic" – P5 (clinical)*

Co-located in ED

Two participants discussed in detail their idea that EPAS would be best situated in ED, rather than in a separate outpatients area. This was partly due to perceived easier access to a sonographer and faster and more efficient management.

> *"My theory is that it should actually be in ED with its own sonographer, because I know the numbers we have, but I don't know the numbers that we reject or that ED doesn't even bother us about or that go through the gynae as an admission. Like there must be twice as many or maybe there's three times as many EPAS patients when you think about those. […] Jumping right ahead, I think EPAS should be run in the emergency department with a dedicated sonographer, even if they do sit around a bit, but it would be so much better. I mean it's a real feminist issue isn't it really? For women to be able to get answers to their questions rather than waiting until the next day" – P13 (clinical)*
>
> *"It belongs in ED is my bottom line. In an ideal world, to have someone in this role associated with an ED department would be really good. Obviously, things like sonography and costings and all that, that you could deal with these women at the time. They come into ED anxious, worried, bleeding. To be seen there and then and be dealt with then I think sometimes would be a lot better, especially a lot of the very early ones." – P20 (clinical)*

Many participants had differing opinions, expressing that one strength of EPAS was that it was independent of ED.

Ultrasound available in clinic

A common suggestion that participants had was the desire for ultrasound to be available in the clinic.

> *"Having a scanner in the department with a vaginal probe would be good" – P1 (clinical)*
>
> *"The other thing that I would love to change is ultrasounds. You should have the ultrasound facility for these patients." – P24 (clinical)*
>
> *"I would like to have a sonographer in the afternoon as well, or more easy access to a sonographer" – P30 (clinical)*

Participant 12 summarised the structural changes needed to improve their service. They expressed that having a space dedicated to their service would allow for improvements in patient literature, location of ultrasound, and clinic atmosphere.

> *"I want my own home. You know, we could do so much more, we could have so many more resources, we could have our information packs and our translation packs and everything just there and we wouldn't have to unpack and pack every day, and we would have the ultrasound machine right next door, it would be much easier, and we wouldn't be right at the entrance to the hospital where the ambulances come in, if I had my way" - P12 (clinical)*

4.5.2 Staff changes

The other common suggestion for change was altering the staff arrangements in the clinic, such as having more senior staff, increased involvement of nursing and midwifery staff, improved training and clearer management.

Participant 16 described their ideal staffing arrangement in EPAS, mentioning many aspects other participants also discussed. This included having both medical staff and nursing staff in the clinic to allow continuity of care and follow-up, alongside social work and/or psychology being readily available for EPAS patients.

> *"I feel as a service we would do much better […] Let's say in every service we have three people to see, I think that would really change the face of early pregnancy assessment*

units. Like if it's kind of mandated that when the patient comes in, we pick up the medical aspects of it, along with the nurse who is quite sensitively trained on this and she can follow up with people and be kind of a team together, in the same way we have a social worker AND a psychologist on our team who deals with them in and out every day." – P16 (clinical)

More senior staff

Many participants considered the benefits of involving more senior staff in the running of EPAS which included decreased wait times and improved support for patients, less stress on junior staff with little experience, and more confidence in escalating issues when necessary.

"I think it would be better if it was a registrar, like had a higher registrar involvement rather than being run by residents who often come into the term sort of knowing nothing about O&G and they're put at the forefront of counselling a woman about a miscarriage when really they're just learning about it themselves. I think that definitely doesn't add to the support that women feel in that sort of situation having someone who is quite junior and who doesn't really feel comfortable in the situation that they're talking about – P28 (clinical)

"I'd like to put more senior people in there […] a nurse and more senior input. I have just spoken to my guy who does the rosters for the RMOs and suggested that we put them on EPAS for 2 or 3 weeks at a time you know so we give one person a longer run, so they can see the same patients, they can sort of get their head around who they are what they're back for because it makes the follow ups quicker – P9 (clinical)

"One of the patients waited four hours to be seen the other day. And I'm like, oh if I had have been here, I would have escalated that to the consultant and once it got past two hours, I would have been nagging the consultant to come and see the patient. But that's just because I've been here a long time and I'm confident to do that, whereas a lot of the new staff aren't." – P30 (clinical)

More nurse/midwife involvement

Increasing the role of nurses and midwives within the clinic was also mentioned often as a method to increase efficiency and continuity of care and improve emotional support for patients.

"Probably even if, you know, if a clinician like a doctor is seeing them and dealing with all the clinical aspects and treatment management and so on, then perhaps a

complementary midwife or someone who's you know sort of part of that appointment who can then you know make sure all the gaps are filled at the end of the clinical appointment. […] I think the follow up issue and it doesn't have to be a clinical doctor that does the follow up. It could be just a midwife, nurse, even a division 2 nurse just to make that call and say well you know how are things going? Are you coping?" – P11 (clinical)

"Being able to have more midwives running it so we can see the women or spend more time with them, maybe having so sort of counselling service beyond just seeing us, having the miscarriage and we follow them up, but it's not really counselling much, it's just the physical 'are they well?' sort of thing. It would be nice to focus more on the emotional side of it" – P21 (clinical)

"I think there probably would be capacity, and I know some hospitals do this, where there's a registrar who's working in the EPAS clinic who does the ultrasound, who sees the woman and sort of takes them through that whole process. As well as having nurses there who can help from a psychosocial perspective as well. Yes I think maybe a little bit more experienced in the department would probably help" – P28 (clinical)

Clearer management

A small number of participants raised the issue of a lack of ownership or unclear management of EPAS. Many services did not have a dedicated EPAS co-ordinator, and instead were considered part of antenatal outpatients. Participants noted that with improved management, opportunities for changes would also improve.

"Getting someone to have ownership" – P4 (clinical)

"We have a lot of things to improve in the service. I think I would say like coordinator. That's what I would like to have like one coordinator maybe like a midwife or a nurse co-ordinator who can organize appointments and follow up." – P15 (clinical)

Staff training

The need for improved staff support, particularly additional staff training, was discussed and included ultrasound training and psychosocial education.

"I think the doctors should be trained up to do ultrasounds" –P6 (clinical)

"It would be really good from a psychosocial aspect that the registrars got better training because it's very much from registrar to registrar handover" – P2 (clinical)

"I think wouldn't it be good if all junior medical staff and nurses and midwives received a thing on how to talk about and what to talk about. It's not about talking about management options. It's actually talking about psychological morbidity" – P10 (clinical)

4.5.3 Counselling options

Many participants expressed their desire to improve the psychosocial aspect of care in EPAS by incorporating counselling or social work to create a multidisciplinary EPAS team.

"I think what actually might be better would be having one in the clinic, so having a counsellor in the clinic and while they're waiting for the doctor they can be counselled or just after they see the doctor they can go to the counsellor. I think that would be a good idea if we had the money for it" – P1 (clinical)

"In an ideal world we have a counselling service beside an EPAS ready to run" – P4 (clinical)

"It's the involvement of the social work as a part of a multidisciplinary team with that coordinator and a social work attached to the EPAS with specifically trained in dealing with early pregnancy losses. It's a really important facility that should be at the hospital." – P15 (clinical)

"Some kind of like after-hours social work, or social work counselling is always present in ED, but miscarriage patients are never their priority" – P16 (clinical)

4.5.4 GP involvement

One of the largest themes that arose from interviews was the desire for more referrals directly from GP, rather than through ED. Participants noted that patients should not be waiting in ED if they were stable as it only added to their potential distress.

"I would love it if more doctors would refer the women directly to here and skip emergency altogether. The wait times can be really bad and these poor women don't have to be sitting there for 8 hours and then get seen just to be told to go home because they'll refer you to EPAS anyway […] they're saving themselves a bed and they're saving these people lots of time" – P3 (clinical)

"In my little audit I think it was less than 1 in 10 were direct GP referrals […] it is something we would think could be expanded" – P7 (clinical)

"There's still a misconception from the GPs that they [should] refer to ED. […] GPs still very much go to ED. You know, they'll get a missed miscarriage, not bleeding, no pain, incidental finding on ultrasound at 8pm and the woman will be sitting here at midnight. It's terrible, it's really terrible. It's rude." – P9 (clinical)

Additionally, some participants also discussed their view that GPs could be managing more miscarriages themselves rather than referring to ED or EPAS.

"Some GPs like to use and abuse us, and you know, if a woman turns up there with a bit of spotting or something, well rather than send them for a scan and organize that stuff themselves, they'll just send them straight up [to us] to sort that out." – P30 (clinical)

"We're also keen to be helping GPs support their patients who are miscarrying and give them some resource to do that." – P8 (clinical)

4.5.5 Online resources

A few participants considered the role of information, specifically information provision through online platforms, in improving women's miscarriage experience through education and expectation management.

"We definitely could have a much better web presence, so that patient expectations really stick, little videos of what you might do first, and this is what you might do second" – P7 (clinical)

"I would like to develop a website, a better website so that women can sort of find out what their expectations are. You know, and could share their stories on the website. You know like, I think I mentioned on the weekend at Tommy's in London has a really good website. So that they could interact with really good information" -P12 (clinical)

4.5.6 Elective list for D&C

Finally, the desire to have dedicated surgical appointments available for women choosing to manage their miscarriage through a D&C was raised by a small number of participants. Typically, EPAS patients are placed on the emergency surgery list if they choose surgical management, and given the low priority of miscarriage they are often faced with long wait times and unnecessary fasting while waiting for potential theatre availabilities. Therefore,

having regular appointments on the elective list available for EPAS patients was described as a method to address these issues.

> *"She should be taken up in the elective list, or whatever you have to do to be the first possible patient in the morning, so she gets the respect that a lost pregnancy deserves." – P16 (clinical)*
>
> *"I nagged and nagged and nagged for many years to get some elective curette spots and we had a few and then I lost them a few years ago. So now they just go on the emergency list. They're hanging around all day, they wait, fasting all day. Sometimes they get bumped to the next day and told to go home, come back tomorrow" – P30 (clinical)*

4.6 Barriers to changing psychosocial support

Although most participants expressed a desire to improve their EPAS, all faced barriers to implementing this change. The most common barriers included a lack of time, space, funding, staff, and therefore resources generally.

4.6.1 Resources

The large majority of barriers that existed preventing change were a lack of resources. This has been broken down into subthemes, however some participants considered limited resources more generally.

> *"It's probably just resources. Mainly people's time, but time does cost money. We all love our jobs, but we're not doing it completely for free either" – P7 (clinical)*
>
> *"Yeah time and money, just bucket loads of that and we'll be fine" – P7 (clinical)*
>
> *"It's just its time, its space, I mean we sort of have a very limited space, you know […] I was going to say medical support yeah, absolutely, it's a whole host of things." – P11 (clinical)*
>
> *"I think we do not have enough information resources for the patients to actually take up them. We do not have nurses giving follow-up phone calls. I feel more people will be making evidence-based decision-making if we had more awareness created on these medical methods of miscarriages. I'm not sure how emotionally does it affect people, but I feel that by providing less information on the medical methods, we kind of force people to make a choice on the surgical method. Like most don't get to choose what they really want to do." – P16 (clinical)*

4.6.2 Time

A lack of time was the most commonly arising barrier to change discussed by participants. Most clinics were overbooked, leaving little time for staff to spend with patients beyond attending to their immediate physical needs, and particularly for the provision of emotional support.

EPAS overbooked

Almost all services appeared to be close to capacity on a regular basis, therefore a lack of time was often the primary limitation to implementing change.

> *"We were getting triple booked and things like that, which is no good for anybody" – P13 (clinical)*
>
> *"They said there's five appointments in the day, I'm very surprised about that. I'm sure I see more than five EPAS patients in a day" – P13 (clinical)*
>
> *"It's pretty fully booked up, so it's probably oversubscribed, and often the registrars are quite pushed and sometimes they need to get help from another registrar to see the patients" – P1 (clinical)*
>
> *"The problem is our clinic is so short, because no matter how good we are, I feel because I take my time with patients, but there would be a point in time where I'll stare at the list and go shit, I have 9 more patients and it's now 3pm" – P4 (clinical)*

Due to this stark limitation on time seen in most services, many EPAS staff worked overtime to attend to all patients or were having to extend their services.

> *"They work overtime because they're meant to see women in 15 minutes and its always more than 15 minutes" – P2 (clinical)*
>
> *"There's only 5 slots a day in the morning. Having said that, most days I see 8 to 10, or sometimes 12 people cause we've got walk-ins as well" – P30 (clinical)*
>
> *"We've only just recently created the extra day so up until maybe 3 months ago we were just Tuesday to Thursday and we were just so over booked so we've opened Monday but we're looking now to opening Friday as well because we just, yeah, it's a big service" – P11 (clinical)*
>
> *"I just had them ring me on Friday to say that mornings probably are not going to cut it anymore, we're going to have to expand" – P9 (clinical)*

Emotional support suffers

Due to this lack of time, and the need to prioritise patients' physical management over the psychological, the emotional aspects of care were often sacrificed.

> *"The major barrier is time and the pressure of the clinic, and there's usually only one doctor I find to look after these patients so if you've got 7 patients to see in 3 hours, or even more, 10 sometimes, you can't spend a huge amount and you need to talk about all this other stuff you can't spend a huge amount on psychosocial counselling. So, for example, I've gotten my psychosocial counselling down to a very quick spiel" – P1 (clinical)*
>
> *"I guess because our numbers are increasing at the moment, we're trying to see more women in the same period of time so that their time spent with the clinician is less. So, they probably you know and it's the psychosocial aspect that's going to be cut short isn't it." – P11 (clinical)*
>
> *"I feel like at the moment you get your work done but you don't get any of that extra stuff done. Things like the reading and doing the Sands training and that stuff. There's just no time for that sort of thing" – P30 (clinical)*

4.6.3 Space

Space was another very common barrier to suggested changes, and was largely due to hospitals underestimating the space required for EPAS. A lack of space available to EPAS was discussed in regards to the inability to provide a dedicated space away from antenatal or maternity services, a dedicated 'cry room', and rooms for a sonographer and nurse within the clinic. However, this was also often considered a barrier that could not be changed.

> *"There's not enough room here. Outpatients is too small." – P13 (clinical)*
>
> *"Space is always a problem, but we do what we can" – P21 (clinical)*
>
> *"I would love to have an area where we could bring them back for their follow-up appointments, away from here. Because it's a very busy place, we don't have the rooms, so we're very limited in space" – P22 (clinical)*
>
> *"I said I wanted a crying room, but they didn't have anywhere to put it" – P30 (clinical)*

A small number of participants spoke of the need to ensure EPAS had adequate staff and resources, which most thought required the clinic to be located close to other maternity

services, and similarly the need for EPAS staff to be close to maternity, which contradicted other participants view that EPAS should be separate from these services.

> *"You don't want to take your doctors too far away from the busy birth suite, you know. So, you've got to meet somewhere in the middle." – P9 (clinical)*

4.6.4 Funding

A lack of funding was commonly reported as an additional barrier to change and was discussed in relation to a broad range of issues such as the physical location of EPAS, provision of resources such as a sonographer in clinic, and clinic accessibility.

> *"Money *laughs* good old money […] it's a reasonable investment, and the you can't just have one because you need leave cover and sick cover and… so the bigger hospitals do it better because they can draw from various resources whereas we are very poor in terms of resources" – P9 (clinical)*
>
> *"We've got a whole lot of opportunity, it's just we're running it on the smell of an oily rag. We're only running on everybody's dedication to even taking the time to meet and talk about these things." – P10 (clinical)*
>
> *"It's space and time, but yeah financial is probably the biggest one" – P21 (clinical)*
>
> *"It's been explored many times over numerous years and it was deemed it would not be cost neutral to women's and children's if we were to have an ultrasonographer working in our department" – P5 (clinical)*

Underfunding was also reported as the reason many EPASs were forced to cut back rather than expand, such as restricting clinic opening hours and changing follow-up procedures.

> *"It used to be a 12 hour service, but due to budgetary reasons we've moved it back to an 8 hour service. […] because we have to try and compact the service, we changed the way we did a few of the follow-ups" – P21 (clinical)*
>
> *"Up until about three or four months ago we were open from 7:30am to 7:30pm seven days a week - public holidays, everything - and it was a walk-in service. But that was costing too much money, so now it's a basically 9-4:30 appointment service" – P23 (clinical)*

"With the D&C we used to bring them back a week later and debrief with them but now that's too much money as well so now we call them on the phone, which is fine but it doesn't seem as personal" – P23 (clinical)

4.6.5 Staff support

A lack of support for staff arose as a limitation, particularly for junior staff or due to under-resourced clinics. Some junior EPAS staff were described as being under-prepared to support patients, and staff burn-out and compassion fatigue were also noted as a consequence.

"You actually see a lot of grief here in quite a short time and it can be quite intense. So I think that's something we need to be mindful of" – P27 (clinical)

"It's got so busy and they've overgrown that area so everyone's getting more stressed and everyone's getting burned out" – P30 (clinical)

"It's gotten so busy down here, it's more like a pregnancy emergency department […] when it gets so busy in emergency department, you lose your compassion" – P30 (clinical)

"We're trying to get a sonographer and registrar for another day, so we've got to push for that" – P3 (clinical)

*"We don't have a dedicated ultrasonographer attached to us, so I always have to put in the order and ring radiology and go down on my hands and knees, and they're very good to me *laugh*, it nearly always works" – P13 (clinical)*

4.6.6 Other barriers

Some participants raised further barriers to service improvements, such as issues regarding in or out patient status when considering involvement of additional support services.

"It's not typically done, because social work mostly see inpatients. Not really so much outpatients." – P14 (clinical)

A perceived lack of GP knowledge was mentioned as a contributing factor to low direct GP referrals and consequently overrepresentation of patients experiencing early pregnancy loss in ED.

"I think it would be good to do a lot more work with GPs but that's more about ED in general. Because just every day, people come to ED who shouldn't be coming, with an expectation that's hard work. It would be lovely to have more GPs. GPs who do a lot of pregnancy work just feeling more comfortable and confident about this work and that they could do it." – P8 (clinical)

Finally, a few participants discussed the need for staff to view miscarriage as a priority, and to be passionate about it in order to facilitate meaningful change.

"If I could change anything it would be encouraging medical staff to really see that as a priority, of getting those forms completed so that these babies can be released to these families as quickly as possible" – P18 (support)

"…and the staff, if anyone is interested in the service? – P15 (clinical)

"It's finding the time to be able to train up people and get people passionate enough about it {…] I want staff to work here that are passionate about it. It's not rocket science" – P30 (clinical)

4.7 Conclusion

This study recruited 31 participants from 13 EPASs and two miscarriage support organisations across Australia through multiple recruitment strategies. This chapter presented findings from semi-structured interviews, audit data, and field notes, which outline the provision of psychosocial support in selected EPAS in Australia. Results were presented in three categories; psychosocial support currently provided, psychosocial support considered ideal by participants, and barriers to changing psychosocial support. The seven themes presented under the first category were structural elements of EPASs, functional elements of EPASs, emotional care provided by EPAS staff, memory making and options for remains, additional psychosocial support, patient follow-up, and staff support. Themes presented under the second category were structural changes, staff changes, counselling options, GP involvement, online resources, and elective list for D&C. Finally, themes presented under the third category were resources, time, space, funding, staff support, and other barriers. Some subthemes were presented within themes, and all were supported by participant quotes. Some audit data were displayed in conjunction with qualitative data to help provide an overview of the current EPAS experience for patients. Implications of these results are discussed in Chapter 5.

Chapter 5: Discussion

5.1 Introduction

This study aimed to explore the provision of psychosocial support in Early Pregnancy Assessment Services in Australia. Literature shows that appropriate psychological support at the time of a miscarriage can protect against psychological morbidity in the months or years following, and consequently leads to better psychological outcomes (34, 35). Despite many women presenting to EPASs to manage their miscarriage, to date, there is no published literature on the psychosocial support available in Australian EPASs. A mixed method approach was utilised and 31 semi-structured interviews with key informants were conducted to answer this research question.

Findings of the provision of psychosocial support were presented in three categories: psychosocial support currently provided; psychosocial support considered ideal by participants; and barriers to changing psychosocial support. Themes and subthemes that emerged from data related to structural and functional elements of EPASs, staffing arrangements, EPAS procedures, GPs, and limitations on resources.

This chapter will discuss the strengths and limitations of the study, interpret findings in the context of the literature, and finally will discuss implications of the findings and recommendations for future research.

5.2 Strengths and limitations

5.2.1 Limitations

One limitation of this study was the employment of convenience sampling and snowballing in the recruitment process, which likely resulted in recruitment bias occurring. Despite some services being recruited through purposive sampling, most were recruited though convenience sampling due to difficulties contacting or engaging services. Therefore, services and staff most passionate about EPASs and psychosocial support were more likely to participate, and consequently also more likely to pass study details onto others who may also have had a particular interest. This may have resulted in a bias sample of services with a keen interest in this area of care, compared to all existing EPASs.

Similarly, the use of these recruitment methods, in conjunction with the time and financial limitations of a Master's project, resulted in a limited sample of EPASs across Australia. Services represented were primarily from metropolitan Victorian hospitals. New South Wales and Queensland were represented by at least one service, however no EPASs were recruited in any other states or territories. Likewise, no rural or regional services could be recruited despite considerable attempts to do so. This may in part be due to a limited number of EPASs exisiting in rural and regional areas, however further exploration and research is needed to understand this. Although qualitative research does not aim to be representative (98), a broader depiction of EPASs from different areas of the country would produce a more comprehensive understanding of psychosocial support provision in EPASs Australia-wide.

Biased perspectives of some EPASs may have been reported due to limited representation from these services. Five of the 13 EPASs included in this study were only represented by one particpant, therefore these services were only described from one staff member's perspective. Likewise, although many particpants mentioned the social work department as having a role in providng psyhcosocial support to patients, no social workers were able to be recruited. This may partly be because when explored in more detail, many participants reported that social work were actually not routinely involved in EPAS patients' care. Only three of the 31 particpants recruited were male, potentially biasing perspectives provided. However, this may reflect the demongraphics of staff working in EPASs, and more research on EPASs in Australia is needed to understand this. Finally, this study explored the provision of psychosocial support in EPASs from the primary perspective of staff working in these services, and therefore did not explore the perspectives of EPAS patients. Hence, a comprehensive understanding of the psychosocial support provided in EPASs from both a practitoner and patient perspective was not obtained.

Data source triangulation was described by Denzin in 1970 as collecting qualitative data from more than one source to gather multiple perspectives and validate data, thereby developing a comprehensive understanding of the phenomena explored (99). Given that some services were only represented by one perspective, and that patient perspectives were not explored, a limitation of this study was that data source triangulation was not established.

Finally, data saturation was difficult to determine given the huge variance in EPASs represented and opinions collected. Although saturation appears to have been reached regarding the barriers to changing psychosocial support, it is questionable whether data saturation was reached regarding psychosocial support considered ideal by participants, as

new themes were continually arising. Unfortunately, due to the time limitations of Masters, further recruitment needed to reach saturation was not possible.

5.2.2 Strengths

A major strength of this research is that it is the first study of its kind to explore the provision of psychosocial support in Australian EPASs. To date, there have been no Australian studies published that explore staff perspectives of the provision of psychosocial support in Australian EPASs.

The employment of a mixed-methods approach allowed a more comprehensive understanding of EPASs, as audit data provided a description of services, while semi-structured interviews allowed a deeper exploration and understanding of services and provision of psychosocial support. In addition, process-mapping and field notes aided researchers' understanding of the patient experience, thereby strengthening the study. Like data source triangulation discussed under limitations, method triangulation has been described as utilising more than one methodology to gain different perspectives and provide confirmation of findings, adding breadth to an understanding of a given topic (100). As this study utilised semi-structured interviews alongside audit data, field notes and process mapping, method triangulation was achieved.

Another strength of this study was the inclusion of a large range of clinical and support staff. Perspectives of registrars, consultants, nurses, midwives, pastoral care workers, and sonographers were included, which allowed a broader understanding of services and explored varied perceptions regarding the provision of psychosocial support.

A strength of the data collection method was that approximately half the interviews were co-conducted by both LC and Honours student SRH, thus increasing the objectivity of the interview schedule. Similarly, the risk of bias occurring during data analysis was reduced as a subset of transcripts were coded by the research team, and consensus on themes were reached. Although results of this study are not generalisable to all Australian EPASs, findings provide a good preliminary understanding of the current provision of psychosocial support in Australian EPASs, and the barriers to change.

5.3 Provision of psychosocial support in EPAS

This study aimed to answer the research question '*What psychosocial support is offered in Early Pregnancy Assessment Services in Australia?*'

The answer to this research question is difficult to summarise as the provision of psychosocial support varied drastically depending on the specific EPAS, as well as the nuanced needs of individual patients. Findings of the support currently provided in EPAS will be discussed in conjunction with the support participants considered ideal. Discussing the findings within the context of the Australia literature is not possible, as there are no published Australian studies on what is currently provided. Therefore, results will be discussed in comparison with best-practice recommendations outlined in part 1 of the literature review, alongside international literature and literature exploring miscarriage care more broadly.

5.3.1 Structural elements of EPAS

Six out of the 13 services included in this study were physically located alongside maternity or antenatal services, and therefore shared a waiting area with obviously pregnant women and babies. This is likely to exacerbate distress and anxiety in women who are experiencing early pregnancy problems, as they may compare themselves to these women (75). Previous studies have demonstrated that patients appreciate EPASs located in a private setting, separate from antenatal clinics and more advanced pregnancies (59, 101). **Queensland best-practice guidelines support this finding, recommending that care should be offered away from maternity units**, where feasible (63). In the UK, most EPASs have been found to be located in a private area (102), while only around half of the services included in the current study were.

The ideal location of EPASs were discussed by many participants, and although most agreed that a major benefit of EPASs are that they remove patients from the often chaotic environment of ED, some discrepancies arose regarding where best to place EPAS. Two participants discussed in detail their view that EPAS should ideally operate out of ED, as patients would receive care in a timelier manner and resources such as access to ultrasound was easily available. Similarly, although participants from all EPASs co-located with antenatal services expressed their desire to be away from these services to improve their patients' experience, some did note that this would take EPAS patients further away from experienced staff and necessary resources.

Only four EPASs included in this study could routinely perform ultrasound in clinic, while nine utilised radiology for routine scans. Some services did have ultrasound facilities in clinic,

however they were not always staffed with clinicians who were trained to scan. Similarly, some services which did offer ultrasonography in clinic, did so for very limited hours on select days. **NHS NICE guidelines referred to by RANZCOG recommend that all EPASs should offer ultrasound in clinic** (4). This sentiment was echoed by what participants deemed to be the ideal situation, as most expressed a desire for improved accessibility to sonography in general. However, barriers to this change occurring exist and are discussed shortly.

Again, only four out of the 13 EPASs included in this study had a dedicated 'quiet room' available to allow patients and families a private space away from the waiting room. An additional three services did discuss that a room could found if required, although its availability depended on whether the space was already in use. **Queensland guidelines recommend a private environment to ensure confidentiality when breaking bad news** (63). Although all services did have a separate consultation room available, this way typically used for necessary medical discussions, and emotional support could not be fit due to time and space limitations. Interestingly, no participants discussed their desire for improved availability of space for this purpose, which may represent a lower priority given the other areas for improvement and the difficulty to finding additional space in a public hospital. However, many participants did discuss their desire for the EPAS to be expanded in general to meet the needs of patients, given that most services were over capacity regularly.

5.3.2 Functional elements of EPAS

Staffing arrangements in services varied, but most EPASs were run by a nurse/midwife alongside a junior doctor. Unlike EPASs in the UK, nurses and midwives in services included in this study appear to generally have limited roles. Experience levels of doctors also varied drastically from residents to senior consultants. Issues appeared to arise in services run by rotating junior doctors, as they had limited training and were then rotated out once they had gained some experience. Despite many services being run by more junior staff, all EPASs did have access to senior consultants either in person or by phone if needed. This practice aligns with Edey et al's 2007 review which reported ideal practice as having the availability of an Obstetrician Gynaecologist consultant to oversee a clinic (101). All participants reported similar ideas on what could be improved in respect to staffing. Increased nurse/midwife involvement was suggested to lessen the workload on all staff, thereby providing more time for patients and improving continuity of care. This has been shown to be effective in a 1999 study by Fox et al which explored the role of a nurse practitioner (103). Similarly, having more senior staff working in services was discussed as a possible method to decrease wait times and improve

the support provided to patients, while also decreasing the stress on junior staff. Senior staff could also take up responsibility of management of EPASs, which was reported as lacking in some hospitals, consequently providing more opportunity to improve services.

Variation was once again seen in the upper gestational limits for patients to be seen in EPASs, with limits varying between 12- and 20-weeks gestation. However, these purported limits were often not what occurred in practice, as staff noted that they would see patients regardless if they needed support. Gestational limits are not discussed in best-practice recommendations, nor were they particularly brought up by participants when considering best possible care. However, Edey et al's 2007 literature review did suggest an upper limit of between 16 and 18 weeks (101), which was met by seven of the 13 services.

The NHS's NICE guidelines state that "Early pregnancy assessment services should accept self-referrals from women who have had recurrent miscarriage or a previous ectopic or molar pregnancy" (4), yet five services did not allow self-referrals or walk-ins in any circumstances. When self-referrals are not accepted, patients must then first present to either ED and/or GP to gain referral to EPAS, thus prolonging the process and possibly exacerbating anxiety.

Most EPASs reported an approximately equal ratio of referrals from ED and GP, however one service which had recently completed an audit on this number reported that less than 10% of EPAS patients were referred directly from their GP. Many participants discussed their desire for an increased number of referrals directly from GPs. More direct referrals would reduce the number of women presenting to ED with EPPs, where they are likely to experience long wait times likely resulting in unnecessary additional stress. Participants believed more awareness of EPAS and improved GP confidence in managing miscarriage would help increase direct referrals. Limited knowledge of EPASs may be because these services are relatively new to Australia, or not commonly discussed. GP knowledge could be increased through the role of a GP liaison, as seen in some services visited, and as described by Crilly et al (2012) (59).

All EPASs had access to either phone or in-person interpreters. Many participants thought phone interpreters were more difficult to use, but they understood it was not always possible to have in-person available. Others discussed the benefits of phone interpreters, such as a reduced risk of the patient and interpreter being connected socially.

Patient literature such as leaflets or brochures were available at all services, fulfilling Queensland Health guidelines of providing information in both written and verbal format (63).

NHS NICE guidelines state that services should provide information on "where to access support and counselling services, including leaflets, web addresses and helpline numbers for support organisations." (4). Almost all EPASs had literature either from pregnancy loss support organisations or had literature with contact details for these included. However, of note is that not all staff were aware of, or routinely offered these handouts to patients.

5.3.3 Emotional care provided by EPAS staff

When given sufficient time, the emotional care provided by EPAS staff appeared to be excellent, and staff demonstrated a high dedication and care for their patients. Most EPAS staff perceived their role regarding psychosocial support provision as primarily expressing empathy, acknowledgement and compassion at the time of consultation, and guilt mitigation; stressing to their patients that they were not to blame, as being of primary importance. Some recommendations from Queensland Health guidelines (63) include, but are not limited to:

- Expressing sorrow for what has happened
- Being open and honest
- Communicating empathetically, clearly and honestly
- Reassure the woman that the loss was not due to anything she did or did not do
- Informing patients that well-meaning family and friends may say hurtful things

These recommendations align well with the current literature on what care patients want from their healthcare providers, such as acknowledgement, comprehensive information provision, sensitivity and follow-up (51, 53, 54).

All of these suggestions were reported to be discussed by participants; in particular, acknowledging women's loss and validating feelings about their loss, and reassuring patients that they were not responsible for their miscarriage. Previous literature finds that women rate recognition of the significance of their loss by healthcare providers as most important following a miscarriage (30, 53, 54, 79). The importance of guilt mitigation was also a significant finding in a recent 2018 Australian study by Jensen et al, which explored healthcare providers views of miscarriage support (55).

Most participants also spoke about avoiding using clinical language, which they thought lacked sensitivity, and instead spoke of mirroring the language used by patients themselves. Patients' desire for the use of sensitive and non-medicalised terminology is well reported in the literature (34, 53, 71, 76, 79).

Individualisation of care and the recognition of the broad range of patient perspectives was also stressed by many participants. Although this aspect of care is essential for good practice, some assumptions about possible influences on patient care are not supported by research. For example, some participants spoke of expecting increased psychological distress in women who have experienced recurrent miscarriage or IVF compared to those who have not or mentioned that patients who experience a loss in the early stages of pregnancy were less at risk of experiencing psychological morbidity compared to those of later gestations. However, there is no evidence supporting these assumptions (15, 24).

Contrary to findings from this study, literature from patients' perspective consistently report that healthcare providers focus on the physical needs of patients, and often ignore the emotional (55, 104-106). This may be due to multiple reasons, including this study only collecting healthcare providers perspectives, staff choosing to participate in this study having a particular interest in the area, or may even be due to improved care in EPAS compared with care provided in other locations. Despite most participants reporting providing emotional care, some participants did acknowledge their inability to provide this support due to limitations on time and experience.

5.3.4 Memory making and options for remains

Most participants did not report offering many memory making opportunities or any discussions regarding handling of remains to patients seen in their service. Instead, participants noted that these services and discussions were largely reserved for patients experiencing late miscarriages, typically past 16 weeks. In these cases, patients would be managed on a ward and arrangements regarding opportunities such as photographs, hand or footprints, memorial books, and teddy bears would be made by either social work or pastoral care. Although many of these options may not be appropriate or possible for early miscarriages, Queensland guidelines (63) recommend that staff:

- Provide an opportunity for parents to see the absence of heartbeat where appropriate
- Offer ultrasound photos in writing/as photo as memento
- Discuss an Early Pregnancy Loss certificate (in relevant states)
- Inform parents that they can make their own decisions about remains

While some participants did offer the option of an ultrasound photos to some patients, others did not discuss the possibility of providing ultrasound results as they thought it would be

"heartless". Furthermore, some incorrectly reported that parents did not have a strong connection with the pregnancy at these early stages.

A small number of participants discussed the options for memory making they could raise with patients, but again noted that they were frequently too limited by time to be able to have that discussion. Instead, pastoral care and social work were reported to be able to offer these, if the patient requested additional information.

5.3.5 Additional psychosocial support

Participants noted that referrals to additional emotional support were not standard, and typically only provided when a patient asked explicitly for them, if the loss was after the first trimester, or if the patient was deemed high-risk. Although social workers were mentioned by almost all participants, in practice they appeared to have a very limited role and were reported to only get involved in cases where there appeared to be other considerations to account for. Similarly, pastoral care practitioners were reported to have a significant role in pregnancy losses in the second trimester but were not routinely consulted for early miscarriages. An exception to this was in two EPASs, where pastoral care reported visiting all patients who were to receive surgical management, therefore providing them an opportunity to offer emotional support. Utilisation of psychological services were almost non-existent and were only reported as a service that patients could see their GP to be referred to. One EPAS was an exception, as it was located next to a fertility clinic with a clinical psychologist available if needed. Participants reported that external support services were preferred due to better continuity of care for patients, and examples of services included requesting a mental healthcare plan for their GP, other psychological or counselling referrals through GP, and connecting with a pregnancy loss support organisation. **Queensland Health guidelines state that healthcare providers should "provide information about accessing additional psychological support in the future"** (63), which was not always reported by all participants as occurring. Although no services included in this study had counselling options available to EPAS patients in clinic, many participants did express their desire to improve the psychosocial aspect of care through incorporating a counselling service within EPASs to create a multidisciplinary team.

5.3.6 Patient follow-up

Patient follow-up was not reported to routinely occur in most EPASs included in this study, and mostly referred to the physical health of women in the days or weeks following miscarriage. In most services, follow-up in clinic only occurred if a patient chose either medical or expectant management. Phone follow-up was utilised by many services to track levels of human

chorionic gonadotrophin, to ensure the miscarriage was complete and patients had returned to pre-pregnancy levels. If follow-up occurred, the focus was on the physical, not emotional state of patients. Some participants reported a decline in the number and extent of follow-up occurring due to limitations on funding or time.

Utilising GPs for medical follow-up in low or medium risk patients was discussed by many participants, and most participants suggested GPs may be best positioned to provide psychological follow-up. However, many participants assumed that patients would seek out their GP if they needed additional help, and therefore often GPs were not discussed in EPAS consultations and no explicit referrals were made as staff relied on women to communicate the need for additional support. Similarly, a discharge summary was rarely sent to the patients GP. These findings echo those of Jensen et al's 2018 study, which also found that follow-up was not routinely offered in public hospitals due to insufficiencies resources, and instead patients would be encouraged to see a GP (55).

NICE guidelines recommend that **"After an early pregnancy loss, offer the woman the option of a follow-up appointment with a healthcare professional of her choice"** (4). Although many participants reported mentioning GPs, this recommendation does not appear to be followed in all cases.

There is ample literature available that reports women's dissatisfaction with follow-up, and reports that it is ideally wanted in the days to weeks following diagnosis (20, 34, 51, 54). Interestingly, follow-up was not reported in discussions regarding what participants deemed ideal care, demonstrating the disparity between what women want and what healthcare providers view as important. This concept will be discussed in more detail shortly.

5.3.7 Staff support

Most EPASs included in this study had limited, if any, formal training available to staff on psychosocial care specific to EPL. A small number of larger services did have educational opportunities for their staff, or participants reported that staff had independently undergone training specific to EPAS. However, most services reported that training was informal, and largely learnt through experience. The low medical complexity of miscarriage can result in junior doctors with limited experience being left alone to run consultations with patients experiencing a physiologically distressing event. These findings both echo recent Australian literature (55). Although the most senior doctors may have learnt how to provide psychosocial support to EPAS patients through years of experience, junior doctors do not have this

experience, and therefore are often under prepared, possibility impacting the care provided to patients.

Both Queensland Health and NICE guidelines recommend healthcare providers involved in caring for women experiencing EPL receive training in how to communicate sensitively and in breaking bad news (4, 63). Yet, specific training is not reported. However, training on how to break bad news and sensitive communication are both foundations of medical education.

5.4 Barriers to changing psychosocial support

Consensus on the barriers to improving psychosocial support in EPASs and closing the gap between what support is provided and what support participants considered ideal was reported. Findings are consistent with themes reported in the literature and therefore are also discussed in Chapter 2. The major barriers reported were EPASs being under-resourced in a variety of ways, and miscarriage being considered a low priority was another finding.

5.4.1 Under-resourced

One of the most prominent findings from this study was the reported lack of resources including time, space and funding, which limited improvement of psychosocial care in EPASs. The most commonly discussed of these was the limitation of time. All participants reported that they did not have sufficient time to manage both the physical care of patients and provide emotional support, and due to the need to prioritise physical care, emotional support was sacrificed. This finding has been reported in the literature extensively, and healthcare providers feel a lack of time prevents the provision of optimal care (15, 54, 55, 104, 105, 107). Evans et al's 2002 qualitative study explored staff's views on hospital provision of psychosocial care, and 56-86% felt they did not have adequate time to listen and talk with patients (15). Similarly, limited resources more generally, and possibly as a cause limited funding, are also reported as a barrier in both this study and previous literature (55, 88)

5.4.2 Staff support

A lack of staff support was also reported as a limitation on optimal care provision. This was discussed primarily regarding compassion fatigue and the need for self-protection of staff. This disproportionately affected junior doctors, who were reported as under-prepared to support patients' emotional needs. The need for self-protection was reported, given that feelings of grief and loss are prevalent in EPASs, a finding reflected in the literature (55, 104, 108)

5.4.3 Low priority

Finally, another finding reported to limit improvements of psychosocial support provision in EPASs is that miscarriage is considered a low priority. Participants described this low priority affecting access to services such as sonography appointments and surgical places for D&Cs, where EPAS patients are typically pushed to the bottom of the list. Similar issues are likely the reason for poor patient experience in ED. This low priority may also help explain the low awareness of EPASs in GP and the public more broadly, consequently affecting patient experience through delayed access to EPAS. Finally, the need for a 'champion', or a member of staff who is passionate about EPL care to push for improvement in service is essential, and if miscarriage is a low priority changes are likely to occur slowly, if at all.

5.5 Practice and perception mismatch

A recent study by Jensen et al (2018) that explored Australian healthcare professionals' roles and practices in supporting women experiencing miscarriage described a 'practice and perception mismatch' (55). The 'practice mismatch' was described as a discrepancy between actual practice and ideal practice from the healthcare professionals' perspective, while the 'perception mismatch' was described as the discrepancy between healthcare professionals' and women's perception of 'ideal' care (55). These same discrepancies can also be seen clearly in the results of this study.

'Practice mismatch' is a key finding of this study and is demonstrated by the first two categories of results; '4.4 Psychosocial support currently provided', and '4.5 Psychosocial support considered ideal by participants'. The contrast between these two categories clearly show the discrepancies which define the 'practice mismatch'. For example, most participants described the ideal location for an EPAS to be away from antenatal or maternity services, yet in practice this was only achieved by seven of the 13 services. The final category of results, '4.6 Barriers to changing psychosocial support' outlines some potential reasons this practice mismatch occurs from healthcare professionals' perspective.

Similarly, a 'perception mismatch' can also be seen in this study. An example of this is the finding that some participants believed patients who experience early miscarriage have a weaker bond with their pregnancy compared to later gestations, and therefore require less psychosocial support, yet literature shows that gestational age does not influence women's level of grief or support desired. This 'perception mismatch' is also evident in the literature

through opposing views of what women want from healthcare providers and what healthcare providers believe they want. Evans et al's 2002 quantitative study explored the contrasting view of staff and patients regarding psychosocial care for women who miscarry (15). This survey found that all participants believed patients' hospital experience could be improved, but staff and patients differed on how this should be achieved. Patients reported a desire for a more considerate and sensitive attitude from staff, while staff reported that patient experience could be improved by the provision of counselling, more privacy and additional staff.

5.6 Implications

Findings from this study have implications for both governance, and clinical practice in EPASs and General Practice.

5.6.1 Governance

Implications for governance and policy are primarily related to the lack of resources available to EPAS staff, which consequently limit the provision of ideal psychosocial support. Findings clearly report that a lack of resources, such as time, space and funding, act as a barrier to improving psychosocial support. Therefore, more funding and resources available to EPASs and miscarriage care more generally are necessary to provide the 'gold standard' care. The large variation in EPASs and lack of clarity around what an EPAS should be may also confuse both healthcare providers and patients. This highlights the need to produce and disseminate Australian-specific guidelines on EPASs which include details on psychosocial support, to assist EPAS staff in providing a consistent and reliable service, as well as demonstrating a benchmark for emerging EPASs to strive for.

5.6.2 EPAS

Findings from this study have several implications for EPASs. The delivery of specific training for staff working in EPASs, particularly targeted towards junior staff with limited experience, is likely to improve psychosocial support received by patients. Given the 'perception mismatch' discussed, more education to EPAS staff on the emotional needs of patients may help better align differing perceptions of the ideal psychosocial support, consequently improving patient satisfaction. This implementation has been effective in a 2002 study by DiMarco et al, which reported healthcare professionals' perceptions of emotional needs of patients increased after participation in a bereavement program (109).

Limited resources were reported as a major barrier to improving psychosocial support provision in EPASs. This limitation is common across many healthcare fields, suggesting a systemic issue, therefore may be difficult to address or change. This leads to the question of whether EPASs are best situated to provide psychosocial support to patients. Although research shows that interactions with healthcare providers at the time of a miscarriage can significantly influence psychological morbidity (37), EPASs are not fundamentally designed for on-going psychosocial support, and more research into the most appropriate support provision is needed.

5.6.3 General Practice

This study also has implications for General Practice, in respect to both referrals from GPs and follow-up with GPs. Some participants noted that GPs may be able to manage low-medium risk patients experiencing early pregnancy issues themselves, without the need to refer to ED or EPAS. Therefore, more education for GPs to enable them to confidently manage some cases without the need to refer patients should be considered. Similarly, more information and awareness about EPASs should be provided in an attempt to increase the number of direct referrals to EPAS, thereby bypassing the need for patients to wait in ED unnecessarily.

Given the often time-poor environment of EPASs, many participants discussed the use of GPs for both physical and psychological follow-up. Whether GPs feel they are best placed to provide emotional follow-up care requires further examination. Similarly, although many participants raised the role of GPs in follow-up care for their patients, very few reported routinely sending discharge summaries to general practices. Therefore, more consensus between EPAS staff and GPs is needed to provide improved care for patients. Likewise, GPs may need to be aware of this expectation and may need education to confidently manage patient follow-ups and information about additional referrals when appropriate.

5.7 Recommendations for future research

This study provided an initial understanding of the provision of psychosocial support in Australian EPASs, leaving many recommendations for future research. A larger study including EPASs from all Australian states and territories, ensuring representation of regional and rural services, is needed for a more comprehensive understanding of EPASs in Australia. This study should aim to ensure perspective triangulation is achieved in all services represented.

Research exploring the feasibility and acceptability of education for EPAS staff on psychosocial aspects of care is also needed before any implementation of training should be considered. Similarly, more research is needed into whether implementing recommendations such is increasing the role of nurses and/or midwives in EPASs, would improve patient care and psychological outcomes in practice.

Studies exploring patients' perspective on psychosocial care received specifically in EPASs are also needed to better understand all outlooks on this topic. Similarly, although there is a large body of research on what types of psychosocial support women want from healthcare providers, such as improved recognition of loss and sensitivity, better information provision, and more follow-up, there is little research regarding where patients would like this care to occur. More research is required to understand patients' support needs and the ideal setting for the provision of psychosocial support from a patient's perspective. As little is known about whether EPAS patients consult their GPs for emotional follow-up, and where they seek support more generally, further exploration of this is needed.

Further research exploring these findings in the context of compassion fatigue and relating them to the breaking bad news literature would also add depth to results.

Finally, given many EPASs are under resourced and lack the time to adequately address psychosocial aspects of care, future research exploring alternative support services should occur. The direction of this research will likely be influenced by findings from studies exploring patient perspectives mentioned previously. Specifically, the role of General Practice and pregnancy loss support organisations should be investigated.

5.8 Conclusion

This chapter outlined the strengths and limitations of the study and discussed and interpreted findings of the study in the context of the literature. Implications of findings were discussed in respect to governance, EPASs and general practice. Finally, recommendations for future research were offered.

The next chapter will summarise this thesis and draw final conclusions.

Chapter 6: Conclusion

Miscarriage is a common event estimated to effect up to one in four pregnancies. In many women it can result in significant psychological morbidity, and it has been well documented that the provision of appropriate psychological support at the time of a miscarriage can lead to better psychological outcomes in the weeks and months following. Given that in the Australian public healthcare system, many women experiencing EPPs will be managed in an EPAS, care provision in EPASs should be understood. However, very little research has been conducted on Australian EPASs, and to date there has been no literature published specifically on the provision of psychosocial support in Australian EPASs. Therefore, this study aimed to answer the research question 'What psychosocial support is offered in Early Pregnancy Assessment Services in Australia?' A mixed method approach utilising audit, field notes and 31 semi-structured interviews was conducted to answer this question.

This study found considerable variation in the psychosocial support offered in 13 EPASs across Australia, supporting anecdotal findings. This was in part due to differences in structural elements of services, such as physical location of EPAS, and availability of a quiet room and ultrasonography. Likewise, staffing arrangements of individual services often influenced the provision of psychosocial support able to be offered. A key finding of this study was the dedicated and caring staff who provided the best possible emotional support to their patients, within their clinical settings. The importance of acknowledging and validating patients' feelings, guilt mitigation, and providing individualised care was reported by almost all participants. However, opportunities for memory making, and additional psychological services both within the hospital and externally were rarely reported. Common barriers to providing the psychosocial support participants viewed as ideal centred around limitations on time and resources, resulting in the physical care of patients taking priority over psychological care.

This is the first study to explore the provision of psychosocial support in Early Pregnancy Assessment Services in Australia, thereby addressing the gap in literature regarding Australian EPASs. Findings suggest a need for future research into EPASs across all of Australia, including a focus on regional and rural areas, to gain a broader insight. Patient perspectives of the psychosocial support provided in EPASs specifically is also lacking in the literature. Finally, more research into where psychosocial support should best be offered is needed to improve patient experience and consequently lower psychological morbidity following miscarriage.

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Appendices

Appendix 1: Initial invitation email

Dear _____,

My name is Lily and I am a Masters student at the University of Melbourne. I am working with a group of researchers who are examining the support for women who experience miscarriage in Australia. We want to explore the provision of psychosocial support to women who miscarry in Early Pregnancy Assessment Services (EPAS), and well as describe the common characteristics between, and pathways into these services across Australia.

Our research will collect non-sensitive information about the EPAS, some of which may be currently available to the public, about the way the service operates. Questions will aim to collect information such as opening hours, referral pathways, specific services or facilities available, average wait times, management options, staff structure and training, and average number of patients seen. In addition, we will ask questions about the types of psychosocial support offered to women and partners who experience a miscarriage, and participants' views on the need for any additional elements to the service.

In order to collect this information, we would like to conduct individual or group interviews, preferably in person, with EPAS staff. Interviews are likely to be 30-40 minutes long, and would be audio-recorded and transcribed verbatim. If possible, we would also like to have an on-site visit to get a better understanding of how the EPAS operates and an idea of the women's journey. All information will be de-identified for the summary report, which we will provide to each participant. However, if an individual service requests a report on their own service this can be provided.

This research project is a low risk study and has been approve by the Human Ethics Advisory Groups of the Department of General Practice at the University of Melbourne (ID 1851563.3).

If you are interested in participating or have any further questions about this research, please do not hesitate to contact me either via email or on my mobile: _____.

Kind Regards,

Lily

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Appendix 2: Plain Language Statement

THE UNIVERSITY OF MELBOURNE

THE PATHWAYS INTO AND COMMON CHARACTERISTICS BETWEEN EARLY PREGNANCY ASSESSMENT SERVICES

PLAIN LANGUAGE STATEMENT

1. Your Consent

You are invited to take part in this research project. This Plain Language Statement contains detailed information about the research project. Please read this form and feel free to ask questions.

2. Who is conducting the research?

This research is being conducted by researchers at the Department of General Practice at the University of Melbourne, led by Dr Jade Bilardi and Professor Meredith Temple-Smith, and Honours Student researcher Ms Sophie Russ-Hall and Masters Student Ms Lily Claringbold.

3. What is the purpose of the research?

Eligibility for entry and services provided by Australian Early Pregnancy Assessment Services (EPASs) vary. This research will examine the pathways into, and common characteristics between EPASs.

4. What will I be asked to do?

If you agree to participate, you will be invited to take part in a single or group interview with a researcher. The interview can be done over the phone or at your EPAS in the form of an individual or group interview. The interview will be audio-recorded so that it can be typed out later for analysis. We estimate that the interview will take about 30-40 minutes. If a group interview is elected, this could take up to 90 minutes, and comments will not be anonymous within this group setting. The interview will involve some basic questions such as:

- the typical journey of a patient from entry to the service to exit from the service.
- opening hours and average wait times
- referral pathway into the service
- specific services offered
- is an ultrasound facility available within the clinic?
- what psychosocial support is offered?

You do not have to answer any questions you are not comfortable answering. With your permission, we may contact you after you have completed the interview if we need further clarification or explanation about the information you have provided.

Process mapping involves exploring the pathway into and through an individual service, and if possible, we would like a researcher to visit the EPAS to allow her to add a non-identifiable description of the service to provide context to the data she collects.

5. Possible benefits

Participation in the project is not expected to directly benefit individual participants. Expected benefits of this study are the provision of baseline information about the service

which will be given to the service, and may be useful for you. De-identified data will also be made available to the EPAS e-Community of Practice and may be included in conference presentations and publications.

6. Risks in participating

We do not anticipate any risks will be posed to you in participating in this study. In the unlikely event that you feel uncomfortable or distressed by any questions, remember that you are under no obligation to answer any questions and you are free to stop the interview or withdraw from the study at any time. If you feel uncomfortable or distressed bythe interview, you can terminate at any time. Professor Meredith Temple-Smith will be in contact, following the interview to see if you require further support. If so, you will be encouraged to visit your GP or mental health provider.

7. How will my confidentiality be protected?

While highly unlikely, the small number of people taking part in this study offers potential for revealing identity so any information obtained that can identify you, including descriptions of specific unusual experiences, and place names, will be removed from interview transcripts. It will be disclosed only with your permission, or in compliance with the law. All information used for the purposes of publications or conference presentations will be de-identified and you will be referred to by a pseudonym only. Any identifying data we collect will be stored separately from coded interview data, in a locked drawer or password protected computer database at The Department of General Practice. Data access will be restricted to only those involved in this study. The Department of GeneralPractice requires a staff allocated, authorised swipe pass to enter the buildings after hours and remains locked. Entry during business hours is managed by reception staff.

The information collected as part of this study will be destroyed after five years following the publication of the final report, resource or journal article from the research. Documents will be shredded and electronic recording material will be erased. It is possible for information to be subject to subpoena, freedom of information request or mandated reporting by some professions. However, given the general nature of the information sought in this research, its release as a consequence of these legal processes is extremely unlikely.

8. Do I have to take part?

Participation in this study is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Please contact the study researchers listed below if you wish to withdraw from the study. If you decide to withdraw from the project we will not use any of the information or data you have provided to us.

9. Results of the study

You may wish to receive a copy of the baseline information about your service. De- identified data will also be made available to the EPAS e-Community of Practice and may be included in conference presentations and publications. Please complete the tick boxin the consent form if you would like to be emailed a copy of the study results.

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10. Ethics

This research project has been approved by the Health Sciences Human Ethics Sub-Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Fax: +61 3 9347 6739 or Email: HumanEthics-complaints@unimelb.edu.au All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project (ID number: ID1851863.1).

11. Where can I get further information?

If you would like to know more about the research, or if you have any concerns during the course of the research, please email or telephone us using the details below:

Dr Jade Bilardi	M: 0402 724 228	E: jbilardi@mshc.org.au
Professor Meredith Temple-Smith	M: 0429 858 248	E: m.temple-smith@unimelb.edu.au
Ms Sophie Russ-Hall	M: 0402 115 744	E: sruss@student.unimelb.edu.au
Ms Lily Claringbold	M: 0437 687 126	E: lily.claringbold@unimelb.edu.au

12. How do I agree to participate?

If you are willing to participate in the interview please read and complete the consent form on the next page and return it via email to sruss@student.unimelb.edu.au or lily.claringbold@unimelb.edu.au .

Appendix 3: Consent form

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THE PATHWAYS INTO AND COMMON CHARACTERISTICS BETWEEN EARLY PREGNANCY ASSESSMENT SERVICES

CONSENT FORM

Principal researcher: Professor Meredith Temple-Smith Other researchers: Dr Jade Bilardi, Ms Sophie Russ-Hall (Honours Project student researcher) and Ms Lily Claringbold (Masters student researcher)

Dr Jade Bilardi	M: 0402 724 228	E: jbilardi@mshc.org.au
Professor Meredith Temple-Smith	M: 0429 858 248	E: m.temple-smith@unimelb.edu.au
Ms Sophie Russ-Hall	M: 0402 115 744	E: sruss@student.unimelb.edu.au
Ms Lily Claringbold	M: 0437 687 126	E: lily.claringbold@unimelb.edu.au

I have been given a plain language statement about the above named research. I understand this project aims to explore the pathways into and common characteristics between early pregnancy assessment services in Victoria.

I understand this form is to gain my consent to participate in this research and I acknowledge:

1. I have read and understand the Plain Language Statement (ID1851863.1, Version 3, 4/6/2018). I consent to participate in the project named above, the particulars of which are to participate in an individual interview which will be audio-taped. A written copy of the information has been given to me to keep.
2. I authorise the researchers to use the information I provide for any academic journal articles and conference presentations that relate to the research referred to above.
3. I authorise the researchers to use the information I provide in any future projects that are closely related to this project, or in the same general area of research as this project.
4. I have been informed that my participation in this project is voluntary and I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any data previously supplied.
5. I understand the project is for the purposes of research.
6. I understand the small sample size in this study may make me more identifiable however any information obtained in connection with this project, and that can identify me, will remain confidential subject to any legal requirements. I understand I will be referred to either by a study ID number or a pseudonym in any publications or reports arising from this study.
7. I understand all data will be securely stored at the Department of General Practice in locked cabinets or password protected databases and access will be restricted to only those involved in this study.

Please tick the boxes below if you consent to us contacting you after the interview for the following reasons (contact will be via email).

- ▪ I agree to being contacted after I have completed the interview for further clarification and follow up
- ▪ I would like to receive a copy of the study results directly.
  Email: _____

I,_____(your name) voluntarily consent to taking part in this research project.

Signature: **Date:**

Researcher signature: **Date:**

Appendix 4: Interview schedule

EARLY PREGNANCY ASSESSMENT SERVICES IN AUSTRALIA

INTERVIEW GUIDE

Participant ID: _____ Interview Date: _____

Interview site: ☐ Phone ☐ EPAS

☐ Group interview ☐ Single interview

DEMOGRAPHICS

Gender: _____

Profession: _____

Time working in service: _____

Interview Schedule

- My project is looking specifically at the provision of psychosocial support to women who experience miscarriage
- We want to get a better idea of what's available, how different EPAS function, what works and what doesn't, and what EPAS staff would like these services to be like in an ideal world.
- Reminder that everything is confidential and will be de-identified
- Happy with this interview being audio-recorded?

1. Please describe your EPAS

- Do you know how long has the service been running?
- How does this service define early pregnancy?
- Opening hours?
- How many appointments scheduled per day/how many in reality?
- Can you please describe the physical structure and location of the service? Is the EPAS physically away from other antenatal services?
- Specific services offered (US, beta hCG etc.)
- How do patients get/make an appointment?
- How would you describe the demand for this service? Are you fully booked?
- Can you please describe any follow up procedures there are? GP/nurse phone call?
- Do you know how GPs find out about this service?

2. **Please tell me about the patient's pathway into your EPAS.**
   - Referral pathway into the service, and approx. numbers from each source
   - Can they self-refer?

3. **Please describe the staff of this EPAS.**
   - Numbers, profession, gender and availability of staff
   - Is there any training undergone specific to the EPAS?

4. **Please describe the management options available here.**
   - Is ultrasound facility available within the clinic?
   - Is a consultant O&G / senior medical officer present physically in the clinic or by phone advice?
   - Is home-based medical management of miscarriage offered?
   - Is there a phone number they can call if they have any issues at home?

5. **Do you know what encouraged the hospital to develop a service like this?**
   - Has the service changed much since it first opened?

6. **Can you please tell me what you think the best aspects of this service are?**

7. **Can you tell be about if there are any counselling services or options offered at the hospital?**
   - Role of social work and/or pastoral care?
   - Provide information about accessing psychological support in future?

8. **Is there any hospital protocol to help inform women of their loss? Is there any training available to help them with this discussion?**
   - Private room to break bad news?

- Language or terminology used when discussing their baby/fetus?
- Are parents offered the opportunity to see the absence of a heartbeat on an ultrasound machine where appropriate?
- Can you tell me a bit about how to communicate with male partners?
- Provide written information such as brochures about miscarriage?
- Do you have interpreter/translator services available?

9. **Is there any memory making opportunities able to be offered?**
    - Ultrasound results in writing or photo?
    - Keepsake box etc?
    - Certificates?
    - When declined, do you offer to provide in future?
    - Memorials?

10. **Do you know what the hospital's options are for the disposal of the pregnancy tissue or the remains?**
    - Offer burial or cremation? Shared or private? Funeral/ceremony options?
    - For parents who decide to take remains home, do you provide information about temperature/timeframes for preservation, and local laws about burial?
    - Cool/cuddle cots?

11. **What do you consider the most important aspect of psychosocial support to women who experience miscarriage?**

12. **If there was anything you could change or improve, what would it be?**

13. **Any further comments?**

14. **Housekeeping**
    - Further contact if we forgot any questions?
    - Do you know of any other staff that may be interested in this project?
    - Is it ok for us to visit the service at a later date and take field notes?

Appendix 5: Ethics approval

26 June 2018

Prof M.J. Temple-Smith

General Practice
The University of Melbourne

Dear Prof Temple-Smith

I am pleased to advise that the General Practice Human Ethics Advisory Group has approved the following Minimal Risk Project.

Project title:	**THE PATHWAYS INTO AND COMMON CHARACTERISTICS BETWEEN EARLY PREGNANCY ASSESSMENT SERVICES IN AUSTRALIA**
Researchers:	**Prof M J Temple-Smith, Dr J E Bilardi, S Russ-Hall, L Claringbold**
Ethics ID:	**1851563.3**

The Project has been approved for the period: **24-Apr-2018 to 31-Dec-2018.**

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.

(b) **Amendments to Project:** Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Advisory Group for further consideration and approval before the revised Project can commence. If the Human Ethics Advisory Group considers that the proposed amendments are significant, you may be required to submit a new application for approval of the revised Project.

(c) **Incidents or adverse affects:** Researchers must report immediately to the Advisory Group and the relevant Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.

(d) **Monitoring:** All projects are subject to monitoring at any time by the Human Research Ethics Committee.

(e) **Annual Report:** Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) **Auditing:** All projects may be subject to audit by members of the Sub-Committee.

Please quote the ethics registration number and the name of the Project in any future correspondence.

On behalf of the Ethics Committee I wish you well in your research.

Yours sincerely

A/Prof John Furler - Chair
General Practice Human Ethics Advisory Group

Department of General Practice
Melbourne Medical School, Faculty of Medicine, Dentistry and Health Sciences
The University of Melbourne Victoria 3010 Australia

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Appendix 6: COREQ guidelines

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	30
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	30
Occupation	3	What was their occupation at the time of the study?	30
Gender	4	Was the researcher male or female?	30
Experience and training	5	What experience or training did the researcher have?	30
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	31
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	32
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	30
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	29
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	30
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	31
Sample size	12	How many participants were in the study?	35
Non-participation	13	How many people refused to participate or dropped out? Reasons?	36
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	37
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	30
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	38
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	33
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	30
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	32
Field notes	20	Were field notes made during and/or after the inter view or focus group?	32
Duration	21	What was the duration of the inter views or focus group?	37
Data saturation	22	Was data saturation discussed?	73
Transcripts returned	23	Were transcripts returned to participants for comment and/or	32

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	33
Description of the coding tree	25	Did authors provide a description of the coding tree?	33
Derivation of themes	26	Were themes identified in advance or derived from the data?	33
Software	27	What software, if applicable, was used to manage the data?	33
Participant checking	28	Did participants provide feedback on the findings?	32
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	40-71
Data and findings consistent	30	Was there consistency between the data presented and the findings?	40-71
Clarity of major themes	31	Were major themes clearly presented in the findings?	35
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	35-71

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357