

MISCARRIAGES AND THE EMERGENCY DEPARTMENT:  
A PHENOMENOLOGICAL ANALYSIS

by

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## DEDICATION PAGE

I would like to dedicate this study the eight women who bravely volunteered to participate in this study. It would not have been possible without their willingness to share these deeply personal, emotionally charged stories.

## TABLE OF CONTENTS

ABSTRACT.....	vi
LIST OF ABBREVIATIONS USED.....	vii
ACKNOWLEDGEMENTS.....	viii
CHAPTER I: INTRODUCTION.....	1
Problem Statement.....	1
Literature review.....	8
Miscarriages and Their Treatment.....	8
Miscarriages and Emergency Care in Canada.....	13
The Unique Context of Miscarriage.....	15
Psychological Implications of Miscarriage.....	20
The Miscarrying Experience.....	27
Supportive Interventions.....	30
Miscarriages and Emergency Departments.....	32
Restructuring Delivery of Care.....	34
Summary.....	35
CHAPTER II: METHOD.....	37
Research question.....	37
Design.....	37
Interpretive phenomenology.....	38
Sample.....	41
Study Participants and Eligibility Criteria.....	43
Data Collection.....	46
Data Analysis.....	49

Trustworthiness.....	51
Ethical Considerations.....	53
Summary.....	54
CHAPTER III: FINDINGS.....	55
The Participants.....	55
The Meaning of Experiences of Miscarriage and the Emergency Department.....	56
Pregnant/Life: Miscarriage/Death.....	56
Deciding To Go To the ED: Something’s Wrong.....	59
Not An Illness: A Different Kind of Trauma.....	62
Acknowledgement Throughout My Visit.....	65
Leaving the ED: What Now?.....	70
Summary.....	79
CHAPTER IV: DISCUSSION.....	80
The Participants.....	80
Life and Death.....	80
Why Women Go to the ED.....	84
Miscarriage is Not an Illness.....	87
Acknowledgement.....	89
Going home.....	97
Summary.....	104
CHAPTER V: CONCLUSIONS.....	105
Implications for Practice.....	105
Implications for Services.....	115
Implications for Education.....	118

Implications for Research.....	118
Study Limitations.....	120
Conclusion.....	121
REFERENCES.....	123
APPENDIX A Letter of Invitation.....	135
APPENDIX B Study Advertisement.....	136
APPENDIX C Thank You Letter.....	137

## ABSTRACT

Miscarriages, pregnancy loss less than 20 weeks gestation, are the most common complication of early pregnancy. Women who are miscarrying generally access care in emergency departments (EDs) where treatment focuses on confirming the miscarriage. Pregnant women over 20 weeks gestation are eligible for obstetrical care that can prevent premature labor and provide supports if loss occurs. This interpretive phenomenology study examined the experiences of eight women who sought care for a miscarriage in the ED to answer the question: “What are the experiences of women coming to the ED for care while having a miscarriage?” Interviews were conducted. Data were analyzed. Five themes emerged: *Pregnant/Life: Miscarriage/Death*, *Deciding to go to the ED: Something’s wrong*, *Not An Illness: A different kind of trauma*, *Acknowledgement throughout my visit*, *Leaving the ED: What now?* The ED environment failed to acknowledge the experience, making miscarriage a marginalized event for women participating in this study.

## LIST OF ABBREVIATIONS USED

CDHA	Capital District Health Authority
CTAS	Canadian Triage and Acuity Scale
CVK	Charles V. Keating Emergency and Trauma Center
D&C	Dilatation and curettage
ED	Emergency Department
EDIS	Emergency Department Information Systems
ENA	Emergency Nurses Association
EPAU	Early pregnancy assessment unit
EPCC	Early pregnancy complications clinic
GP	General practitioner
HRM	Halifax Regional Municipality
IWK	IWK Health Center
PI	Principal investigator
PTSD	Posttraumatic stress disorder
REB	The Capital District Research Ethics Board
RN	Registered nurse

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## **Chapter I**

### **INTRODUCTION**

#### **Problem Statement**

Miscarriages, pregnancy losses occurring prior to 20 weeks gestation or a fetal weight of less than 500 grams, are the most common complication of early pregnancy (Statistics Canada, 2012; Tulandi & Al-Fozan, 2011). Up to 20% of pregnancies result in spontaneous miscarriage prior to 20 weeks gestation, 80% of these occur before 12 weeks (Tulandi & Al-Fozan). A miscarriage can be a significant event in a woman's life and may lead to prolonged grief, depression, anxiety and symptoms of posttraumatic stress (Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O'Connor, 2011; Engelhard, 2001; Lok, Yip, Lee, Sahota & Chung, 2010; Marcinko, Marcinko, Dordevic, Oreskovic, 2011). Treatment for a miscarriage is focused on confirming its occurrence, ruling out ectopic pregnancy and medically managing the process rather than preserving the pregnancy, as nothing can be done to halt it (Huanchuari, 2012; Tulandi & Al-Fozan; Promes and Nobay, 2010). Women frequently seek medical care in busy emergency departments (EDs) due to the urgency and uncertainty associated with vaginal bleeding, abdominal pain and their implications for the wellbeing of the pregnancy (Bacidore, Warren, Chaput & Keough, 2009). Depending on the severity of their symptoms, women may also be concerned for their own physical wellbeing (Bacidore, Warren, Chaput & Keough). Women tend to want reassurance that their baby is safe and seek urgent care because the loss, or threatened loss, of a pregnancy can be devastating as for many it signifies the loss of a child, a future and the motherhood role (Adolfsson, 2010; Adolfsson, Larsson, Wijma & Bertero, 2004; Bansen & Stevens, 1992; Frost, Bradley, Levitas, Smith & Garcia, 2007; Gerber-Epstein, Leichtentritt & Benyamini, 2009).

However, even if a woman is ambivalent towards the pregnancy, or relieved that it has ended, miscarriage can be a stressful life event (Stirtzinger, Robinson, Stewart, & Raleski, 1999; Wong, Crawford, Gask & Grinyer, 2003).

Despite ample literature describing the psychological sequelae associated with miscarriages, the emotional needs of the patient, the impact of the event, and the grieving period following the loss are often overlooked and underappreciated by health care workers (Kong, Lok, Lam, Yip & Chung, 2010; Stirtzinger, Robinson, Stewart, & Raleski, 1999). Depending on the significance of the pregnancy and the presence or absence of psychosocial support, women who have experienced miscarriages are at higher risk of developing prolonged grief, anxiety, depression and, in some cases, even post traumatic stress disorder (PTSD) (Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O'Connor, 2011; Engelhard, van den Hout & Arntz, 2001; Lok, Yip, Lee, Sahota & Chung, 2010; Marcinko, Marcinko, Dordevic, Oreskovic, 2011).

According to the *Nova Scotia emergency care standards*; “emergency departments in Nova Scotia are intended for rapid assessment and management of patients with unknown problems, as well as those with deteriorating pre-existing illness or injury requiring emergency care” (Ross, 2010a, p.13). Meanwhile, according to the Canadian Association of Emergency Physicians (n.d), the mandate of ED care is based on providing life saving measures to the critically ill or injured and rapid treatment during medical emergencies. Regardless, less than 10% of all Canadian ED patients actually require lifesaving measures and the majority are triaged as less urgent or non-urgent patients (Canadian Institute for Health Information, 2005). Non-urgent patients wait the longest for physician assessment. Hence, given that nothing can be done from a medical standpoint to prevent a pregnancy from miscarrying and miscarrying women are

generally stable, the loss of a pregnancy prior to the age of fetal viability is typically not treated as an emergency (Huancahuari, 2012). If the mother herself becomes physically unstable due to heavy vaginal bleeding for example, care is expedited. In this case, health care professionals prioritize patients according to their physical symptoms based on whether there is an immediate threat to the mother's life (not the pregnancy). Although there is no way for emergency health care professionals to prevent a miscarriage from occurring, only addressing the potential loss of a mother and not the pregnancy (if under 20 weeks gestation) may send the message that it is the mother's life that is valued and not that of the unborn child, minimizing the significance of the pregnancy.

The assessment of miscarriages in EDs is common. Approximately 1.2% of all patients presenting to EDs in the United States and Australia seek care for early pregnancy related complications (Indig, Warner & Saxon, 2011; Pitts, Niska, Xu & Burt, 2008). The Charles V. Keating Emergency and Trauma Center (CVK) in Halifax, Nova Scotia's largest ED, treats on average 1-2 patients per day with miscarriage related presentations (D. Urquhart, personal communication, March 21, 2012). For women under 20 weeks gestation, living in Halifax who are experiencing early pregnancy related complications, going to one of the three EDs in the city that provide adult acute care is the fastest way to access health care professionals and the appropriate diagnostic medical technologies 24 hours a day and 7 days a week. Miscarriages can occur at any time and without notice; therefore, general practitioners (GPs) are often unavailable for timely care.

Hospitals providing emergency care to women who miscarry in Halifax typically do not have in-house obstetrical and gynecological specialists. Such services instead are offered at the IWK Health Center (IWK). All pregnant women experiencing pregnancy

complications after 20 weeks gestation are referred to the IWK for specialized obstetrical care. Women experiencing pregnancy complications under 20 weeks gestation are assessed and treated in adult EDs or by their GPs. Those seen in adult EDs are typically discharged home to follow up with their GP, and/or manage physical symptoms alone. In some cases women may be referred from the ED to the Early Pregnancy Complications Clinic (EPCC), an early pregnancy assessment unit (EPAU), at the IWK. The EPCC provides treatment options, counseling, diagnostic evaluations and follow up care for women under 12 weeks gestation, who have not completed the miscarrying process.

In the past, attempts have been made to provide urgent services to women having miscarriages through the pediatric ED at the IWK; however, ED physicians and registered nurses (RNs) did not feel comfortable expanding their specialized scope of practice from pediatric emergency to include this population. As well, the Early Labor Assessment Unit at the IWK did not have the capacity or resources to expand beyond the assessment of pregnancies greater than 20 weeks gestation (Dr. A. Armson, head of IWK Department of Obstetrics and Gynecology, personal communication, October 25<sup>th</sup>, 2012). Similarly, in other Canadian hospitals, early pregnancy bleeding leads to an ED visit and if the service is available then a subsequent referral to an EPAU for first trimester complications (Rhone, Hodgeson, Moshrefzadeh & Maurer, 2012; Tunde-Bypass & Cheung, 2009). EPAUs were developed in order to offer accessible, specialized care for women who are miscarrying and to reduce the number of ED visits for this patient population. However in Canada they are not standard, they are not available to every women in every community and existing EPAUs do not necessarily offer care 24 hours per day, seven days a week (Rhone, Hodgeson, Moshrefzadeh & Maurer; Tunde-Bypass & Cheung). Therefore, most Canadian women who are miscarrying continue to access health care through the ED.

Regardless of where care is offered or what care is offered, there are no formal supportive measures or follow up care in place for this patient population unless they require further physical medical management. Therefore, these women are left to deal with potential emotional sequelae on their own.

It is challenging to provide holistic patient care in the ED setting, particularly with respect to the psychological and emotional needs of patients (Muntlin, Gunningber & Carlsson, 2006; Olive, 2003). However, health care professionals working in EDs are not exempt from attending to these needs. Nursing, for example, is rooted in the provision of holistic care that attends to physical, psychological, spiritual, cultural and emotional dimensions of patients (Canadian Nurses Association, 2007). The challenge of providing holistic care in the ED setting has not gone unnoticed by patients as they have expressed that ED RNs at times lack empathy and solely focus on the technical and medical aspects of care (Muntlin, Gunningber & Carlsson, 2006; Olive, 2003). I too have found it challenging, as an RN, to provide holistic nursing care to patients in the ED. Functional physical tasks can often take priority over supportive emotional care in order to deal with the pressures associated with prolonged wait times, overcrowding and the urgent physical needs of acutely ill patients who are deteriorating (Chan, 2004; Olsen & Bone, 1998). In my experience, if patients require additional emotional support (particularly with loss), and it is a particularly busy day, the task is delegated to other members of the health care team such as social workers. Over 80% of patients accessing EDs are triaged as *less urgent* or *non-urgent*, yet at times, staff still find it difficult to prioritize emotional care (Canadian Institute for Health Information, 2005).

Having worked as an RN in an adult ED in Halifax, NS for five years I have cared for a number of women experiencing early pregnancy complications and miscarriages.

Working in an environment that values efficiency and speed, I have often struggled with providing supportive emotional care to this population. Patients in EDs (including those having miscarriages) often experience prolonged wait times, overcrowding, and fragmented care, as well as having to interact with multiple healthcare providers and being moved many times to different rooms in one visit (Canadian Institute for Health Information, 2005; Olive, 2003; Ross, 2010b). Such actions fail to convey a message of caring to someone in the midst of experiencing a loss or potential loss. One participant in a study about the meaning of miscarriage reported that she believed her needs to be less of a priority than those of other patients in EDs because she was not overtly physically ill like the other patients seeking care in EDs (Adolfsson, Larsson, Wijma & Bertero, 2004).

Nearly 20 years ago the American Emergency Nurses Association (ENA) (1994) released a position statement recognizing the ED as an inappropriate environment for the emotional and physical wellbeing of patients undergoing miscarriages due to lack of privacy, inappropriate resources, staffing, monitoring and physical space. Yet it is often the point of entry into the health care system for women miscarrying and, in Halifax, institutions offering emergency care to women experiencing a miscarriage do not offer women-centered services and, specifically, those relating to the obstetrical and gynecological specialty. Further, facilities offering obstetrical and gynecological care are either not accessible or not easily accessible to those experiencing a miscarriage, which sends a message to the patient population that she does not belong.

The treatment and management of miscarriage is also recognized by the ENA (1994) as an obstetrical specialty requiring specialized care and appropriate follow up. Evidence shows that structured follow up and supportive interventions for women who have experienced miscarriages help women cope with their loss, reduce the psychological

distress, and increase overall wellbeing (Adolfsson, Bertero, Larsson, 2006; Neugebauer et al., 2006; Sejourne, Callahan & Chabrol, 2010a; Swanson, 1999a). Despite this knowledge, there are few such services/supports offered within Halifax, NS either in the EDs or other institutions. When obstetrical and gynecological services are not offered within the institutions where this population seeks ED care, how can an event such as a miscarriage be a priority and valued? The involvement and consultation of gynecological services for patients within the ED experiencing miscarriages is dependent on the ED care providers' clinical judgment. The amount and quality of emotional support the patient receives from either ED providers or obstetric/gynecology specialists is health care provider dependent.

It appears that women who seek medical attention for miscarriages receive conflicting messages about how to access the health care system. On the one hand, one might think that it is appropriate to seek care from obstetrical and gynecological services, yet they are not eligible unless their pregnancy is over 20 weeks gestation. Therefore, women are instructed to go to EDs, which do specialize in rapid treatment of medical emergencies but often do not prioritize miscarriages as emergencies. Furthermore, the ED environment has been identified as inappropriate for managing miscarriages, yet women must continue to seek care there as no alternatives exist (ENA, 1994). Such inconsistent messaging and lack of clarity may devalue the impact of the experience for women.

There is evidence showing the benefits of supportive interventions for this patient population (Adolfsson, Bertero, Larsson, 2006; Neugebauer et al., 2006; Sejourne, Callahan & Chabrol, 2010a; Swanson, 1999a). However, health care services in Nova Scotia are currently not designed to provide an alternative to the ED for women who are miscarrying. Further, there are no formal follow up supportive interventions for those

women. Therefore, given that women experiencing miscarriages will continue to access the ED, it is important to develop an understanding of their unique situation so that the delivery of patient care can be improved. The intent of this proposed study is to gather the stories of women experiencing miscarriages who have accessed the ED, using an interpretive phenomenological approach, in response to the questions “tell me about your experience of coming to the ED for care while having a miscarriage and how it compares with what they were looking/hoping for.”

## **Literature Review**

### **Miscarriages and Their Treatment**

A miscarriage is a pregnancy loss occurring prior to 20 weeks gestation or a fetal weight of less than 500 grams (Statistics Canada, 2012; Tulandi & Al-Fozan, 2011). Miscarriages are the most common complication of pregnancy and, depending on the significance of the pregnancy, can result in prolonged grief, anxiety, depression and symptoms of PTSD (Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O’Connor, 2011; Engelhard, 2001; Lok, Yip, Lee, Sahota & Chung, 2010; Marcinko, Marcinko, Dordevic, Oreskovic, 2011). Women often seek care in emergency departments (EDs) when experiencing a miscarriage, only to find that their care is prioritized according to their physical needs and that their emotional needs are often overlooked (Baciadore, Warren, Chaput & Keough, 2009; Wong, Crawford, Gask & Grinyer, 2003).

Between 8-20% of pregnancies will spontaneously miscarry within the first 20 weeks of gestation and 80% of those lost will occur prior to 12 weeks gestation (Tulandi & Al-Fozan). These numbers do not include miscarriages that occur without the woman knowing she was pregnant. When gestation is less than six weeks woman may attribute



vaginal bleeding to an irregular period (Huacahuari, 2012). Miscarriages occur for a number of reasons including abnormal embryonic development, maternal systemic infections, and exposure to teratogens, or due to unknown causes in healthy women and structurally normal embryos (Tulandi & Al-Fozan). It is difficult to accurately track the number of miscarriages that occur in a population, as women do not always seek care from health care professionals and therefore miscarriages are not recorded (Hemminki & Forssas, 1999; Wadhera & Millar, 1996).

Clinically, miscarriages can be divided into different categories: completed miscarriage, threatened miscarriage, incomplete miscarriage, inevitable miscarriage, and missed miscarriage. Ectopic pregnancy will be discussed in this literature review as well, as it can be a life threatening complication of early pregnancy. A completed miscarriage is defined as heavy vaginal bleeding and abdominal pain during which a woman passes all products of conception from the uterus and upon examination the cervix is closed (Tulandi & Al-Fozan, 2011). At this point, from a medical standpoint, the woman is considered to have completed the miscarriage and therefore requires no medical intervention. With a threatened miscarriage, the cervix is closed and the woman experiences slight vaginal bleeding and mild pain. In this case, over half of women experiencing a threatened miscarriage go on to carry their pregnancy to term. Typically women with threatened miscarriages seek care to confirm the pregnancy is viable and their clinical management consists of by observation until symptoms resolve (Murphy, Jones & Horsley, 2008a; Tulandi & Al-Fozan, 2011).

An incomplete miscarriage occurs when heavy bleeding has occurred and most of the products of conception have been passed; however the cervix remains open and bleeding continues (Tulandi & Al-Fozan, 2011). In this case, tissue may remain in the

uterus. An inevitable miscarriage is defined as a miscarriage that cannot be avoided, heavy bleeding occurs and the cervix remains open (Tulandi & Al-Fozan). A missed miscarriage occurs when fetal death has occurred without any signs or symptoms, the cervix is closed and is only confirmed by ultrasound (Huanchuari, 2012). Incomplete, inevitable and missed miscarriages can all be treated with expectant, surgical or medical management (Tulandi & Al-Fozan).

An ectopic pregnancy is the implantation of a fertilized ovum outside the uterus. Ruptured ectopic pregnancies are the leading cause of maternal death in the first trimester of pregnancy and are therefore treated as life threatening emergencies (Huanchuari, 2012). Unruptured ectopic pregnancies have similar symptoms to that of a miscarriage, including bleeding and abdominal pain; therefore, when women with symptoms of miscarriage present to the ED, patient assessment includes ruling out ectopic pregnancy (Huanchuari).

There are no means for preventing a miscarriage (Tulandi & Al-Fozan, 2011). Interventions are focused on medically managing the process based on a woman's symptoms. The first intervention, expectant management, allows for a miscarriage to proceed following its natural course with no medical intervention (Tulandi & Al-Fozan). The second intervention, dilatation and curettage (D&C), involves a surgical procedure to remove the products of conception. D&Cs have been performed since the late 1800s as a way to reduce blood loss and infection rates following miscarriages (Nanda, Pellogia, Grimes, Lopez & Nanda, 2007). Although still performed regularly to remove retained products of conception, D&Cs are no longer standard practice as they increase the risk of uterine trauma, postoperative infections and cervical incompetence (Nanda, Pellogia, Grimes, Lopez & Nanda). Lastly, miscarriages can be managed pharmacologically using

misoprostol, a drug inserted vaginally that causes cervical ripening, induces contractions, increases vaginal bleeding, leading to uterine emptying (Huancahuari, 2012; Murphy, Jones & Horsley, 2008b).

In Halifax, women experiencing pregnancy related complications under 20 weeks gestation such as abdominal pain or vaginal bleeding are directed to the ED or their general practitioner (GP) for care. With a pregnancy over 20 weeks gestation, women at risk of premature labor are referred to the IWK for obstetrical care to prevent early delivery. Twenty weeks and/or fetal weight of 500 grams is significant as it is considered the age of fetal viability. At this point the fetal lungs have matured enough to survive outside of the uterus and specialized interventions may be able to inhibit premature labor (Leifer, 2011; Statistics Canada, 2012). This distinction creates two groups of women in terms of how their loss, or potential loss, of a pregnancy is clinically managed, both physically and in terms of the supportive interventions provided. One group has direct access to an obstetrical and gynecological specialist. The other group, those experiencing miscarriages, does not.

For those patients under 12 weeks gestation who are diagnosed with inevitable, incomplete, or missed abortions or ectopic pregnancies are eligible upon discharge from the ED for referral to the early pregnancy complications clinic (EPCC) an EPAU at the IWK Health Centre for follow up medical intervention. These diagnoses often require consultation and medical intervention to complete the process of miscarrying to avoid complications such a hemorrhage and infection associated with retained products of conception (Nanda, Pellogia, Grimes, Lopez & Nanda, 2007). However, the care at this clinic is focused only on the physical medical management of those women under 12-weeks gestation with no specific care strategies or protocols to address emotional and

psychological needs of the women (P. Slaunwhite, Clinical Leader of EPCC, personal communication, September 21, 2012).

According to Dr. Tony Armson, head of Obstetrics and Gynecology at the IWK, attempts have been made in the past to migrate the urgent care required for miscarriages to the IWK pediatric ED (personal communication, October, 25<sup>th</sup>, 2012). However those attempts failed due to the lack of comfort felt by pediatric ED RNs and physicians with the expertise (both physical skills and emotional support) required to care for this adult patient population. Further, referring this patient population to the early labor assessment unit at the IWK was not seen as an option given the increased patient volume that such a change would bring to an already busy unit (A. Armson, personal communication, October, 25<sup>th</sup>, 2012). Such decisions unfortunately may convey a message to women who are miscarrying that there is no place for them.

Currently in Canada, reduced access to primary health care providers is contributing to ED overcrowding and the majority of patients seen in EDs are non-urgent cases that do not require emergency care (Canadian Institute for Health Information, 2005). Women experiencing miscarriages are no exception to this phenomenon; however if they do not require emergency care, no other overt options are presented as a means of accessing the health care system to address their unique physical, emotional and psychosocial needs. In attempt to reduce pressure on the ED and to provide specialized care to women with early pregnancy complications or miscarriages, EPAUs have been developed (Rhone, Hodgeson, Moshrefzadeh & Maurer, 2012; Tunde-Bypass & Cheung, 2009). Although EPAUs exist in Canada and they are considered standard care in the United Kingdom, they are not readily accessible to all Canadian women and may require an ED visit for clinic referral.

When a miscarriage occurs, the legitimacy of the loss and the significance of the mother-baby attachment may be clouded by the medical *treatment* and *management* of miscarriage (Cosgrove, 2004). In EDs, the experience of miscarriage may be marginalized by the focus on physically assessing, managing and stabilizing the patient. Thus women may be left to cope with the experience and its meaning without acknowledgment or emotional support.

### **Miscarriages and Emergency Care in Canada**

With approximately 10 million visits per year, Canadian emergency departments (ED) are undoubtedly serving as a major thruway for Canadians to access health care for all needs (Canadian Association of Emergency Physicians, 2005). Although ED's function on the premise of providing *emergency* care, nearly 80% of ED visits are for less urgent or non-urgent complaints (Canadian Institute for Health Information, 2005). These patients tend to have the longest wait times and are usually discharged home when a family physician or another primary health care provider may manage many of their health care concerns adequately. Care is often sought in EDs because accessing a primary health care provider in a timely manner is either difficult or impossible in some cases (Canadian Institute for Health Information, 2011; Rust, Ye, Baltrus, Daniels, Adesunloye & Fryer, 2008).

Patients are prioritized in EDs using The Canadian Triage and Acuity Scale (CTAS). Therefore, once a patient has been taken into the department for nursing and physician assessments, regardless of the patient problem, care is prioritized according to the level of urgency of a patient's physical condition. CTAS was developed by the Canadian Association of Emergency Physicians and the National Emergency Nurses Affiliation of Canada to carry out a number of critical functions: rapidly identify patients

with urgent or life threatening conditions, identify appropriate treatment areas for patients, decrease ED congestion, provide guidelines for ongoing patient assessment, provide patients and families with information about wait times and care, and to offer information about the overall acuity of patients within the department (Beveridge et al., 1998). Upon arrival in the ED, patients are assigned a triage score that will determine who will receive care first based on the triage nurse's physical assessment. Triage scores are: Level I resuscitation, level II emergent, level III urgent, level IV less urgent, level V non urgent. Patients triaged as a level I require immediate physician attention whereas those triaged as a level V exhibit no evidence of deterioration and can wait over 2 hours for physician assessment (Beveridge et al., 1998).

Women experiencing pregnancy related complications and early pregnancy loss are generally triaged at acuity level III or level IV and, therefore, fall into the largest group of patients visiting EDs and the group that also tends to wait the longest for physician assessment (Canadian Institute for Health Information, 2005). The emotional distress associated with the potential loss of pregnancy is not necessarily a factor taken into consideration when assigning a triage score or prioritizing care. If women are physically deteriorating with heavy vaginal bleeding and unstable vital signs, physical treatment is expedited and they may be triaged as a level II warranting physician assessment within 15 minutes of triage time (Beveridge et al., 1998). However, for the majority of time this is not the case. Only when the woman is physically deteriorating in a way that threatens the loss of her own life, and not just her pregnancy/baby, will treatment be expedited. In this case, working from the standards of emergency care, health care professionals are prioritizing patients according to their physical symptoms based on whether or not there is an immediate threat to the patient's life. The loss of a

pregnancy is not viewed as urgent as the potential loss of the mother's life. Such decisions focus on the woman as the patient, not the baby she is carrying inside, since nothing can be done to prevent a miscarriage from occurring; this negates the potential emotional attachment the women has to the pregnancy and baby, despite the fact that activities to promote mother-baby attachment are promoted by healthcare professionals from the moment a pregnancy has been confirmed and throughout pregnancy (Solchany, 2001).

### **The Unique Context of Miscarriages**

Since the majority of miscarriages occur within the first trimester, women often have not announced their pregnancy, nor are they exhibiting any outward physical signs of pregnancy that are visible to the public (with the exception of vomiting in some cases) (Bansen, 1992; Tulandi & Al-Fozan, 2011). This can make it difficult for a woman who has experienced an early miscarriage to seek emotional support and understanding from family and friends, creating an isolating experience of loss (Bansen, 1992; Frost, Bradley, Levitas, Smith & Garcia, 2007). Furthermore, loss occurring in the early weeks of pregnancy may be conflicting for the mother as she still may be in the process of accepting the pregnancy itself (Adolfsson, Larson, Wijma & Bertero, 2004; Corbet-Owen & Kruger, 2001). According to Rubin (1976), women during the first trimester are in the process of accepting and conceptualizing pregnancy and incorporating it into their identity. Pregnancy itself may be an abstract concept, hence the fetus, and what it is and represents, is ambiguous (Frost, Bradley, Levitas, Smith & Garcia, 2007).

In contrast to a miscarriage, a stillbirth is a gestational loss greater than 20 weeks, a weight of 500 grams and showing no signs of life at delivery (Reproductive Care Program of Nova Scotia, 2012; Statistics Canada, 2012). When a stillbirth occurs, parents

are encouraged to engage in ritualized mourning practices as a means of expressing grief and love for their child (Hughes & Goodall, 2013; Kohner & Henley, 2001). These practices include naming of the child, spending time with the child, holding a memorial service and collecting mementos (locks of hair, handprints and foot prints) (Stadtlander, 2012). Acknowledging death through rituals provides comfort and mends the social fabric torn by a death (Layne, 1990). Yet there are no rituals to mourn the loss of a pregnancy less than 20 weeks gestation adding to the silence surrounding the loss. Generally, women know little about miscarriages and it is a hidden experience (Frost, Bradley, Levitas, Smith & Garcia, 2007). Unfortunately in today's modern secular society, with the decline of religion and public mourning rituals, death and loss have become a private, sequestered affair, which may further contribute to the marginalizing experience of loss associated with a miscarriage (Frost, Bradley, Levitas, Smith & Garcia).

The dominant cultural discourse also plays a role in shaping a women's response to early pregnancy loss. Layne (2003) argues that in western society, in an attempt to reclaim control over their bodies from the biomedicalization of women's reproduction, the women's health movement has portrayed pregnancy and birth as something that can be individually controlled and that birth is a natural, joyful experience. This sense of control combined with the imagery of happy endings and fantasized birthing experiences have created a false sense of normalcy, thus marginalizing negative birth experiences and pregnancy loss (Layne, 2003). Particularly with advances in medical technologies that have allowed for a reduction in infant mortality rates, the public may have come to believe that miscarriages may also be controlled and subsequently reduced in numbers (Layne, 1990).



Women have expressed their loss of control over the body as a distressing component of the miscarriage experience (Adolfsson, Larson, Wijma & Bertero, 2004; Wall-Haas, 1985; Wojnar, Swanson & Adolfsson, 2011). According to Layne (2003) perpetuating the silence around miscarriages is the “American moral obligation to always be happy, a hegemonic narrative preference for narratives of linear progress for stories with happy endings, and a culture of meritocracy which hold individuals responsible for misfortune”(p.1889). It is not uncommon for women to feel responsible for their miscarriages, as though they did something wrong (Adolfsson et al., 2004; Andersson, Nilsson & Adolfsson, 2012; Bansen & Stevens, 1992; Hale, 2007; McCreight, 2008; Wong, Crawford, Gask & Grinyer, 2003). This can lead women to believe that their bodies have failed them and, therefore, they are failures themselves even if for some, the pregnancy was unwanted (Frost, Bradley, Levitas, Smith & Garcia, 2007).

Despite western society’s focus on individual control, in most cases the causes of miscarriages are beyond a woman’s control. Alcohol consumption, smoking, advanced maternal age and caffeine all increase the risk of miscarriage, but there is little that women can do to prevent a miscarriage caused by abnormal embryonic development due to chromosomal abnormalities, congenital abnormalities, trauma, maternal infection or endocrine disorders and other unknown factors (Tulandi & Al-Fozan, 2011). When a miscarriage does occur, medical professionals can often give no one reason as to why it happened, nor can they predict the success of future pregnancies. The ambiguity around the cause for the miscarriage and the unknown success of future pregnancies has been shown to lead to self blame and anger (Cordle & Prettyman, 1994; Wall-Haas, 1985).

Childbirth and motherhood are central to a woman’s gender identity and are viewed as the ultimate goal for all women by society (Corbet-Owen & Kruger, 2001).

Through motherhood, women obtain power and social value that makes them unique and provides them with a sense of empowerment that they are unable to obtain in other areas of their life (Corbet-Owen & Kruger). In Israel for example, adding further pressure, the tie of femininity to childbirth and motherhood are reinforced through religious beliefs and governmental policies that perpetuate the pro-natalist ideology embedded within their culture (Gerber-Epstein, Leichtentritt & Benyamini, 2009). The significance of pregnancy loss is therefore heightened and Israeli women have expressed that it is not necessarily just about being unable to bear children or the potential loss of motherhood but also about the essential meaning of being a woman (Gerber-Epstein, Leichtentritt & Benyamini, 2009). North American society also values successful and completed femininity with the virtues of motherhood and maternity and, therefore, a pregnancy loss is viewed as a sense of failure and incompleteness of womanhood (Frost, Bradley, Levitas, Smith & Garcia, 2007).

Adding to the complexity of a miscarriage are the conflicting messages that a woman experiences throughout her pregnancy. Despite lacking empirical support, the medical discourse has long formed a correlation between level of emotional attachment with gestational age: As the embryo, then fetus, becomes more complex, so does the mother's level of attachment (Carter, Misri & Tomfohr, 2007; Cosgrove, 2004; Swanson, Connor, Jolley, Pettinato, Wang, 2007). However, the meaning that a woman ascribes to her pregnancy plays a greater role in attachment and the significance of the loss than does the gestational age (Cosgrove). For many women, the life of their child begins long before its actual birth. Although the development of maternal identity and the mother-child relationship is a subjective experience, it generally begins in early pregnancy (Rubin, 1984; Solchany, 2001). With pregnancy comes fantasizing of who the child will

be and what the mother-child relationship will be like. This leads to the nurturing of the baby in-utero that then develops into the nurturing of a child after birth (Solchany). This mother-baby attachment and nurturing is encouraged throughout pregnancy by health care professionals and through educational materials to promote healthy mother-baby relationship that will transfer into post partum parental attachment (Adolfsson, Larson, Wijma & Bertero, 2004; Sochany1). The use of ultrasounds has also allowed for early identification of fetal personhood, increased attachment and integration of the pregnancy into the family (Frost, Bradley, Levitas, Smith & Garcia, 2007).

The medical terminology used surrounding miscarriages can be marginalizing. First, the actual medical term for miscarriage is spontaneous abortion. The word abortion has a negative connotation and in a study conducted by McCreight (2008), women reported that the term abortion implies a personal decision to terminate their pregnancy. Also, referring to the baby regardless of gestational age as an embryo, fetus or as products of conception in the time of loss can undermine and depreciate the woman's experience and the meaning attached to the pregnancy (Cosgrove, 2004; Frost, Bradley, Levitas, Smith & Garcia, 2007). From an obstetrical point of view, measures to preserve pregnancy and interventions to save a fetus occur at the age of fetal viability and from a governmental perspective according to the Criminal Code of Canada s. 207 (1985) life itself is defined at birth: Once the child is able to breathe independently, has independent circulation and the umbilical cord has been severed. It is easy to see how individual, social and political factors can create the context in which a woman experiences a miscarriage which results in a range of emotional responses that may or may not negatively impact a woman's wellbeing.

## **Psychological Implications of Miscarriage**

It has long been acknowledged that perinatal loss, including miscarriages, can affect the mental health of women who have experienced this type of loss (Adolfsson, 2011; Huancahuari, 2012; Peppers & Knapp, 1980). Over the years, studies have been conducted to examine at depression, anxiety and posttraumatic stress disorder (PTSD) in women who have experienced a miscarriage.

A cohort study compared rates of depression and depressive symptoms using the Center for Epidemiologic studies depression tool (CES-D) between 3 groups: pregnant, women who recently miscarried and non-pregnant women in the general public (Neugebauer, Kline, O'Connor, Shrout, Johnson, et al., 1992). The number of women who experienced a miscarriage who scored highly symptomatic of depression according to the CES-D was 3.4 times more than pregnant women and 4.3 times more than non-pregnant women in the community. Those who miscarried and had living children were still symptomatic of depression but their scores were lower than those without living children (Neugebauer et al.). Regardless of the number of weeks gestation at the time of loss, symptoms of depression were equivalent throughout the cohort of women who miscarried. Furthermore, symptoms of depression have been shown to be elevated in unwanted pregnancies following a miscarriage (Neugebauer et al.). Although the mean ages of the women from each group were between 29 and 30 years, characteristics between groups such as marital status and reproductive histories varied, making it difficult to account for confounders (Neugebauer et al.). Particularly, the characteristics of the non-pregnant women recruited from the community were significantly different making it difficult to make a justified comparison between groups. Also data regarding history of mental health issues were not gathered and therefore may affect the results.

Depression symptomology and general psychological distress were measured following immediately miscarriage, at 3 months, 6 months and 1 year post miscarriage in women who miscarried on a gynecology inpatient unit and compared with non-pregnant women in the community (Lok, Yip, Lee, Sahota & Chung, 2010). Women who experienced a miscarriage were found have significantly higher depressive scores and psychological distress immediately following a miscarriage than the comparison group. These scores reduced over time but still remained substantially higher at the 1 year mark (Lok, Yip, Lee, Sahota & Chung). Some women, although not initially complaining of psychological distress post miscarriage, were found to have developed depressive symptoms 3 and 6 months later, indicating that there may be a risk for this population of developing a delayed depression (Lok, Yip, Lee, Sahota & Chung). Furthermore, 25% of women who experienced high levels of distress immediately following a miscarriage continued to have elevated depressive symptoms at 6 months and 1 year following the event (Lok, Yip, Lee, Sahota & Chung). The participants who miscarried were recruited from an inpatient unit; therefore it is difficult to say if the findings would be consistent with and applicable to women who were cared for in an ED and subsequently discharged home without further medical care.

The psychological impact of a miscarriage may, for some women, carry over into subsequent pregnancies. Marcinko, Marcinko, Dordevic and Oreskovic (2011) compared depression and anxiety symptomology in pregnant women with a history of miscarriage, pregnant women without previous miscarriage and non-pregnant women. Depression symptomology across groups was the same. However, anxiety levels were significantly higher in the group that had experienced previous miscarriages when measured at 10 weeks and 20 weeks gestation. Findings are difficult to generalize, as the sample size was

small (25 participants per group) and no power analysis was given to justify sample size. Similarly, Bergner, Beyer, Klapp & Rauchfuss (2008) found anxiety levels to be higher in the first trimester of pregnancy for women who had previously experienced miscarriage than pregnant women with no history of miscarriage, however this anxiety decreased as they passed the date in which their previous pregnancy was lost. Anxiety levels were also significantly higher in women who have a history of recurrent miscarriages (Bergner, Beyer, Klapp & Rauchfuss). Dissimilarly, Woods-Giscombe, Lobel and Crandell (2010) found pregnancy related distress and state anxiety to be the same during the first trimester for pregnant women who miscarried as for a comparison group of pregnant women with no history of miscarriage. However unlike other studies, measurements were repeated throughout the pregnancy and in the group with previous miscarriage, state anxiety was significantly greater in the second and third trimesters than the comparison group (Woods-Giscombe, Lobel & Crandell). Additionally, Woods-Giscombe, Lobel and Crandell, found that having living children does not always provide protection from anxiety and distress in subsequent pregnancies post-miscarriage.

Recognizing the impact miscarriage can have on women and their subsequent pregnancies, Andersson, Nilsson & Adolfsson (2012) conducted a qualitative study in which they explored how women managed their feelings during pregnancy following a pregnancy that had ended in a miscarriage. Participants described feeling isolated and alone and at times distanced themselves from the pregnancy in case it would end in another loss (Andersson, Nilsson, Adolfsson, 2012). The authors stated that participants spent a significant time talking about the event of their miscarriage and that they did not know where to turn for support afterwards. The study gives insight into the impact miscarriage has on women and their experience with subsequent pregnancies. However,

the 13 interviews take place over a period of four years, which may influence the researcher's interpretation of the findings if a significant time passed between each interview and between the data collection and analysis phase.

When measuring symptoms of anxiety and depression, no significant differences were found between women who have had miscarriages and women who have had stillbirths (Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O'Connor, 2011). This study went on to report that with subsequent pregnancies, among women who had experienced either a miscarriage or a still birth, symptoms of depression and anxiety not only continued in subsequent pregnancies but persisted when measured 33 months after the birth of a healthy child (Blackmore, et al.). These findings support the argument that the significance of a pregnancy loss is not dependent on the gestational age of the pregnancy when the loss occurs. However such a study does not provide the context and quality of care the participant received and its implications on psychological outcomes.

As studies have shown, the psychological impact of a miscarriage can persist up to 12 months, to 33 months, and even carry over into subsequent pregnancies (Bergner, Beyer, Klapp & Rauchfuss, 2008; Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O'Connor, 2011; Lok, Yip, Lee, Sahota & Chung, 2010; Marcinko, Marcinko, Dordevic & Oreskovic, 2011). However, the psychological impact of miscarriage and the length of grieving period women are often underestimated by healthcare workers (Kong, Lok, Lam, Yip & Chung, 2010; Stirtzinger, Robinson, Stewart, & Raleski, 1999). Using a prospective, cross-sectional survey, Kong, Lok, Lam, Yip and Chung, assessed the attitudes of health care professionals and the attitudes of pregnant women and their spouses towards the psychological impact of miscarriage. Compared to the pregnant women, health care professionals significantly underestimated the impact of the loss and

the women believed there to be a lack in psychological follow up services following a miscarriage. It is worth noting that only 23% of the pregnant participants had experienced a miscarriage themselves, thus the rest of the pregnant participants' responses were based on their anticipated response to a miscarriage. The study does however highlight the discrepancies between patient and provider perceptions of perceived health care needs in terms of psychological support following a miscarriage (Kong, Lok, Lam, Yip and Chung). The result may also be indicative of the fact that healthcare professionals have difficulties conceptualizing the significance of the pregnancy for individuals.

The traumatic nature of the miscarriage experience must also not go unrecognized (Engelhard, 2004). The physical experience itself can involve intense pain, heavy bleeding with clots and tissue that may be extremely disturbing for some women. In some cases, the miscarriage itself may not only be threatening to the pregnancy but also to the life of the woman herself. PTSD is an anxiety disorder precipitated by a traumatic event in which the integrity, or life of self or others, is threatened leading to a range of symptoms causing significant impairment for the individual (Engelhard, van den Hout & Arntz, 2001). Women who have been studied at 1-month post miscarriage have been found to display symptoms congruent with that of a PTSD diagnosis and depression which in some unresolved cases continued to be measured at the 4-month mark as well (Engelhard, van den Hout & Arntz). This suggests that miscarriages are not only seen as events of loss that lead to depression, but as threatening events that can cause PTSD, adding to the significance of the event and its potential impact on women (Engelhard, van den Hout & Arntz; Engelhard, 2004). Furthermore, Engelhard (2004) found that women with low educational level were at an increased risk for developing PTSD following a miscarriage. Neither of the studies indicated what the nature of the participants'



miscarriages was like. It is not known what happened to these women while they were miscarrying and what type of care they received for their miscarriage. Patients experiencing miscarriages in EDs are at times physically unstable whether it is due to a ruptured ectopic pregnancy, heavy vaginal bleeding and/or hemorrhage. Therefore it is important for ED staff to recognize the potentially traumatizing nature of the events both mentally and physically for the patient.

Stirtzinger, Robinson, Stewart and Ralevski (1999), investigated the quality and severity of grief following a miscarriage and the impact of demographic and social variables on grief. This longitudinal study used multiple psychometric tools to evaluate 175 women at three months and 119 women at 12 months following a miscarriage. At both points of data collection, participants showed high levels of depressive symptoms, self-blame, stress and persisting grief. They also found that age plays a role in the reaction to miscarriage. Younger women (less than 30 years of age) have been found to exhibit higher rates of depression and anxiety post-miscarriage than older women (greater than 30 years of age) and younger women with multiple miscarriages are more depressed than their older counterparts with multiple miscarriages (Stirtzinger et al., 1999). These results may in part be due to the level of coping skills that age and experience brings. In this study, younger women found social supports and health care professionals discredited their loss by saying they would have other opportunities to conceive (Stirtzinger et al., 1999). Furthermore, depression symptomology was also found to be greater in women who reported ongoing family discord and in women who reported feeling responsible for the loss (Stirtzinger et al., 1999). This study provides insights about many variables that may influence a woman's grief response following a miscarriage, however it does not provide insight into the role the health care system plays in eliciting these responses. The

study also does not define what it included as a miscarriage in terms of weeks at time of loss making it challenging to generalize the results.

A descriptive study was conducted to assess women's responses to miscarriage at one, six, 16 and 52 weeks following their miscarriage and responses were classified into: healing, actively grieving and overwhelmed (Swanson, Connor, Jolley, Pettinato & Wang, 2007). Responses at one week and six weeks indicated that women were in a crisis period with active grieving and feelings of being overwhelmed. Women who did not conceive again or did not deliver a baby within one year following their miscarriage continued to express active grief. This study gives insight into the trajectories of emotional responses following a miscarriage however it has limitations as the authors are unaware of previous mental health histories of participants and it is a secondary analysis from a previous study (Swanson, Connor, Jolley, Pettinato & Wang). The importance of previous history of mental health issues is important, as Rowlands and Lee (2010a) found that women with a previous history of depression are at greater risk for depression post-miscarriage than those women without a history of depression.

Women are at risk for psychological issues such as depression, anxiety and PTSD following a miscarriage. It is important to acknowledge these risks but it is also important to expect, allow for, and support normal grief associated with loss as grief has therapeutic properties (Stirtzinger, Robinson, Stewart & Raleski, 1999). Unresolved grief can lead to depression, and the period of grief as well as its intensity following miscarriage may be underestimated, given that depression and PTSD have been identified in women for several months and up to 33 months after their loss (Blackmore, Cote-Arsenault, Tang, Glover, Evans, Golding & O'Connor, 2011; Engelhard, 2001; Neugebauer & Ritsher, 2005).

Studies examining mental health of women following a miscarriage use a variety of psychometric tools and have varied definition of miscarriage in terms of gestational age at the time of loss. The majority of studies are also dated and it is difficult to determine if they would be generalizable to women today. They do however confirm that regardless of gestational age, the presence of living children and whether the pregnancy was desired do not have an effect on the mental health of women following a miscarriage. While understanding the psychological implications following a miscarriage is important, these studies do not give us insight into how the health care system and care women receive for their miscarriage shapes their experience of having a miscarriage, specifically within the context of ED care.

### **The Miscarrying Experience**

Many qualitative studies have been conducted to explore the meanings and experiences of women who have had miscarriages.

A hallmark study, using interpretive phenomenology, aimed to describe the meaning of miscarriage for 13 women (Adolfsson, Larson, Wijma & Bertero, 2004). The overall essence of the experience was reflected in one overarching theme of emptiness and guilt with five subthemes. Women in this study felt emptiness and guilt after their loss as they blamed themselves for the pregnancy loss (Adolfsson, Larson, Wijma & Bertero). The women expressed losing the pregnancy, their baby, their hopes and dreams for their future life with that child, and their self esteem with respect to their own ability to reproduce. In terms of interactions with health care professionals, women felt abandoned and described professional avoidance (Adolfsson, Larson, Wijma & Bertero). When interaction did occur, health care professionals were perceived as not empathetic and lacking understanding. The only insight into ED care for miscarriage was

reflected in the statement from one participant who described feeling distressed having to go to the ED for care and waiting for many hours in the waiting room while she was losing her baby (Adolfsson, Larson, Wijma & Bertero). This is a valuable statement, as it provides insight into what the ED experience may be like for women miscarrying and warranting further exploration.

Gerber-Epstein, Leichtentritt and Benyamini (2009) further corroborate women's feelings of guilt and emptiness following a miscarriage as they too found women's feelings were associated with the loss of the expected child, their future with that child and motherhood role (Gerber-Epstein, Leichtentritt & Benyamini, 2009). Women in this study found the most understanding support came from others who had miscarriages, and following pregnancy loss, interactions with other pregnant women often elicited emotions of envy, failure and feelings of distress (Gerber-Epstein, Leichtentritt & Benyamini). It is important to note this study explored the experience of women who had a miscarriage with their first pregnancy and the study was conducted in Israel where there is a unique pro-natalist ideology embedded within the culture, adding further pressure on women to successfully reproduce. The only comment in the reported findings regarding accessing health services and health care professionals was the importance for health care professionals to communicate and educate women about the potential emotional responses they may have following a miscarriage (Gerber-Epstein, Leichtentritt & Benyamini).

Also using a qualitative constructivist methodology, Corbet-Owen and Kruger (2001) interviewed eight South African women, including three that were purposefully selected because they identified their pregnancies as unwanted. Amongst the participants who miscarried desired pregnancies, findings were similar to that of Adolfsson, Larson,

Wijma and Bertero (2004) and Gerber-Epstein, Leichtentritt and Benyamini (2009) in terms of the meaning of the loss. The participants who miscarried unwanted pregnancies felt indifferent or intense relief, as the pregnancies had symbolized unhappy or abusive relationships (Corbet-Owen & Kruger, 2001). The study provides insight into how the care women receive from health care professionals affects their miscarrying experience. Women in this study expressed the need for their emotional and physical experiences to be validated by health care professionals, and they also yearned for knowledge and information about their miscarriage so that they could process the experience (Corbet-Owen & Kruger, 2001). While providing valuable information into how women would like to be cared for following a miscarriage, the study is dated and does not specify the type of health care setting in which these women received care for their miscarriage.

Rowlands and Lee (2010b) interviewed nine women up to two years after experiencing a miscarriage using an unidentified qualitative methodology. Results indicated that the interactions participants had with healthcare providers, family members and society shaped their miscarriage experiences (Rowlands & Lee, 2010b). Unfortunately these interactions were not always positive. Healthcare providers were identified as lacking empathy, being insensitive and did not provide support and acknowledgement, which inadvertently minimized the experiences for the participants (Rowlands & Lee). Although this study provides insight into understanding how health care professionals can influence the miscarrying experience, it is not specific to the ED setting.

One study, using a feminist exploratory methodology, examined the experience of six women who received care for their miscarriage in the hospital setting (McLean & Flynn, 2013). The hospital setting included the ED and obstetrical clinics and women

interacted with multiple disciplines such as midwives, ED physicians and obstetricians. The majority of women described having negative experiences and described compassionate care to consist of three components: 1. Prompt assessment, 2. Provision of clear information, 3. Acknowledgement of the loss (McLean & Flynn). Although the study is not specific to the ED setting, four of the six participants had interacted with ED health care professionals, and the results may give an indication of how the miscarriage experience is shaped by the ED. Despite claiming to use an exploratory methodology, the researcher asked specific questions about the involvement of social workers in the care of women who have experienced miscarriage and the researcher was a social work student (McLean & Flynn). It is misleading, as the study's purpose does not reflect this line of inquiry.

There is a level of silence surrounding miscarriages and many qualitative studies have found that there is a need for acknowledgement from healthcare providers, families and society to validate the experiences of these women (Adolfsson, Larson, Wijma & Bertero, 2004; Corbet-Owen & Kruger, 2001; McLean & Flynn, 2013; Rowlands & Lee, 2010b). Despite multiple studies that provide rich descriptions of the miscarriage experience, there have been no qualitative studies completed with the primary objective of exploring the experience of women who have miscarried specifically in the ED.

### **Supportive Interventions**

Women have expressed their immediate needs following a miscarriage to be the acknowledgement and validation of both the physical and emotional aspects of the experience. They have expressed difficulty in dealing with the emotional impact, feeling unprepared for managing the physical symptoms at home and have described feeling abandoned by health care professionals (Adolfsson, Larson, Wijma & Bertero, 2004;

Corbet-Owen & Kruger, 2001; Sejourne, Callahan & Chabrol, 2010b). Yet, currently in Halifax, there is no specific follow up resource addressing the psychosocial needs of women who have had miscarriages. Due to the emotional intensity of the experience for some women, a structured follow up might provide facilitation of more relevant care than being left to seek extended care independently from their GP (Wong, Crawford, Gask & Ginyer, 2003).

Follow up interventions aimed at reducing the psychological impact of miscarriage have proven successful. In a pilot study testing telephone based Interpersonal Counseling (time limited, symptom focused psychotherapy) sessions, women were found to have lower depressive symptomology than those participants who did not receive the counseling (Neugebauer et al., 2006). Three 1 hour caring based counseling sessions were found to minimize the impact of miscarriage through a reduction in emotional disturbance, anger and depression while increasing overall well-being (Swanson, 1999b). On the other hand, depending on the type of miscarriage, structured follow up visits by midwives were found to be beneficial for some women, but not all, who had miscarriages, (Adolfsson, Bertero, Larsson, 2006). Also, a single session of cognitive behavior therapy immediately following medical management of a miscarriage has been found to result in lower levels of anxiety, depression and PTSD than those who did not receive the intervention 3 weeks post miscarriage (Sejourne, Callahan & Chabrol, 2010a). The intervention was also seen as a beneficial measure in providing basic support to help women cope with their loss and in screening for those who may be at greater risk for psychological distress such as those with a previous history of depression. Women expressed that they felt supported and understood which helped them deal with their guilt and irrational beliefs about why the miscarriage had occurred (Sejourne, Callahan &

Chabrol, 2010a). Given the potential for poor mental health outcomes for women following miscarriage, supportive interventions are undoubtedly warranted as the literature suggests. However, we still do not understand how to best support and care for women who come to the ED to get care for their miscarriage. Understanding their experiences of miscarriage in the ED can provide health care professionals with insight into the needs of this population, potentially allowing for more responsive provision of care.

### **Miscarriages and Emergency Departments**

The ED literature predominantly focuses on the medical management (of miscarriages: diagnostics, treatments, interventions and assessments required to rule out life threatening ectopic pregnancies (Huancahuari, 2012; Promes & Nobay, 2010). Minimal literature acknowledges miscarriage as a loss, potentially requiring emotional support. There is only one study specifically examining miscarriages in the ED setting (Zaccardi, Abbott & Koziol-McLain, 1993). This central focus on the medical management within the ED miscarriage literature may represent a discourse that values physiological care over psychological care in the ED.

With the objective of describing the psychological and functional consequences of miscarriage after an ED visit, Zaccardi, Abbott and Koziol-McLain (1993) conducted a prospective telephone follow up study interviewing 44 women two weeks following their ED visit. Women reported satisfaction with physical care in EDs but expressed the need for more emotional and educational support (Zaccardi, Abbott & Koziol-McLain, 1993). It is unclear how psychological and functional status were measured, as no psychometric tools were used to collect data and there is no definition of what constitutes an



individual's psychological and functional status. Furthermore, the study was conducted over 20 years ago and the findings may not be generalizable to women today.

One participant in Adolfsson, Larsson, Wijma and Bertero's (2004) qualitative study made reference to her experience in an ED for her miscarriage. The participant described her loss as having minor significance and low priority within the ED, given that she waited for many hours because she was not overtly physically ill (Adolfsson, Larsson, Wijma & Bertero, 2004). However it is only one participant in one study.

Recognizing that the ED may not meet the needs of women who miscarry, Baciadore, Warren, Chaput and Keough (2009), developed a collaborative fetal loss framework to facilitate the delivery of holistic care to this patient population. The authors suggest that the framework will address the typically under-appreciated emotional needs of women who have experienced a miscarriage and based the framework on obstetrical and emergency literature (Baciadore, Warren, Chaput & Keough). The framework has yet to be tested in the clinical setting and therefore it is unclear if it meets the needs of the population or if it is practical for the ED setting. Again, given the scarcity of literature, there is no clear understanding about what the experience of miscarriage is for women in the ED.

Johnson and Langford (2010) also proposed a protocol to provide emotional support to women experiencing pregnancy loss less than 20 weeks in the ED based on *The Guidelines for Medical Professionals Providing Care to the Family Experiencing Perinatal Loss, Neonatal Death, SIDS, or Other Infant Death* (Ilse, Cross, Bazon, Dennis, Isaacs & Bronheim, 1989). The protocol was tested comparing a group of women who received care using the protocol (n=20) with a group who did not (n=20); two weeks later the group exposed to the protocol were found to have lower levels of despair than the

control group but both groups had similar levels of active grief and difficulty coping (Johnson & Langford, 2010).

The presence in the literature of two protocols for caring for a woman miscarrying in the ED acknowledges that improvement in the delivery of care to this patient population is needed. While Johnson and Langford's (2010) protocol had positive results when tested, there remains a lack of understanding of what the experience of miscarriage is like for women, from the perspective of the women. The voice of women who have experienced a miscarriage in the ED or who have received care for a miscarriage in the ED is notably absent from the literature.

### **Restructuring Delivery of Care**

Steps have been taken to improve the delivery of care to women who miscarry (Adolfsson, 2011; O'Rourke & Wood, 2009; Wren & Craven, 1997). The development of early pregnancy assessment units (EPAU) to assess women with concerns relating to the viability of pregnancy has been one major step in reducing visits to EDs and maximizing access to gynecologic and obstetrical specialists (O'Rourke & Wood; Wren & Craven). The National Institute for Health and Care Exchange (2012) in the United Kingdom has clear guidelines recommending dedicated services for women with suspected miscarriages or ectopic pregnancies and offered seven days a week. In Sweden, Adolfsson (2011) found a 50% reduction in unscheduled ED visits relating to early pregnancy complications when telephone support by gynecological clinic personnel was implemented. Standardized written guidelines (algorithms, decision-trees) were developed to provide support and guide clinical decision making and management, and whether a prompt gynecological clinic appointment might be sufficient or if symptoms warrant an after hours ED visit (Adolfsson, 2011). As a result, women were generally

more satisfied with their care because it came from health care professionals (midwives, gynecologist and obstetricians) who understood the significance of the event and structured follow up and support were offered (Adolfsson, 2011). The combination of telephone contact with professionals and the monitoring of emotional health were viewed as important components in improving care for women experiencing miscarriages (Adolfsson, 2011). EPAUs implemented in Canada have been found to reduce return visits to Canadian EDs and increase patient satisfaction with care, however they are not standard, nor are they accessible 24 hours per day, seven days a week (Rhone, Hodgeson, Moshrefzadeh & Maurer, 2012; Tunde-Bypass & Cheung, 2009). Despite the existence of EPAUs, women who are miscarrying continue to access care through EDs: thus exploring the meaning of the experience of women who received care for a miscarriage in the ED remains a relevant line of inquiry.

### **Summary**

When miscarrying, pregnant women often present to adult acute care EDs that do not specialize in obstetrical and gynecological services. Their miscarriages are often not treated urgently unless the woman herself is physically unstable. To a woman who is miscarrying, the loss of a pregnancy is urgent regardless of whether it is wanted, and requires emotional support and acknowledgement (Adolfsson, Larson, Wijma & Bertero, 2004; Gerber-Epstein, Leichtentritt & Benyamini, 2009; McLean & Flynn, 2013; Rowlands & Lee, 2010b). The ED environment often does not convey a message of caring to its patients, as they are often exposed to prolonged wait times and are kept uninformed about tests, procedures and what to expect from their ED visit (Gordon, Sheppard & Anaf, 2010; Nystrom, Nyden & Petersson, 2003). The EDs remain the entry point for miscarrying women who are accessing health care services. This population

experiences mixed messages from health care providers regarding the appropriate site to access care: they must present to the ED- but their pregnancy loss is not an emergency; they are pregnant women - but unable to easily obtain obstetrical and gynecological services until they are greater than 20 weeks gestation. Despite the ample literature describing the meaning of miscarriage, the negative psychological implications associated with miscarriages, the benefits of supportive interventions and follow up care, literature pertaining to miscarriages and the ED remains scarce. ED literature predominantly focuses on the medical management of miscarriage, leaving the voice of women who have experienced miscarriage in the ED unheard. How can decisions about care and protocols for caring for this population in the ED be made when their needs are unknown? In order to understand the needs of women who go to the ED to get care for their miscarriage, it is important to hear their stories to build understanding through the knowledge of their experiences. This study will seek to answer the following question: “What are the experiences of women coming to the ED for care while having a miscarriage...and how it compares to what they were looking/hoping for?”

## **Chapter II**

### **METHOD**

The following chapter will discuss the research question, design, methodology, sampling, data collection, analysis and ethical considerations used for this research study.

#### **Research Question**

This qualitative study gathered the first person experiences of women who have sought care for miscarriages in the emergency department (ED): “What are the experiences of women coming to the ED for care while having a miscarriage...and how it compares to what they were looking/hoping for?”

#### **Design**

The first hand accounts of women who have had miscarriages in an ED were collected in order to gain deeper insight into this unique experience. Interpretive phenomenology was the chosen methodology as it is used to understand the essence of the meaning of human experiences (Van Manen, 1997). In this case, the lived experiences of women who come to the ED to get care for their miscarriage.

An interpretive phenomenological approach to research is based in the constructivist paradigm as the research is carried out in the setting of everyday life and the realities of the participants are constructed through historical, social and experiential contexts (Creswell, 2007; Lincoln, 1992). There is no one single truth or reality, as with positivism; instead constructivism recognizes the existence of multiple co-constructed realities between the researcher and participants (Lincoln, 1992).

The constructivist paradigm is a natural fit with health care sciences because the complexities of health care cannot be described solely through reductionist methods of research. Rather, the behavioral and social aspects that influence health and health care

must be studied to understand the meanings and multiple realities of individuals (Lincoln, 1992). Developing an understanding of the multiple factors and constructs shaping one's health will add richness and contextual data to the delivery of health care that is already shaped significantly by positivist methods of inquiry and the biomedical model within the ED setting.

### **Interpretive Phenomenology**

Phenomenology is a philosophical movement and research method with diverse approaches and viewpoints (Walters, 1995; Wojnar & Swanson, 2007), all of which share a common purpose of “gaining deeper understanding of the nature, or meaning, of our everyday experiences” (Van Manen, 1997, p.9). Phenomenology offers an alternative to other scientific approaches that attempt to categorize and classify the human experience by being in the *life world*- “the world as we immediately experience it pre-reflectively” (Van Manen, 1997, p.9). A phenomenological approach to research is concerned with uncovering the essence of human experiences and understanding these experiences and their meaning in a deeper manner (Van Manen).

Two phenomenological approaches are typically used in nursing research. The first approach, descriptive phenomenology, is that of German philosopher and modern day founder of phenomenology, Edmund Husserl (Walters, 1995). Husserl's phenomenology is concerned with the essence of human experiences as absolute truth, universal and unchanging. This approach is a means of creating a rigorous, scientific understanding of human consciousness. A central tenant of Husserl's phenomenology that is key in providing unbiased, reductionist analysis of the phenomenon in question is that of *bracketing* (Walters, 2005). *Bracketing* is a means of removing one's personal biases and preconceived notions regarding the topic of inquiry in order to maintain objectivity

(Wojnar & Swanson, 2007). Husserl's descriptive approach to phenomenology is seen as a means of uncovering a universal description of the meaning associated with an experience (Wojnar & Swanson, 2007).

The phenomenological approach to inquiry has evolved from Husserl's reductionist methods. Martin Heidegger, a student of Husserl's, rejected the notion of bracketing as it conceptualized human reality in an objectified way. Instead, Heidegger's interpretive approach is based on the importance of context. The historical, sociopolitical and cultural context in which people live plays a key role in shaping individuals and their experiences and is central to understanding the meaning of *being* rather than what can be known (Mackey, 2005; Wojnar & Swanson, 2007). Heidegger's concept of *Dasein*, that human beings are in and of the world, emphasizes the situatedness of human reality. Human beings (both researchers and participants) cannot remove themselves from the various contexts in which they live. Furthermore, the context in which one lives creates *situated freedom* - individuals are free to make their own choices; however, this freedom is circumscribed by the conditions of their day to day lives (Lopez & Willis, 2004).

Using Heidegger's interpretive phenomenology, researchers are inseparable from the world in which they are studying (Burke, 1999). All individuals bring forth previous experiences and understandings to interactions to create understanding and subsequently interpret reality, which Heidegger refers to as fore-structures (Burke, 1999; Wojnar & Swanson, 2007). Since it is impossible to separate oneself from these fore-structures and how they influence the research question, they become a critical component of the interpretive process in this methodology. Together, the researcher and participant bring forestructures, shaped by their personal histories, to the research relationship and

subsequently co-create a shared understanding of the studied phenomenon together (Wojnar & Swanson, 2007).

Nursing has been described as both an art and a science that has a unique holistic perspective of health and wellbeing for patients and families (Lopez & Willis, 2004). The values that shape the nursing profession are rooted in the works of nursing theorists such as such as Hildegard Peplau and Kristen M. Swanson. Peplau (1952) was the first nursing theorist to place the nurse-patient relationship as the central component of nursing care. Peplau's (1997) *theory of interpersonal relations* argues that the patient is not the sole focus in the nurse-patient relationship and that nurses bring their own assumptions and experiences that in turn have an affect on patient outcomes. Swanson's (1993) *theory of informed caring for the well-being of others* also influences my perspective of nursing and caring for patients as she describes that to attain the goal of client well-being when caring, one must attempt to understand the events of illness in terms of their meaning for the patients.

Interpretive phenomenology is a natural fit with nursing research as it takes into account the sociocultural and historic traditions that create meaning in our lives (Van Manen, 1997). As nursing theorists recognize that patients, families and nurses bring their own experiences and assumptions to a relationship, phenomenology can seek to develop a deeper understanding of the human experience in illness in the context of today's health care setting (Wojnar & Swanson, 2007). It is necessary to develop nursing knowledge that is reflective of the social realities and cultural contexts in which patients live (Lopez & Willis, 2004).

My experiences as a registered nurse working in a large emergency and trauma center have informed my topic of inquiry. With this understanding, I chose to use



Heidegger's interpretive approach to phenomenology. My own encounters of working with women who have experienced miscarriages in a busy emergency department, as well as experiences in my personal life influenced my interpretation of the data as well as my relationship with study participants. The research process is influenced by sociopolitical and historical contexts of all individuals involved and the experience of health.

As the literature review has indicated there are no methodologically sound studies designed to examine the experience of women miscarrying within the context of emergency care. Thus interpretive phenomenology was chosen and used to assist in giving voice and developing understanding regarding a topic in which little is known (Wojnar & Swanson, 2007). The results from an interpretive phenomenological study can be used as the starting point for change, influencing policy and practice as it seeks to understand the life worlds of participants (Benner, 1997).

### **Sample**

To obtain information rich data, purposeful sampling strategies were used. The term purposeful sampling stems from targeting participants who can yield in-depth data that informs the *purpose* of the study (Patton, 2002). As the purpose of the study was to explore and understand the experiences of women who have had miscarriages and sought care in the ED, participants were eligible based on having had this specific experience.

Just as with determining a sample strategy, when considering sample size it is important that it is reflective of the study's purpose, time available and resources for data collection (Morse, 2000; Patton, 2002). A small sample size was used, as rich data were collected from each participant to understand the phenomenon in question. The purpose of the research question was not to generalize findings; rather, it was to develop an in depth understanding of the lived experience from each participant and identify

commonalities within the phenomenon in question. The quality and amount of useable data obtained from each participant determined the number of participants required to reach saturation (Morse, 2000). A sample size of 8-10 participants was anticipated in order to reach thematic saturation; however, the number was dependent on the nature and scope of information collected and participant recruitment. A flexible sampling strategy was used in order to achieve data saturation. Sampling was completed after recruiting and interviewing 8 participants, as the data collected became redundant and no new themes emerged-thus reaching thematic saturation from the interviews (Lincoln & Guba, 1985). No statistical analysis was applied to the data. The purpose of qualitative phenomenological research is to develop a deeper understanding of the meaning of a lived experience. It is not meant to generalize findings but instead to provide insight into a topic in which little is known about.

Since the implementation of the Emergency Department Information System (EDIS) in June, 2005, the Charles V. Keating Emergency and Trauma Center in Halifax, Nova Scotia has been able to track a variety of statistics related to patients accessing the ED. In consultation with David Urquhart, information technology specialist at the Charles V. Keating Emergency and Trauma Center ED, crude numbers were generated to determine how many patients were seen and given *miscarriage related* diagnoses between June, 2005 and March 2012. Patients with discharge diagnoses of incomplete spontaneous abortion, inevitable abortion, threatened abortion and missed abortion were included in the search. On average 1-2 patients per day were discharged from the ED with miscarriage related diagnoses (D. Urquhart, personal communication, March 21, 2012).

## **Study Participants and Eligibility Criteria**

Participants for the study included women who sought treatment in an emergency department while actively miscarrying and have experienced a completed miscarriage. Participants received one of the following miscarriage related diagnoses: incomplete spontaneous abortion, complete abortion, inevitable abortion and missed abortion. The diagnosis of threatened abortion was excluded because 90-96% of women with this diagnosis between 7-11 weeks gestation will go on to carry pregnancies to term (Tulandi & Al-Fozan, 2011).

Women were invited to participate in the study if they met the following criteria:

1. Adult women 18 years of age or older
2. Pregnant with a gestational age of less than 20 weeks at time of loss
3. Ability to engage in conversation and read the English language
4. Have visited an ED to receive care for a miscarriage.
5. Diagnosed with incomplete miscarriage, complete miscarriage, missed miscarriage or inevitable miscarriage.
6. Willing to be interviewed and audio-recorded for approximately 1-1.5 hours and engage in a follow-up telephone conversation regarding the themes uncovered during the analysis.

Women were included regardless of age (18 years or above) or parity. The literature has indicated that the presence of living children does not diminish the emotional impact associated with a miscarriage and age may play a role in the level of distress experienced by the woman (Neugebauer et al., 1992; Stirtzinger et al., 1999; Swanson, Connor, Jolley, Pettinato, Wang, 2007). If all participants had fit a similar

demographic profile, recruitment would have continued in order to see if there was thematic consistency with demographic variation.

Recruitment began after receiving ethical approval from Capital District Health Authority (CDHA) and approval from the Charles V. Keating Emergency and Trauma Center. Approval to recruit from Cobequid Community Health Centre Emergency Department was also received as an amendment. However this site was not used as recruitment for the study had completed soon after receiving the amendment approval. Attending physicians and registered nurses were asked to assist in identifying potential participants based on the inclusion criteria. The attending physician or registered nurse gave recruitment letters (Appendix A) to potential participants upon discharge. The letter emphasized that participation was voluntary and would not affect any future care received at CDHA. Patients who received a letter and wished to learn more about the research and/or participate in the study were invited to contact the researcher directly via a study specific email address or telephone.

The following strategies were applied to ensure physician and RN participation in recruitment: 1. A presentation about the study was given to the physicians at their monthly staff meeting, providing them with the opportunity to learn about the study and ask questions. Study updates were provided at every monthly meeting during active recruitment; 2. The area, which the participants were recruited, had designated liaison nurses who were in charge of patient flow and screen all patients presenting to the department via the waiting room. Each liaison nurse was spoken to individually and asked to be a “study champion”; 3. A member of the thesis committee, Dr. Simon Field, was the champion amongst the physician group to facilitate recruitment; 4. When a physician or nurse entered the patient’s discharge diagnosis into The Emergency Department

Information System, a reminder popped up on the computer display which read “is this patient eligible for the miscarriage study?” “If yes, provide patient with a letter of invitation”, “If a letter was not given, then why?”; 5. A poster reminding staff of the study with the eligibility criteria was placed next to the door of room 5 in the department (this is the room where all gynecological exams take place).

Additional methods of recruitment were also used. A generic study advertisement was developed for use in a variety of settings (Appendix B). First, the advertisement was posted on the patient televisions in the ED waiting room. These televisions are used to convey general health information to patients and general information about emergency care. Secondly, posters advertising the study were placed in room 5 and the women’s washroom in the waiting room which had tear away tabs with the principal investigator’s (PI) contact information, so the patient could contact the PI at their own volition. The study was also advertised in public places such as family resource centers and GPs offices. The IWK Health Center allowed posters to be placed in the Early Pregnancy Complications Clinic, where women who have miscarried are often referred from the ED and their GPs. Ethical approval from the IWK Health Center was not required, as approval had been received from CDHA, which is sufficient for a poster advertisement. The poster was displayed in online communities such as Kijiji and Facebook to recruit participants. The advertisement was placed on Kijiji and the poster was circulated to different interest groups on Facebook who posted it to their page.

The snowball sampling technique was also used to recruit participants. This method is often used when recruiting difficult-to-research communities (Sadler, Lee, Lim & Fullerton, 2010). Individuals with specific characteristics are identified and are asked to recruit people within their own social network with similar characteristics. Once

identified, the new participants are asked to recruit within their own social network, hence the snowball analogy (Sadler, Lee, Lim & Fullerton). After completing an interview, participants in the study were asked to share the recruitment poster within their own social network.

Once potential participants contacted the researcher, they were informed of the purpose, significance, time commitment, expectations, voluntary nature, potential harms and benefits of the study. As well, they were provided with assurances about confidentiality. For those who agreed to participate, an interview at a mutually agreeable time and safe location was determined (participant's home if appropriate, a private room at the library or the researcher's office were used). Prior to beginning the interviews, informed consent was obtained and participants were given the opportunity to ask questions and seek clarification regarding the study. Participants were provided a copy of the consent form and the researcher kept the original. The consent form also included the option for participants to receive a 1-page summary of the research findings. Recruitment of participants ceased when data saturation was reached, no new data was emerging and an understanding of the phenomenon was achieved.

### **Data Collection**

Interviews served as the source of data collection as they provided interaction with participants and narrative experiential data necessary for the development of an understanding about the phenomenon in question (van Manen, 1997). Observation alone cannot tell the whole story; whilst interviews are valuable in uncovering personal histories, emotional experiences and thoughts (Patton, 2002).

To obtain information rich data, each participant engaged in an open-ended, face-to-face, semi-structured interview. Each interview was audio recorded and ranged from

30-80 minutes in length. The interviews were transcribed verbatim by a hired transcriptionist and coded for anonymity (all identifiers removed). The following open-ended question, with probes, was used to ensure that the interviewee remained close to the lived experience and the questions created a conversational relationship where personal experiences were shared (van Manen, 1997):

1. Tell me about your experience of coming to the ED to get care for your miscarriage?
  - a. Start from the beginning, and tell me the whole story
  - b. Tell me about the care you needed?
  - c. What type of care did you receive?
  - d. From your perspective did you get the care you needed? And if so did that fulfill your need?
  - e. If not how? What was missing?
  - f. What feelings and thoughts are you left with after having received care for your miscarriage in the ED?

At the end of each interview, demographic information was collected to determine age, parity (number of pregnancies, live births, previous miscarriages and therapeutic abortions), whether they had received treatment in an ED for a previous miscarriage, the weeks of gestation at time of loss, how long it had been since their ED visits and whether they were in a committed relationship. Establishing age was important as it has been implicated in the emotional reactions to miscarriage and the risk for developing anxiety and depression following a miscarriage, as is the presence of living children and/or previous pregnancy losses (Bergner, Beyer, Klapp & Rauchfuss, 2008; Marcinko, Marcinko, Dordevic, Oreskovic, 2011; Stirtzinger et al., 1999; Woods-Giscombe, Lobel

& Crandell, 2010). Relationship status is also of interest as the presence of emotional support from a significant partner can influence a woman's emotional reaction to the loss (Rowlands & Lee, 2010a).

Face to face interviews were conducted in order for the researcher to observe the participant's non-verbal communication and interaction with the environment. Field notes were taken to describe observations of the interviewee during the interviews that are not captured with tape recording alone (Streubert & Carpenter, 2011).

Van Manen (1997) states:

the purpose of phenomenological reflection is to try to grasp the essential meaning of something . . . The insight into the essence of a phenomenon involves reflecting appropriately, of clarifying, and of making explicit the structure of meaning of the lived experience (p.77).

To facilitate reflection, the researcher kept a journal throughout the research process as a means of documenting insights and understandings of the lived experiences of participants. Particularly, journaling was done at the end of each interview to ensure initial thoughts and feelings about the experience and interview were captured. This method is consistent with interpretive phenomenology as researcher and participants co-generate an understanding of the phenomenon in question (Wojnar & Swanson, 2007). It is also a method in which the researcher can acknowledge differences between personal and participant interpretations of the experience (Walters, 1995). The documentation of continuous self-reflection throughout the research process is a reflexive approach to research and will inform the data analysis process (Morrow, 2005).



## **Data Analysis**

The process of hermeneutical interpretive analysis was used which involves writing, re-writing, reading, re-reading and constant revisiting of the data to uncover depth and meaning (Mackey, 2005). This circular method of data analysis “distances the researcher from the phenomenon, encouraging perspective; and draws them towards it, allowing focus on the phenomenon alone” (p. 183, Mackey, 2005). The concept of temporality was also a part of the interpretation process as it is a hallmark of Heidegger’s phenomenology. It allows for the consideration of time (past, present and future) and its relation to the researcher, participants and their experiences in the quest for meaning and understanding (Mackey, 2005).

The thematic analysis was used to interpret the collected data. Phenomenology is a human science used to understand meaning, developing themes is the way the researcher formulates this understanding of meaning (Van Manen, 1997). Identifying themes gives structure to the meaning that the researcher is attempting to extract (Van Manen). Themes are the categorical statements that make up the structures of experience of the phenomenon in which the research is attempting to describe (Van Manen). Within the constructivist paradigm thematic analysis is concerned with how context and conditions shape the experiences of the participants (Braun & Clarke, 2006).

Van Manan’s (1997) three approaches to identifying and isolating thematic statements within text were used to analyze the data. The first approach, the holistic sententious approach, involves expressing the overall essence or meaning of a text (Van Manen). This involved reading and rereading interview transcripts while listening to the audio recordings of the interviews to get at the essence of each interview. The second approach, the selective or highlighting approach, involves identifying statements that are

particularly illuminating about the phenomenon in question (Van Manen). In this case, statements were highlighted when reading transcripts or listening to audio recordings that stood out, that seemed to represent a particular theme or capture the overall essence of the phenomenon. Lastly, the detailed line-by-line approach was also used. This involved carefully reading each line and asking the question “what does this sentence reveal about the experience of women who attended the ED to get care for their miscarriage?” (Van Manen). This assisted in always keeping the purpose of the study in mind when analyzing the data.

Wojnar and Swanson’s (2007) step by step process of hermeneutic textual analysis was also used to guide the data analysis process. The first step in data analysis is to read over transcripts in their entirety while listening to the audio recordings. This provided not only an overall understanding of the interview but also ensured transcription accuracy. The second step involved writing interpretive summaries and creating codes that represent emerging themes. The third step involved selecting transcripts and identifying themes that emerge from the group. The fourth step involved writing an interpretive summary of each transcript. Each text was then compared and contrasted to identify common meanings. Patterns were then identified to link the common themes that emerged from the data.

The data collected was managed in a confidential and secure manner. Audiotapes and paper forms were kept in a secure, locked filing cabinet when not in use. The electronic forms of data were stored in password-protected files. Collecting, storage and coding of electronic data was facilitated using the computer program NVivo 10. These data were also stored in password-protected, encrypted files.

## **Trustworthiness**

Phenomenological research involves the researcher as an instrument and criteria used to establish trustworthiness therefore differ from that of positivist methodologies (Creswell, 2007; Lincoln & Guba, 1985). Trustworthiness is a means for establishing confidence in the research findings through judging its credibility, applicability, consistency and neutrality (Lincoln & Guba, 1985).

**Credibility.** Establishing credibility is determining that the findings are expressed as *truths* to both the researcher and the participants; that the data are reconstructed accurately (Lincoln & Guba, 1985). The researcher listened to the tapes immediately after each interview and explored any issues with other participants in subsequent interviews to gain a better understanding of the matter and clarify any misunderstandings (Patton, 2002). Member checking was also used as the primary method for establishing credibility. Following data analysis, core themes identified in the findings were presented to the participants and they were asked whether their stories and experiences were reflected in the identified themes. Methods of triangulation were also used to establish credibility through field notes, documentation of insights and observations. Data were also triangulated with other investigators such as my thesis supervisor and the other committee members. The use of different investigators is a means of keeping the primary investigator 'honest' thus increasing the likelihood that the findings be credible (Lincoln & Guba). Lastly peer debriefing was used as a method of establishing credibility. During the analysis phase, I meet frequently with my supervisor to discuss insights, meanings, and test working hypotheses and to clear my mind of emotions and feelings associated with analyzing such emotionally laden data. Peer debriefing is a means of "exploring

aspects of inquiry that might otherwise remain only intact within the inquirer's mind" (p.308, Lincoln & Guba).

**Transferability.** With Heidegger's concept of temporality, it is difficult to transfer the findings of a phenomenological study because they were generated in a given time with respect to meaning in that particular life world (Lincoln & Guba, 1985; Mackey, 2005). A thick description of information was provided in the findings to aid the readership in determining the extent to which the findings are transferable (Lincoln & Guba, 1985; Mackey, 2005).

**Dependability.** The data collection process occurred over time and the researcher's interview style evolved and new insights were gained. This influences the data collection process and can create inconsistencies (Graneheim & Lundman, 2004). With this in mind, the researcher provided a detailed description of each step in the research process and continually wrote in the reflective journal to create an audit trail as such (Lincoln & Guba, 1985). Another method used to ensure dependability suggested by Lincoln and Guba (1985) is to have a study audit completed to determine its authenticity. In this case my thesis supervisor acted as the auditor and reviewed interview transcripts, codes and themes that emerged from the data to ensure the findings were authentic. My thesis supervisor also independently coded transcripts to compare and ensure we each had similar findings that emerged from the data. Thus the data, findings, interpretations and recommendations are supported by the data (Lincoln & Guba).

**Confirmability.** Lastly, confirmability is used to ensure the research findings are grounded in the data and is established through creating an audit trail (Lincoln & Guba, 1985). All raw data sources (audio recordings, interview transcripts, reflective journals, field notes, personal notes and data reduction and analysis products) were thoroughly

reviewed multiple times to determine whether they were logical, appropriate and reflective of the findings. Raw data was also kept according to ethical standards so that if audited, the findings would reflect the data collected. The researcher respected the importance of remaining honest to the challenges associated with the study and overall, the participants' voices were heard.

It is important to note that even when one follows the outlined steps, trustworthiness can never be absolute, as the nature of qualitative inquiry is an open system (Lincoln & Guba, 1985). In order to reduce threats to trustworthiness, the aforementioned steps were applied throughout the research process rather than solely at the end (Morse, Barret, Mayan, Olson & Spiers, 2002).

### **Ethical Considerations**

Approval to conduct research in the Charles V. Keating Emergency and Trauma Center was received through The Capital District Research Ethics Board (REB). In congruence with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, the REB protects participants by ensuring that research maintains respect for persons, concern for welfare and justice through fair and equitable treatment (2010).

The attending physician and assigned registered nurse assisted in identifying potential participants based on their diagnoses in order to distance the researcher from recruiting the participants, to avoid coercion. Participants were thoroughly informed of the study's purpose and methods to ensure transparency. In addition, consent was obtained voluntarily prior to the initiating the first interview. Participants were informed that they were free to withdraw from the study at any point during the interview process. To ensure confidentiality and anonymity, identifiers (e.g., names) were substituted with

code numbers and pseudonyms. All written and taped data were then stored in a locked drawer while not in use by the researcher. Signed consent forms were be stored in a file separate from interviews.

At the end of the interview a thank you letter was given to the participants. Given the sensitive nature of the topic, in the event that significant emotional responses were elicited during the interview process, the letter included community resources available for support such as The Helpline, The Mental health Crisis Line, the Nova Scotia 211 service and the Pregnancy and Newborn Loss Support Group. Since qualitative research methods:

are highly personal and interpersonal, because of the naturalistic inquiry takes the researcher into the real world where people live and work and because in-depth interviewing opens up what is inside people-qualitative inquiry may be more intrusive and involve greater reactivity than surveys, tests and other quantitative approaches (Patton, 2002, p.407).

However, some women identified participating in the interview process as a therapeutic experience following their miscarriage. In congruence with the evidence that suggests people often find that talking about a traumatic experience with a trusted other provides acknowledgement (Patton, 2002). That being said, this was not the purpose of the study

### **Summary**

Interpretive phenomenology was chosen as the methodology to understand the essences of the experiences of women who came to the ED to get care for their miscarriages. The primary goal of the study was to understand the participants' experiences and give voice to a group who has yet to be heard and find the meaning within their experiences.

## **Chapter III**

### **FINDINGS**

The following chapter is a summary of the five themes that emerged from the data collected. The meaning of the experience of miscarriage in the emergency department (ED) is reflected in five themes and 16 subthemes. A description of the eight women who participated in the study is also provided.

#### **The Participants**

A total of eight adult women participated in this study. Participants varied in age, parity, gestation at time of loss and the ED they visited.

All women sought care for a miscarriage in any one of the three EDs within the Halifax Regional Municipality (HRM). Seven of the eight women sought care at the Charles V Keating Emergency and Trauma Centre (CVK), the largest ED in HRM. One woman went to the Dartmouth General ED. One woman went to the CVK for her first miscarriage and then to the Cobequid Community Health Centre ED in HRM for her second miscarriage. Half the women who participated in the study were referred to the early pregnancy complications clinic at the IWK Health Centre or admitted to the gynecology unit at the IWK following their ED visit.

The women ranged in age from 21-36 years ( $\bar{x} = 31$ ). Seven of the eight women were married during their pregnancy and one woman was in a committed/supportive relationship. The women in this study were highly educated individuals; seven had completed post-secondary education, and two had graduate degrees. Only one participant did not complete post-secondary education.

Four of the eight women in the study had experienced previous miscarriages with their first pregnancies and subsequently had gone on to deliver full term babies before

experiencing the miscarriage investigated in this study. One participant had a neonatal death, followed by a miscarriage five months later (investigated in this study). Two participants had two consecutive miscarriages between live births, one woman between her first and second child and the other woman between her fourth and fifth child. Gestation at time of loss ranged from 5-14 weeks.

### **The Meaning of Experiences of Miscarriage and the Emergency Department**

Five themes emerged from the interviews with the eight women who participated in the study: 1. *Pregnant/Life: Miscarriage/Death*, 2. *Deciding to go to the ED: Something's wrong*, 3. *Not an Illness: A different kind of trauma*, 4. *Acknowledgement throughout my visit*, 5. *Leaving the ED: What now?* Each woman's story is reflected in each of the five themes and the themes are broken down further into subthemes. Throughout the chapter, names have been attached to quotes to humanize the stories being told. Pseudonyms have been given to each participant to protect their privacy.

#### **Pregnant/Life: Miscarriage/Death**

The theme *Pregnant/Life: Miscarriage/Death* captures the dichotomous meaning associated with the experience of miscarriage. Women presenting to the ED with miscarriage are in fact *pregnant* and what they are experiencing is its *loss*. As human beings we celebrate pregnancy and the birth of new life and when life ends in death we mourn and grieve loss. All of the participants in this study used terms such as 'baby', 'life', 'death', 'loss' and 'miscarriage'. When recounting their stories they became overwhelmed with emotion and the meaning associated with the loss was felt deeply by the researcher. Within this theme 2 subthemes emerged: *Life/Death* and *Backstory* both of which reflect the *Pregnant/Life-Miscarriage/Death* theme.



**Life/death.** Seven of the eight women told stories describing the meaning of being pregnant with a baby and how they prepared for the future with this baby. These stories about the life growing inside them were contrasted with the miscarriage and how it was the loss of a life, or a death, and the loss of a future. For women in this study, regardless of the gestational stage, or parity, whether the pregnancy was planned or plans had been made for its termination, the loss was met with an emotional intensity that extended beyond the ED visit.

The stark contrast of meanings within the *Life-Death* subtheme was reflected in the participants' stories of how they had imagined their future with their child but then how quickly it all came to an end with their miscarriage.

I mean I go back to when [husband] was so excited and we were so excited. I mean we were like shocked when I was pregnant, when I first found out I was pregnant. But we were also really, really... We got really excited about it. And we were like, you know what, this is going to be awesome. And it's all about potential, right. It's all that awesomeness. And then it just gets sucked away. (Sheri)

And you know that you're losing your child and, you know, every...all that you've kind of built in your head as to what that could be. Because you know, again just it's all in sort of I would say your thought process and how you conceptualize, you know, when is a baby a baby, and all of that, of course. And I think even for the most scientifically-minded individual, you know, once that stick says positive, you're automatically going into, you know, dream mode and what's this going to amount to? Who is this person that's forming inside of me? (Isabel)

And no matter how far along you are, it's a death. And it was still a baby. And so I wrote a letter. [emotionally upset] And I just explained how much I wanted that baby, and I to him, or her, how much I loved it and how much I would have wanted to see the whole pregnancy through, and my hopes and my dreams for that pregnancy. Because the moment you find out you're pregnant, you have that whole life planned out. You know, the hopes and dreams for that child. And that's what you mourn because it all changes. (Kristy)

Because I remember our real estate agent, every time we were like... Every time we were looking for houses, she was always like, "You have to have lots of kids to fill up the house." But I was already pregnant and hadn't told people yet at that

time. Anyway, but I lost the baby like a month before we moved in here.  
(Theresa)

Only one participant did not use the term ‘baby’ in the interview. She did however talk about how she coped with losing her ‘pregnancy’ which indicates it was a difficult experience for her.

Well, I had quit smoking. And then so I had started smoking again during that time. That was basically it. I did do a lot of crying and grieving. (Alyson)

**Backstory.** The second subtheme, *Backstory*, acknowledges that all participants had a unique set of circumstances surrounding their pregnancy and subsequent miscarriage. These personal stories shaped how women felt about the pregnancy and experienced the loss.

And personally, I can’t really... I don't think of that as it’s a separate incident. I see it simply as an extension of losing [son] and just living that a little bit more, and that that just adds a little bit more to his...to that story. But I guess that just goes to show whoever is going in, you know, for a miscarriage, there's some back story. Like there's more to it, right, than just, ‘Oh, that person is having a miscarriage,’ right. Because whether you think that that’s just a common, you know, occurrence, or whether it’s a horrible thing to go through, you know, it does happen a lot. And even you know that logically, it doesn’t resonate at the time, right. (Isabel)

There’s definitely a stigma that goes with young girls getting pregnant. And like, you know, it’s hard. It’s a hard experience to go through. And those girls need support. And I feel like it doesn’t really exist so much in the emergency room. (Alyson)

Because the first miscarriage was a total shock. I'd had 4 babies, no miscarriages. Right? I really was totally, totally shocked that my body... I even laugh because it's kind of statistically, you know, the 1 in 5. Like statistically I was due. But it didn’t feel like it could happen. It just felt absurd to me that it actually happened. (Janet)

Being pregnant was not a choice or decision that necessarily came easily for one participant and her partner. Processing the news of being pregnant...then envisioning life with a child... and then making the decision not to carry the pregnancy to term while

weighing the alternative was arduous. Subsequently, the woman made the difficult decision to have a therapeutic abortion but she had a miscarriage, which was a very traumatic experience, before she was able to have the procedure.

Well, I felt like it would be irresponsible for me to carry a child at this point in my life. And like it's just not realistic like in my life to have a child. And so I felt okay with that decision. I felt like it was the responsible choice for me. And like that was already hard. To make that decision and, you know, for my boyfriend and I... You know, that was already something we were dealing with and going through. And he's like, 'You know, when the time is right, you know, I'll be here and everything.' So that was hard. (Erin)

### **Deciding to go to the ED: Something's Wrong**

The theme *Deciding to go to the ED: Something's Wrong* reflects participants' actions triggered by fears that something was wrong with their baby and the need to get help for fear that something was physically wrong with their own bodies and threatening their own personal health. Four subthemes illuminate this aspect of experiencing a miscarriage in the ED: *Taking action*, *Where do I go? Which ED?* and *Holding onto Hope*.

**Taking action.** The first subtheme *taking action*, reflects the moments when women identified that something was indeed wrong with them or their babies and required action. For women experiencing their first pregnancy or their first miscarriage, there was a lack of knowledge or understanding about what was happening within their bodies and/or with their babies.

I had started having like really heavy bleeding. And it was like I had no idea what was happening so I called the nurses hotline. And just described what was happening. And eventually she said, "Okay, you have to get your things ready and go to the emergency room." Oh my god! Like it was something very serious, I guess. (Erin)

Had one participant known that nothing could be done to prevent a miscarriage from occurring she may not have accessed the ED.

I would assume, you know, maybe if you've gone through this a few times and you kind of know there's really nothing that necessarily can be done, and you kind of just deal with it on your own rather than put yourself through an extra, you know, layer of bad stuff to deal with at a bad time. (Isabel)

It was very clear, however, that women experiencing vaginal bleeding and/or pain knew that it was abnormal and a sign that something was potentially wrong with their baby that required action. In some cases, the lives of the women were threatened due to the large quantity of blood loss associated with their miscarriages. Recognizing the seriousness, of these situations, two women called 911 for an ambulance and then had no choice but to go to the ED.

The pain was so bad that basically I couldn't talk. And I had soaked through to the chair of the restaurant. And my husband didn't know what to do. And he was like, 'What do I do?' So I said, 'Call an ambulance,' because that's what I had to do. ...And it was kind of unnerving. The paramedics were not very responsive to what I thought was a medical emergency. Like I'm a nurse so... And you can strike that if you like. But I understood bleeding and I understood that this was a lot of bleeding. And I was bleeding quickly. And I understood what can happen. So I did understand enough at that point to be really scared. (Janet)

So I got in the shower. And it was a lot of blood. It was just... I had never seen that much blood in my life. And I felt like I was dying. My brother walks upstairs ... and he's like, 'What's happening?' And I just said, 'I feel like I'm dying. I don't know what's happening. I feel like I'm dying.' And like I was... There was no colour. And they called 911. (Kristy)

**Where do I go?** The subtheme *Where do I go?* reflects the fact that although these women could sense something was wrong and that *action needed to be taken*, they were not clear on *where to go* or *what to do*. Women sought advice from others to determine their next steps.

Immediately called my family doctor and said I'm spotting. And in my opinion, I don't think bleeding is normal even though they tell you every time you're

pregnant, some spotting is to be normal and stuff. So I knew in my heart that something was wrong. And I just said, 'What do I do' And the secretary to the doctor suggested go right to the hospital. And they said the QEII. And so I went there. (Kristy)

I actually called [husband 's mom], and she's a nurse. And she said if you're bleeding then you should go to the emergency room. So that's why we went. And I don't know, I figured something was wrong. (Tammy)

The women's choice to go to the ED was often because it was the only way to access health care services on weekends, holidays and after hours, their family physicians were unavailable or they did not know where else to go.

Well, I started spotting over the weekend. Well, it was actually on a Friday but my doctor was on vacation. So I waited about 2 days. Ended up going into Emerg. on Sunday because I really didn't know where to go. (Alyson)

And it was a Saturday night, probably around 10:30. And I noticed that I was bleeding. So we went to the emergency room. (Tammy)

It was that it was the holidays and I wanted to either know 'yes, you've lost your baby' or 'there's something wrong with you'. (Sheri)

**Which ED?** The subtheme *which ED?* speaks to the fact that for 2 women in the study, it was not always clear which ED would serve their needs; the adult acute care ED or the women's and children's hospital with obstetrical and gynaecological services (that does not have emergency services for adults).

911 came very quickly. ... And on the way in to the hospital, they said, 'What hospital would you prefer to go to?' And I said, 'The IWK.'...And they said they couldn't see me. That I again had to go back to the QEII. So they... I was just heartbroken because it was like why can't they just see me at the IWK? Like they deal with women and babies. So back to the QEII I went. (Kristy)

One participant actually presented to the adult care ED thinking that she was ill and her symptoms were completely unrelated to the pregnancy. She said that if she thought it had to do with her baby she would have presented to the ED at the women's hospital not

knowing that she would have been ineligible for their services because her pregnancy was not of viable age (>20 weeks).

**Holding onto hope.** The subtheme *Holding onto Hope* reflects the notion that even if the women knew that, logically, they were losing their babies, they still had hope that something could be done and that everything would be ok. Since going to the ED was the way to access care then it was where the women went to find out/confirm what was happening to their bodies.

You know what was happening. But I mean probably 95% of me knew that that's what was occurring. But I just still felt that need to go into the hospital and make sure that there wasn't anything, right. And of course there's nothing. And I know that logically but still, you see that need to try something. (Isabel)

And I just kept reading that damn book [pregnancy book] and just like am I reading this, this is right? [that I'm having a miscarriage] You know, very like objective. And [husband] kept saying, 'You're going to be fine. We're going to take you to the hospital and they're going to check and see that everything is fine, and you're going to be fine.' (Sheri)

### **Not An Illness: A Different Kind of Trauma**

The essence of the third theme, *Not an Illness: A Different Kind of Trauma* describes the meaning of the experience of being a woman in the ED having a miscarriage and how and why it differs from other ED presentations. People come to the ED for a variety of reasons ranging from critical injury, life-threatening illnesses to minor non-urgent complaints. Losing a pregnancy, a child, was something completely different and participants were conscious of that difference and expressed that it made them feel like they did not belong or that their needs were not a priority, thus marginalizing their experience. The magnitude of what was happening to these women was not necessarily understood or acknowledged by staff nor that what they were experiencing was something very different from what other patients were experiencing.

But yeah, so it was kind of just, you know, we were told to go in and sit in the waiting room with everyone else who was, you know, suffering from the flu or whatever. And you know that you're losing your child and, you know, every... all that you've kind of built in your head as to what that could be, right. (Isabel)

I think that pregnancy and birth and all those things, it's something that I feel is very sacred. To create life and, carry life, it carries a different kind of weight to it than other types of sickness. Everything carries its own weight but it's just a very particular different thing. I can't quite articulate it. (Erin)

I really just... I don't feel comfortable waiting in the waiting room. Like there's a lot of people there for many reason, and I'm sure I'm making a big scene. And I'm trying not to but I mean you're losing something. (Kristy)

The physical manifestations of the participants' miscarriages did not appear to be of high priority to ED staff. Given that nothing could be done to save the pregnancy, participants were left feeling like they did not belong in the ED as it was geared to patients in which help was a possibility. One participant expressed feeling that a miscarriage is not seen as a priority, that she did not belong in the ED and that she was taking the place of someone of higher priority as ED services might help.

I just know there's other people who have higher priorities. If I was having a heart attack, it's one thing. But when you're having a miscarriage or you have this inkling in the back of your mind that you could be. ... You just feel like you're taking someone else's space. (Sheri)

Participants felt a sense of urgency as they waited in the waiting room, or inside the department for assessment. Their own sense of urgency was incongruent with how they were triaged and prioritized within the ED according to their symptoms. Some participants were also unaware that nothing could be done to prevent their miscarriage.

At that point it was just light spotting. And I was pretty stressed out and trying not to fear the worst but fearing the worst. I just knew in my heart. ... I sat in the waiting room for almost an hour, maybe even longer. It felt like forever. And I just remember people staring at me. (Kristy)

My boyfriend, when we first got there, he's like 'you know, its going to be probably 2 hours until you get in there.' I was like 'What?! That's crazy. I'm in so much pain. I can't believe they would let me sit out here for that long.' (Erin)

I remember thinking when I went I wouldn't have to wait. Like I thought that I would get in sooner. Do you know what I mean? Because to me it's a big deal but to them it's just, you know, it happens a lot. (Tammy)

It was as if having to be clustered with patients having other physical needs belittled the significance of what women enduring miscarriages experienced.

And I also just felt like there wasn't... I felt like there wasn't any place for me there. It's like I feel like miscarriage is kind of a really... It's traumatic. It's like a very particular. Like it should be a specialized care for that kind of thing happening. But I felt like I was just like lumped in there with all other kinds of things happening around me. (Erin)

Nothing pulls at me emotionally when someone says, "I'm sorry, you have a UTI. We're going to give you an antibiotic." But when someone tells you that... Or you know, you have a second degree sprain of your ankle, take these painkillers and stay off it for 6 weeks. No one tells you... Those things aren't life-altering. But I think when you have a life-altering thing being delivered to you, it does. (Sheri)

It was basically just like talking to a wall, for better or for worse, I don't know. But you know, there was really no... Like I don't know how many times in a week someone hears, "I think I'm having a miscarriage." If that's their job, right, to register patients at the hospital, probably quite frequently, sadly. But it was just, "Okay, I'll take your blood pressure," or whatever, you know. I think if I had said I broke my arm, it would be the same response, right. (Isabel)

In contrast, 2 participants experienced haemorrhages resulting from their miscarriages, which were treated as medical emergencies. Swift *physical* care was provided and both noted that their physical needs were being met.

The bleeding was being taken care of. And I think they were worried about me. But I think they were also very like gauging how I was doing. There was clearly assessment going on the whole time. Like seeing how I was doing overall. I think there wasn't as much focus on the loss at that point because it couldn't be. And that was okay. (Janet)

And I got in pretty quickly. And then I saw another doctor. ... And she said 'you did the right thing by coming.' What had happened is my body was going into shock because I was passing blood clots that were so large, they were getting



lodged in my uterus. ... And it couldn't get rid of it so my body was shutting down. ... So she did an internal, and she was able to scoop out any other blood clots and stuff she saw that could pose problems. (Kristy)

### **Acknowledgement Throughout My Visit**

The theme *Acknowledgement Throughout My Visit* speaks to how miscarriage is recognized and acknowledged by the care women receive while in the ED. The experience is influenced by what is said and what is not said (the language and terminology) and the actions and inactions of health care professions. The theme *Acknowledgement throughout my visit* is represented in the following 4 subthemes:

*...While Waiting and Wondering, ...While Delivering the News, ...While Caring for the Whole Self., and ...In Privacy.*

**...while waiting and wondering.** The subtheme *...while waiting and wondering* speaks to the importance of acknowledging what is happening to the women throughout their stay in the ED and their experience of miscarriage – both through the language used and care provided. As one participant stated, often women do not know what to expect or what is happening to their bodies. It is, therefore, important for health care providers to keep them informed.

And the doctor kept coming in. And no one was really saying anything. Like I had all my blood work drawn, and I was asking about some of my levels and stuff like that, and no one would tell me. (Alyson)

Like there was no one there to support me through anything. Like no one came in to be like, "Okay, like you know, miscarriages happen to people because of these reasons." Or even, "Here's a pamphlet." Like just nothing. No... I had no idea. (Erin)

As ED health care providers performed tests and tasks, women yearned for acknowledgement and support. The women felt dehumanized; they wanted to be

acknowledged as someone experiencing a death, not as someone just requiring medical tests or procedures.

I was examined and stuff by a few people and the nurses, and they took blood. They were trying to take samples. I had to provide urine samples and stuff like that. But the whole process felt like very...just very medical. Like I felt kind of like I was like a patient. I didn't feel like a human being going through a loss at the time. I felt like somebody going through a medical procedure. And I didn't like that feeling. And I just remember I just...I wanted it all to be over. (Kristy)

So I just think when you go in there and there's absolutely no acknowledgement of any sort of emotional thing happening, and it's all just very cut and dry. Like, "Oh, this happens. And we'll do blood tests and send you home." That's really disheartening, I think. And I've like thought about it since and just thinking, you know, if that were your first pregnancy and... You know, a lot of women don't know how common miscarriages can be until it happens to them, right. Like how devastating, you know, it would be. And even if it's your fourth or your fifth or, you know, if you were suffering with infertility and you finally conceive, everyone is going to bring a story to it, right? (Isabel)

*...while waiting and wondering* also speaks to the women's need to be listened to and to have their needs met. Even when the woman's life was potentially threatened, neither the miscarriage, nor what was happening either to her baby or her body, were acknowledged or respected. In this case the paramedics' inactions were dismissive of the experience.

And it was kind of unnerving. The paramedics were not very responsive to what I thought was a medical emergency. Like I'm a labor and delivery nurse so... And you can strike that if you like. But I understood bleeding and I understood that this was a lot of bleeding. And I was bleeding quickly. And I understood what can happen. So I did understand enough at that point to be really scared. And I had paramedics put me on a stretcher, cover me with blankets. They didn't ever look at the bleeding ever, even though I was saying... I was saying to them, "I'm soaking through this." (Janet)

One participant felt that despite communicating needs, that she was experiencing intense pain, they were not being met as she waited in the waiting room for over 4 hours with no support from staff or intervention.

‘You know, its going to be probably 2 hours until you get in there’ [says boyfriend]. I was like, ‘What! That’s crazy. I’m in so much pain. I can’t believe they would let me sit there for that long.’ Then it was 4 hours. (Erin)

... **while delivering the news.** The subtheme *delivering the news* speaks about the way health care providers delivered the news to women having a miscarriage and how it shaped each woman’s experience. Patient-provider rapport, the provider’s bedside manner and the presence of family or a support person had implications as seen in the following participants’ quotes. For some women the delivery was cold and impersonal and they had wished their partners could have been with them.

I had forgotten my water bottle in the waiting room so [husband] actually ran out to grab my water bottle. And when he was out grabbing it, the doctor came in, sat down, looked at me and goes, “You’ve miscarried. Here’s the name and number of the clinic you’re going to have to go to because you’re going to need a D&C.” And I was like, “You couldn’t wait until my husband came back? Like I don’t even know what to say right now.” And he just kind of like sat there and he was like, “Well, you know, I don’t know what to tell you. This really isn’t my area of expertise.” He said, “This clinic will...at the IWK will take care of it.” (Alyson)

Whereas this doctor just kind of came in, you know, introduced himself because all doctors introduce themselves, and just said like, "Yeah, you were here last night. You know, you had your ultrasound. Like yeah, you definitely had a miscarriage. You know, what you can expect in the next whatever? Like you can expect period cramps. You can take Tylenol." You know? And then you're like, "Okay." And then he's like, "Okay, see you later." Like I don't know, that was kind of weird. (Tammy)

He said, ‘I’m going to... It appears that you’re having a miscarriage.’ So he said, ‘I want to check and make sure everything is fine.’ So he did a whatever, an exam. And he said, ‘Yeah, I can see your cervix is open,’ or whatever, ‘and you’re having a miscarriage.’ And [emotionally upset] it was really shitty. He was so nice but he didn’t know what to do. I was in there by myself at that point, and [husband] was still out... I don’t know where the hell he was, if he was out in the waiting room or if he was out in that early room where I was lying in one of the beds getting my blood work done. And anyway, he said, ‘Is someone here with you?’ And I said my husband is here. He said, ‘Okay, I’ll go get him.’ (Sheri)

Three women did have both positive and negative interactions with ED health care professionals during their visits. Allowing for grief, providing support, being attentive to

physical and emotional needs and responding empathetically eased the experience for some women.

Especially after having had such a warm... Like when I had that big cry over the placenta that I saw, like the sobbing cry, like the nurses were so good to me. Like they encouraged me to cry. They were empathetic. Like I don't remember what they said but I remember them giving me permission to grieve. Like I remember them acknowledging it as a loss. Like I remember feeling like they understood that this was a dead baby for me even though it wasn't. I think they at least understood that it was a loss. So I felt really like they got it. (Janet)

It was like he [the nurse] knew that something really like traumatic was happening to me. He didn't like say it with the exact words of like I know this is really traumatic. He was just like he just treated me that way. Like treated me like I needed comforting. So I felt... I did feel comforted by him. (Erin)

Two male physicians who had personal experiences with miscarriage used self-disclosure as a way of supporting women through their loss.

I feel like he [the doctor] did seem like really, you know, concerned with how I was dealing with the situation. Because I felt like he was really like probing. Like he was constantly... Like he's like, "Are you okay? Like are you sure?" And he just kept like kind of telling stories about his own experience to like kind of get like an idea if I was okay or if I was just like, you know, being okay just for them type of thing. (Tammy)

Then he [doctor] came in. I don't know who he was. He was very nice. And just told me that I had had a miscarriage, and that there was no heartbeat, and the baby was smaller, you know, had stopped growing some time ago, and stuff. Anyway, the doctor was really nice. He told me about his wife had had a miscarriage. ... I remember him saying like don't underestimate how hard it is, you know, on the guy too, and make sure you're supportive for each other. Yeah, he just told me it was really common and all of that stuff. But yeah, I mean I definitely wasn't prepared for any of that. (Theresa)

**...while caring for the whole self.** The subtheme *...while caring for the whole self* refers to caring for both the physical and emotional needs of women who are experiencing miscarriages in the ED. It appears that participants had a range of encounters, both positive and negative, when interacting with ED health care providers and the ED environment. Some women had positive experiences with their first visits but

then had negative experiences when required to return to the ED. Regardless of whether there were positive aspects to their ED visits, participants still expressed that something was missing from the experience.

I wonder if that's really...if it's really serving the purpose of looking after the whole self and not just the physical, you know. That being said, I guess there was a part of me that just wanted somebody to go, "Oh, that's horrible. Let's get you in here and make sure that this is really the case." Like knowing how that would affect someone just... (Isabel)

Like I felt like I was disappointed in, you know, like people that were supposed to be taking care of me. Like they did take care of me in one way but then in another way, I felt like it was a bit lacking in like that kind of support. (Erin)

So it was just so...I was heartbroken when, you know, that trip into the hospital by ambulance and they said, "no you're not far enough along to go to the IWK." And then at that moment, I felt like 'was my baby not as important?' Like I mean yes, the baby is dying or is not even alive but I left like why don't I get to go? Like I'm still a woman. And it's still a baby. Like I just felt like not validated, I guess. And then I felt like I wouldn't be taken care of because they don't specialize in that in the QEII. (Kristy)

**...in privacy.** The subtheme *...in privacy* became evident as the women recounted their experiences of miscarriages in the ED and that they required privacy and also wanted and needed support. The lack of privacy in the ED left women feeling exposed emotionally while processing what was happening to them and their babies. Having to sit in the waiting room, wait for test results and wait for assessments by health care providers were all moments in which women felt exposed.

If I could have come back maybe in a room by myself. I don't know, that might have been awful too. But I remember there was a girl like sitting next to me, and I like had tears like, you know, streaming down my face. And her asking me if I was okay. And you know, me saying like I had just had a miscarriage. (Theresa)

It was the first time it's ever happened to me. And I just didn't know what to expect. And I was scared. And I just needed some peace and...like a peaceful safe place to deal with those emotions. (Kristy)

And then sat in the waiting room for, you know, umpteen hours. And finally I got in. And my husband and I were placed... We weren't in the gynae room, we

ended up being like in the minor side. So there were quite a few people around us. ... So you can hear... I mean you hear what your neighbours and everything are saying. And then of course they can hear what we're saying... Like I think the news should have been given to me with my husband in the room and maybe in a little bit more of a private setting because you're still experiencing a loss, right. (Alyson)

### **Leaving the ED: What now?**

The theme *Leaving the ED: What now?* speaks to how the women felt their physical and emotional needs were met, or not met, upon discharge from the ED. Feeling unprepared was a common experience for all of the women participating in this study. Women were either unprepared for what would happen to their physical bodies as they continued to miscarry at home, or unprepared for how they may respond emotionally to the pregnancy loss. *Leaving the ED: What now?* also refers to how the experience of miscarrying is shaped by what happens after leaving the ED. Women in this study either went home to miscarry or were referred to gynecology and obstetrical services for follow up care at a different hospital such as an outpatient dilatation and curettage (D&C) procedure. Women felt in limbo as they waited for follow up without knowing what would happen to their bodies. This theme also explores how, after leaving the ED, the experience of miscarriage is a lonely loss as it is not an experience that is openly shared and discussed in society. The meaning of this experience is expressed through the following subthemes: *You Can Go Now: Abandoned*; *You Can Go Now But Come Back, Then What?*; *Waiting for Follow Up, What Is It?*; *Suffering in Silence: Lingering Effects*.

**You can go now: Abandoned.** The subtheme *you can go now* reflects women's feelings of abandonment upon discharge from the ED following pregnancy loss. They felt as though what had just happened to them was quickly dismissed.

Anyway, and I keep thinking... I remember... And then he left. I don't... They didn't give me any information. And I just sort of was in the room with [husband] and I just was sobbing uncontrollably. [upset] And then I left, and that was it. (Sheri)

They gave me your study piece of paper. And then I was like, oh, is there like a pamphlet on miscarriages in here maybe? Like is there anything? I kind of felt like it was like, "Okay, you can go now." Like after like this crazy like 12 hour experience, and then all of a sudden it's just like I walk out the front door and then that's it. Nothing like, "Is there someone here with you?" Like maybe I had said my boyfriend. But like... Or anything. It's like it was kind of like, "Okay, well, here's your Tylenol and here's this study," and that's it. It was kind of like, okay, see yah. (Erin)

One participant and her husband had the unfortunate experience of choosing to terminate their baby due to a severe congenital heart anomaly. She delivered her baby at 25 weeks and he exhibited signs of life for up to 2 hours. This happened just 5 months prior to her miscarriage. In this circumstance, the loss of her son at 25 weeks was acknowledged and she felt very cared for. The participant was aware of the stark difference in care when she was in the ED for her miscarriage under 20 weeks and subsequently discharged home.

And then it was just like, 'okay, we're done. See yah.' You know? And its like you just walk out of there and you're going 'Did that really happen? And was that...is that it?' Like it seemed so just like anything else, you know. It didn't really register or it didn't for me until I got home how shitty an experience that was, you know. And you just kind of get through it and don't think about it at the time but and I certainly know the experience would vary so much depending on where you were in the pregnancy. (Isabel)

**You can go now but come back.** The subtheme *you can go now but come back* reflected women's thoughts that the ED staff did not seem to understand or acknowledge what they were experiencing. For example, some women were told to return to the ED the following day for a formal ultrasound. Women who required formal ultrasounds expressed anxiety about having to go home, sit with the possibility that they were

miscarrying, or that they were carrying around a dead baby, and have to return to the ED  
...but not until the following morning ...to confirm their suspicions.

And I just remember being like I have to come back in here? Like, I just didn't want to. I just... I wanted it to be over. And I just remember thinking like that night when I went home, I was like, you know, why me? . . . And in the morning... Like that whole night, I kept dreaming that I was going to wake up and it was going to be a bad dream. And I remember thinking, you know, tomorrow morning I'm going to have that real ultrasound, that really detailed one, and they're going to say, "No, it was a mistake. You're pregnant with twins, and one is surviving." Like I was really hoping. (Kristy)

And then they had given us the requisition to go for the ultrasound the following morning. And there's no appointments or anything so you just show up. So we had to spend the night knowing that, you know, there was potentially something wrong. So I mean you don't sleep. So the next morning we got up early and we went for the ultrasound. So we get to the ultrasound. My husband is not allowed to come in with me. I had asked, you know, can he come in for the ultrasound with me, and she said, "No, there's no one allowed." (Alyson)

Well, I kind of thought it was pointless because I felt like everything had kind of... I felt like he already knew, like I had already been given enough information to know that this was happening or had happened. So I just remember like, you know, getting up and being like ah, like I wish I didn't have to do this right now because I already knew what the outcome was going to be. (Tammy)

The process of returning for an ultrasound was even more uncomfortable for women because after the test is done, they had to return to the ED, be triaged again and wait in the waiting room, for an unknown length of time, to see an ED physician once again in order to confirm the miscarriage.

'Well you have to go back to triage and be triaged in, wait in the waiting room until a doctor can see you in emerg.' So I started crying. We leave where the ultrasound is and we walk down through emerg. We sit in the line-up to be triaged. Get up. Go through whole have your blood pressure taken and all that stuff, and you know, why are you here? And so I told her, we were just told I had a miscarriage by the radiologist. And then we were sent back to the waiting room where we waited for probably about 2 hours. (Alyson).

So I came back the next day. . . . And then I had to wait an hour and a half longer than my actual appointment [for ultrasound] was actually for. . . . Anyway, so I went in for that ultrasound. And then the tech said she had to agree with the



doctor. That was the first time that I ever really was like oh, everything is not ok. ... Then he came in. And just told me that I had had a miscarriage. ... And then that was pretty much it in that part. And then I called [husband] to come pick me up because he was at work. So I had to wait for him to come. And I had to go back to the emerg and see that doctor. I wasn't there very long but I know I was sitting in emergency [waiting room] crying all by myself, which was awful. (Theresa)

**Then what?** In the subtheme *then what?* women expressed an overall feeling of unpreparedness regarding how to manage their miscarriage symptoms, what to expect emotionally and with respect to follow up care with obstetrical and gynecological services provided at another hospital - the women's hospital.

During a miscarriage or following a miscarriage, women did not know what to expect or necessarily understand what would happen to their bodies. In some cases what they were told was incongruent with what they experienced.

No, I mean he was like emotionally reassuring but not practical. You know, like there was no sort of the stuff that you start having questions about after you leave. You know, like when am I going to expect to start bleeding? Or does that happen? Or you know, how do I get rid of what's inside? Like there was none of... I don't remember that he talked to me about any of that stuff. (Theresa)

Like the doctor the next day told me that I was going to have pain. But what he told me I was going to have and what I actually had was nowhere near. Like he told me to expect...He's like, "Some women say that it's like period cramps." So I was like, okay, I can deal with that. Like period cramps, not a big deal. No. Like the pain was unbearable that I had during my miscarriage. So I remember... And like that scared me because I didn't know what was going on. (Tammy)

But then you bleed for what feels like forever. I bled for a month. Spotting. And it's just like when you have a baby, postpartum, you can have bleeding up to 8 weeks. And it was for 4 weeks. And I just remember thinking it's a constant reminder every single day of what you lost. And that sucked. (Kristy)

Some women had more serious complications associated with their miscarriages, such as haemorrhaging, for which they were equally unprepared by both emergency care providers and those providing follow up care at the early pregnancy complications clinic.

I don't know, like they didn't really prepare me for the amount of bleeding. And I didn't think that could happen. So when I... They told me blood clots the size of a

toonie or larger is not considered normal. Kind of like after you have a baby. They said, "Watch out for the size of your blood clots." So I knew something was not right by the amount of the bleeding. And then after I got out of the shower, I sat down on the toilet because I knew I was having contractions. Like my body was actually in full on contractions. I was in labour. (Kristy)

I was also then very angry. Because I was angry because nobody told me it could be like that. Like I had all those Early Pregnancy Complication Clinics, and nobody thought to like really talk about hemorrhage. (Janet)

Two participants shared their need for resources and supports following a miscarriage. The intense emotional reactions and the lingering effects following their miscarriages came as a surprise for most women.

Or even after the fact, you know, instead of just kind of like setting you free, like just having some sort of resource there, I think, yeah, would certainly benefit. But I just thought, you know, it would be... I'm sure, I think personally for me, I need to talk about, you know, what has happened to me. And I find it very therapeutic to be able to do so. So to be able to do that in this type of setting is a positive for me personally. (Isabel)

However, I think I really should have been told that some people, you know, find it very difficult emotionally afterwards. There's all kinds of ways you can get help. Like really I just needed a counsellor, is what I needed. Like I just needed somebody to talk to. I didn't necessarily need bereavement, grief stuff. I mean that's what I ended up...counselling ended up doing for me. But it didn't have to be within that perinatal loss sort of context. (Janet)

The subtheme *waiting for follow up?* reflects the experience and feelings of women who required follow up care. Some participants, depending on their miscarriage, needed gynaecological and obstetric follow up to determine whether a D&C, or other medical intervention, was required to assist the miscarriage process. Waiting to hear from clinic staff, waiting for an initial assessment appointment and waiting for a D&C (if required or requested) was taxing for women as they continued to deal with the pregnancy loss, the physical symptoms and the emotional implications.

And then that was like a Tuesday. And it was coming up to a long weekend, and I couldn't get an appointment at the IWK until a week later. So like that, you have to leave a message. Like you don't get a person right away. So you have to leave a

message. So I didn't really know what to expect. Like no one told me... That's the part I found the hardest. Like no one was very clear about what to expect. So even when... I think I didn't hear back from them until the next day. ... And I just remember being so devastated that I wasn't going to be able to be seen until like Tuesday. Like it was like 7 days later. I still think that's crazy. (Theresa)

I would love to have it (D&C) this afternoon. Because at that point, you know, you know its dead and you just want to be rid of it and you just want to move on. So she checked. They couldn't. So the best they could do is put me on the wait list for Friday. So it was Tuesday. So we went home and, you know, we had our fingers crossed that we could take care of it by Friday. Just I mean for your own mental sake, you know, because you know it's there, you know it's dead, and you kind of want to get rid of it. (Alyson)

"You know, your options are..." He's like [the physician], "You can go home and you will most likely pass the fetus within a few days." And he said, "You'll have some bleeding." And I said, "No, I can't do this at home." My fear was that I was going to see a living baby. I knew it wouldn't be very big. But I didn't want to pass that. I couldn't for my own sanity. And I said, "I need to have a D&C. Like what do I do to do this? Like who does this? You need to get me in contact with the right people." And he said, "Well, the process is that I will fax over your information." And this was Thursday morning. "I'll fax it over to the IWK," he's like, "and then they will contact you." He said, "Unfortunately, they only do D&Cs on Friday." And he said, "Chances are by the time they got the paperwork and by the time they called you, they won't be able to see you until next week." And I was just... I was crying. And my husband was literally holding me. And I said, "I can't wait that long." I said, "I will not make it". (Kristy)

One participant had 2 miscarriages in the ED. With her first, she was referred for follow up as an outpatient at the IWK as she required a D&C. With her second miscarriage, she was not referred to the IWK because she did not require a D&C. The participant noted the stark difference in care when she did not require follow up at the IWK.

No one followed up with me. And I went home and just continued on with my merry Christmas. And there was nothing. Like no support, not a single piece of paper. No paper saying, you know... The IWK provided me with so much stuff. And I actually referred back to it the second time. (Kristy)

**What is it?** Upon discharge, some participants were told to expect vaginal bleeding and blood clots. This is what their *baby* would look like as they continued to

miscarry. Despite having described their miscarriage as the death of a baby and the loss of a life, participants described the actual physical manifestations of their miscarriage using different language. They used terms such as '*blood*', '*blood clots*', '*tissue*', '*fetus*' and '*it*' which are conceptually, very different from a *baby*. These terms were given to the participants by the health care professionals in attempts to prepare them as they continued to miscarry at home.

So again they had told me like I would pass tissue and that you have to go home and check the toilet every time you go to the toilet to see what's in there. Which is super disturbing. . . . Anyway, I actually passed an intact fetus. It was not tissue. . . . And I was not prepared for that either. (Theresa)

I said, 'Do you think that's it? Like is that a placenta?' I didn't think it would be that big. I wasn't sure. And he [husband] said, 'I don't know. I don't want to look at it,' he goes, 'to be honest.' And I understand that. I didn't want to look at it. I was like, 'I don't see anything in it. I don't see any fetal tissue.' I mean those are things you don't want to even talk about or even have to deal with. You just want it to be over with. (Kristy)

One participant found that looking at the blood and blood clots that were removed from her body in the ED helped her come to terms with what had happened to her pregnancy and her body. Again this participant is someone who was deeply affected by the loss and wrote a very personal letter to her *baby* that talked about her hopes for the future but struggled to understand the experience of losing her pregnancy and reconcile how the emergency medicine paradigm viewed her baby.

I needed to see it [the baby after she miscarried]. I think maybe just a different orientation. Maybe from an emerg orientation, it's not a baby and it's not a pregnancy, it's not your body. It's debris. Like it's waste almost. You know what I mean? Like it isn't. Versus for me, it was a pregnancy and it was part of... It was a pregnancy and I needed to understand it. And I think seeing would help me understand what happened. (Janet)

The language used to describe what a miscarriage may look like made one participant angry as it did not accurately describe what she would see or experience and it was disrespectful of her loss.

And then that I could have some bleeding and pass some stuff, is what she said to me. And I was like... Even now that makes me so mad. Anyway, I was like, 'What stuff? Like I don't even know what you're talking about.' And I think it's so common to them, you know. (Theresa)

**Suffering in silence: Lingering effects.** The third subtheme *Suffering in silence: Lingering effects* reflects the isolating experience of having a miscarriage. Family and friends may or may not have known that the woman was pregnant and therefore not realized a loss had occurred, thus making it a lonely loss. Unlike other deaths that are more obvious and often grieved in the public sphere, miscarriage is hidden; *the baby, the embryo* or *the fetus* is flushed away along with the experience and then women are expected to resume *normal* life.

So once I started getting out and like I told a couple of friends like what had happened. You know, because they were like, "Where have you been?" Because I was saying I was sick. I took some time off work. And you know, like having those conversations with them. And feeling like, you know, the more support that I felt that I had, I felt strengthened by that. Like it's not so bad. And I kind of felt like... You know, because it is like, you know, a small death. (Erin)

And so during the miscarriage time when I was really disconnected was one of the worst times because I didn't have anybody. Like I didn't really have support around me. Like friends and family didn't really acknowledge it. My sister did. My sister kind of got it. And she came and stayed with me for a while. But nobody else really kind of got it. . . . So I got really a lack of acknowledgement. It was almost like people treated it like a disappointment, like you didn't get a job you wanted. That's what it felt like. Like I felt like it was, "Oh, that's too bad." And [husband], because him and I weren't on the same page. Like I didn't know but at that time, he was very scared and trying to figure out what he should do. (Janet)

Immediately following their miscarriages, some women took time off work to cope with the loss.

But I certainly, you know, took some mental health days [from work] after the miscarriage that I just experienced. But it didn't hit me really until a couple of weeks later. Yeah. Even a week later really that I just found myself getting into more of a depression and, yeah, just an overall sort of sadness bubble, I guess. Because I worked really hard to have framed [son]'s birth into my psyche in such a way that it's a positive and that it's something I can live with and incorporate into my life. (Isabel)

But like I cried a lot. Like even I only took... Well, I took like... I took like that whole week off. So I mean I went back to work like the Tuesday after the long weekend. But I mean I had to go back to my office frequently to cry. Yeah. (Theresa)

I had a really hard time going back to work. That [first miscarriage] happened when I was off that year on leave. So I didn't have to go back after that one. But then after the second one [miscarriage], I did. I took whatever sick leave. I used all my sick leave to stay off as long as I could. And then I still...I had to go back and it was really, really difficult. (Janet)

The participants discussed the lasting emotional effects of the experience and the impact of the loss. Whether the loss occurred 1 month or 6 years before the interview the emotional effects of the loss still lingered and elicited intense emotional responses from participants while recounting their stories regardless of how much time had passed.

Most women suffered the loss of their pregnancy in silence not knowing how common the experience actually is or why people are not open to talking about it. Only later with the passing of time were women able to share their stories.

It never crossed my mind that I would have a miscarriage when I was pregnant. Isn't that interesting? . . . It never crossed my mind that that would happen. 'Oh, you'll have a miscarriage'. It never crosses your mind when you find out your pregnant that your baby won't be a baby. (Sheri)

It's just surprising, it's just so many people have experienced it. And they don't say anything, right? Everyone is suffering in silence. Which is really sad. . . . Until you open up and share your story, you're probably not going to hear of that many people who experience this type of thing, for sure. You know, it's not something that people necessarily want to talk about, when babies die. (Isabel)

And then she said to me [staff at the Early Pregnancy Complications Clinic] and I never forgot these words, she's like, 'all of a sudden you become part of a club

that you never knew existed and a club you never wanted to be a part of.’ And I said ‘Yup, I feel like that.’ She said, ‘But take comfort in knowing that there are so many women like us out there.’ (Kristy)

### **Summary**

This chapter described the meaning of the experience of eight women who went to the ED to get care for their miscarriage. The five themes that emerged from the data included: *Pregnant/Life-Miscarriage/Death*; *Deciding to go to the ED: Something’s wrong*; *Not An Illness: A different kind of trauma*; *Acknowledgement*; *Leaving the ED: What now?* The diverse stories belonging to this group of women are reflected throughout the five themes and create a picture of how ED care shapes the miscarrying experience.

## **Chapter IV**

### **DISCUSSION**

#### **The Participants**

Eight women participated in this study and shared their lived experiences of having a miscarriage and getting care for their miscarriage in the emergency department (ED). These accounts revealed the following five themes: 1. *Pregnant/Life: Miscarriage/Death*; 2. *Deciding to go to the ED: Something's Wrong*, 3. *Not an Illness: A different kind of trauma*, 4. *Acknowledgement throughout my visit*, 5. *Leaving the ED: What now?* The essence of the meaning of each woman's experience is reflected in each of the themes.

The women who participated in the study were between the ages of 21 and 36. They also had diverse obstetrical histories. For four participants it was their first pregnancy that resulted in a miscarriage, another participant had planned on having her second therapeutic abortion but ended up miscarrying, and still another participant had two miscarriages before giving birth to her 5<sup>th</sup> child. One participant had neonatal death just months prior to her miscarriage, while another participant miscarried twice before giving birth to her second child. Regardless of age and parity, all participants described the traumatic nature of the loss and the intense emotional reactions associated with their experiences of loss.

#### **Life and Death**

Early pregnancy is a time of transition as women begin to accept that they are pregnant, conceptualize the meaning of their pregnancy, and incorporate it into their identity to plan for the future (Rubin, 1976; Sochany, 2001). The women participating in this study experienced pregnancy loss between 5 and 14 weeks gestation. Consistent with



other qualitative studies exploring the miscarriage experience (Adolfsson, Larson, Wijma & Bertero, 2004; Frost, Bradley, Levitas, Smith & Garcia, 2007; Gerber-Epstein, Leichtentritt & Benyamini, 2009; Wall-Haas, 1985; Wojnar, 2007; Wojnar, Swanson & Adolfsson, 2011), whether the pregnancy was planned or unplanned, wanted or unwanted, 7 of the 8 participants' described their miscarrying experience as the '*loss of a life*', the death of a '*baby*', and expressed the emotional weight associated with such a loss. The one participant who did not use the word '*baby*' did state that she mourned and grieved the loss. Plans for the future with their unborn child, dreams of who their child would be, and the value placed on life were evident in all the interviews. Even the participant who had planned to have a therapeutic abortion (but ended up having a miscarriage) found the decision to terminate very difficult and still acknowledged her miscarriage as a death. Conceptualizing a pregnancy and coming to terms with how a baby will fit into their life and their future is a complex process for women and does not necessarily mean that choosing to terminate, or to keep, a pregnancy is an easy decision to make. Indeed, this conceptualization process is integral to the development of maternal identity and the development of mother-baby attachment (Goulet, Bell, St-Cyr Tribble, Paul & Lang, 1998; Rubin, 1984).

Each woman brings a different backstory to her pregnancy and subsequent loss. The women who participated in this study had diverse obstetrical histories. While some participants had experienced only one miscarriage at the time of the study, other participants had had multiple experiences. Indeed, one woman had experienced the realities of pregnancy loss initially following the neonatal death of her first child (from a congenital heart anomaly) at 25 weeks gestation and again following the miscarriage (under 20 weeks gestation) of her second pregnancy. She was no less overwhelmed with

her miscarriage. Regardless of the number of experiences of pregnancy loss, participants in this study felt unprepared and their needs unheard.

Yet, evidence shows that when health care professionals take time to explore and understand the meaning of the pregnancy for each patient and the event, within the context of the individual's life regardless of parity, their individual needs can be addressed (Corbert-Owen & Kruger, 2001; Swanson, 1999a). For example, the woman who had planned to terminate her pregnancy, but ended up having a miscarriage and seeking care in the ED, thought the staff were judgmental about her prior decision. She noted that no one took the time to ask her how she came to the decision to have a therapeutic abortion, or help her understand her fears about what was happening to her body, or why she was having a miscarriage.

The time between participants' miscarriage and the interview for this study ranged from one month to six years. In addition, regardless of the length of time that passed between the loss and the interview, it was evident that all participants considered the event to be significant in their lives and felt the need to talk about it and share. All study participants described the miscarriage as a *death* and a traumatizing event with emotional ramifications - regardless of their gestation or parity. Historically, health care professionals tended to believe that as gestational age increased so did the mother's level of attachment to her baby (Carter, Misri & Tomfohr, 2007; Cosgrove, 2004; Swanson, Connor, Jolley, Pettinato, Wang, 2007). However, evidence shows that maternal attachment is not dependent on gestational age but rather on the meaning that a woman ascribes to her pregnancy (Carter, Misri & Tomfohr,; Cosgrove; Swanson, Connor, Jolley, Pettinato, Wang). This view is still prevalent as health care practitioners often underestimate the psychological impact of miscarriage and perceive the emotional

needs/responses of women who have miscarried to be less significant than those of women who have experienced a stillbirth or neonatal loss (Dimarco, Renker, Medas, Bertosa & Goranitis, 2002; Kong, Lok, Lam, Yip & Chung, 2010).

Women in this study had a number of questions surrounding their pregnancy loss - regardless of whether they already had living children: were they responsible for the death of their baby; was something wrong with their body; would they be able to conceive again; would they be able to carry a pregnancy to term and give birth to a child who lives. A miscarriage is an existential loss, given that it isn't necessarily tangible, making it difficult to understand (van Earde, Canadian Pediatric Society & Fetus and Newborn Committee, 2001). With miscarriage also comes the physical loss of being pregnant (sensation, changes in body); the future motherhood role to that child; and the ability to successfully create life, carry life and give birth which society espouses as central to a woman's gendered identity (Adolfsson, Larsson, Wijma & Bertero, 2004; Corbet-Owen & Kruger, 2001; Frost, Bradley, Levitas, Smith & Garcia, 2007; Gerber-Epstein, Leichtentritt & Benyamini, 2009). However, the complexities of these thoughts are often minimized by health care professionals, family and friends with dismissive comments such as 'its not your fault' or 'you can always get pregnant again' (Adolfsson, Larsson, Wijma & Bertero; McCreight, 2008; Morrissey, 2007; Rowlands & Lee, 2010b). Furthermore, health care professionals often underestimate the grieving period associated with miscarriage despite the evidence that manifestations of grief can last up to a year following the event and can lead to negative psychological implications such as depression, anxiety and posttraumatic stress disorder (PTSD) (Engelhard, 2001; Engelhard, 2004; Kong, Lok, Lam, Yip & Chung, 2010; Stirtzinger, Robinson, Stewart, & Raleski, 1999). It would not be surprising if participants in this study experienced some

of these responses given that most had little or no emotional support from the health care system following their miscarriage.

Marginalization is defined by Hall (1999) as “the peripheralization of individuals and groups from the dominant, central majority” (p.89) and is seen as a sociopolitical process producing both vulnerabilities and strengths. The concept of *voice* with respect to marginalization suggests that the dominant power’s language and concepts silences the voice of those who are marginalized (Hall, Stevens & Meleis, 1994). Women who have miscarried are potentially a marginalized group who may experience vulnerabilities. If the dominant group does not acknowledge miscarriage as a death, the voice of women who miscarry is potentially silenced and their experience becomes minimized or non-existent.

### **Why Women Go to the ED**

Participants in this study made the decision to go to the ED for two reasons; they were either concerned that something was wrong with their babies or that something was wrong with their own bodies. Five of the eight participants experienced vaginal bleeding, ranging from light spotting to heavy bleeding and cramping that alerted them that something was wrong. Whether it was their first pregnancy or their first miscarriage, they went to the ED with hopes that they were not losing their baby and that their intuition was mistaken. These women suspected that something was wrong and their pregnancy was threatened but hoped that something could be done to save their baby. Consistent with the literature, women viewed the presence of bleeding and cramping as an ominous sign in early pregnancy, alerting them to the fact that something was wrong, yet they maintained hope that they were not experiencing a miscarriage (Adolfsson, Larsson, Wijma & Bertero, 2004; Bansen, 1992; Frost, Bradley, Levitas, Smith & Garcia, 2007; Limbo, Glasser & Sundaram, 2014; Wojnar, Swanson & Adolfsson, 2011). Despite its

commonality, most women knew little about miscarriage, unless they had previously experienced it themselves, and were often told that light spotting or bleeding in early pregnancy can be normal, which might have given women a false sense of hope (Frost, Bradley, Levitas, Smith & Garcia).

Three participants presented to the ED with personal health concerns apart from their pregnancy. One woman had abdominal pain that she thought was completely unrelated to her pregnancy and both she and the ED physician believed that she could have cholecystitis. The physician kindly offered to perform an ultrasound of the woman's abdomen to show her the baby for the first time. Sadly however, upon examination, a missed miscarriage was found which came as a complete shock to the woman as she did not think her abdominal pain was related to her pregnancy. Another participant with vaginal bleeding did not consider miscarriage because she thought she was too young to have a miscarriage. Again, like other participants, she did not know what was happening to her body and did not know that she was miscarrying or understand the experience. A third participant had a massive hemorrhage while miscarrying and required an ambulance to transport her to the hospital because her own life was threatened. Whether they did or did not know they were having a miscarriage, these three participants were concerned for their own physical health, which influenced their decision to seek care in the ED.

Choosing the ED as a point of entry to the health care system hinged on a variety of factors for participants. Some women in this study sought help from a health care professional, such as their family physician or a registered nurse via the telephone help line, who directed them to the ED. For other women, the ED was the only option if they wished to access health services during evenings, weekends or holidays, or if they could not get a timely appointment with their family physician. And also, some participants

who were urgently concerned for their own physical wellbeing chose to go to the ED. EDs remain a common point for accessing the health care system among women who are miscarrying as they are often referred to the department by their GPs or attend on their own accord if they cannot access other services (Adolfsson, Larsson, Wijma & Bertero, 2004; Adolfsson, Tullander-Tjornstrand & Larsson, 2011, Condous 2008; Wren & Craven, 1997).

All participants in this study attended EDs in hospitals that did not have in-house gynecological or obstetrical services. This was the only option, as the hospital for women and children does not provide services for women experiencing *early* pregnancy complications. One participant noted that she had wished she could attend the local hospital for women and children because she thought that the ED practitioners in the other hospitals lacked the specialized care she and her baby needed. Steps have been taken in countries such as the United Kingdom and Sweden to divert women who are miscarrying away from EDs in order to avoid distressing ED visits for women miscarrying and to reduce the ED workload (National Institute for Health and Clinical Excellence, 2012; Adolfsson, Tullander-Tjornstrand & Larsson, 2011). It is standard for hospitals in these countries to have dedicated early pregnancy assessment units (EPAU) or telephone screening combined with increased access to gynecological appointments (National Institute for Health and Clinical Excellence; Adolfsson, Tullander-Tjornstrand & Larsson). Although EPAUs do exist in Canada, they are not part of standardized care and they may have limited service hours requiring referrals from GPs, ED physicians or obstetricians making them not easily accessible for women experiencing miscarriage (Rhone, Hodgeson, Moshrefzadeh & Maurer, 2012; Tunde-Bypass & Cheung, 2009). In the case of this study, the EPAU was only accessible with a referral from an ED physician

or GP. Otherwise, services at the hospital for women and children were only readily accessible for pregnant women *over 20 weeks gestation* through the early labor assessment unit.

Therefore, the ED remains *the* entry point for pregnant women in Canada to access the health care system and receive care for their miscarriage. They have valid, reasons for attending the ED. While in the ED their presence, along with the loss they are experiencing, must be acknowledged in order to legitimize their loss and attend to both their physical and emotional needs.

### **Miscarriage is Not an Illness**

Participants in this study were very aware that there was a stark difference between what they were experiencing and the other patients in the ED. They expressed that losing their baby carried a different weight; it was a loss, and not an illness. Having to sit in the waiting room, either knowing that they were losing their baby or that something was wrong with their baby, left participants feeling exposed and vulnerable. They processed their emotions without privacy surrounded by other patients who were sick or injured. Being clustered with patients who were there for different reasons, while losing their baby, made the women think they did not belong either because their needs required a different type of care/service or that other patients were more in need. Either way they believed that losing their baby was not a priority for the ED staff, which they believed diminished and devalued the phenomenon that they were experiencing. This experience is well documented in the literature (Adolfsson, Larsson, Wijma & Bertero, 2004; McLean & Flynn 2012; Murphy & Merrell, 2009). The prioritization of patients and their needs is further supported by the Canadian Triage and Acuity Scale (2008) as it

ensures that the sickest patients are seen first and patients are triaged according to the severity of their presenting signs and symptoms.

Regardless of whether participants knew that little or nothing could be done to save their baby, they felt a sense of urgency. Their potential loss warranted urgent attention which was incongruent with how they were triaged and prioritized within the ED. Given that patients who are experiencing a miscarriage are usually physically stable, typically, they are not triaged as urgent unless they are hemorrhaging as a result of the miscarriage or have a life threatening ectopic pregnancy with the potential of rupturing (Promes & Nobay, 2010).

Two participants did experience hemorrhage with their miscarriages and required urgent transport to the ED via ambulance. Both of these women were seen very quickly and felt their physical needs were being met. One participant noted that while the primary focus was on saving her life, supporting her through the loss of her baby, justifiably, was a secondary need at that point. Patients in the ED are triaged according to the severity of the signs and symptoms of their illness, the patients with most urgent physical need are typically treated first and ED health care professionals are trained to respond quickly in life threatening situations (Beveridge et al., 1998; Chan, 2005). In these cases the women themselves were in fact *ill* first, their lives were threatened and the loss they were experiencing was secondary to their urgent physical needs. The literature does state that miscarriage can be a traumatic experience leading to posttraumatic stress disorder (PTSD) and that while providing urgent physical care to patients, health care professionals should integrate and acknowledge the emotional needs of patients as well (Engelhard, van den Hout, Arntz, 2001; Engelhard, van den Hout & Schouten, 2006; Swanson, 1999a; Winman & Wikblad, 2004).



Women who attend the ED to get care for their miscarriage are marginalized by the *exteriority* of their circumstances. *Exteriority* is a property of marginalization, described as the condition of being outside of the dominant system (Hall, 1999). These women are not necessarily *ill*, unlike other patients whose physical presence dominates the ED and the illness lens through which health care providers view patients in order to assess, treat and deliver care. Furthermore, given that their pregnancy of under 20 weeks cannot be saved, the voice of these women regarding the impending loss of their child is suppressed.

### **Acknowledgement**

Interestingly, in this study, unless a participant perceived her own health to be threatened, she did not necessarily view herself as a patient requiring medical treatment. Instead she viewed herself as a *pregnant* woman experiencing the death of a *baby*. Participants felt dehumanized as health care professionals in the ED performed tests and examinations on them without acknowledging that they were *pregnant* and losing their *baby*. The dominant discourse within the health care system is the biomedical model which focuses on a restorative approach that seeks to identify and treat disease entities within individuals (Cahill, 2001; Layne, 2006). The professionalization of medicine and rising value of scientific knowledge allowed room for the creation of the medical specialties of gynecology (women's reproductive systems) and obstetrics (childbirth) that medicalized healthy women and pathologized pregnancy (Cahill; Layne). Within this worldview, miscarriage loss less than 20 weeks gestation has been shaped as a clinical event requiring treatment to prevent adverse outcomes such as hemorrhage and infection and not necessarily prevent the loss of a baby (Cosgrove, 2004; Frost, Bradley, Levitas, Smith & Garcia, 2007). From a biomedical stance, since nothing can be done to prevent a

miscarriage from occurring, the role of the health care provider is to monitor symptoms and provide treatment as necessary (Promes & Nobay, 2010). This, however, does not negate the fact that while providing physical, task oriented care, the emotional needs must also be addressed (Cronqvist, Theorell, Burns & Lutzen, 2004). Four participants in this study explicitly expressed that while they were experiencing the death of a baby they felt the loss ignored by health care providers who often focused only on caring for the physical needs.

The care and health care services that women receive for their pregnancy loss less than 20 weeks is distinctly different from that provided for a pregnancy loss over 20 weeks gestation. Pregnancy loss over 20 weeks gestation, or a birth weight of greater than 500 grams, is considered a stillbirth (Statistics Canada, 2012). At this point in gestation, the baby looks like a baby and when medical personnel agree that there is a *baby*, different measures can be taken to prevent early onset of labour in an attempt to preserve the pregnancy. Further, if delivery occurs, there is potential for the baby to survive (Ray & Urquia, 2012). One participant and her husband had the experience of having to terminate their pregnancy at 25 weeks gestation due to a severe congenital heart anomaly in the baby. This participant noted the how supportive the care was that she received for the loss of her pregnancy over 20 weeks gestation at the local hospital specializing in women and newborn health. It differed greatly from the care she received for her miscarriage five months later in the adult acute care ED which had no in-house women and newborn health services. This woman and her husband were provided the opportunity to spend time with their son, name him, take pictures of him and hold him after he was delivered at 25 weeks. They were also provided bereavement support at the hospital, encouraged to seek counseling, and had the benefit of maternity leave. The participant

believed it critically important that the loss be acknowledged and adequately supported by the health care team throughout this process. She recognized the distinct difference in care and lack of supportive intervention when miscarrying in the ED. Despite the evidence that maternal-infant attachment is not dependent on gestational age but rather the meaning ascribed to the pregnancy, health professional support for a pregnancy loss *under* versus *over* 20 weeks gestation differs greatly (Carter, Misri & Tomfohr, 2007; Cosgrove, 2004; Swanson, Connor, Jolley, Pettinato, Wang, 2007). The importance of health professionals providing care for families experiencing a *stillbirth* (over 20 weeks) is well documented in the literature with an emphasis on bereavement support, assisting parents to create memories with their baby, providing the option to hold their baby, spend time with their baby and informing and counseling parents about how to navigate the loss; however those experiencing a *miscarriage* (under 20 weeks) often leave the ED feeling abandoned (Adolfsson, Larson, Wijma & Bertero, 2004; Hughes & Goodall, 2013; McCreight, 2008; McLean & Flynn, 2012; Rowlands & Lee, 2010b; Saflund, Sjogren & Wredling, 2004; Schott & Henley, 2009). That being said, one should not assume that the needs of women following a miscarriage are exactly the same as those of women experiencing a stillbirth, as women in some studies have not described their experience following miscarriage as bereavement (Murphy & Merrel, 2010; Johnson & Langford, 2010; Swanson, 1999a).

However, six of the eight participants described their miscarriage as a death, and felt that what they were experiencing was not acknowledged as such. Death in the ED is not uncommon. Often, the cultural milieu of the department requires practitioners to support families through the death of a loved one after attempting resuscitation and then to refocus their efforts in order to move on to subsequent patients requiring medical

attention (Candrian, 2013; Chan, 2004). Beyond ever present departmental demands, the challenges that practitioners face in providing good end-of-life care in the ED includes their own personal fears (Buckman, 2005; Chan). These fears include not knowing what to say, dealing with the emotions of those experiencing the loss and their own personal fears surrounding death (Buckman; Chan). However, miscarriage is a different kind of death than what is typically seen in the ED. Because what is lost does not necessarily look like a *baby*, its meaning and conceptualization may be an abstract concept to the health care professionals providing care. In contrast to a miscarriage, the death of a family member in the ED is a more tangible loss, as the physical body is present. The personal fears of health care professionals may have played a roll in the way they interacted with women experiencing miscarriage in this study. The lack of acknowledgement of the death when delivering the news of the miscarriage may have been related to the health care professional's discomfort with the situation. They may not have known what to say, or have had fears around dealing with the patients' emotions during a difficult time. Furthermore, given that miscarriages are often not a visible or tangible loss, unlike other deaths in the department, health care professionals may have struggled with the ambiguity of the loss and turned their attention to the physical tasks at hand rather than the emotional needs of their patients. Such actions may also be acts of self-preservation for professionals and as ways of coping with intense feelings that cannot be processed in the moment in order to continue working (Candrian, 2013; Chan, 2004). Avoidance by health care professionals is also common with other types of patients, such as those suffering from mental health issues, and results from personal fears and discomfort, which are perpetuated by negative attitudes (Horsfall, Cleary & Hunt, 2010; Reed & Fitzgerald, 2005).

Most women in this study reported that health care professionals (nurses, physicians and paramedics) focused on completing physical tests and procedures during their ED visit with little to no acknowledgement of their loss. Emergency nursing has been described as conveyor belt care in which nurses' focus is fixed on the medical and technical tasks devoid of emotional support (Nystrom, Nyden & Petersson, 2003; Winman & Wikblad, 2004). Participants also felt uninformed about what was happening throughout their visit: how long the wait would be, what was happening to their bodies, and what to expect. Sadly, such participant concerns were not unique to this study. Indeed, patients waiting for long periods of time in the ED is well documented in the literature along with being uninformed about what to expect throughout their visit, and wanting information about tests, procedures and their conditions (Gordon, Sheppard & Anaf, 2010; Nystrom, Nyden & Petersson). While the needs of women having miscarriages are clearly very different from other types of health care presentations in the ED, it appears that their unique circumstance is not acknowledged. Failure to acknowledge the needs of women who are miscarrying is not unique to the ED setting. Indeed, studies have found that women interacting with health care professionals during and after their miscarriage *in a variety of settings* express a strong need for their loss to be acknowledged, for emotional support and for information regarding the physical self (Adolfsson, Larson, Wijma & Bertero, 2004; Corber-Owen & Kruger, 2001; Frost, 2007; McCreight, 2008; McLean & Flynn, 2012; Rowlands & Lee, 2010b). Given that these women are at risk for adverse psychological outcomes, the interactions they have with healthcare professionals may be critical (Lok, Yip, Lee, Sahota & Chung, 2010; Marcinko, Marcinko, Dordevic, Oreskovic, 2011; Neugebauer & Ritsher, 2005; Stirtzinger et al., 1999).

When health care professionals in this study focused on tests, tasks and examinations without acknowledging the woman's loss and attending to the human aspects of care, it dismissed the loss and minimized what the participants were experiencing. Participants in this study clearly articulated that something was missing from the care they received. Failing to acknowledge and support the participants in this study through their miscarriage may have been perpetuated by the nature of the ED environment itself. The biomedical model permeates emergency care and interactions between health care providers and patients in the ED setting focus on physical assessment, diagnostic tests, labeling patients with a physical diagnosis and providing physical medical treatment in a timely fashion (Fazio, 2009). The ED environment is driven by quality indicators such as mean length of stay, median time in waiting rooms and hours per patient per visit, all of which focus on treatment and discharge in a timely fashion, requiring high levels of productivity from staff (Chan, 2004). Emphasis on efficiency and speed, combined with the technical aspects of clinical care can distance practitioners from the caring, humanistic aspects of the patient-practitioner relationship (Chan). Tension often exists (not just in the ED setting) between structural demands of health care organizations and the mandates of healthcare professions, such as nursing, that are based in *caring about* the patient while *caring for* the patient (Olsen & Bone, 1998). The mandate of the ED and its demands sent clear messages to participants experienced that their needs were not a priority. Failing to acknowledge the emotional needs while attending to the physical needs is incongruent with the philosophy of caring in which the nursing profession is rooted. Caring relationships enhance the well-being of patients through therapeutic practices that address both physical and emotional needs and

understand the personal meaning that patients ascribe to clinical situations about how they impact their lives (Swanson, 1993).

If ED practitioners struggle with providing end-of-life care for patients and families when the death is visible, when a physical body is present and tangible, how do they conceptualize the loss of a baby when we may not be able to see the baby or what we think of as a baby? The pregnancy has technically not reached fetal viability and all they may see or handle is blood, blood clots or maybe a small fetus (depending on gestational age). It is a different type of death and yet all participants referred to it as a *death*. Seven women in this study consistently referred to the loss as a 'baby' or 'child'. If women express that they are losing a *baby*, then it is a *baby*. Miscarriage, as the participants in this study described, regardless of gestational age, is the loss of a future and the loss of hopes and dreams for that child. This may not necessarily be understood by health care professionals due to their own discomfort with the situation or if they do not understand that the patient they are caring for is losing a *baby*.

Miscarriages are common in the ED, thus monitoring blood loss and managing pain may be seen as routine tasks for staff that they must complete as they provide care to a number of different patients. Although it may be routine for staff, it is a significant event for the patient. Similarly, on gynecology wards, staff are required daily to deal with fetal remains of inpatients who are miscarrying, creating a stark difference in realities between patient and provider. One stakeholder sees it as daily, routine work, the other as the loss of a child (Murphy, 2010). Health care professionals do not necessarily see or acknowledge tissue, blood clots and blood loss as life or as a human who has died. It may be a means of self-preservation; staff do not necessarily want to see it as a human, as the

remains are often disposed of by flushing them down the toilet or sending them away in a specimen container for analysis.

The participants in the study reported that the way in which health care providers in the ED delivered the news of their miscarriage affected their experience. Five of the eight women were alone when they received the news: for two of these, their partner had stepped out of the room momentarily, while the other two were not allowed to have their partners in the room with them and one woman did not bring her husband with her for her follow up ultrasound in the ED because she did not believe that she was miscarrying. A miscarriage has been reported as a shared loss between the woman and her partner (Adolfsson, Larson, Wijma & Bertero, 2004; Swanson, 1999a; Swanson, 2003; Wojnar, 2007). Offering to involve significant others when delivering bad news to a patient is seen as an important supportive measure (Buckman, 2005). By not asking the patient if she would like to have a person of support in the room as she receives the news sends a dismissive tone about the significance of the experience or loss.

There was a range of approaches used by health care providers to verbally deliver the news and support the participants. Some providers were empathetic, warm, caring and used self-disclosure to build rapport with the women as they told them they were miscarrying. Other providers failed to develop rapport with participants and delivered the news abruptly and in a cold, insensitive manner. Poor delivery of bad news by health professionals and poor relationship development with patients can have negative ramifications for patients, both in terms of satisfaction with care and psychological adjustment (Buckman, 2005; Ford, Fallowfield & Lewis, 1996; Roberts, Cox, Reintgen, Baile & Gibertini, 1994;).



Death and dying remains a challenging topic for North American society; people often do not know how to talk about it and or feel uncomfortable confronting it. In health care, great strides have been made in helping health care practitioners in building skills to be more open with patients when discussing terminal prognosis and providing end of life care (Buckman, 2005). However, the death of a child or a baby is particularly distressing and may be seen as more upsetting than the death of an adult or elderly person (McConnell, Aston, Randall & Zwaagstra, 2012). The importance of caring for and acknowledging a stillbirth has also become more recognized, yet, miscarriage remains a marginalizing experience within health care. There are many ways health care professionals in the ED, and the ED environment itself, perpetuate a lack of acknowledgement with respect to the experience of miscarriage. The marginalizing experience of *exteriority*, being outside the dominant system, may occur as women are dehumanized by the focus on physical tests and tasks without acknowledging the miscarriage (Hall, 1999). The *voice* of the dominant medical discourse used language such as *blood*, *products of conception* and *clots* to describe the baby that a woman is losing when she is miscarrying while the voices of study participants used the word *baby*. Marginalization occurs when the language used to express one's experiences differs from that of the dominant voice (Hall, 1999). Furthermore, when the dominant group avoids, ignores or fails to acknowledge the significance of the experience it marginalizes women who have experienced or are experiencing a miscarriage.

### **Going home**

Upon discharge from the ED, some women felt inadequately prepared for what would physically happen to their bodies and what miscarrying their *baby* would actually look like. Two participants were shocked to learn that what they had passed was, in fact,

an intact fetus. Others were shocked at the amount of blood loss they experienced. The physical manifestation of the participants' losses did not necessarily look like a baby and women reported that they were not adequately prepared for what happened to their bodies or what they might see as they continued to miscarry following discharge. It is recognized that it may prove to be challenging for health care providers to prepare women for what they may see, as it can range from light bleeding to blood clots to a small intact fetus. However, by not using clear, specific plain language to describe what miscarrying a baby looks like, the ambiguous nature of the loss (both physically and conceptually), combined with the use of medical terms (products of conception, tissue or clots) or insensitive lay terms can cause further distress for women and/or fail to capture the loss they are actually experiencing (Cosgrove, 2004; Frost, 2007; Murphy & Philpin, 2010). It may be challenging for both the woman experiencing the loss and the healthcare professional providing care to make sense of the loss of the baby and pregnancy while what is lost may not physically look like a baby. Thus, health care professionals may need to carefully consider the language they use when informing women about what they can expect to see as they continue to miscarry at home. One participant was angered when a nurse told her that she might pass "*stuff*". She did not understand what "*stuff*" was and she eventually passed what she described as an intact 'fetus' in her toilet; an experience for which she had not been prepared and found most disturbing. Such events are described in the literature as traumatic in nature and some women have developed posttraumatic stress disorder (PTSD), with symptom severity similar to other traumatized populations, which also increases their risk of developing depression (Engelhard, van den Hout, Arntz, 2001; Engelhard, van den Hout & Schouten, 2006; Limbo, Glasser & Sundaram, 2014).

Respectful disposition of the *baby* may also prove to be a difficult matter for health professionals to address. While in the ED, larger clots and tissue passed may be collected and sent to the laboratory for analysis, when women are discharged home they are instructed to either collect the tissue that they may pass and bring it back to the ED or to flush it down the toilet. One participant said that while she was in the ED she needed to have the opportunity to thoroughly look at what had come out of her so that she could conceptually understand what was happening to her body and what her *baby* looked like. Meanwhile, other participants found it difficult to deal with the fetus, their *baby*, they had passed. Studies recognize that a tension exists as the blood, clots and tissue are disposed in the same way in which physical waste is disposed - down the toilet. Yet, what is being disposed is a baby and not waste - a person carrying meaning and personhood (Limbo, Kobler & Levang, 2010; Murphy & Philpin, 2010).

In addition to being inadequately prepared for what they may *see* when miscarrying at home, women in this study also felt unprepared for other physical manifestations as they were discharged, such as pain, the amount of bleeding, when bleeding would start and how long it might last, and how the miscarriage may disrupt their day to day lives. Participants said they were discharged with little information. One participant was told she could have period cramps; however, what she experienced was, in fact, pain comparable to labour. Meanwhile, another participant was unprepared for vaginal bleeding that continued for over a month, reminding her daily of what she had lost with nothing to show for it. Other studies have noted that there is a lack of basic, clear medical information regarding what to expect after discharge leaving women who are miscarrying unprepared to manage their physical and emotional symptoms at home

(McLean & Flynn, 2012; Sejourne, Callahan & Chabrol, 2010; Smith, Frost, Levitas, Bradley & Garcia, 2006).

Three participants in the study were discharged from the ED and required follow up with the EPAU for consultation to further manage their miscarriage with either a D&C, misoprostol or expectant management. The participants found the period following ED discharge to EPAU follow up distressing as they wished for the experience to be over. Again, these three participants were unprepared for what could physically happen to their bodies, distressed by the possibility of passing a fetus and further distressed by knowing that they were carrying around a dead baby. Again, with respect to language, the women referred to carrying around their *dead babies*, yet used terms like *fetus* and *tissue* to describe what they passed into the toilet as they miscarried at home. The participants noted a gap in care as they waited up to a week for their follow up appointment and found the support received between discharge and follow up to be minimal at best. Similarly, other studies have reported participant uncertainty regarding the physical manifestations of the loss to be expected and management plans have been found to be distressing and anxiety-provoking for women experiencing a miscarriage (Adolfsson, Larsson, Wijma & Bertero, 2004; Adolfsson, Tullander-Tjornstrand & Larsson, 2011; Condous, 2008)

Women in this study were required to have an ultrasound while miscarrying. It is standard care for ED physicians to provide bedside transabdominal ultrasounds to women in order to rule out ectopic pregnancy and confirm the presence of an intrauterine pregnancy when miscarriage is suspected (Promes & Nobay, 2010). If the pregnancy is not visible on ultrasound at the bedside, women are scheduled to have a formal ultrasound performed by the radiology department (Promes & Nobay). Women experiencing miscarriage have reported that having ultrasound confirmation provided a level of

certainty regarding the loss that was not necessarily tangible (Limbo, Glasser & Sundaram, 2014). This has also been shown to help inform the decision-making process regarding treatment options for some women (dilatation & curettage (D&C), or expectant management, or medical management). Two of the eight participants struggled to make the decision to have a D&C; they wanted to make sure their baby was in fact dead, so that the procedure would seem less like a therapeutic abortion. One participant expressed that she wanted to be ‘put out’ so that she did not have to experience having her baby taken from her. Other studies have shown that when confirming that the pregnancy was not viable via ultrasound, women had an easier time opting for a D&C since the baby was already dead (Limbo, Glasser & Sundaram, 2014; Smith, Frost, Levitas, Bradley & Garcia, 2006). For pregnant women who previously have had miscarriages, their anxieties about miscarrying again were often relieved when the viability of the pregnancy was confirmed by ultrasound (Andersson, Nilsson, Adolfsson, 2012).

Often, when a woman comes to the ED to get care for her miscarriage, depending on the time of her visit, she may be required to return the following morning for the formal ultrasound because the radiology department is unable to accommodate her needs at that time. Women in this study found this to be a distressing aspect of the ED visit for two reasons. First, they did not want to return to the ED for a second visit and wished the ultrasound could be performed during their first visit. Secondly, as they went home the thought of the death of their child or having a dead child inside of them weighed heavily on their mind disrupting their sleep and prolonging the inevitable diagnosis. Having an ultrasound may be the standard of care and a requirement to rule out ectopic pregnancy (which can be life threatening); however, waiting until the following day to perform the test can cause further distress. Physically, the miscarriage may not have been a medical

emergency, but emotionally, for the women in this study, it was urgent. In addition to the ED, miscarriages are not classified as urgent in other health care settings, they are usually given low priority for surgical time with D&Cs. As well, they are not typically handled as urgent consults for gynecology & obstetrical services (McLean & Flynn, 2012; Murphy & Merrell, 2009; Condous, 2008). Although with the implementation of EPAUs steps have been taken to attempt to streamline care and meet both the physical and emotional needs of this population. By minimizing the number of health care visits, it is evident from this study that some EDs and their radiology departments may not view a woman having a miscarriage as a patient requiring urgent diagnostic imaging after hours, unlike other ED presentations (National Institute for Health and Clinical Excellence, 2012).

Furthermore, confirming via ultrasound that a woman is carrying a viable pregnancy carries a different emotional connotation than that triggered through ultrasound by other health matters. Patients returning the following day to rule out appendicitis or the presence of a deep vein thrombosis are likely not experiencing the same emotional turmoil as a woman experiencing pregnancy loss. Again, as the findings of this study suggest, the women viewed themselves as experiencing something very different from other patients attending the ED. They did not see themselves as ill but rather as losing a baby. Health care providers who request that women return to the ED on another day for an ultrasound and then wait for a diagnosis not only prolong the inevitable but fail to acknowledge the suffering that these women are experiencing. Women commonly experience further distress with delays in care while waiting to find out if they are miscarrying, or waiting for follow up to determine the need for medical management for their loss (Adolfsson, Tullander-Tjornstrand & Larsson, 2011).

All of the participants in this study struggled with their miscarriage and the effects of the loss following their ED visit. Emotionally, the women experienced sadness and six participants took time off work. They looked for support from friends, family and partners; sometimes receiving it and sometimes not. Upon discharge, two participants were cautioned about the emotional effects their miscarriage may have on them and the rest were not. Either way, the experience of having a miscarriage had a lasting emotional impact on all the participants. The experience was significant enough that each participant felt the need to share their story and became emotional when doing so. Again, as with this research, other studies also report that women who have experienced miscarriages are often unprepared for the grief and emotional responses they felt following their miscarriage and were left feeling unsupported by health care professionals (Adolfsson, Larsson, Wijma & Bertero, 2004; McLean & Flynn, 2012; Neugebauer, Kline, O'Connor, Shrout, Johnson, et al., 1992; Rowlands & Lee, 2010b; Sejourne, Callahan & Chabrol, 2010; Smith, Frost, Levitas, Bradley & Garcia, 2006). In addition, studies that have provided supports to reduce the risk of psychological morbidity following a miscarriage have reported a positive effects on women (Adolfsson, Bertero, Larsson, 2006; Rowlands & Lee, 2010a; Sejourne, Callahan & Chabrol, 2010a; Swanson, 1999b; Swanson, 2003).

The lack of support from both the health care system and family and friends for a woman who has miscarried as she is discharged home speaks to society's inability to acknowledge this experience, further marginalizing this type of death and rendering it invisible (Andersson, Nilsson, Adolfsson, 2012; Cosgrove, 2004; Frost, Bradley, Levitas, Smith & Garcia, 2007; Hall, 1999; McConnell, Aston, Randal & Zwaagstra, 2012).

## Summary

In summary, the overarching response to study participants when accessing the ED for care for a miscarriage was one of marginalization. For most women, their loss was either not acknowledged or dismissed as not meaningful. Such responses were conveyed both through health care professionals' actions and the ED environment itself. Furthermore, once discharged, the experience in terms of "health care" was essentially over with minimal or no follow up care offered, sending a message to women that what happened to them was insignificant. Although participants' experiences were predominantly negative, two participants reported having interactions with health care professionals that were positive. The health care professionals supported the participants using empathy and self-disclosure. Using such methods with women who are miscarrying may warrant further exploration in future studies.



## Chapter V

### CONCLUSIONS

This study focused on understanding the meaning of the experiences of women who received care for their miscarriage in the emergency department (ED). Eight women between the ages of 21 and 36 years were interviewed. While there was diversity in the sample in terms of obstetrical histories, age and the EDs that participants visited, the findings do not represent every woman who has received care for a miscarriage in an ED. The study themes represent the lived experiences of all the women who participated in this study and can provide insight about what the ED experience could potentially be like for other women who experience a miscarriage.

#### Implications for Practice

The study themes included *Pregnant/Life: Miscarriage/Death; Deciding to go to the ED: Something's wrong; Not An Illness: A different kind of trauma; Acknowledgement throughout my visit; Leaving the ED: What now?* The participants' need for acknowledgement of their pregnancy and miscarriage permeated each theme, which raises a number of potential implications for practice that are guided by Swanson's Theory of Informed Caring (1993).

Despite an impending loss of pregnancy, the women in this study were, first and foremost, pregnant with a baby. Whether the participants knew that they were miscarrying, the women wanted their pregnancy and their potential loss of their baby to be acknowledged, regardless of their obstetrical history, age or gestation. Coming to know a woman, what her pregnancy means to her and how it fits into her life could be a way for health care professionals to acknowledge the experience and to care for a patient who is miscarrying. Swanson's Theory of Informed Caring (1993), which is based on

research with women who have miscarried, describes five caring processes unique to nursing that comprise the caring relationship. It guides the suggested implications for practice that arose from this study. First, Swanson (1993) states that *maintaining belief* is the foundation for a caring nurse-patient relationship, and begins with having a fundamental belief in patients and their capacity to “make it through events and transitions and face a future with meaning” (p.354). The theory also states that caring involves *knowing*, “striving to understand events as they have meaning in the life of the other” (Swanson, p. 355). While it may be challenging to balance department demands with human caring in the ED environment, if approached with *knowing* competence, it may not take much time to get to know patients, or to understand what their pregnancy and miscarriage mean to them. Such actions not only convey a message of caring during a time of loss, but also allow the health care professional to identify the patient’s needs and to address them accordingly (Chan, 2004; Corbert-Owen & Kruger, 2001; Swanson; Winman & Wikblad, 2004). For example, the participant Isabel, who had experienced a neonatal death a few months before her miscarriage felt as though her miscarriage and her previous loss were not two separate incidents but a continuation of what she had already experienced, adding to the complexity of her miscarriage. *Knowing* is also congruent with principles of patient-centered care, and collaborative provider-patient relationships based on respecting the uniqueness of individuals in the context of their own life worlds (American Academy of Pediatrics, 2012; Epstein & Street, 2011).

*Knowing* also includes avoiding assumptions; that is, one must not assume the meaning of the pregnancy and its impending loss for each woman (Swanson, 1993). For women in this study, whether it was a fifth pregnancy or a pregnancy in which plans for termination had been made, the miscarriage was still traumatic. *Knowing* also means

avoiding assumptions with respect to what women know about miscarriage. Women may or may not know they are miscarrying and may or may not know that nothing can be done to prevent the miscarriage from occurring. Each patient can have a different level of understanding and when using a patient-centered approach, patients and practitioners can work together to identify and meet those individual needs (American Academy of Pediatrics, 2012; Epstein & Street, 2011).

*Doing for*, is another component of Swanson's theory of informed caring. It occurs when actions are performed by nurses on behalf of the patient's long-term physical and emotional well-being. For example, the participants expressed the need for privacy as they grieved the impending loss of their baby. What they were experiencing was something very different from the needs of other patients who were attending the ED. The participants in this study were very aware of that fact and felt exposed and out of place as they processed their emotions publically in the waiting room. *Doing for* women experiencing a miscarriage in the ED could potentially be offering a private space for these women as they wait, allowing them to process their emotions, and asking them what they may need. An example of a private space may be the family room, which is often used for health care professionals to deliver bad news to families or for families to wait as their loved one is being cared for. Interestingly however, women who are experiencing miscarriage, while they are sitting in the waiting room, feeling exposed and vulnerable are *not* guided there for privacy.

A simple, practical implication for practice that emerged from the findings was the need to keep patients informed about various aspects of care and ED processes throughout their visit. The participants in this study were not necessarily familiar with the process of being a patient in the ED. In addition to the distress caused by the uncertainty

surrounding their pregnancy and miscarriage, participants also did not know how long they would be expected to wait for tests, examinations and results. Even though nothing could be done to prevent a miscarriage from occurring, and the care the participants received in an ED was focused on confirming the loss and managing symptoms, the literature suggests that making frequent contact with patients, keeping them informed throughout their visit and providing reassurance and support as necessary can ease the experience of miscarriage (McLean & Flynn, 2012; Murphy & Merrell, 2009; Stead, 1996). Given the evidence that women who are miscarrying can feel abandoned by health care professionals, such actions could acknowledge what this patient population is experiencing (Adolfsson, Larsson, Wijma & Bertero, 2004; Rowlands & Lee, 2009b). In essence these actions would reflect *doing for* in Swanson's (1999) Theory of Caring, where health care providers would comfort patients while anticipating needs and providing skillful and competent care. They also allow for opportunity to invite patients to participate in their care by asking them what they may need.

The actions of performing tests and examinations required to confirm a miscarriage provide opportunity for patient-provider interaction during which the health care professionals can acknowledge and support the patient. Integrating a caring humanistic approach that acknowledges the loss as the needed tests are being completed could both validate and ease the experience, rather than leave the patient feeling dehumanized, as some participants felt in this study. *Being with*, in Swanson's Caring Theory (1993), means being emotionally present and conveys a message that the health care professional values the patient's experiences. Murphy & Merrell (2009) recommend that health care professionals use a respectful, sensitive approach when engaging with

women who are miscarrying. Whether the woman is physically stable, or hemorrhaging, health care professionals can *care about* the patient while *caring for* the patient.

Participants in this study had both positive and negative interactions with health care professionals when receiving the news that they were having a miscarriage. This is not to say that health care professionals were intentionally being *uncaring*. When dealing with death and other uncomfortable situations, personal fears and discomforts can lead to behaviors of avoidance on the part of health care professionals (Chan 2004; Buckman, 2005; Horsfall, Cleary & Hunt, 2010; Reed & Fitzgerald, 2005). Delivering the news to a woman that she is miscarrying can be done in a sensitive manner that acknowledges and validates what she is experiencing. The S-P-I-K-E-S strategy (Buckman, 2005), originally developed for breaking bad news to oncology patients, is a protocol that might be used to guide such a conversation. The protocol can be used as a tool for communicating with patients and allows the health care professional to continually assess the situation as it evolves and respond with empathy and support (Buckman).

The S-P-I-K-E-S strategy begins with *Setting* (S). This speaks to ensuring a private setting, offering to involve significant others and delivering the news in a calm attentive manner, at eye level. Having these conversations in inappropriate settings, such as on a stretcher with the curtain open as one participant in this study experienced, can affect the way in which this difficult news is received and, in turn, the overall experience (Buckman, 2005). Furthermore, offering to involve a loved one, particularly if it is the woman's partner, may be important for support and also because they too may potentially be experiencing the loss. Assessing the patient's *perception* (P) is also important to gain insight into the patient's understanding of what is happening to them (Buckman). It assists in identifying gaps between patient expectations and the actual situation. In the

case of the ED setting, if the health care professional has taken the time to understand the patient's perception of what is happening to her body and her baby throughout the visit, then this is a step that can begin early in the visit. *Invitation (I)* suggests obtaining permission from patients regarding the level of medical information they would like disclosed to them (Buckman). Patients in this study often felt that they did not receive enough information regarding their miscarriage, and/or did not necessarily understand the information they received. Health care professionals can obtain permission from patients regarding appropriate timing in which to discuss details of what to expect physically, and emotionally, and treatment options, throughout the rest of the ED visit and following discharge, as they may require time to absorb the news of their loss.

*Knowledge (K)* speaks to the way in which the news is delivered, beginning with warning patients that they are about to receive bad news, as this provides them with a moment to prepare themselves (Buckman, 2005). It is suggested to use language that the patients use when talking to the patient. For example, some participants referred to their loss as a baby, therefore health care professionals should have used the word *baby* when referring to their loss (Buckman). The protocol also suggests avoiding technical and scientific language as it can misconstrue the interpretation of the message being delivered. It is therefore key to be upfront about what is actually occurring. Terminology with respect to early pregnancy loss has shifted from the use of *spontaneous abortion* to *miscarriage* (Hutchon, 1998). It is suggested that using words such as *incompetent cervix* and pregnancy *failure* are to be avoided as they have negative connotations and can contribute to negative self-perceptions and worsen any sense of failure, shame, guilt and insecurity that women may experience following a miscarriage (Bacidore, Warren, Chaput & Keough, 2009; Hutchon; Royal College of Obstetricians and Gynecologists,

2006). One participant in this study was disturbed when a health care professional referred to what she may see as she miscarried as *stuff*. She did not understand what *stuff* meant or what she should expect. Furthermore evidence shows that when delivering news, it is best to do so in small chunks and to tailor the rate at which it is given and to gauge how the patient is doing and allow them to absorb the information (Buckman).

*Empathy* (E) is a key step in the protocol used to acknowledge the patient's emotional response to the news and validate her feelings. Many participants felt that their loss was not acknowledged, and those who did have positive experiences stated that the health care professionals conveyed empathy. In one case, a physician used self-disclosure when he told a participant that his wife had had a miscarriage. When used appropriately - to provide, *not seek*, support - self-disclosure can be seen as an empathetic gesture. With the focus on patient, *not professional*, need, it can strengthen a patient-practitioner partnership and reduce feelings of alienation (Baldor, 2011). In this way, self-disclosure helps to inform the patient and normalize the experience while being careful to return the focus to the patient (Baldor). Lastly *strategy and summary* (S) is used to summarize the information given to the patient to ensure that it is understood and how the next steps will unfold in the care process (Buckman). Again, this invites opportunity for health care professionals to ask patients what they may need.

It needs to be acknowledged that telling someone that they are having a miscarriage is indeed *bad news* and it requires sensitive communication skills. Participants in this study were not being told they had cancer, nor were they being told *they* were dying but, instead, were experiencing the death of their baby. Therefore, using an approach such as the S-P-I-K-E-S strategy might be one way to assist health care

professionals in alleviating their own fears or discomforts when communicating with patients about miscarriages and loss of a baby (Buckman, 2005).

In addition, there are guidelines and protocols regarding how to care for families experiencing stillbirth (loss greater than 20 weeks gestation or birth weight greater than 500 grams) (Hughes & Goodall, 2013; Saflund, Sjogren & Wredling, 2004; Schott & Henley, 2009). These involve providing bereavement support to parents, encouraging and assisting parents to create memories with their baby, providing the option to hold or view their baby, and further counseling with respect to navigating the loss going forward (Hughes & Goodall; Saflund, Sjogren & Wredling; Schott & Henley). Two protocols exist in the literature for health care professionals who are caring for women miscarrying in the ED. These are similar to bereavement protocols for families experiencing perinatal loss in general, as well as stillbirth (Adolfsson, Larson, Wijma & Bertero, 2004; McLean & Flynn, 2012; Rowlands & Lee, 2010b). However, there is no indication that the protocols are readily used in EDs or used in the EDs that study participants attended. For parents experiencing stillbirth, creating a supportive environment and providing options for making an informed choice with respect to how they would like to grieve their loss have been found to provide an opportunity for autonomy and control during a life altering experience, reflective of patient-centered care (Epstein & Street, 2011; Hughes & Goodall). While principles of bereavement care for stillbirth can be applied to a miscarriage, assessment of individual needs is still required as evidence shows that while women experience grief following a miscarriage, not all women consider what they are experiencing to be bereavement requiring ritualistic acts of mourning (Murphy & Merrel, 2010; Reagan, 2003; Swanson, 1999a). One participant in this study said that she would have liked someone to tell her that she would grieve the loss of her baby and that she may



require psychological support but she explicitly stated that she did not think her loss fit with typical perinatal bereavement support available in the community. Only one participant specifically identified feeling as though her psychological support needs would be different than those women with losses greater than 20 weeks. Future research may be warranted to determine *whether* and *how* women differentiate their loss less than 20 weeks from those women with losses over 20 weeks and how to meet their needs.

When providing bereavement care to a woman who is miscarrying, health care professionals could work with the patient to address their individual needs and potentially offer women to see what their baby may look like (if there is something to see), discuss ways to create memories, offer spiritual care or social worker services, and prepare women for ongoing psychosocial needs following discharge (Bacidore, Warren, Chaput & Keough, 2009; Johnson & Langford 2010). These are all steps that an ED health care professional can take in collaboration with the patient, to facilitate her transition through this difficult experience while acknowledging and validating what is happening. One challenge that sets a stillbirth apart from a miscarriage, which is not reflected in any protocols, is that women whose pregnancy is under 20 weeks may be discharged from the ED to continue their miscarriage at home with no readily available support. Participants in this study felt unprepared for the physical and emotional manifestations of their miscarriage following discharge. When women are discharged home following a miscarriage in the ED, or if they are discharged home and the miscarriage is not yet complete, it is important to explain to them that it is not necessarily finished at this point. In keeping with the S-P-I-K-E-S approach, it is important to ask permission first, then share with patients, honest, complete information that covers a range of potential physical symptoms and emotional reactions. These are actions of *enabling* from Swanson's (1991)

Theory of Caring that assist in providing patients with the tools necessary to take action, build understanding and make informed choices about their health as women transition through unfamiliar events and strive towards long-term wellbeing. Women may experience vaginal bleeding, ranging from light spotting to heavy bleeding with large clots, or potentially a hemorrhage, along with abdominal pain ranging from mild cramping to intense labour pains. (Promes & Nobay, 2010). Also, depending on the time of the pregnancy at miscarriage, a woman may pass an intact fetus, which some participants in this study were unprepared for and found disturbing. Thus communicating what they may see using sensitive, but clear language can prepare women and potentially alleviate some distress associated with the experience. In addition, taking a patient-centered approach when preparing a woman who is miscarrying for discharge also means working with the woman to understand her individual needs in order to alleviate fears and show respect for her unique life world, this means empowering patients to make informed decisions about their own health (Epstein & Street, 2011).

Similarly, preparing women for the emotional responses that may ensue following their miscarriage can normalize their feelings. For example, women may experience intense grief following a miscarriage, similar to that of losing a child or a close family member, and some women may need to take sick leave or another form of leave from work. Also, women commonly have feelings of guilt that they did something to cause the miscarriage (Adolfsson, Larsson, Wijma & Bertero, 2004; Gerber-Epstein, Leichtentritt & Benyamini, 2009). Again, knowing the patient, engaging in a respectful, sensitive manner reflective of patient-centered care, can alleviate the distress associated with the uncertainty of the experience (Epstein & Street, 2011). That being said, a patient's ability to retain such information following a long, potentially traumatic visit to the ED may

prove to be challenging and verbal instructions may need to be supplemented with a plain language, written handout. Furthermore, realistically, delivering discharge instructions in the ED is challenging and time allotted to this task is often compressed due to competing demands within the department and other patients (Jeanmonod, Boyd, Loewenthal & Triner, 2010; Vashi & Rhodes, 2011). Therefore, it may be essential for practitioners to find another way to convey key messages in a sensitive patient-centered manner to this marginalized patient population.

### **Implications for Services**

Potential implications for services emerged from the participants' accounts. Several participants discussed the lack of continuity in care when returning to the ED for ultrasound, and it was also noted that following discharge from the ED there were little, to no supportive services available for women.

Participants in the study who were discharged from the ED and required to return the following day for ultrasound found the multiple visits to the department, combined with long wait times that prolonged the inevitable diagnosis, to be an added stressor during an already distressing experience. In keeping with the philosophy of patient-centered care, if radiological services are offered on site, it may be prudent when an ultrasound examination is indicated, for it to be performed the same day to reduce the number of ED visits for the patient who is miscarrying. Typically, miscarriages are not viewed as an emergency requiring urgent radiologic services; however health care professionals may be unaware of the distress caused by delaying diagnostic imaging and multiple ED visits. Working with the women to understand their needs has been found to help acknowledge and respect their experience (Epstein & Street, 2011). Similarly, McLean and Merrell (2013) found that timely diagnostic tests reflect compassionate care

for women who are miscarrying. Performing all of the necessary diagnostic tests in one ED visit, rather than multiple visits, may also reduce the burden on the ED.

Some participants received referrals to the early pregnancy assessment unit (EPAU) for further management of their miscarriage. These units have been shown to reduce ED visits and increase patient satisfaction, improve the overall experience for women who are miscarrying by providing a 'one stop shop' (Rhone, Hodgeson, Moshrefzadeh & Maurer, 2012; Royal College of Obstetricians and Gynecology, 2006; Tunde-Byass & Cheung, 2009). However, similar to interactions with ED staff, participants found support and acknowledgement from the EPAU staff to vary. Participants also found the time between their ED visit, their first contact with the clinic, and their scheduled D&C to be long and distressing. This was particularly tough given that participants were not informed about what might happen to their bodies while they waited for an appointment or what to expect from the clinic visit. They also did not feel comfortable carrying around a dead baby in their bodies for days. The EPAU clinic to which the women were referred in this study was closed during weekends, only open during mornings and only offered D&Cs on Friday. The National Institute for Health Care Excellence in the United Kingdom, recommends that ideally, services be offered 7 days a week and within 24 hours of referral (2012). This may not be feasible, or realistic, for all settings; however, preparing women for what may happen during the time between their ED visit and their first follow up appointment, as well as having supportive resources available in the interim if women have questions or concerns, may help mitigate feelings of abandonment that some participants had expressed following ED discharge.

Not every woman in the study required a follow up appointment with the EPAU; some were merely discharged home and left to deal with their miscarriage on their own.

For participants in this study, there was no formalized support available after they were discharged from the ED following a miscarriage. This is true of many health centers as studies show that women feel abandoned by health care professionals following their miscarriage and the level of social support from friends and family can vary (Adolfsson, Larsson, Wijma & Bertero, 2004; Rowlands & Lee, 2009b). A formalized follow up appointment may prove to be beneficial in alleviating any potential psychological implications following a miscarriage. As well, it may provide an avenue for acknowledging that what happened to the woman was indeed a significant event worthy of further care. The EPAU was the only formalized follow up available for participants in this study and they were only eligible for the service based on specific criteria as the clinic's purpose is only to assist women in medically (physically) managing their miscarriage. Thus the primary purpose of EPAU centers on addressing the physical needs. The perinatal loss support group in the community where the participants lived was located in the hospital specializing in maternal-child health and not in the acute care EDs that the participants in this study visited. Therefore, health care providers in the ED may have been unaware of the group's existence. Women may or may not wish to have follow up care or attend support groups, but knowing what is available in the community and asking the women what may assist to alleviate feelings of professional abandonment after discharge in providing ongoing support. Previous research findings have indicated that supportive interventions following miscarriages have had positive effects on the mental health and well being of women who have experienced miscarriages (Adolfsson, Bertero, Larsson, 2006; Rowlands & Lee, 2010a; Sejourne, Callahan & Chabrol, 2010a; Swanson, 1999b; Swanson, 2003). Unfortunately, such services are not readily available.

### **Implications for Education**

The results of this study have implications for educating health care professionals, not only those practicing in EDs, but also those in primary care and those practicing in obstetrics and gynecology. This study provides insight into the lived experiences of women who have received care for their miscarriages in the ED. Having an understanding of what the experience might involve can influence the way in which health care practitioners interact with, and care for/about, women who are miscarrying in the ED. Primary care professionals can also use the results to prepare women for their ED experience when they are referred for further assessment.

For those practicing in the ED, it is important to ensure that their education includes a component regarding miscarriage, including the physical and emotional components, how to confirm a miscarriage, and how to treat and manage symptoms. Equally important is the need for how to acknowledge and how to adequately support the unique needs of this patient population within the chaos of the ED setting. Such support includes, applying principles of Swanson's Theory of Informed Caring (1993), taking a patient centered approach to care and using strategies such as the S-P-I-K-E-S protocol for breaking bad news, interacting with women throughout their visit, and adequately preparing them to be discharged home (Buckman, 2005).

### **Implications for Research**

Upon discharge, women who had experienced miscarriages felt very much alone and had difficulty sharing their experiences with others, further marginalizing the experience. Even those participants referred to the EPAU still felt very much alone and abandoned by health care professionals. Further research could include exploration of the benefits of an intervention such as a supportive telephone follow up call following ED

discharge. Telephone follow up calls have been shown to be a low-cost, effective alternative means of providing follow up care (Hannan, 2013).

Further research relating to miscarriages and emergency care could focus on health care professionals in terms of their knowledge and attitudes relating to miscarriages and the barriers and facilitators they face when providing care to women who are miscarrying. Having an understanding of the challenges associated with providing care to this patient population from the health care providers' perspectives may provide valuable information when considering ways to improve ED care.

Protocols regarding caring for patients who experienced miscarriage have been described in the literature. Considerations for future research may also include testing such protocols and their effects on the overall well being of women following their loss to determine if they do indeed meet the unique needs of this population (Bacidore, Warren, Chaput & Keough, 2009; Johnson & Langford 2010). However, because these protocols are adapted from the stillbirth bereavement literature, they do not contain steps for those women who do not complete their miscarriage in the ED and continue to miscarry at home following discharge. Given, that marginalized groups are not always consulted directly for their opinions with respect to research, these protocols may have been developed without considering the voices of women they intend to serve (Hall, 1994). Future research may need to focus on developing protocols for care that reflect the experiences of women who miscarried in EDs and their unique needs.

It must be noted that much of the literature and research focusing on miscarriage is dated, which may reflect the silence that persists with respect to the topic. Even studies, examining the effectiveness and safety of different treatment options are minimal, dated and of poor quality (Hemminki, 1998; Nanda, Pelligia, Grimes, Lopez & Nanda, 2007).

The lack of acknowledgement from the health care system, and moreover society, regarding miscarriage persists. Therefore, continuing to study the topic can help give a critical voice to this marginalized experience.

### **Study Limitations**

Limitations of the study include the challenges associated with recruitment. Initially the intent had been to recruit participants with recent miscarriage experiences (within 1 month of the ED visit) so that participants' recall of the experience would be fresh. However, the majority of study respondents had at minimum of 1-2 years between their ED visit and the study. One study has found that if a crisis period following a miscarriage occurs, it may last up to 6 weeks, leaving women feeling overwhelmed and actively grieving (Swanson, Connor, Jolley, Pettinato & Wang, 2007). Women who received letters of invitation for the study while in the ED for their miscarriage may have been too overwhelmed emotionally with their grief to participate in the study. Regardless of the amount of time that passed between their miscarriage and they study interview, those who did participate were able to recount their stories in great detail.

Another limitation includes the homogeneity in some aspects of the participants' demographics. All participants, with the exception of one, had at minimum of post-secondary education. As well, they were all Caucasian and in partnered relationships. Thus, there was minimal variation with respect to cultural diversity and socioeconomic status. However, it is arguable that through sharing their experiences, the participants were able to give voice to some women who were unable to share their stories.

Participants may also have been motivated to participate in this study because they had negative experiences and used the study as a forum to voice their complaints. Some participants did have a combination of both positive and negative experiences and, given



the sample size, the experiences of the participants in this study are not representative of every woman who has attended an ED to get care for a miscarriage. However, even if the study is not representative of the entire population of women who have miscarried in an ED, it gives health care professionals insight into what the experience can be like for some women, thus influencing the way they interact with this patient population.

Lastly, my experience as a registered nurse in the ED can be both a limitation and a strength with respect to how I interpreted the data. First, based on my own experiences of caring for women who have experienced miscarriages in the ED, I assumed that participants would have had negative experiences. As the findings suggest, this was not always the case, and I had to ensure that the range of voices of participants were accurately represented. This was verified by my thesis supervisor, as she independently coded each transcript and participated in thematic analysis. My personal experience was also a strength in this study as my interactions with women who came to the ED to get care for their miscarriage influenced me to ask this research question. My personal experience also helped me understand the nuances and subtleties of participant responses relating to the ED environment.

### **Conclusion**

Using interpretive phenomenology, this study explored the meaning of the experiences of eight women who sought care for their miscarriage in the ED. Five themes emerged from the data: *Pregnant/Life: Miscarriage/Death; Deciding to go to the ED: Something's wrong; Not An Illness: A different kind of trauma; Acknowledgement throughout my visit; Leaving the ED: What now?* All themes reflect the participants' need for their experience to be acknowledged by health care professionals. While this study gives us insight into the experience of miscarriage in the ED in which lessons can be

learned, it is only the beginning step to understanding and improving care for women with this marginalizing experience.

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## APPENDIX A

### Letter of Invitation

You have been given this letter by your treating doctor or nurse because you came to the emergency department today to get care for your miscarriage. I know and respect that this may be a difficult experience for you.

I am a Masters of Nursing student at Dalhousie University. I am interested in speaking to women who would like to share their story about getting care in the emergency department for a miscarriage. I am looking to understand what the experience was like for you. What went well, what didn't go so well and what could be done differently.

The chief of the Charles V. Keating Emergency and Trauma Center, Dr. Samuel Campbell, has approved this study. Your treating physician or nurse will not be informed of your participation and it will not affect any care you seek at this emergency department in the future.

If you wish to participate you will be asked to commit to 1 interview lasting 60-90 minutes and 1 follow-up telephone call lasting up to 30 minutes.

If you wish to receive more information about participating in the study please contact the principal investigator Kate MacWilliams by phone at 902-402-1424 or by email at [miscarriageed@gmail.com](mailto:miscarriageed@gmail.com).

It is important to note that I am a registered nurse employed at Capital Health. But I will not have provided care to you when you came to the emergency department for your miscarriage.

Thank you for your time and I appreciate your consideration,

Kate MacWilliams RN

## APPENDIX B

### Study Advertisement



Capital Health

### **Are you here today to get care for a miscarriage?**

### **If you received treatment today for your miscarriage in the emergency department then we would like to speak to you**

I want to talk to women over the age of 18 who have come to the emergency department to get care for their miscarriage. I would like to know what the experience was like for you. I would like to hear your story.

### **Contact Information**

If you would like more information please contact Kate via [miscarriageed@gmail.com](mailto:miscarriageed@gmail.com) or by calling 902-402-1424



## APPENDIX C

### Thank You Letter



Capital Health

Dear [Participants name],

Thank you for participating in my research study. I value the time you have taken to share your experiences with me. I hope that the results can be used to better understand the care experience of women having miscarriages in the emergency department and what women want.

For some women, sharing their experience can be an emotional process. If you think that sharing your experiences with me has left you wanting to talk more or has left you feeling sad, anxious or depressed I have provided some contact information of community supports that you may find helpful.

- The Nova Scotia Helpline 902-421-1188
- IWK Bereaved Parents Support Group 902-470-8149
- Mental Health Crisis Line 902-429-8167
- Nova Scotia 211

Thank you for your time,

Kate MacWilliams RN  
Dalhousie University  
School of Nursing

[miscarriageed@gmail.com](mailto:miscarriageed@gmail.com)