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ENGAGING VULNERABLE WOMEN WHO USE ILLICIT DRUGS: EXPERIENCES OF DRUG-USING WOMEN AND FAMILY PHYSICIANS

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ENGAGING VULNERABLE WOMEN WHO USE ILLICIT DRUGS: EXPERIENCES OF DRUG-USING WOMEN AND FAMILY PHYSICIANS

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ABSTRACT

Aims: This thesis explored the experiences of vulnerable women using illicit drugs and inner-city family physicians in order to better understand the process of engagement.

Methods: This qualitative, phenomenological study used in-depth interviews with vulnerable, drug-using women and inner-city family physicians. An iterative and interpretive analysis was conducted.

Findings: All participants identified proximal and distal contexts that were barriers to engagement. Women and family physician participants took actions that served to both facilitate and hinder access to primary health care. Lastly, participants identified the central role of the patient-physician relationship in the process of engagement and maintenance.

Conclusions: Engagement is a two-step process characterized by engagement and maintenance phases. Strategies which enhance engagement include: 1) housing, 2) harm reduction programs 3) investing in peer programs, 4) concurrent social and medical services; and 5) patient-centered care.

Key Words: engagement, patient-physician relationship, substance abuse, primary health care, marginalized populations

CO-AUTHORSHIP

The research for this thesis was conceived, planned and conducted by the author.

The following contributions were made:

Dr. Judith Belle Brown provided input and advice regarding the research protocol and ethics submission.

Dr.'s Amardeep Thind and Judith Belle Brown contributed to the thematic analysis of the qualitative studies from both sets of in-depth interviews.

DEDICATIONS

This thesis is dedicated to the courageous and inspiring women for whom I have the privilege of being their family physician. In particular, this thesis is dedicated to Carolyn Connolly, who was murdered August 2, 2008 and RK who is currently missing.

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CHAPTER 1: INTRODUCTION

1.0 THESIS OVERVIEW

This study explores the experiences of vulnerable women using illicit drugs and family physicians providing care to this population in order to better understand the process of engaging such women in the patient-physician relationship and the primary health care system. Engagement refers to the initial contact of the patient with a health care professional and the health care system. This thesis will be presented in four chapters. Chapter 1, the Introduction, will provide an overview of the pertinent literature and discuss the relevance of the study topic. Chapter 2 is a qualitative study exploring the experiences of vulnerable women who use illicit drugs and the process of engagement. Chapter 3 is also a qualitative study. It explores the experiences of a group of inner city family physicians who care for this population and their experiences with the engagement process. Lastly, Chapter 4 integrates the findings presented in Chapters 2 and 3 and puts forward pertinent policy suggestions, including those relevant to medical education and continuing medical education.

1.1 GENERAL INTRODUCTION

While anecdotal evidence suggests that vulnerable, drug-using women are harder to engage in the patient-physician relationship than men in similar circumstances, there is no evidence to confirm this. If true, the trend is puzzling because of the significant difference from the health-seeking behaviours of women in the general population who access medical care more than men[1-3]. This population of women is in significant need of medical care, making low rates of engagement in patient-physician relationships even more puzzling. In fact, a study by Cheung and Hwang revealed that compared to women in the population as a whole, homeless women not only lose their survival advantage over men, but are ten times more likely to die than women in the general population[4]. The main causes of death for this group of women were HIV/AIDS and drug overdoses - making an exploration of sex work, risk behaviours and homelessness pertinent to the current study[4]. The findings by Cheung and Hwang justify the urgent need for this study and resulting policy development aimed at decreasing the morbidity and mortality faced by these women.

Just when drug-using, vulnerable women are at the highest risk of health problems, they are the least likely to seek medical care. This confirms Hart's "inverse care law" which states that: "*The availability of good medical care tends to vary inversely with the need for it in the population served*"[5] (p405). It is important therefore to explore the reasons behind this trend and propose solutions.

In order to fully explore the process of engaging vulnerable women who use illicit drugs, this study sought to explore the experiences of such women and family physicians known to provide care to this population. A review of the literature was conducted in order to provide context to the topic under study. In particular, the following general areas were reviewed and will be explored in further detail below: 1) context of women's lives; 2) context of physicians' lives; and 3) the patient-physician relationship.

1.2 CONTEXT OF WOMEN'S LIVES

In order to explore the experiences of women using illicit drugs with respect to accessing medical care and engaging in the patient-physician relationship, it is important to have an understanding of the day-to-day realities faced by this population. The following contextual factors were reviewed: 1) drug use; 2) homelessness; 3) sex work; 4) stigma and 5) access.

1.2.1 ILLICIT DRUG USE IN WOMEN

Crack cocaine use in North America, including Toronto, is far more prevalent than opiate use. Its use in North America has been described as the "neglected epidemic" and crack users are often described as the "marginalized of the marginalized"[6-8]. Crack is the drug of choice for marginalized populations in the city of Toronto, where this study was conducted[6,9,10]. In Toronto, a recent survey of injection drug users indicated that almost 80 percent had smoked crack in the last six months[11]. Crack use also tends to be long-term and persistent in those who are addicted[12]. Crack users tend to be disproportionately poor and lacking basic subsistence needs[6,8].

The high prevalence of crack use is concerning because it is associated with severe poverty, a lack of the social determinants of health, high risk behaviours such as sex work and a multitude of physical and mental health problems[6-8,13-21]. Specifically, crack use is associated with high rates of respiratory and cardiac diseases, HIV/AIDS, Hepatitis C, sexually transmitted infections, pregnancy terminations and mental illness[6,13,22-27]. It has also been postulated that many crack users have premorbid mental illness for which crack is used to self-medicate[28]. In a study by Booth and colleagues, individuals who smoked or injected crack only were more likely than injection drug users who did not use crack to report multiple sex partners and to exchange sex for drugs and/or money[29]. In addition, 80 percent of the almost 28,000 drug users studied reported having not used a condom[29]. Crack users also experience high levels of homelessness[6,17,30].

Drug use is gendered. Specifically, the introduction of crack into a community has a disproportionate effect on women[20,25]. Women who use crack are further marginalized because of the sex work and homelessness that often accompanies crack addiction[6,18-21,31]. When crack is introduced into a community, there is a concomitant increase in novice sex trade workers, a decrease in the value of sexual transactions and an increase in higher risk sexual acts[20]. There is also an increase in rates of physical and sexual violence and victimization[20]. Crack also increases the risk of sex-related violence through its differing effects on libido in men and women. Crack has been reported to disinhibit male sexual behaviour while having the opposite effect in women[18,32]. This puts women at particular risk of sex-related violence – both because of the power difference between the sexes and the psychotropic effects of the drug. As such, the vulnerability of women has increased substantially with the crack epidemic.

Because crack addiction is particularly difficult to treat as compared to opiate addiction, strategies to decrease its impact are challenging[8]. The lack of a pharmacological equivalent to opiate replacement therapy (e.g. Methadone maintenance) for crack cocaine makes treatment options limited [33,34].

In summary, despite the abundance of literature outlining the health impacts of illicit drug use, there have been few studies exploring the management of crack addiction in primary health care. In addition, there are no studies exploring strategies drug-using women use to access health care and advocate for themselves in the patient-physician relationship. Much of the literature on crack cocaine takes a public health perspective and focuses on high risk behaviours and strategies to decrease rates of HIV/AIDS and Hepatitis C[15,16,26,27,30,35,36]. There have been two important sociological qualitative studies interviewing women crack users in downtown Toronto[18,20]; however, these studies fail to offer solutions. Thus, despite the current research into the health of crack users, a Canadian study using a family medicine framework with a focus on solutions is warranted.

A discussion of the effects of drug use and its management in primary health care cannot occur without an understanding of harm reduction. This is particularly true considering the limited treatment options for stimulant drugs such as crack. As such, a summary of harm reduction principles and its benefits will be examined. Harm reduction has been defined by the International Harm Reduction Association as:

> *...policies, programmes and projects which aim to reduce the health, social and economic harms associated with the use of psychoactive substances. It is an evidence-based and cost-effective approach – bringing benefits to the individual, community and society (website).*[37]

Harm reduction provides health care providers with a pragmatic framework from which to approach addictions in patients unable to abstain. There is an abundance of literature indicating its effectiveness in reducing the general morbidity and mortality of active drug users[4,38-50]; however, there is less literature about the applications of harm reduction in primary health care. As such, the current study will explore its applications in primary health care from the perspective of both family physicians and women drug-users.

1.2.2 HOMELESSNESS

Given the high rates of homelessness among drug users, a discussion about homelessness is relevant to any study about illicit drug use[9,17,30]. Approximately 250,000 people experience homelessness each year in Canada[51]. Canada is one of the only industrialized countries in the world not to have a federal housing policy. When the Canadian government removed itself from the housing sector in the 1990s, it was assumed that the private sector would step in and build affordable housing[51]. This has not happened. Instead, housing responsibilities have been downloaded to the provinces, many of whom have, in turn, downloaded social assistance and housing responsibilities to local municipalities[51].

During times of unprecedented surpluses in Ontario in the 1990s, significant cuts were made to social housing and regulations which protected tenants[51]. Currently, vacancy rates for affordable rental units in Canada are very low and of the rental housing that is available it is often of very poor quality[51]. As such, people often have to rely upon unregulated and substandard housing such as basement apartments and rooming houses that do not meet standard building codes[51]. Of note, there is a strong correlation between neighborhoods with poor housing quality and poor health outcomes[51].

Toronto has the largest population of homeless people in Canada with the need continuing to grow[51,52]. The average occupancy of Toronto's homeless shelters has been over 90 percent for many years[51]. In a report by the Toronto Disaster Relief Committee, it was concluded that Toronto shelters did not meet the emergency shelter standards set by the United Nations High Commissioner for Refugees[53]. In Toronto, there is also a growing gap between the rich and the poor[54]. Income inequality has been associated with poor health outcomes[55-57]. Lack of secure housing affects other social determinants of health because fewer resources are available for things such as food, transportation and education[58]. This can lead to social exclusion[58].

The consequences of homelessness affect women disproportionately[9,59]. This can be partially explained by the link between homelessness and violence against women. Violence often places women's housing at risk and being homeless is associated with high rates of victimization[9,59,61-63,65].

Being homeless also has devastating effects on health. Homeless women have high rates of mental illness, infectious and respiratory diseases, skin problems, gynecological symptoms and traumatic injuries[4,9,17,52,59,60,61,65]. Homeless women also die at higher rates than their housed counterparts and have similar mortality rates to homeless men[4,58]. Because of their sexual and reproductive health needs, homeless women face additional health burdens[59,60,65].

There are also high rates of past and current victimization among homeless women. In a survey of homeless individuals in Toronto, 20 percent of women reported having been raped or sexually assaulted in the last year[17]. In a study by Wenzel and colleagues, 23 percent of women surveyed reported being physically or sexually victimized in the 30 days before their interview[60]. Although reported rates of physical victimization were similar between men and women, women reported experiencing higher levels of sexual victimization than men[60]. They also found that substance use substantially increased risk of victimization[60]. Although the above cited studies describe the high prevalence of violence experienced by homeless women and the role drug use plays in increasing this risk, they do not elucidate upon the relationship of violence to sex work and the way in which drug use increases risk. This current study explores the complex relationships among drug use, homelessness, sex work and violence.

In summary, these findings suggest an urgent need to find effective ways to assist homeless women to access primary health care. An exploration of ways to engage drug-using women, many of whom are homeless, is thus justified.

1.2.3 SEX WORK

Women who sell sex for drugs, often termed survival sex, operate at the bottom of the “street hierarchy”, placing them at exceedingly high risk for violence, sexual exploitation and health problems[18-21,31]. In a survey of sex workers in East Toronto, rates of recent sexual and physical victimization among sex workers were reported to be as high as 65 percent[31]. Women may participate in sex work for a variety of reasons. Sex work is often a means to secure drugs, safe housing and food[18,31]. Thus, sex work provides an economic means of survival allowing low-income women with little education and chaotic drug use to meet their basic needs[21].

Much research has explored the needs and health problems of women who sell sex for drugs[16,18,19,21,25,29]. In a study of approximately 4,600 female crack users, differences between women who exchanged sex for drugs and/or money were reported[16]. Women who exchanged sex for crack or money were more likely to have more sexual partners, had sex more often, used drugs before and during sex more often and had higher rates of self-reported sexually transmitted infections[16]. Homelessness was an independent risk factor for exchanging sex for drugs and/or money[16]. Crack use is also intimately associated with sex work[18,20,31]. Most studies about sex work take a public health approach exploring risks for HIV/AIDS and sexually transmitted diseases and thus focus on a narrow range of risk-reduction strategies[16,25]. These studies fail to take into account the possible benefits to sex workers of a positive and supportive patient-physician relationship. In addition, by focusing on the barriers these women face, they also fail to explore ways for women to advocate for themselves in order to access primary health care.

1.2.4 STIGMA

Stigma is a common reason why marginalized groups do not access health care [31,66-73]. Illicit drugs users, in particular women who sell sex for drugs, are seen by society as highly deviant and are often stigmatized, including by health care providers[6,18,19,20,31,66,67,68]. Marginalized women may feel powerless and disempowered by previous negative experiences with the health care system or health care providers and therefore make a decision not to seek health care[74]. Similarly, previous research indicates that past experiences with violence can lead to a decreased ability to assert oneself and create barriers to communication[75]. Thus, exploring the effects of stigma on the health-seeking behaviours of drug-using women in a primary health care setting is important.

1.2.5 ACCESS

Previous studies have determined that vulnerable women, particularly those who use illicit drugs, are homeless and/or work in the sex trade, have low rates of health care usage[6,9,17, 31,59,76,77,78 79,80]. This is contrary to women in the general population who access the health care system more than men[1-3]. Specifically, marginalized women have been found to have low usage of outpatient services and high rates of walk-in clinic, emergency department and hospital usage[9,36,63,76,79,80,81]. Many of these studies are from the United States and cite a lack of health insurance as a significant barrier to access, making these findings less relevant to the Canadian context where women are more likely to have insurance. In a survey of 94 homeless women living in Toronto, just under one-third had a regular source of care or used the emergency department for their primary health care[17]. In addition, just over half (56 percent) did not have a family doctor[17].

There is less research exploring why and how this population of women access primary health care. Some studies have found that the way in which marginalized women access health care is different from women in the general population. For example, Hatton concluded that homeless women had circuitous routes to health care services and often relied upon a social service network to link them to medical care[80]. Other studies have noted that the way primary health care is delivered is also a determining factor as to whether or not vulnerable women access medical care[59,65,80]. For instance, having drop-in hours and health care professionals who treat stigmatized populations with respect were major factors facilitating access[59,61,65]. Again, these are all studies from the United States whose findings need to be examined in a Canadian setting.

There is also no research studying strategies used by women to cope with this lack of primary health care. The idea of studying strategies women use to access primary health care and advocate for themselves within the patient-physician relationship is novel. Such findings could be used to develop targeted programming and modify primary health care delivery so as to better support and care for vulnerable women. Having a better understanding of how to engage this vulnerable population is an important part of this process.

1.3 CONTEXT OF PHYSICIANS' LIVES

1.3.1 GENERAL OVERVIEW

Just as there are women-related factors which hinder how and whether drug-using vulnerable women seek primary health care, there are also physician-related factors which can impede health care access. Poor physician remuneration, poor working conditions, poor physician training, lack of organizational support, lack of respect from colleagues and judgment by physicians have all been found to impede how physicians care for marginalized populations[82-84]. Doblin and colleagues explored the impact of patient drug use on care provision by conducting telephone surveys and found that financial constraints such as poor remuneration and working conditions impeded clinics' ability to provide primary health care to the homeless[82]. Because of the differences in health care coverage between Canada and the United States, an exploration of the barriers faced by vulnerable women from the perspective of physicians should be examined in Canada[82,84]. Moreover, the above cited studies did not explore the emotional impact of caring for marginalized populations on physicians' ability to provide care[82,83]. A discussion of the possible emotional impact of providing care to marginalized populations will be explored below.

1.3.1.1 VICARIOUS TRAUMA

Caring for people who share their stories of trauma can often cause trauma in the care provider themselves. This phenomenon has been described in the literature as vicarious trauma and/or compassion fatigue. These terms are often used interchangeably; however, for the purposes of this study, the following distinctions will be made. Vicarious trauma is the natural and inevitable process which occurs as a clinician bears witness to the trauma experienced by his or her patient. By engaging in an empathic relationship with his or her patient, the clinician undergoes a transformation in his or her inner experience impacting the clinician's emotions and cognitive patterns[85,86]. Compassion fatigue, on the other hand, occurs when the clinician develops symptoms similar to post-traumatic stress disorder. The clinician is no longer able to cope with the cumulative stress and burnout occurs[85].

There has been much research exploring vicarious trauma and compassion fatigue in health professionals working with victims of trauma and torture and some research exploring these phenomena in health care professionals working in hospital and mental health care settings[85-88]; however, no literature was found identifying the phenomenon of vicarious trauma or compassion fatigue in family physicians working with people with chronic and persistent addiction problems, the homeless or sex workers. Therefore, studying the experiences of family physicians who work with this population and identification of their coping strategies is novel.

1.4 PATIENT-PHYSICIAN RELATIONSHIP

There is very little research studying the active role that family physicians can play in reducing the morbidity and mortality of vulnerable women who use illicit drugs, particularly within the context of the patient-physician relationship[65]. The idea of studying the experiences of family physicians known to be advocates for vulnerable women in their communities is novel. Important feminist-based primary health care research exists about the role of communication in the physician-patient relationship[3,89]; however, it is important to extend that research to include more marginalized women, particularly considering their increased risk for morbidity and mortality. Understanding how family physicians perceive their role in positive patient-physician relationships may be useful to inner city family physicians trying to achieve such objectives. Engaging vulnerable populations such as women who use drugs is an important part of this process.

There is a lack of research about the role of the patient-physician relationship in extremely vulnerable women. In a telephone survey by O'Malley and Forrest, low-income women were asked about the quality of primary health care services and the patient-physician relationship[90]. Although important conclusions were made about the role of the patient-physician relationship, participants were all over the age of 40 and housed[90]. This current study seeks out the experiences of adult women of all ages and focuses on those who are homeless or precariously housed. There have also been qualitative studies exploring the patient-physician relationship in marginalized women[59,74,80,91]. These studies fail to elucidate upon the impact of drug use on homeless women's lives and subsequent impact on the patient-physician relationship and were mostly limited to an exploration of the barriers homeless women face. The present study explores how family physicians and drug-using women engage with one another and strategies they each use to enhance the patient-physician relationship.

Research has demonstrated that continuity of care and having a positive patient-physician relationship can have beneficial effects on health[92-100]. Elucidating exactly how these objectives can be accomplished and encouraged in family physicians' relationships with women who use illicit drugs could have far-reaching health implications. Although there is a dearth of literature studying the role of continuity of care and its impact on homeless women, the majority of the existing literature is from the United States[90,91,101]. Although many of the participants in these studies also used illicit drugs, drug use was not an inclusion criterion. As such, these studies do not reflect the needs of women with pervasive drug problems who are often involved in the sex trade. Drug use and sex work add another layer of complexity and vulnerability in these women's lives and seeking to understand the role of the patient-physician relationship, particularly continuity of care, is important. In addition, since there is no universal health care insurance in the United States, generalizations of these studies are limited. Therefore, by recruiting the most vulnerable drug-using women, this study will add new and important perspectives on how drug use and sex work affect homeless women's experiences of the patient-physician relationship and continuity of care.

1.5 GENERAL CONCLUSIONS

This introduction has provided the context in which this study was conducted. Moreover, it has brought attention to some of the gaps in the current literature and provided reasons as to why the current study fills some of those gaps. A summary of these reasons is outlined below:

- Because of the lack of Canadian studies, particularly regarding primary health care access, the current study exploring the health of women drug users is warranted.
- This study explores how harm reduction principles inform primary health care and not just public health.
- This study explores the complex relationships among drug use, homelessness, sex work and violence from the perspectives of both women and family physicians.
- Due to the lack of research on the emotional burden of working with this population, an exploration of vicarious trauma in inner-city family physicians is also warranted.
- The present study explores strategies drug-using women and family physicians use to enhance rather than weaken the patient-physician relationship.

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CHAPTER 2:

"People forget that [we're] human beings": Providing patient-centered care to stigmatized women using illicit drugs

2.1 INTRODUCTION

Poverty, homelessness, mental illness, physical health problems and risky sexual behaviours are ubiquitous among women who use illicit drugs - particularly among women who use crack cocaine [1-14]. Crack use in North America has been described as the "neglected epidemic" and crack users are often described as the "marginalized of the marginalized"[2,9,15]. Crack is the drug of choice for many marginalized people in the city of Toronto, where this study was conducted[1,2,16]. Women who use crack are even more marginalized because of the sex work that often accompanies crack addiction[2,13,17-19]. Because of the high rates of homelessness and/or sex work among vulnerable women using illicit drugs, literature about these populations of women was explored in order to provide background information for this study[2,13,17-20].

Women who use drugs, are homeless and are involved in sex work all have low rates of health care usage[1,2,9,21-25]. This is contrary to women in the general population who access the health care system more than men[26-28]. These vulnerable women have low levels of primary health care usage but high rates of walk-in clinic and emergency usage[1,2,9,21,29-32]. This lack of continuity is of particular concern given the high morbidity and mortality in this population[1,2,12,15, 33-42]. In addition, vulnerable women such as those who use drugs and/or are homeless have low follow-up rates, poor adherence to medical advice, and lower rates of participation in health promotion activities and disease screening than women in the general population[1,2,21,33,43,44]. Thus, there are high primary health care needs among these women but they are largely being unmet and/or are being met in settings where there is little continuity of place and person[34].

Women who use illicit drugs are a hard-to-reach population for several reasons. These women face numerous barriers to seeking medical care including lack of a health card, mental illness, lack of transportation and stigma [1,2,21,24,45]. Sex workers and/or women who sell sex for drugs, food or housing (often referred to as sex "trading" or survival sex) are seen by society as highly deviant and are often stigmatized, including by health care providers[2,11,13,14,17-19]. Sex workers operate at the bottom of the "street hierarchy", placing them at exceedingly high risk for violence, sexual exploitation and health problems[11,14,19]. In fact, 65 percent of sex workers in south east Toronto reported sexual and physical victimization in the last year[46].

Women may thus feel powerless and disempowered by previous negative experiences with the health care system or health care providers and make a decision not to seek health care[47]. Similarly, previous research indicates that past experiences with violence can lead to a decreased ability to assert oneself and create barriers to communication[48].

There is little research exploring these women's experiences of their health, their relationships with physicians, and their abilities to access the primary health care system. Of the literature that does exist, there is again very little studying strategies used by women to cope with the lack of primary health care. The idea of studying strategies women use to access health care and advocate for themselves within the patient-physician relationship is novel. Such findings could be used to develop targeted programming and modify primary health care delivery so as to better support and care for vulnerable women using illicit drugs. Having a better understanding of how to engage this vulnerable population is an important part of this process.

2.2 PURPOSE

This study set out to explore the experiences of vulnerable women using illicit drugs in order to better understand the process of engaging these women in the patient-physician relationship. Engagement refers to the early contact of the patient with a health care professional and the health care system.

2.3 METHODS

2.3.1 CONTEXT

This phenomenological study used the qualitative method of in-depth interviews. In-depth interviews are useful when exploring a relatively narrow research question and when the experiences and understanding of the participants are the primary interest, not the broader context of that understanding[17,49]. This method is often used to explore sensitive subject matters where other qualitative methods such as focus groups would be inappropriate[13,17,18,50,51]. In this study, investigators were seeking to explore the experiences of street-involved women using illicit drugs; in particular, the process of engaging this disenfranchised population. In order to fully understand the process of engagement, it was necessary to explore the context in which this engagement occurred. As such, understanding the impact of drug use and sex work on participants' lives was important. Thus, in-depth interviews were the most appropriate choice of methodology to discuss such sensitive and potentially traumatic topics. Also, qualitative methods are an ideal method when studying complex problems such as the patient-physician relationship and health care delivery to marginalized populations[52-54].

There were few identified risks to participants for participating in this study. Participants were made aware that some topics may be emotionally difficult to talk about and memories of past trauma might be elicited. If participants were to experience significant distress, they were offered support through a mental health crisis line and mental health support staff at participating agencies. Of note, neither of these services was necessary. Benefits of study participation included giving voice to a group of women under-represented in the medical literature and participating in a process whereby they are helping family physicians provide better care to a high risk group of women.

2.3.2 SETTING

Inner-city Toronto, Ontario.

2.3.3 SAMPLE

Vulnerable, street-involved women using illicit drugs between the ages of 18-64.

2.3.4 PARTICIPANT RECRUITMENT

Vulnerable, street-involved women living in Toronto's inner city were purposefully sampled. In order to ensure maximum variation and richness of the data, recruitment was conducted in a variety of settings across Toronto including: street outreach, community health centres [harm reduction programs, women's drop-ins and medical drop-ins] and shelters. The researcher initially contacted agencies or individuals thought to be helpful in recruiting women. Twelve agencies were contacted and eight of these participated. Two of the remaining four agencies did not return calls and the last two contacts consisted of individual family physicians where it proved too challenging to set up interview times with patients.

Recruiting happened differently at each agency. Some agencies had interested women sign-up and interview times were arranged. At one agency, the researcher attended a harm-reduction programs' peer meeting and answered questions about the study. In this instance, interview times were arranged directly with women. Other agencies invited the researcher to attend drop-ins where posters had previously advertised the study. The researcher also went on street patrol with an outreach organization and two outreach workers helped with linking the researcher to eligible participants. All women that were approached by the researcher agreed to participate. In total, fifteen interviews were conducted. Recruitment ended when saturation was achieved (e.g. no new data were revealed or disconfirmed previous data)[55,56].

If women expressed an interest, they were screened to ensure they met the inclusion criteria. Inclusion criteria were as follows: vulnerable women between the ages of 18 and 64 using illicit drugs (priority given to women who were homeless and/or involved in sex trade). Exclusion criteria consisted of a woman being unable to give informed consent (e.g. language barrier, severe mental illness, under the influence of drugs or alcohol such that informed consent could not be obtained).

Participants were compensated for their time with a ten dollar voucher for a local grocery store or pharmacy and provided with two tokens for transportation.

2.3.5 DATA COLLECTION

The interviews took place in Toronto, Ontario. Each interview lasted between 20-60 minutes. Interviews were conducted by one researcher (SW). The interviews with the women took place on the street (two interviews), in offices at shelters, or in offices/examination rooms at community health centres. Two to three interviews were conducted at each site. Interviews were recorded using two tape recorders. A semi-structured interview guide was used to facilitate the data collection (Appendix II). At the beginning of the interviews, participants were asked basic demographic information. All participants were asked the same open-ended question to begin the interview (i.e. How has your drug use affected your life?). Probes were used as necessary. The interview guide was adapted as new information emerged from the data analysis and questions were subsequently modified. Informed consent was obtained from all participants prior to each interview although participants were not required to sign any consent form as researchers wanted to ensure that anonymity was preserved. Field notes were taken during each interview.

2.3.6 DATA ANALYSIS

Each interview was transcribed verbatim. The data were analyzed using an iterative and interpretive process. After each interview, the data were read independently by each researcher who identified pervasive themes. The researchers then met to compare and combine their respective analyses looking for key words, phrases or concepts. When common themes were identified, they were manually introduced into a coding template. Each theme in the coding template was assigned a numerical value and subsequent data used these numerical codes to identify common themes in subsequent interviews. The coding template was continually expanded, reviewed and revised as new themes emerged throughout the data collection. Upon reaching saturation, earlier transcripts were re-coded to ensure congruence with the final coding template. Once all the data were analyzed, dominant themes were identified and the coding template was condensed as some themes were identified as overlapping with others. This iterative method of theme identification and coding is consistent with phenomenological methods[56].

Appropriate pacing of data gathering and analysis occurred allowing for optimization of the iterative process[56]. There was a constant interaction between sampling, data collection, emerging analysis and theory construction[56]. This iterative process allowed for the data collection to be redirected in order to elicit, confirm and/or negate previous ideas. Theme saturation was achieved by the sixth interview. As this was early in the data collection and analysis process, four more interviews were conducted to ensure that no new themes were emerging and previous themes resonated with participants in the later interviews. This strategy is called member checking and involves asking participants if identified themes, concepts and interpretations are congruent with their own experiences[57]. If participants share different experiences, then further interviews and a re-visiting of the data analysis is warranted. Member checking increases the trustworthiness and credibility of a study[57].

2.3.7 TRUSTWORTHINESS AND CREDIBILITY

Trustworthiness and credibility are measures of reliability and validity in a qualitative study. Ensuring methodological rigour was achieved in this study by a variety of means. First, there was significant diversity among the sample population with respect to age, sexual orientation, engagement with social services, intensity of drug use, participation in sex work and location of recruitment. All these variables were considered to impact participants' level of engagement with the primary health care system and subsequently, the patient-physician relationship. Significant effort was made to recruit extremely marginalized women who don't traditionally use social or health services. Participating in street outreach and recruiting women living on the street helped to ensure that women using illicit drugs from multiple backgrounds were included in this study. Second, trust was established between participants and the interviewer. Novel ways of obtaining this trust were carried out. For example, the researcher went to a peer-run drug users group at a local community health centre to answer questions about this research. Women were given opportunities to ask the researcher about the study, interest in this particular field and potential conflicts of interest. Interested women were then offered the opportunity to sign up for interview times. The researcher also made relationships with staff at local agencies serving vulnerable women who then, in turn, introduced her to potential participants and helped establish trust vicariously. Street credibility was extended to the researcher through her various relationships with health professionals and social service providers.

The third way methodological rigour was achieved was by analyzing the data with a team. Researchers provided one another with checks and balances to ensure that they were being true to the data. The principal researcher worked with a similar practice population. This had advantages and disadvantages. Participants likely had an increased trust in the researcher because they felt she "understood". This implicit trust was likely beneficial for participants feeling comfortable enough to disclose their personal narratives of loss, stress and isolation. Being granted this trust also allowed for an interview guide to be created that was appropriate to this population of vulnerable women. The disadvantage of being so knowledgeable about street-involved women was the potential for loss of objectivity and the introduction of self-indulgence[57]. Great lengths were taken to avoid these errors and it was felt that this was achieved in this study; in particular, by ensuring that reflexivity took place.

Reflexivity is the process of reflecting on your role and influence on the data collection and analysis[58]. This was ensured by having two co-investigators who did not work in the field of interest and who reviewed transcripts and analysis for indicators of bias (e.g. leading questions, introduction of personal experiences and other patient narratives into interviews and into analysis etc.). Reflexivity is also an integral part of the immersion and crystallization process – a process whereby researchers immerse themselves into the data and constantly reflect for new interpretations[58]. This process not only requires reflexivity but also solid data acquisition and congruence of researcher personality with methodology and time[58]. It was felt that all these conditions were met for this study.

Lastly, methodological rigour was achieved by allowing the findings to lead the data collection and analysis. The interview guide was adjusted as needed throughout the study to reflect emerging themes or new directions suggested by the previous interviews.

2.3.8 ETHICS APPROVAL

Ethics approval was obtained from the University of Western Ontario's Health Services Research and Ethics Board (see Appendix V – Approval #13383E).

2.3.9 FINAL SAMPLE AND DEMOGRAPHICS

A total of fifteen women were interviewed. The average age of participants was 41 (range 22-54). The drug of choice for participants was crack cocaine. However, almost all participants were polysubstance drug users with participants also using opiates (mostly prescription pills) and marijuana. Alcohol use was also common. Two participants had stopped using crack cocaine; one of these was on methadone maintenance and the other smoked marijuana regularly. The method of drug delivery was primarily inhalation although three participants were actively injecting crack on a daily basis. Just under half of participants were homeless with three women living outside, three living in shelters and one woman "couch surfing". The remaining eight participants identified as having an address which they called home. However, despite being housed, most of these eight participants lived in substandard housing such as rooming houses – a circumstance described as relative homelessness (i.e. shared bathroom and kitchen facilities)[35].

In terms of income, four participants were receiving disability benefits through the Ontario Disability Support Program. All other participants were receiving income through social assistance. If they were housed, they were eligible for full benefits whereas if they were homeless, benefits were reduced to a personal needs allowance of approximately $100 per month.

Over half of the women interviewed participated in sex work or had a recent history of working in the sex trade as a means of supplementing their income. Half of participants identified as lesbian, bisexual or transgender.

Participants differed in terms of their ability to access primary health care. Eleven participants reported receiving varying degrees of primary health care. Five women saw their family physician at a community health centre, three at a medical drop-in a shelter for homeless women and one from an academic family practice site. One participant received some primary health care from her methadone physician although was trying to find a family physician. Another one of the ten participants accessing primary health care received sporadic care from a nurse practitioner at a local community health centre. Five participants did not access primary health care.

2.4. FINDINGS

2.4.1. OVERVIEW

The proximal and distal contexts of women's lives were predominant themes discussed by participants. Proximal contexts included three inter-related and inter-dependent themes: participants' drug use, the "hard lives" of participants and chaos. Because of these persistent and overwhelming challenges, another subtheme emerged - stigma. Participants also described lacking many of the social determinants of health – these composed the distal context of participants' lives. Just as the proximal and distal contexts of participants' lives could either facilitate or hinder their engagement with a family physician, the manner in which the primary health care system was designed and delivered also played an enormous role in determining whether or not participants were able to access primary health care. The provision of social services greatly enabled participants' engagement in the primary health care system. Lastly, in order for a patient-physician relationship to be established many factors had to fall into place for participants. Both participants and their family physicians took specific actions to facilitate the formation or maintenance of this relationship.

2.4.2. CONTEXT OF WOMEN'S LIVES

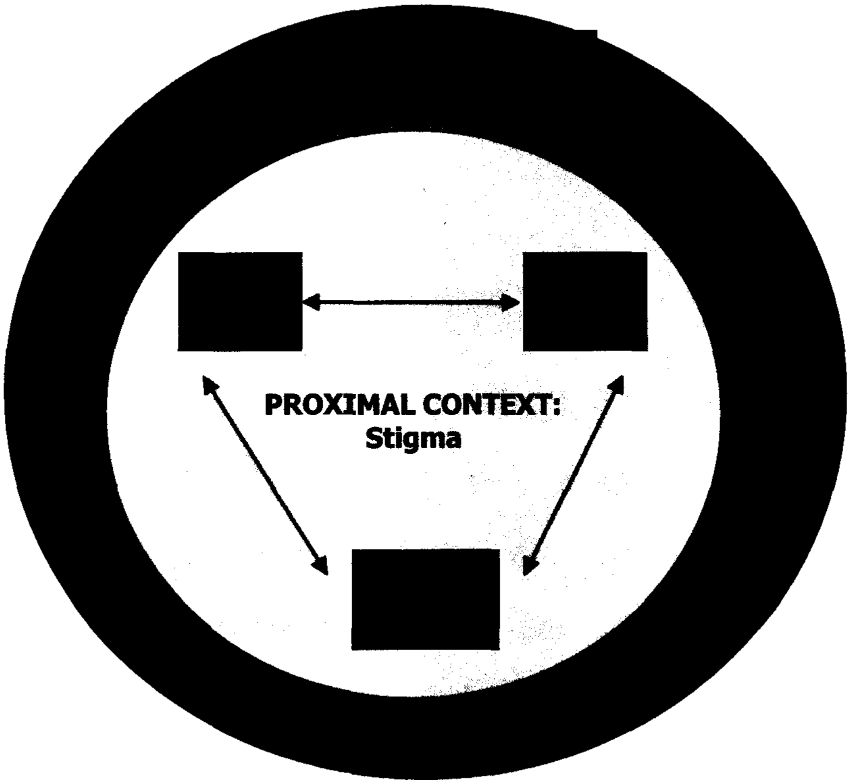


Figure 2.1

2.4.2.1 Overview

The proximal and distal contexts of women's lives were predominant themes discussed by participants (see Figure 2.1). The analysis of the data identified four subthemes within the broader theme of the proximal contexts. These included three inter-related and inter-dependent themes: participants' drug use, the "hard lives" of participants and chaos. Because of these persistent and overwhelming challenges, another subtheme emerged - stigma. Participants' behaviours were associated with significant stigma and this was a source of shame for most women. Subsequently, participants had difficulties trusting the health care system and health care professionals. Participants also described lacking many of the social determinants of health – these composed the distal context of participants' lives.

2.4.2.2 Proximal Context

A: DRUG USE

Drug use was a major component of participants' proximal contexts. Participants spoke frankly about their drug use and the impact it had on their lives. Most participants had been using drugs for most of their adolescent and adult lives. *"I've been doing it for twenty-two years and it's a habit now. Hard bad habit to break."* Many participants used drugs daily. For instance, one participant referred to smoking and injecting crack cocaine: *"… every day…as many [times] as I can…opiates, oxy's, marijuana…I [just] did a smash of dilaudid…".* With this intensity of drug use, addiction became part of an identity:

"That is just what I do…I am just an addict. This is the only thing I know how to do right now." Conversely, other participants had been able to cut down their drugs use over time: *"Well, it used to be daily, but [now] twice a week, three times a week. Sometimes less. Not near as much."*

The need to get high often superseded all other needs: *"…that's pretty well what I'm doing [finding drugs], running around every day doing that."* Using drugs permeated every aspect of participants' lives at times resulting in devastating consequences. For example, losing contact with family was a common theme discussed by participants: *"It's keeping me away from my family"*. This isolation contributed to feelings of loneliness:

> *It's scary. Especially if you're by yourself and there's nobody around and you don't know what to do…I felt like I was alone, lost, scared, frustrated. I felt like I was in a dark hole and I was never coming up.*

In addition, using drugs led to behaviours that participants would not otherwise have engaged in had it not been for their drug use: *"It's not put me in a good place. It put me on the street and I'm doing stuff I don't normally do if I was not using drugs…"*.

Participants were honest about the intensity of the cravings: *"…women will do whatever they need to do to get their drugs…"*. Participants also told stories reflecting how difficult it was to stop using. One participant recalled being diagnosed with a serious brain aneurysm requiring surgery. She was so terrified and unable to cope without using drugs that she tore out her intravenous line and ran from the hospital: "*Boom, I was out of there. Call my dealer, meet me in the parking lot right across the street from [hospital]."* The line between physical and psychological dependence was frequently blurred for participants as their drug use was often used as a coping mechanism. As the participant quoted above expressed: "*It was just too overwhelming, it was just too scary…I needed my drug to comfort me, I needed my drug to say, it's OK, I'm here.*" Thus, another subtheme raised by participants was how using drugs was both a way to escape from the harsh realities of daily life on the street and to numb physical and psychological pain: "*You feel like you're…flying. Like you're in a whole different world. You don't care. You have no feelings. Everything just kind of escapes…You're kind of lost. It's a band-aid. A gateway.*".

There was an incongruity between what participants observed and knew to be the potential lethal consequences of drug use and their continued risky behaviour. Recalling injecting crack cocaine for the first time, a participant shared being terrified at how close she came to dying: "*I could've been dead that day. And nobody would've cared…another dead junkie…I really scared myself. Almost to the point where I didn't want to do it anymore. But I like the high and I was addicted.*" Many participants had friends who had either died of overdoses or suffered serious complications. "*One of my girlfriends' had a heart attack and now she has brain damage.*" Furthermore, some participants had been hospitalized for multiple and serious overdoses. *"I was in the hospital before because I smashed a gram and a half of speed and my heart stopped three times…and I had three seizures."* Misconceptions as to the safety of crack cocaine appeared to contribute to participants' high risk behaviours: *"I never thought you could OD doing crack…".* Thus, despite either personal near-death experiences or having friends overdose, participants were still unable to overcome the powerful force of addiction.

In summary, participants' drug use was extensive, pervasive and often quite risky. Many participants had suffered physical, social and emotional consequences because of their drug use but still continued using.

B: HARD LIVES

Another subtheme within the proximal contexts of women's lives was that of the "hard life". Analysis of the study data identified five factors which contributed to this "hard life": health problems, current experiences of violence and trauma, past experiences of violence and trauma, sex work and barriers related to sexual and gender identity. Participants described the overwhelming struggles which made daily life so difficult. As a participant summarized: *"Nothing has been very easy..."* .

Health Problems

All participants described significant physical and mental health problems. These were both acute and chronic and often disabling. The majority of participants complained of fatigue and poor sleep:

> *I sleep way more than anybody should. Like it's crazy...I thought at first it was just my body making up for all the years of my own abuse...[it's now]apparent that there's a bigger problem there.*

Some participants also suffered from chronic pain: "*I am not very well and I have pain.*"

There was also a high prevalence of respiratory complaints among participants: "*Lung problems. Asthma. Breathing problems. My doctor told me you had to stop smoking or else you are slowly going to kill yourself.*" The following participant recalled having had the flu and being rushed from her family physician's office to the hospital by ambulance:

> *I hadn't eaten or drank anything for about 7 days and finally I just dragged myself over here and I had a temperature of 104 and she called the ambulance and I had pneumonia. Kept me in the hospital for two days.*

Thus, the burden of respiratory disease was high among this population of crack-smoking women.

Another common source of morbidity was infection with Hepatitis C. *"I got Hep C …not [from] using dirty needles but using the same cookers."* Some participants articulated a misplaced yet fatalistic view about this diagnosis and felt that trying to be healthy was futile. The following participant with Hepatitis C did not bother to get tested for HIV because: "*…I don't care…I'm already sick…I already have Hep C…I'm already dying so if I have AIDS, it's going to make me more pissed and…go and use more.*" Other participants, however, described positive experiences when given information about the disease after joining a program for drug users infected with Hepatitis C:

> *When I found out I had Hep C, was kind of devastating for me. But then I joined the Hep C class here. Then they did the more extensive Hep C test on me and…I don't have Hep C anymore.*

Other infectious diseases such as sexually transmitted infections were also prevalent among participants: " *I actually got infected …an STD. And I was embarrassed …it's gross. I have to be more careful with what I'm doing.*"

Pregnancies were common among participants. Some participants described having terminated their pregnancies. This was an emotion-laden topic for participants. A participant spoke about having an abortion, or dilatation and curettage (D&C) when pregnant: *"I go for a D&C. Done. I don't want to talk about that."* Other participants continued with the pregnancies and had given birth: *"...[my son] – he's 17 now, so yeah, that's a long time ago."* The following participant described a pregnancy resulting in a miscarriage: *"I had a D&C and a clean out. I was in the hospital."*

Mental illness was another medical problem faced by participants. The following participant suffered from obsessive-compulsive disorder. She described a time when her mental health deteriorated such that her family physician considered hospitalizing her against her will; however, she eventually agreed to a voluntary admission: *"I just looked really ill, I guess...A very depressed state...It ended up, my addiction counselor ... I ended up going with her [to hospital]. And I got a lot of my shame and guilt out."* Participants also noted that illicit drugs themselves had psychoactive properties. For example, a participant described how smoking crack induced such a severe paranoia that she isolated herself in her room for weeks:

> *I hid from people. And didn't answer my phone, didn't answer my door... because I was so paranoid...I was just really crazy. I was going insane in my head. 'Cause of the drug.*

Although not all participants spoke about specific mental health diagnoses, many participants referred to being stressed: "*The only thing that's getting to me is the stress. And you know, stress can play a huge role on your* *overall health. And it's pretty stressful, this life."* Stress was sometimes associated with behavioural problems: *"I'm under a lot of stress right now...I don't want to hit anybody. I just don't want my temper to come out."* In fact, some participants recalled experiences where their disruptive behaviour had resulted in being banned from a social service and/or health care facility: *"It was like three years years ago...I got into an argument with a person...and I got banned from there...."*

Current Experiences of Loss, Trauma and Violence

Participants' current experiences of loss, trauma and violence were pervasive. This violence was acknowledged as a reality of street life: *"It's a dangerous lifestyle...a very violent lifestyle."* Although it was clearly difficult for participants to talk about the violence in their daily lives, some women gave candid and brutal accounts of the harsh realities of this life. For some participants, violence was precipitated by fights over drugs and money: "*It was over being short ten bucks and of course he got mad. And so he stabbed me. And plus I owed him money, like eighty bucks...but I came up short...so they stabbed me.*"

Sexual violence was widespread and commonplace: "*A lot of girls get raped. Beat. Raped. And their money taken...It's just a fact of the drug world. The drug game."* The risk of being killed was a constant reality facing participants as illustrated by the following quotation:

> *I was almost killed two years ago with a marble coffee table over my head. I was stabbed a half-inch away from my kidney 6 months ago with a butcher knife...I just was run out of a car, I had my collarbone broken...".*

Past History of Loss, Trauma and Violence

Not only was violence a part of daily life for participants, but a part of their past experiences as well. *"I've had so much happen to me, I just don't even want to go there."* Loss also came in the form of lack of contact with family and friends which for many participants was particularly devastating and isolating: *"I've lost a lot of friends, lost my job, lost my house…I've lost so much…".*

Participants had few social supports and relied heavily on their "drug" community to provide them with a sense of family and moral support: *"I got no family or nothing…just my guys I drink with. They're all pretty well in the same boat, you know?"*

Many participants who had given birth were not caring for their children. The loss of their children to the child welfare system was a theme raised by many participants: *"C.A.S. [Children's Aid Society - child welfare] definitely don't help you. I had to give my kids up to C.A.S.. Cause I was in the wrong crowd."* The pain and grief resulting from these losses was a source of enormous distress: *"I don't really want to talk about it because I'm still hurting."*

For some participants, drug use was a way of coping with these devastating losses and trauma. For example, the death of her daughter precipitated decades of drug use for one participant who stated: *" I lost a little girl when she was ten. And I've been using ever since."* The gravity of the trauma and the multitude of losses were often so overwhelming and painful that many participants were unable to talk about with health care providers. *"I just tell them* *[doctors] I don't want to talk about it. Which I don't. It's a part of my past…I don't want people to know…I've been raped."*

Sex Work

Sex work was a reality faced by most participants as this was the method of obtaining money to pay for drugs. The desperation to get high overcame participants' shame at having to participate in the sex trade: "*I do it sometimes but I don't want to say much about that. There's not really much I can say about it…I do it and I don't really enjoy doing it."* Being paid more money to have sex without a condom was commonplace and placed participants at higher risk of contracting infectious diseases: "*Sometimes people don't use condoms because they want to get paid more. They want their drugs…I've caught a few infections from not using protection and shit."* Some participants tried to decrease the risks associated with their work by engaging in lower risk sexual activity in their sex work: *"I don't do* ***sex*** *sex. A blow job or something."* The physical violence and poor health participants experienced impacted their ability to work at times. Considering how important body image was to participants, it was understandable that one participant was quite traumatized by a severe infection with impetigo on her lower legs which resulted in significant scarring:

> *Yeah, it's really not jelling with me… my body's always been free of marks and stuff like that…in the prostitution field…in the summer, when you're wearing those short skirts and whatever…you can't really have stuff like that.*

Engaging in sex work resulted in participants' lower participation in primary health care for fear that they would be judged:

> *I know girls out there that haven't had check up in six, seven, eight years. God knows the last time they had a pap smear…if women knew they had a place to go where they wouldn't be judged, I think they would access health care a lot more.*

Thus, sex work played a large role in the lives of participants and placed them at risk for both physical and sexual violence as well as health problems.

Barriers Related to Sexual and Gender Identity

Transgendered participants and those who identified as lesbian or bisexual identified barriers in accessing health care that were specific to their sexual or gender identity. Having a family physician who was accepting of their sexual orientation was important for lesbian and bisexual participants: "*I'm a lesbian and I didn't want…to see a man doctor…I was so thankful that she [family physician] was a woman…I talked to her about my partner.*" Participants who were transgendered were at increased risk of physical and sexual violence because of their gender identity. For some participants, this led to avoidance of many parts of the city where they did not feel comfortable or safe:

> *I've been hassled a lot and I've ... gone through a lot of shit. Obviously there are certain parts of the city that just aren't safe for someone like me, and ... as much as it sucks to have those kind of restrictions, it's just that way…I could be a boundary pusher… But breaking down the boundaries isn't worth breaking my legs.*

In addition, participants who were transgendered found it difficult to find a family physician comfortable dealing with these issues:

> *I still haven't really found a doctor, because there are so many waiting lists. And because I'm looking for one … that deals with transgender, transsexual issues – it's a little harder.*

Therefore, participants who were lesbian, bisexual or transgendered experienced additional barriers to seeking primary health care. Health care professionals who work with both drug users and/or this community need to be aware of the increased risk of drug-related harms and violence facing this population. Primary care delivery may benefit from targeted programming for this population.

C: CHAOS

Chaos was a predominant aspect in the lives of participants. Having lives that were so disorganized led to challenges in setting priorities. The theme of competing priorities was discussed by many participants. Participants' lives were so busy trying to survive that seeking health care was often not a priority for many of them: *"I just don't see doctors…Nope. It's not in my schedule."* Appointments were hard for many participants. *"Like some things I don't even get done period…my appointments."* However, for some, the severity of illness dictated whether or not they would be able to make an appointment: *"But if it was something serious enough, of course I would go to a specialist."*

Timing of appointments was also critical because of the disorganized lives led by participants. *"…being up all night and everything, I just want to stay in bed and sleep."* Spending time finding ways to get high and securing their drugs was another contributing factor to this chaos: *"…you're so busy all the time running around getting it [drug]…"* Using drugs was noted to lead to poor memory: *"I don't have the best memory"* and unreliability: *"…when you use drugs, you're very unreliable…You don't know what you're doing from minute to minute."* For another participant, going to the doctor was something she simply did not think about: *"I'm just saying, I just don't really think about it."*

Participants often lost important documents: "*...a lot of girls lose their IDs, they leave the purse and everything and two months later get out of jail and don't bother going back and getting it"*. Losing identification only led to further disorganization and chaos, as participants then had difficulty accessing social and health services. Losing things that most people take for granted, like a telephone, was not only frustrating and interfered with participants' ability to function day-to-day, but also was emotionally distressing.

> *I had a phone for three weeks but then someone stole it...it's really hard for me to hold onto things because people either take them or I leave them somewhere...when I had the phone it was great...and then all of a sudden somebody comes and takes it...I just don't understand.*

Thus, for this participant, the loss of her telephone as a result of her chaotic lifestyle served as a reminder of how even the possession of a basic necessity was out of her reach.

Participants' chaotic lives also interfered with their ability to follow-though on medical recommendations and referrals. A participant joked that it would take a *"...$50 piece [of crack] there waiting..."* for her to follow-through with investigations and specialist appointments. Thus, the chaotic lives lived by participants made follow-through and follow-up with physician-directed management plans very challenging.

Of note, pregnancy was a time in many participants' lives where priorities shifted and women took a break from their drug use to focus on staying well and giving birth to a healthy baby: *"...when I was pregnant, I was straight...priorities* *change…everything's about the baby…I enjoyed it."* For other women, however, abstaining from using drugs during pregnancy was still too difficult and this was hard for some to admit: *"I used straight through…okay?"*

D: STIGMA

Stigma was another dominant theme arising from data analysis. Drug users, the homeless and sex workers are all stigmatized in our society. Experiences of this stigmatization relegated participants to the margins of society. Being stigmatized was associated with intense feelings of shame which subsequently led to participants' mistrust of health care professionals and the health care system.

Shame

Feelings of shame and subsequent isolation prevented participants from seeking primary health care:

> *…a lot of places you feel a little bit intimidated - especially if you've been out for a couple of days … and you just don't look your best… people judge you…I think that has a lot to do with why drug users don't access health care …they feel ashamed.*

Shame led to low self esteem and feelings of worthlessness:

> *I think a lot of people forget that they're human beings because of the drugs …[you] lose your self-esteem … if you're a prostitute…You look in the mirror and all you see is whatever, right? If you don't feel good about yourself, you're not going to…get any better.*

Participants were aware that sex workers and drug addicts were stereotyped: "*They're [the public] afraid of things they don't have any knowledge* *about…and most people think drug addicts…rob people…we are stereotyped."* Thus, shame resulted when participants were not treated with dignity and respect and thus unable to maintain their pride. As a consequence, many participants avoided seeking health care.

Mistrust

Stigma and the associated feelings of shame contributed the high levels of mistrust among participants. Not trusting health care professionals or the health care system was a subtheme that reverberated among all the participants: *"I don't trust people at all…I can tell on one hand how many friends I have, cause I don't trust a lot of people…you earn your trust with me."* This mistrust of authority figures made it challenging for women to engage with health care providers. Participants often relied on a social service provider whom they trusted for assistance in accessing primary health care:

> *…I'll go to people I'm familiar with…I tell them I'm feeling like shit… [I ask] 'Who should I talk to, can you introduce me?… Can you walk with me and support me and hold my hand - because I'm scared?'*

A positive first experience with a physician was crucial to building trust and subsequently engaging participants in the patient-physician relationship: *"…I got introduced to my doctor…and I found her pretty good. So I kept going…to her…I feel comfortable with her. I trust her."* Until participants had established that it was "safe" to share their stories with a family physician, many were selective about the information they provided to a physician:

> *I would have to figure you out first…I might not be able to trust you. And I'd have to trust you before I could open up to you…And if I could*

> *trust you, then 'Have you got all day, I'll sit here and tell you'...If I can't trust you, then I'm not saying nothing to you.*

Health care professionals made frequent assumptions about the etiology of a symptom or the reason for seeking care leading them to mistreat participants. For example, some participants shared stories of being accused of drug-seeking behaviour:

> *[The doctor said] 'I can't give you something stronger than this ...we don't know if you're going to go out and sell it or something.' Why would I go out and sell your prescription drugs if I need it? ...I said... stick your prescription up your ass and I'll go buy it on the street... if I [ask] for something you know I need it...*

The following participant was angry when mistreated by a labour and delivery nurse who was giving her Demerol to control her labour pain. The participant had been abstinent for years and was on Methadone:

> *And the nurse [said]:... 'I just want you to know that you're* ***only*** *getting* ***one*** *of these'...and just because you have a past...addiction doesn't mean that you're going to be drug-seeking the rest of your life...[that] really pissed me off.*

In addition to health care professional making assumptions about participants' reasons for seeking care, they also felt that health care providers didn't want to waste their time taking care of drugs users. Participants frequently expressed that since health care providers did not care about them, they need not bother with health care:

> *He [family physician] said I was taking too much of his time and I was just abusing medication...I was slowly hurting myself and that I wasn't responsible for my actions.*

Thus, for this particular participant, rejection by her family physician because of her drug use reinforced the shame and guilt that she felt secondary to her lack of will power and served only to perpetuate the cycle of drug use. She felt like a burden. When participants felt that they were a burden and that health care providers did not care about them, this reinforced the sentiment of them not caring about themselves: *"You just don't give a shit because you think nobody else does…".*

Previous negative experience with health care professionals served to perpetuate participants' mistrust of physicians. *"Learning how to trust my own senses"* was an essential survival strategy for a participant who witnessed her mother "*…go through a lot with doctors…".*

A decreased ability to trust others was an inevitable consequence of having experienced violence and trauma and led to further isolation and stigmatization making it more difficult for participants to engage with health care professionals and to receive much-needed medical care. Mistrust was also a result of being stigmatized and consequently mistreated by health care professionals.

E. SUMMARY: PROXIMAL CONTEXT

Drug use among participants was pervasive and had an enormous impact upon their psychological and physical well-being. Many participants had past experiences of abuse. These horrific experiences contributed to participants' drug use. The cycle of violence was further perpetuated in their adult lives as the "drug life" was described as harsh, violent and dangerous. Drug use was therefore another tool used to cope with the tragedies of daily existence. The stigma of being a drug user and someone who sold sex for drugs was a significant source of shame for participants. The humiliation of not being able to control their drug use and subsequent degradation that went along with searching out ways to get high left participants vulnerable, marginalized and isolated. A mistrust of the health care system and health care professionals was a resulting consequence.

2.4.2.3 Distal Context

A: LACK OF SOCIAL DETERMINANTS OF HEALTH

Just as the proximal contexts of participants lives played a role in determining how easily women could access the primary health care system, so too did the distal context. A major component of the distal context for participants was the social determinants of health. Participants identified how lacking housing, transportation, identification, food security and access to primary health care posed significant barriers to health care access and health in general.

Housing

Access to affordable and safe housing was inextricably linked to participants' ability to control their drug use and their need to participate in sex work. The frequency of drug used decreased when participants obtained housing: *"I used to use 24-7-365 before when I was homeless and I didn't have anywhere to go or anything to do…but that's slowed down."* In other words, without housing, life on the streets was dangerous and resulted in participants engaging in higher-risk behaviours.

> *Since I've been housed, it seems I don't have to be outside so much, don't have to work the streets so much. It seems like my crack use had gone down quite a bit. Which is a good thing.*

When participants had nowhere to sleep, they were often forced to do favours for people in exchange for a roof over their heads or use drugs all night to simply stay warm. This usually entailed providing someone with sexual favours in return for a place to sleep.

> *...either I had to make money to pay somebody to sleep in their place. Or I had to do this [sex work] to do drugs to stay awake because it's so damn cold outside...you had to stay high to stay warm or pay somebody...*

Housing gave participants control over their lives. When housed, participants did not need to participate in sex work to have a place to sleep and thus were able to decide to participate in sex work on their own terms – usually based on the need to use drugs. The following participant explained that since being housed, she had not needed to work the streets for over a year: "*And if I go out and do that, I choose to ...I rarely do that anymore. I haven't worked the street in over a year. I'm over it.*" As another participant stated: "*I'm more settled now...if I want to use, I know that I can take it home, and I know that I can lock my door and...the door only opens if I open it.*"

Violence was less common for participants who didn't have to rely on sex work and were housed: "*[Violence] was an everyday thing...But not so much now because now I can just go to my room and shut the door.*" Despite the fact that having housing clearly improved the lives of those housed participants, the housing they had was often described as grossly inadequate:

> *I wish I could afford a better place to live. It's depressing where I live... It's a dump...I pay $500 for a room maybe twice the size of this [small*

> *office]…I have to share a washroom…if I could just afford a better place to live, I'd probably feel so much better about myself.*

Participants had insight into the link between housing and worsening health. A participant noted that her health was *"a lot lower"* and she was *"more tired"* when living on the streets. Another participant stated: "*Housing is very important to me…I can't live that life again…I won't allow myself to go more than a month without being housed.*" Despite the improvements in quality of life that came with housing, some participants were still living outdoors: *"I lived outside for four years and then I came here [social housing] and now I'm back outside".*

Housing was therefore a way participants could garner some stability in their lives through reducing their reliance on sex work, decreasing the risk of violence, decreasing drug use and improving health.

Transportation

A lack of transportation was a frequently-cited barrier to seeking health care. Transportation was also reported as a necessary means of accessing other social determinants of health such as food: "*And where I live, there's a food bank, but you need transportation for that too. So you're damned if you do, it's damned if you don't."* Participants often relied upon health and social service agencies to provide them with fare vouchers for transportation in order to get to their appointments: "*It's very hard. I get a [bus] token to get me home today cause I have no other way of getting home. So I was going to ask Dr. X for a bus ticket."*

Identification

Although all participants were eligible for a health card under the Ontario Health Insurance Plan (OHIP), participants described losing or having their health cards stolen and often the identification required to replace it. *"A lot of people don't have their OHIP."* Without any identification, participants could not apply for government benefits such as welfare or disability and thus were not able to access the government drug benefit program (Ontario Drug Benefit program). *"I haven't been getting any prescriptions anyway, because I haven't got a drug card."* Some participants relied on family physicians providing samples of medications:

> *So the one time I had a respiratory infection…and I went to [clinic] And she [family physician] gave me an inhaler. I just told her I didn't have a drug card…and she just gave me one.*

Moreover, not all medications are covered under the provincial drug benefit plan. Not having access to much-needed medications was particularly problematic for the following participant, placing her at severe risk of anaphylaxis when she was not able to pay for her epinephrine (EpiPen): *"…it [prescription] was no good because they don't cover Epipens anyway. So it was just a waste."*

Food Insecurity

Some participants reflected on their struggles to have enough food to eat every day let alone to eat nutritiously. *"Not eating properly, cause I don't have food…It makes it hard."* Poor nutrition was thus another factor contributing to poor health and made it difficult for participants to access health care due to fatigue and weakness: *"Well you got to eat for your nourishment…You can't be* *lying around weak."* One way in which participants' food security was addressed was by outreach workers distributing food necessities, particularly to participants who were living outdoors: "*...she's got cans and juices and fruit and stuff and she gave them to us....".*

Poor Access to Primary Health Care

Many participants did not have a regular family physician despite wanting one: *"I don't have a doctor. I wish I did have one though."* Making the decision to access health care often took a lot of courage for participants and yet when some participants finally made the decision to see a family physician, they were turned away: *"I went there but they wouldn't take me."*

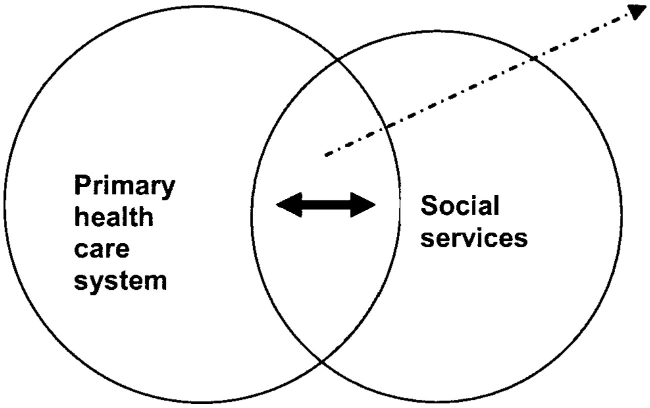
Not having access to a regular family physician prevented participants from receiving important cancer screening tests. The following participant had not been able to find a family physician in over ten years: *"...like when I had a regular doctor I would go every year or every six months, get paps, get mammograms."* Considering that so many participants found it difficult to go to a doctor, when they finally made the decision to go, they only found more barriers thus reinforcing a health care system that they could not trust and was not "for them".

2.4.3. PRIMARY HEALTH CARE DELIVERY

2.4.3.1 Overview

Just as the proximal and distal contexts of participants' lives could either facilitate or hinder their engagement with a family physician, the manner in which the primary health care system was designed and delivered also played an enormous role in determining whether or not participants were able to access primary health care. The provision of social services greatly enabled participants' engagement in the primary health care system. There was a bidirectional interaction between the primary health care system and social services (see Figure 2.2). This interaction was facilitated by the following factors: flexibility of service; location of services; partnerships; and institutional transference.

Figure 2.2: Health care access



Bidirectional interaction between the primary HCS and social services increased access through:
- **flexibility**
- **location**
- **partnerships**
- **institutional transference**

2.4.3.2 Flexibility of Service

The method in which primary health care services were delivered to participants either served to facilitate or hinder their access. The more flexible and creative service delivery was, the greater the ease of access for participants. For example, many participants used health care facilities which offered drop-in hours in order to access a family physician, nurse practitioner or nurse.

> *I have a terrible time keeping appointments. I just can't seem to manage them. So – then I just come in here [drop-in clinic] announcing like: 'I'm here! Take care of me!'.*

Moreover, some agencies offered the flexibility of both appointments and drop-in times:

> *Like tomorrow I have an appointment to see [my doctor] for my annual check-up but if you're not feeling well, a nurse practitioner or doctor... keep a couple of hours open...if you're sick, they'll find someone to see you.*

Thus, the availability of drop-in hours in addition to regular appointments allowed for the delivery of comprehensive primary health care with more acute illnesses being attended to during drop-in hours and preventive health care offered during appointment times. Some participants, however, preferred appointments:

> *I haven't done well at those places where you just hang out with a bunch of addicts, because I just find you end up making more connections...they're not a good choice for me.*

For this participant who had been abstinent for years, sitting at a drop-in with other drug-users served as a trigger. This illustrates that primary health care services for drug users need to be varied. Flexibility of appointment hours was also reported as being important to participants: "... *having a clinic open in the evenings, a lot of girls would ...go...I'd always make my appointments. I really would."* For this participant, having clinic hours that accommodated night-time sex-work may have made it easier for women to access primary health care.

2.4.3.3 Location of Services

The location of primary health care services also determined whether or not participants would access them. Because of the constant threat of violence, participants were often forced to keep within certain geographical boundaries. As such, if participants were expected to seek out primary health care, it needed to be in the areas where they felt safe and most comfortable:

> *...you have little boundaries when you're a drug user...you rarely go out of those little boundaries...which could be the roughest place in town but you know that area and you are comfortable ...*

Some participants stated that they were more likely to access care: *"If it was just next door, around the corner."* The chaos in participants' lives and lack of transportation also posed significant barriers to women being able to travel long distances to receive primary health care. Thus, having services geographically located in areas where participants lived and spent their days helped to improve rates of follow-up and follow-through.

2.4.3.4 Partnerships

Partnerships were described by participants as occurring both internally and externally. In terms of internal partnerships, collaboration between primary health care and social services professionals within agencies occurred. This collaboration allowed for individual agencies to provide multiple services. The idea of "one-stop-shopping" was appealing because participants could address their social, psychological and physical needs at one location. Offering concurrent health and social services allowed for easy access to a family physician, nurse or specialist and made accessing primary health care simple and straightforward.

> *They have a doctor, nurse, psychiatrist, massages, bloodwork, everything, a dentist, hygienist...women's studies that are just*

> *strictly for women to get screening…*

Another participant expressed how helpful it was to have vocational resources at the agency where she could also see a nurse and if necessary, a family physician:

> *… [it] has a computer lab in there…it's just a … building full of resources and programming that women can use to enrich their lives and make them better…*

The variety of programming offered at primary health care facilities varied depending upon the type of agency. The ability to receive services in one location was more than just convenient; it also helped to decrease the chaos in participants' lives:

> *I think it works because it's all in one building so you don't have to run around…that's given us more of a chance to do things…*

Partnerships also occurred externally. The need for social services by participants was enormous and there was a critical interplay between community social services and primary health care professionals. These partnerships were crucial to assisting participants to form links with family physicians. Almost all participants who had a family physician described having had a referral from a social service provider.

> *I found him [family physician] through this drop-in…I was living outside at the time, and I was sick…somebody said…there's a doctor that goes there…so I went there…and I've been seeing him ever since.*

These partnerships were also extremely important because these referrals enabled participants to establish a baseline of trust with a new, unknown health care professional. If participants were reassured by an outreach worker whom they trusted that a particular family physician was also to be trusted, then they would be more likely to see that physician: *"It all depends on who's affiliated... if it's a reputable [referral] source that I trust, than yeah, I go."* These sorts of referrals were an effective strategy to engage high risk women because the oral culture typical of street life helped word spread quickly if there was a helping professional who could be trusted:

> *That word of mouth thing is really big for me...recommendation goes a long ways. Word of mouth travels fast, especially out there on the streets.*

Therefore, internal and external partnerships allowed for the provision of multiple services and facilitated referrals of participants to primary health care professionals.

2.4.3.5 Institutional Transference

The ability to receive primary health care in a place where women felt safe, not stigmatized and accepted at face-value was a recurring theme in the data analysis.

> *...it's one of the reasons they opened this program [for drug users] ...is because crack users didn't have a place to go where they could feel comfortable and not feel so isolated...and they don't judge you ...they kind of embrace you.*

Some participants had such strong experiences of institutional transference that they described an agency as their home:

> *Because I do so much stuff here, and I have so many groups here and I have so many people here that support me...it's amazing...this is like my home away from home. And I feel safe here...*

An essential part of institutional transference was participants feeling like they "looked like everyone else". "*...there are other people who use crack [who]* *come here so I don't feel like I stand out like a sore thumb."* Identifying oneself as part of a community of others in similar situations created opportunities for participants to form bonds with one another and the community agencies where they received social and primary health care services. Considering that participants were frequently stigmatized because of their drug use and suffered from low self-esteem, coming to a place where they were treated with dignity and respect was identified as an essential part of their primary health care.

2.4.3.6 Primary Health Care Delivery: Summary

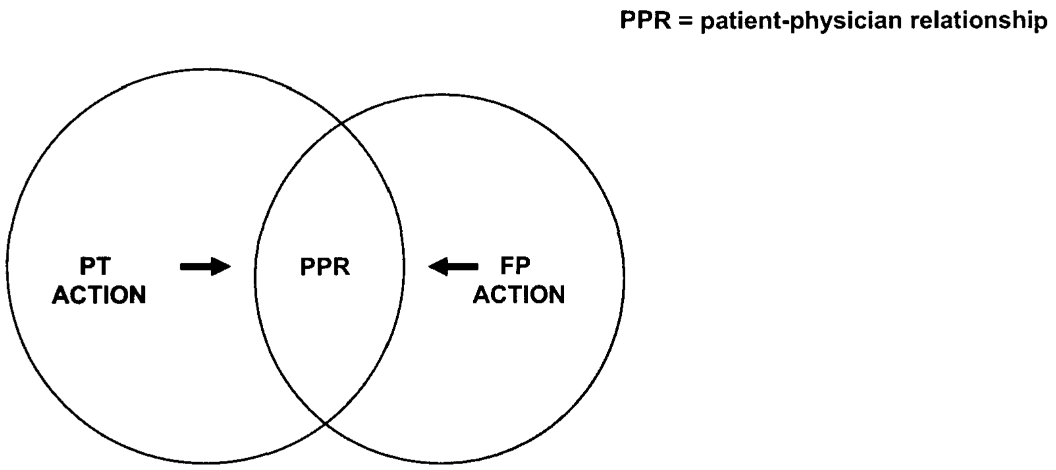
Flexibility and location of primary health care services, in part, determined how easy it was for participants to access primary health care. When delivery of these services was combined with the provision of social services, access was even further facilitated. Providing multiple services in one location along with concurrent social and primary health care services allowed for easier and more convenient access to primary health care. When this inter-disciplinary collaboration took place, institutional transference could develop and be fostered.

2.4.4 PATIENT-PHYSICIAN RELATIONSHIP

2.4.4.1 Overview

Another theme arising from the data analysis was that of the patient-physician relationship. In order for a patient-physician relationship to be established many factors had to fall into place for participants. Both participants and their family physicians took specific actions to facilitate the formation or maintenance of this relationship as detailed in Sections 2.4.4.3 and 2.4.4.4 (See Figure 2.3).

Figure 2.3: The Patient-Physician Relationship



2.4.4.2 The Relationship

Despite the individual actions that participants and their family physicians took to foster the process of engagement, there were many obstacles faced by participants that made seeing a family physician and developing a relationship with that physician difficult. These factors comprised both the proximal and distal contexts of participants' lives and factors related to health care delivery. Despite these hurdles, some participants readily described the positive relationships they had with their family physicians. There were four subthemes which emerged from the data analysis reflecting factors which allowed for the development of this relationship. These subthemes were: being non-judgmental; listening; continuity of care; and trust.

A. BEING NON-JUDGMENTAL

Being non-judgmental was identified by all participants as an essential quality in a family physician. Because most participants struggled with low self-esteem and were constantly bombarded with negative societal stereotypes of women who sell sex for drugs, it was crucial for their family physicians to treat them with dignity, respect and compassion. The following quotation exemplifies being treated in a non-judgmental manner by a family physician: "*...there's no judgment call there...there's no 'Well, you got yourself into this mess, suffer the consequences. There's none of that shit.*" Part of being non-judgmental was being treated with compassion: "*I would definitely say that the compassion and understanding and caring that's shown from the doctor definitely makes me feel like I'm not being judged.*" Another aspect of being non-judgmental described by participants was taking sufficient time during patient visits: "*They show concern, it's not like an in-and-out thing, hurry up...There's a humanity about someone like that. It's not like cattle...*".

It was particularly meaningful to participants when their family physicians stopped to talk with them outside of the office visit as in the following example when a family physician stopped to speak with a participant on the street:

> *How many doctors or nurse practitioners do you know that on the way to their lunch...take an extra two blocks out of their way to come over and say: 'How are you doing?' to a bunch of people ...sitting drinking wine in a laneway...*

When treated with compassion and dignity, participants could begin on a journey of empowerment supported by their family physicians: "*She told me that I could be better than anybody else. Put yourself first...because...I'd always put other* *people before myself…and that's what made me feel good towards her… Now I feel better."* Another participant expressed how, after her mother had died, with her family physician's support, she felt empowered to make positive changes:

> *My doctor saved my life because I wanted to kill myself…it felt like I was wanted. Somebody that was …not a friend or family…She helped me through a lot… wow, somebody can actually…care so much for you…after that I realized that wow, I do have more to live for.*

Thus, a central feature of a positive patient-physician relationship was having a family physician who was non-judgmental and accepted participants at face-value.

B. LISTENING

Another important sub-theme raised by participants was having a family physician who was a good listener – a quality which was vital to forming a strong patient-physician relationship. *"…my doctor is my best friend…she listens…she doesn't open up her mouth. She sits there and she listens."* When asked what physicians could do to better help women in similar situations, a participant spoke passionately about the need for physicians to listen to their patients:

> *Everybody should be heard… The world will be a better place if there was a lot more doctors that would listen. Instead of saying 'Well, this is what is going to happen. You need to do this. You need to do that.' To hell with you. That's what I would say to the doctors.*

Listening was therefore identified by participants as a factor that facilitated maintenance of the patient-physician relationship.

C. CONTINUITY OF CARE

Another subtheme which emerged from the data analysis relating to the patient-physician relationship was that of continuity of care. A few participants had been seeing their family physicians for over ten years: *"...Same doctor. Twenty five years."* When participants had been seeing the same physician for this length of time, it became progressively easier to talk about their drug use and pasts: *"They know me."* In fact, continuity of care was so important to one participant that she wouldn't move from her neighbourhood: *"...I'm here, and I like it here, and I'm not moving out of the area."* Participants therefore felt supported by those family physicians with whom they had long-term, continuous relationships.

D. TRUST

When a family physician treated a participant in a non-judgmental manner, the process of establishing trust could begin and thus trust was another important subtheme raised by participants. For example, the following participant only decided to return to a particular family physician for a second visit after meeting him for the first time because: *"...I trust him."* Without trust, continuity of care could not be established.

Although most participants spoke about the importance of trust within the patient-physician relationship, most found it difficult to articulate how trust was established and admitted that it was usually instinct and intuition that served as their guide: *"It's a gut feeling, that's all. Sometimes it's great. Sometimes it's* *bad."* Presence during difficult times was also described as a way of establishing trust within the patient-physician relationship. The following participant recalled having her family physician provide support for her during a mental health crisis: *"I love her to death. I trust the woman with my life. When I was in my deep depression…who was here for me? Dr. [X]."*

Thus, non-judgment and presence paved the way for trust to be established between participants and their family physicians. Furthermore, trust was a necessary prerequisite for sustaining the patient-physician relationship allowing for continuity of care to take place.

2.4.4.3. Patient Action

Patient actions helped facilitate relationships between participants and their family physicians and also helped participants advocate for themselves within the primary health care system. Many participants tried very hard to take control over their lives and took various actions to be as healthy as possible. Five subthemes reflecting patient actions were revealed in the data analysis: peer work; resilience; readiness for change; health as a priority; and preparing for physician visits.

A. PEER WORK

Informal and formal peer work was a significant subtheme within the broader theme of patient action. In terms of informal peer work, participants shared their experiences of supporting other vulnerable women and helping keep each other safe. This included distributing condoms and clean needles to more marginalized women who did not or were not able to access harm reduction programs.

> *I take a bunch of shit out in the street ...I know all the girls out there... I know where a lot of their hiding holes are ...where all the crack houses are ...I'm a regular face so, they're more trusting of me...I bring them crack pipes and condoms.*

Volunteer work was also common among participants: *"I volunteer over at [agency X] ... it's a drop-in for psychiatric survivors."* This informal network of women helping other women served to occupy participants' time and, as a consequence, their drug use often decreased: "*And now I do so many programs...I work at another couple of drop-ins, volunteer ...so I don't have time to use [drugs] as much as I used to.*"

Some participants had access to formal peer education programs directed at training sex workers and/or drug users to become outreach workers distributing safer sex supplies and drug use kits to other street-involved women.

> *They had an outreach class... I graduated and got a certificate for that. And then I did a peer...working class...you go around and you deal with sex workers...giving condoms. If they need information for hostels...I think it's going to be a great thing.*

Participants expressed feelings of ownership and pride when referring to these programs:

> *...this program's been going on for a year and a half now. And it's like the first one of its kind in Canada. Like a pilot project. And it's done tremendous [things].*

Participation in such peer activities was empowering and participants felt as if they were making an important contribution to their community, helping to form and sustain a sense of social belonging.

B. RESILIENCE

The theme of resilience underlay many of the stories which participants shared and contributed to them being able to overcome what often appeared as insurmountable obstacles. Central to this resilience was a "survivor attitude". Despite the hardships placed in front of them, participants portrayed an attitude that they would make it no matter what obstacles life placed in their paths.

> *I just suck it up. Because it's really all you can do…what I remember most from my childhood is…my mom saying 'Life's a bitch, get over it' … So I'm sucking up it.*

Thinking they had survived the worst of it, participants believed they would be able to cope with any future hardships. In fact, some participants felt that the "average" person would be unable to survive if faced with similar hardship:

> *But if other people were in our shoes, like doctors and teachers…they wouldn't be able to, honest to God, I do not think they would be able to deal with it. They'd give up.*

Experiencing problems with one's health also contributed to participants' "survivor attitude": "*I do realize how strong I am…I've walked down so many roads that no normal human being would want to walk down…or come out of it in one piece…*".

When life was so chaotic and disorganized, participants described coping by adopting a "one day at a time" mentality: "*…one day at a time. That's all you* *can do."* "Just getting by" was another expression used by many participants to describe how they coped: *"Just getting by. You don't have a house [or] ... a shower...So whenever it's available, we take it."*

Thus, having a survivor attitude helped women cope with overwhelming stressors and a lack of basic necessities.

C. READINESS FOR CHANGE

The theme of readiness for change was pervasive among participants. Participants were clear that only they could make the decision to stop or decrease their drug use and that this would happen only if and when they were ready. "*You gotta want to help yourself first...If you don't want it you're not gonna come [seeking help]."* Some participants were obstinate in their refusal to seek help for their drug use:

> *I'm not happy about my life situation right now – but I love myself and I don't care if other people want to be around me or not...if you don't like me, you can fuck off. I'm not going to change myself for anybody.*

For one participant who had been abstinent for many years with the help of a methadone maintenance program, hitting rock bottom was the driving force propelling her to quit using drugs: *"It was just a matter of being ready and...hitting my own personal bottom."* There was a laissez-faire attitude expressed by some participants: *"I'm just not there [ready for help] right now. If I ever get there, I get there. If I don't, I don't."* Thus, another action participants took to take control over their situations was to take responsibility for their drug use and recognize that only they could ultimately make change in their lives.

D. HEALTH AS A PRIORITY

Placing health as a priority was another strategy used by some participants to ensure that they stayed as healthy as possible despite the many mental and physical health problems they suffered from or for which they were at risk. For some participants, recognizing the health risks associated with drug use, being homeless and/or being involved in sex work driving them to participate in these screening tests. This sentiment is illustrated by the following quotation:

> *And when I was living outside, I was really careful. I was at the doctor's all the time…pap smear there, checking for AIDS…because you care about yourself…just because you're homeless, doesn't mean that you've given up total hope.*

Although facing multiple barriers in accessing primary health care, one participant expressed: *"Health is always a priority, it has to be. Because there are so many things out there you can contract."* Another participant who had a history of cervical cancer recognized the importance of getting regular pap smears: *"I come probably once every three months to have a pap smear…even if I'm not sick…just touch base."* Thus, placing their health as a priority was a strategy used by some participants to maintain an element of control over their lives.

E. PREPARING FOR PHYSICIAN VISITS

Preparing for the physician visit was another subtheme identified by participants. Strategies participants used to prepare for and enhance the visit with their family physicians included: timing of drug use; respect; being selective about their drug history; and seeking out non-judgmental care.

Timing of Drug Use

Participants did not like seeing a physician when they were high or in withdrawal. Many participants commented that they wanted to see their family physician when they were clear-headed: *"I'd rather go in clear-headed and be able to talk to him on a somewhat intellectual level, and not all frazzled."* Some participants went to great lengths to ensure that they did not use the night before an appointment. This might have entailed staying in and not answering the door to friends or hanging out with friends who did not use drugs.

> *...if I know I've got an appointment, I won't use the day before...I just stay home and vegetate and go to my appointment. That way I don't screw up.*

Respect

Treating their family physician with respect was another subtheme reflecting patient actions. Participants felt that if they expected to be treated with respect, they too were obligated to be respectful. Respect helped to form a strong patient-physician relationship. Participants named two strategies to demonstrate their respect for their family physicians: reciprocity and honesty.

Participants felt that not being high when visiting their family physicians both demonstrated and earned respect. "*...You have to give respect to demand respect back...*". This reciprocity helped to build trust. Although some participants simply wanted to be clear-headed when they had an appointment, many saw their family physicians' time as valuable. *"Well I know her time is valuable and I really like her a lot…I feel like she really cares about my health."* Thus, visiting their family physicians when they were high was seen as a waste of both their own and their physicians' time.

Reciprocity was also demonstrated when participants took responsibility for their own behaviour. If participants were under the influence of drugs and behaved inappropriately or used drugs on site, they expected repercussions. *"I wouldn't come here [clinic] under those condition…if I got caught smoking in the bathroom, it'd be a month [ban]…a month is a long time when you get respect from a place. I couldn't afford that."* Thus, being drug-free was a way of indicating respect for a trusted professional.

Honesty was another patient action which helped to show respect for health care professionals:

> *I am smoking crack every day…let's say I miss a day of the methadone and I would do an opiate – so I would tell him, right?…if I fool myself, it doesn't get me anywhere. 'Cause a lot of people are into cheating and …it doesn't do me any good.*

Thus, when participants' showed respect through reciprocity of behaviour and being honest, they contributed to establishing trust and building a solid patient-physician relationship.

Selective About Drug History

Another method participants used to prepare for a visit with a physician was deciding what part of their drug use history was relevant and they were willing to share. Discussing their drug use made participants vulnerable and open to stigmatization, so many women chose to be selective about their drug history with physicians – particularly ones with whom they did not have long-term relationships. The following participant revealed that she would not recount her drug use history with a physician at an initial visit: *"I have to wait and see about you, to trust you."* If the drug use was seen as pertinent to the current health problem, participants were often more willing to reveal their drug use: *"…I don't know if I'd be forthcoming …it depends what I was there for…".* Thus, this was a method of self-preservation, protecting themselves from unnecessary stigmatization.

Seeking Out Non-judgmental Care

Because of the stigma attached to being a drug-user, many participants strived to find a health professional whom they thought would be non-judgmental. Many other participants simply avoided health care for fear of mistreatment: *"I just wouldn't go…and face the humiliation."* This led to some participants relying on self-care when they fell ill: *"…if something happens to me I just let it heal…".* A few participants only sought out health care if they felt their lives were seriously compromised – in other words, they would only get help if they were desperate. *"I would have to be in a lot of pain or something really wrong…".* Seeking out non-judgmental care was therefore a survival strategy whereby participants protected themselves from mistreatment by health care professionals. Coping strategies such as self-care were then used to compensate for a lack of medical care.

Preparing For Physician Visits: Summary

One way participants exerted control and put order into their lives was by preparing for visits with their family physicians. When they had trusting relationships, participants wanted to maximize the time spent with their family physicians and timed their drug fixes accordingly. They were creative and resourceful in ensuring that health care providers had only the necessary information about their drug use in order to protect themselves from stigmatization. Participants also took great strides to protect themselves from mistreatment by health care professionals and the health care system by seeking out non-judgmental care.

2.4.4.4 Physician Action

Another major theme arising from the data analysis was that of physician action. Specific actions of individual family physicians nurtured the development and maintenance of the patient-physician relationship and determined whether or not participants engaged with the primary health care system. Subthemes which emerged within the broader theme of physician action included: harm reduction philosophy; quality care; and going the “extra mile”.

A. HARM REDUCTION PHILOSOPHY

Many participants described having positive experiences with family physicians who adopted a harm reduction approach to their work and displayed empathy with respect to participants' addictions. Participants were more likely to report positive experiences with a family physician if he or she displayed comfort in working with drug users and used direct language and questioning about participants' drug use. *"I don't like people who beat around the bush…I don't like when people try to confuse me…[be] direct and simple."* They also appreciated receiving counselling about harm reduction strategies and being given harm reduction supplies. The following participant had a positive experience with a family physician she was visiting because of a cough when the physician reminded her not to share her crack pipes: *"…she [said] 'well don't share your pipes'…She was good, this doctor."*

Many participants also discussed the importance of having family physicians who could relate to them: *"That's why I like the health care here…they can relate to us…"* and had experience in working with this population: "…*maybe have an actual doctor that knows about drug use and women who do street work and what we're going through…someone educated on it."* Another participant described how having a family physician who knew when to back off and not push too hard around stopping her drug use was critical to maintaining engagement with her family physician: "*Yeah, if they're hard on you, you're just going to continue to do it. If they just leave you alone… you're going to stop on your own."*

B. QUALITY CARE

Having a family physician who provided quality care was another important attribute expressed by participants. One aspect of providing quality care was being competent: *"…that they know what they're talking about. That's very important with my health problems."* This competence also extended to specific procedural skills and to other team members. The following participant reported how important it was for her nurse to be able to perform a successful venipuncture: "*She's the only one who can take my blood. No one else can take my blood."*

Another physician action that was repeatedly expressed by participants as helpful was that of knowledge transfer. Participants wanted a family physician who was able to explain things in terms that were easily understood. "*I had a hysterectomy done two years ago. And she explained the whole situation, what I'd be going through…It was… a lot of help."* For this participant, having the appropriate knowledge before her surgery was both empowering and reassuring.

Part of being able to translate knowledge about health problems was having information available that was appropriately geared towards this community. "*Just give them [drug users] more information and be more open to what they have to say…maybe get into wanting to help, give them pamphlets, place to go…".* Being able to translate information clearly and accurately was of particular importance given the low rates of literacy in this population. In the following quotation, a participant explained how her family physician explained information well to patients who could not read:

> *...she explains it to them so they understand that it's important because ...you can know all the medical jargon that you want, but when it comes down to telling somebody how sick or whatever it is they have, you put it in terms that they can understand, it's very important.*

Having a family physician that made appropriate referrals was another subtheme reflecting physician action. *"She helps me...she refers me to places where I can go to get help...with my addictions...I think it has worked."* The following quotation describes a situation where a participant wanted to ensure that she was being referred to the appropriate specialist for her Hepatitis C:

> *...if I'm going to be into transplants eventually, than I'd rather ... be at [the hospital] where they do the transplants. So that way I can start building a network of specialists there. And so she did some research and found out who I should be seeing.*

Therefore, having a family physician that had relationships with good specialists was believed to be an important aspect of providing quality care.

Lastly, family physicians who helped their patients navigate the health care system and helped give voice when they might otherwise not be heard were also looked upon with gratitude.

Once participants found a family physician who they could trust, they expected that physician to be competent, provide appropriate referrals and be an advocate. Providing high quality care thus was another factor determining whether or not participants continued to see a particular family physician.

C. EXTRA MILE

Acts of kindness and generosity which were outside the normal domains of the physician-patient relationship were highly valued by participants. "Going the extra mile" was something some family physicians did to support participants: *"She does a lot for me. A LOT. My doctor even paid for me to go to my father's funeral...No doctors do that...And my doctor did it."* A homeless participant felt cared for when her nurse practitioner came and visited her outdoor "camp": *"...they came up to the work camp...they came up the tracks to see how we were doing...to see if we're alive and well...".* When another participant did not show for her appointments for long stretches of time, her family physician would call her and remind her to come in. *"I got in shit for [not coming in]."* Thus, having family physicians step outside of traditional roles and boundaries made participants feel valued.

2.5. DISCUSSION

This phenomenological study set out to explore the experiences of vulnerable women using illicit drugs and in particular, how these women engage in the patient-physician relationship and the primary health care system. This study was important for a few reasons. First, although there is an abundance of literature exploring the health care usage of street-involved women there is little research exploring how these women engage in primary health care. Second, this study investigated not only the barriers women face in accessing primary health care, but also patient- and physician factors that facilitated this access, from the perspective of the patient. Lastly, this study served to explore the strengths of this population and ways family physicians and primary health care delivery models can support and foster these strengths.

2.5.1 THE CONTEXT OF WOMEN'S LIVES

Participants were honest and straightforward as they articulated the ways in which their drug use, sex work and lack of housing impacted their daily lives, health and ability to access primary health care. These aspects of women's lives comprised the proximal and distal contexts[59]. Providing patient-centered care requires an understanding of the contextual factors which give meaning to the health and illness of an individual[60]. Understanding of such contextual factors leads to a richer understanding of the patient, as a whole person, and helps explain changes in their health status. For example, changes in context can lead to exacerbations of chronic disease states[61].

2.5.1.1 Proximal Context

In this study, proximal factors included three inter-related and inter-dependent themes: drug use, the "hard life" and chaos. Participants' drug of choice was crack although polysubstance use was common. This finding confirms previous studies indicating crack to be the most common drug used in inner-city Toronto[1,2,13,15,16,18,62]. Drug use among participants was pervasive and risky. This study therefore also confirms the findings of previous studies indicating that crack use is associated with high rates of risky behaviours and marginalization (e.g. homelessness, mental illness, sex work etc).

A: DRUG USE AND HARM REDUCTION

Stopping drug use was something most women in this study were unable to do. Using drugs to numb both physical and emotional pain was an important coping mechanism for this group of women who had negligible social supports and little access to mental health care. The relationship between drug use and emotional distress is complex and it is unclear what state precedes the other[63]. Participants in this study clearly used drugs to self-medicate; however, some of their emotional distress may have also been caused by the drug use itself. Studies have indicated that drug use is very common among people suffering from post-traumatic stress disorder and this study would lend support to the self-medication theory[63]. Participants continued to use drugs despite the numerous and serious health complications brought about by the drug use. Many participants had experienced overdoses and some reported almost dying. Thus, the "drug life" only led to more health problems and mental distress perpetuating a cycle of self-destruction.

Many participants, however, were able to reduce their drug use and decrease drug-related harm. Strategies which facilitated use of harm reduction programs (e.g. needle and crack stem distribution) were housing, participation in peer-work and a supportive patient-physician relationship.

Thus, this study adds to the current literature recognizing the vital role that harm reduction plays in decreasing drug-related morbidity and mortality in a population of vulnerable, drug-using women[64-69]. All participants who were active drug-users reported use of needle and crack stem distribution programs and were aware of the risks of sharing drug-related paraphernalia reflecting the success of such programs in the city of Toronto. For almost all participants, abstinence was simply not feasible. Yet, those who were able to decrease their drug use reported increased stability and participation in the primary health care system.

B: "HARD LIFE"

Participants' lives were fraught with challenges and this constant uphill battle was captured by another recurring theme – the "hard life". There were five factors which contributed to this "hard life": health problems, current experiences of violence and trauma, past experiences of violence and trauma, sex work and barriers related to sexual and gender identity.

There was a high disease burden among participants. Respiratory diseases such as asthma and infection with Hepatitis C were commonly reported. Previous studies have reported similar findings[13,35]. Although there is an abundance of research examining the effects of inhalational use of crack cocaine, the majority of the research is specialist-driven and does not address what can be done in the primary health care setting to reduce disease burden and manage acute and chronic illness[70-72]. Further studies should examine the respiratory effects of crack in the primary health care setting in order to describe appropriate management strategies. Infection with the Hepatitis C virus was also common and indicates the need for primary care management of this disease with particular attention to the needs of illicit drug users[73-75].

Violence was endemic among participants and was an undercurrent in the narrative accounts of participants' daily lives. Previous research has examined the violence associated with homelessness, drug use and/or sex work[11,13,14,17,18,19]; however, this research often compartmentalizes risk of violence within specific populations. This study provides a rich picture of the complex relationships of drug use, homelessness and/or sex work to violence and how they are intertwined and inter-connected. This finding lends itself to a quantitative study elucidating upon these relationships.

Violence comes in many forms for street involved women: past histories of violence and trauma, sex-work related violence, intimate partner violence, and violence due to living on the streets or as part of the drug culture[11,13,14,17,18]. Witnessed violence is also common and can have just as devastating an impact on women's well-being. Although this study did not elucidate the different forms of violence, it was clear that violence, both enacted and the threat of, was a constant and underlying reality in all participants' lives.

Women living in poverty who are marginalized by violence have been found to have high levels of dissatisfaction with their care from a family physician[47]. This has been found to be because of poor communication within the patient-physician relationship and having little control over the patient-physician encounter[47]. Family physicians need to understand the role of violence in marginalization and the potential decreased ability for such patients to articulate their concerns. As such, family physicians should communicate clearly and ask what women's needs, fears and expectations are of a particular medical visit[47]. This can serve to decrease the power differential between patient and physician[47].

There was also a high prevalence of mental illness among study participants. The high rates of mental illness among drug users points to the need for concurrent disorder services. Considering that many mental health programs exclude people with drug addictions, this finding seems particularly important. Any program geared towards drug users must account for the epidemic of violence and must treat addictions in conjunction with emotional trauma. As drugs may be used to ease symptoms of mental illness, treating an addiction without concurrent trauma treatment could destabilize patients and trigger a mental health crisis.

Engaging in sex work was a strategy participants used to increase their financial security, to secure safe shelter and to buy drugs. Sexual acts were often traded for drugs and housing and thus the term “survival sex” may be appropriate[11]. Although some sex workers are employed as autonomous agents and have a clear choice in their work-related activities[19,76,77], this was not the case for women in this study. Participants in our study had few alternatives to sex work and were rarely able to exercise significant amounts of free will. On the other hand, women were not helpless victims. They often made decisions about what type of sex to engage in (oral versus vaginal or anal), which clients to engage with and they took frequent action to protect their health. Health protecting actions included enforcing condom use and getting screened for sexually transmitted infections.

Despite trying to exert as much control as possible in their work, survival sex served to further marginalize and stigmatize this group of women. Participation in sex work was associated with significant feelings of shame. Sex work also placed them at exceedingly high risk of violence and many participants had had their lives threatened and had come close to being killed. Life-threatening sexual and physical violence has been reported in other studies of sex workers[11,13,17-19]. In fact, in a study by Romero and colleagues, 60 percent of female sex workers interviewed had been raped while working, over 90 percent had been physical assaulted by a male client while at work and 20 percent reported incidents where they were almost killed[19]. Awareness of these risks is essential for health care providers so they can work effectively with women to reduce the harms inherent in their work – a strategy called sex work harm reduction[14].

Factors related to being pregnant were frequently discussed by participants. Many participants had experiences with child welfare services, usually because of drug use and/or homelessness and loss of children to child welfare services was common. The reasons for these losses were not fully explored in this study although other studies have reported non-drug related causes such as mental illness and intimate partner violence to be factors[18]. One study interviewing female sex workers who used crack found: "Many of these women recognized on their own that active mothering and cocaine use were incompatible" [18]. Thus, drug-using women may actively choose not to mother their children recognizing that they are unable to provide optimal care at that time[18]. Pregnant women who use illicit drugs are an elusive population. Strategies to engage this particular population and an exploration of the effects of offering harm reduction programs specifically geared to pregnant, drug-using women are areas deserving further study.

Some participants revealed an inability to stop their drug use while pregnant, while others identified that pregnancy provided an opportunity to stop their drug use and focus on their wellbeing. This finding is in keeping with a qualitative study by Butters and Erickson where most pregnant participants reported receiving prenatal care and paid attention to the health of their unborn child despite insecure financial and personal situations[13]. Pregnancy also intensified women's experiences of violence and drug use pointing out the need for family physicians to screen pregnant women for violence and substance use[78].

A striking finding of this study was that half of the participants identified as belonging to a sexual minority. Barriers related to sexual and gender identity were numerous and simply added another obstacle to seeking primary health care. Being part of a sexual minority also placed participants at high risk of violence. Few studies have reported the prevalence of sexual and gender identity minorities among illicit drug users in Canada, particularly among women; however, in a survey of 364 homeless people in Toronto, 18 percent reported as being gay, lesbian, bisexual or transgender[1]. Two Canadian studies have reported the prevalence of transgendered people among the homeless and sex worker populations to be approximately one to two percent[1,79]. Previous research has found that lesbian, bisexual and transgender women are more likely to report illicit drug use and drug use which impaired function[80-83]. The use of crack by lesbian and bisexual women has been found to be strongly associated with social isolation, problems with the law, unmet health needs and underutilization of drug treatment[84].

This study provides new insights into why this population of women may underutilize drug treatment programs including: stigma and subsequent mistrust of health care professionals and the health care system, need to seek health care within a particular geographical area (i.e. to minimize violence) and unfamiliarity of health care professionals to the specific health care needs of transgender people. Although the high prevalence of sexual minorities in this study cannot be extrapolated to illicit drug users in general, it does illustrate the unique needs of lesbian, bisexual and transgender women and the need for health care professionals to recognize the higher rates of drug use within this population. Considering that transgender people have higher rates of sex work participation and HIV infection as compared to their heterosexual counterparts[85,86], family physicians must be aware of these increased risks and ensure appropriate harm-reduction counselling and screening for sexually transmitted infections and infectious diseases such as HIV and Hepatitis C.

C: CHAOS

The lives of participants were marked by chaos, crises and disorganization. This chaos led to a competition of priorities and subsequent difficulties adhering to health management recommendations. The need to get high, secure safe housing and find adequate nutrition often superseded the need to seek medical care. Competition of priorities is a phenomenon that has been reported in previous studies exploring the health of homeless women[21,31]. Need for medical care does not determine street-involved women's use of primary health care services partly because of these competing priorities[31]. In light of this finding, primary health care services should be designed to be flexible, convenient and allow for drop-in patients.

D: STIGMA

Participants' lives were greatly influenced by another proximal context – stigma. Stigma has been defined as: "...a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group"[87]. For participants, the stigma associated with being a drug user, sex worker or person who is homeless led to feelings of immense shame and a general mistrust of physicians and the health care system. This is not surprising considering that stigma often targets diseases and populations that are associated with behaviours considered deviant. Research has demonstrated that many populations experience significant stigma. These include drug users, sex workers, gay, lesbian and bisexual youth and people infected with HIV/AIDS and Hepatitis C[14,87-94]. Individuals and/or populations who are often stigmatized are seen as posing a hazard or threat to society[14]. A more appropriate lens from which to view the process of stigma would be to examine the societal factors that contribute to and/or perpetuate the problem[87]. Viewing sex work from a public health lens may decrease the stigma affecting this population of women[14].

In this study, feelings of shame as a consequence of being stigmatized contributed to participants' experiences of marginalization perpetuating a cycle of further marginalization and isolation. These findings are consistent with other studies exploring the effects of stigma such as low self-esteem, undermining social support structures used to access medical and social services and decreased help-seeking behaviours[87,89].

2.5.1.2 Distal Context

Just as the proximal context of women's lives greatly influenced their level of engagement with a family physician and the primary health care system, so too did the distal context – the social determinants of health. Lack of housing, transportation, identification, food security and access to primary health care were social determinants of health identified by participants.

A: HOUSING

Lack of stable housing was the greatest influence on the participants' stability. Lack of housing has been linked to high mortality rates, poor health, high rates of witnessed and experienced violence, isolation, a decreased ability to cope with stress, lack of social supports and mental illness[1,12,21,23,24,35,36,38-

[40,95,96]. Housing not only provided participants with shelter from the elements, but it also decreased their reliance on sex work and drug use. As a consequence, women who were housed experienced less violence. The link between housing and violence is self-reinforcing. Violence, including intimate partner violence, can lead to homelessness and homelessness places women at higher risk of violence[21,36,97].

There is little research on the relationship between housing and sex work. This study provides important new insights about the role of housing as an important determinant of sex work involvement and high amounts of drug use. Previous research has explored the need for housing in order to address homelessness among sex workers; however, there is little information available about the subsequent changes in high-risk behaviours and activities after sex workers are housed[98]. This study suggests that housing improves the health of sex workers and this information can be used to advocate for more affordable housing.

Housing provided participants with increased control over their lives. When participants had a safe place to retreat, they experienced less street- and drug-related violence and did not have to provide sexual favours in exchange for shelter. Housing was therefore empowering. Increased control has been found to increase self-esteem which can increase an individual's ability to cope with stress[14,99]. Furthermore, having housing can improve health and there is an abundance of literature outlining the health effects of homelessness[1,12,21,23,36,35,96]. Quality of housing was another theme raised by participants. Even when participants were housed, their housing was often inadequate. Poor quality housing has been linked to poor mental health[100]. Thus, besides housing being a fundamental human right as declared by the United Nations, there are indisputable benefits to find urgent housing for this population of women[101].

B: TRANSPORTATION, IDENTIFICATION, FOOD SECURITY AND LACK OF ACCESS TO PRIMARY CARE

Lack of secure housing affects other social determinants of health because individuals have fewer resources available for accessing other health enhancing factors such as food, transportation and education[96]. Given their lack of housing, participants in this study were thus lacking determinants of health such as transportation, identification, food security and access to primary care. This can lead to further social exclusion[96,102]. Lack of identification as a barrier to receiving health care has been identified elsewhere in the literature; however, this study identified the potentially devastating impact this problem can have on patients' access to prescription medications, particularly life-saving ones such as epinephrine[1,35,103]. The lack of social determinants of health contributed to participants' competition of priorities as meeting basic needs superseded the need to seek medical care.

2.5.2 PRIMARY HEALTH CARE DELIVERY

Participants provided rich and detailed accounts of their efforts to access the primary health care system which has not been elaborated upon in the medical literature. The manner in which primary health care services were delivered influenced the level of participant engagement. As outlined above in Section 3.5.1, there were many factors which made it difficult for participants to engage in the primary health care system. Participants identified four main facilitators to access: flexibility, location of services, partnerships and institutional transference.

Providing varied and multiple services in a flexible environment was critical to engaging this high-risk population. This flexibility was characterized by providing both drop-in and appointment times. The need for drop-in services for marginalized populations has been described elsewhere[43,104] but our study found that specific structures do not work for everyone, and having different options available can increase drug-using women's access to primary health care services. This study also elucidated the effects of sex work and drug use on appointment adherence. The timing of clinical services was important to some participants because they needed clinic hours to reflect the night-time hours held by sex workers. Although there was no consensus among participants, having morning or evening appointments appeared to be preferable.

Providing a "one-stop shopping" model also facilitated access. Participants provided resounding support for agencies which provided both medical and social services. Although the concept of providing social and health care services at one location is not new, this study found that there was a bidirectional relationship between social and medical services and that medical care was often dependent upon social services[25,104]. Providing multiple services was much more feasible when collaboration was present. Both external and internal partnerships fostered this collaboration and allowed for the provision of appropriate referrals to family physicians or to social service providers. A novel finding of this study was that most participants accessed social services prior to seeking medical care and the majority of participants who had a family physician had found that physician through the help of a social service professional. Thus, communication among agencies serving drug-using women is essential. Providing concurrent social and medical services in one building can further facilitate this communication.

Location of services was paramount for participants. The drug-users in this study identified strongly with particular neighbourhoods – areas where they felt accepted and less judged. Participants did not want to leave the neighbourhood where they felt safe for fear of discrimination secondary to stigma and violence. Thus, community agencies offering programs to drug users need to be keenly aware of the role of their location. Providing services in one area also helped to foster the development of social cohesion and a strong sense of family for a population that had few family ties. Social cohesion is an important social determinant of health and has been linked with lower rates of mortality[102,105,106].

Strong experiences of institutional transference occurred for participants who received multiple services at one location. These were often agencies where they picked up their harm reduction supplies and had programming specific for drug-users. Institutional transference is characterized by a feeling of acceptance and non-judgment. Previous literature has reflected the need for respectful and non-judgmental attitudes towards drug-users[14]. Furthermore, although there is research expounding the benefits of institutional transference, particularly in the mental health field, there is no literature extending this concept to services for drug-users[107]. Institutional transference was thus an outcome of successful collaboration among peer programming, health care professionals and social service providers and fostered the engagement process.

2.5.3 THE PATIENT-PHYSICIAN RELATIONSHIP

2.5.3.1 The relationship

Having a positive patient-physician relationship was highly valued by participants and the support many received from their family physicians contributed to feelings of increased self-worth. Factors which facilitated the formation of a positive patient-physician relationship and helped sustain it were: being non-judgmental, listening, continuity of care and trust.

Participants who had positive relationships with a family physician described how meaningful it was to have someone treat them in a non-judgmental fashion. Non-judgmental care was expressed as treating individuals with dignity and compassion. Feeling cared for and valued for who they were helped to mitigate some of the feelings of stigma participants faced on a daily basis. Having a physician who spent time with them and took time to say hello when walking on the street helped foster a nurturing patient-physician relationship. Treating people in a non-judgmental fashion facilitated continuity of care. Previous studies confirm how stigmatized patients are often mistreated by health care professionals and how this can lead to decreased help-seeking behaviours[47]. This study provides important new information about how being treated in a non-judgmental manner benefits both the patient and the patient-physician relationship.

Participants in this study also identified how having a family physician who listened to their concerns contributed to their feelings of self-worth and encouraged continuity of care. When people feel heard, they feel valued. For a population of women who are largely voiceless, it is therefore crucial to allow them the opportunity to tell their stories. Listening to the illness narratives of patients is an essential role of the patient-physician relationship. Listening to and interpreting these narratives are fundamental aspects of family physicians' decision-making processes[108,109]. These activities not only help physicians to make a diagnosis and to validate a patients' self-worth, but they allow for a richer understanding of their patients' illness experience and their proximal and distal contexts[109,110]. Understanding the illness experience of the patient and the proximal and distal contexts are crucial elements of the patient-centered clinical method and can culminate in finding common ground with patients[109,110]. Because of the effectiveness of such patient-centered strategies, family physicians should be reminded of the effectiveness of giving space to their patients to share their stories.

Continuity of care was another essential attribute of the patient-physician relationship identified by participants. This study adds to the already abundant literature exploring the benefits of continuity of care[111-119]. Considering how difficult it was for many participants to find and then trust a family physician, it is not surprising that once they found that trusted individual, they were loyal. Two participants had been with the same family physician for over ten years. They expressed what it meant to them to have a stable source of support and someone who would not "abandon" them.

Trust was a crucial component of the patient-physician relationship identified by participants. When patients trusted their physician, they were more likely to take their advice, to adhere to treatment plans and to return for follow-up visits. Trust, however, did not occur in every patient-physician relationship. The trust of these patients was hard-earned. Trusting someone made participants feel more vulnerable and open to being hurt. For a population of women that were already so emotionally traumatized, keeping up the emotional barriers and not engaging were often easier than developing trust. Thus, it is significant that so many participants had such faith in their family physicians. What is novel about this study was how it set out to explore what facilitated these positive, long-term relationships from the perspective of the patients rather than a focus on family physician weaknesses. Much can be learned from these strong patient-physician relationships and these findings provide further evidence of the vast benefits of providing patient-centered care.

2.5.3.2 Patient Action

The women in this study had effective and creative strategies to assist them in navigating both the patient-physician-relationship and the primary health care system. Participants were resourceful and motivated to increase control in their lives as a means of getting their health care needs met. Patient actions included: peer work, resilience, readiness for change, health as a priority and preparing for physician visits.

Almost all participants engaged in either informal or formal peer work. This finding illustrates that these women had a keen awareness of each other's vulnerabilities and made efforts to support one another through informal peer work. Collective action aimed at improving both individual and community quality of life, such as formal peer programs, can foster increased self-esteem and self-efficacy leading to empowerment[14,120,121]. The term empowerment is used in many different contexts leading to differing definitions. In this study, however, empowerment refers to the internal process defined by Rappaport whereby people gain control over their lives and is thus a construct distinct from self-esteem and self-efficacy[120,122]. The increasing awareness of community, as achieved through peer work, not only nurtures empowerment but may also foster social cohesion. Social cohesion has been associated with improved health outcomes[102].

Drug use and sex work harm reduction philosophies are vital to developing and implementing any successful peer programs[14,123,124]. Central to peer work philosophy is that community-based knowledge is as important, or even more important, than expert-driven knowledge[123]. Individuals respond to information provided to them by others who are "like them"[123]. Peer-driven programming is not a new concept in the provision of services for drug users and sex workers. In fact, there are numerous examples of successful peer-led programs for these populations[123,124,125]. Much of the literature about peer-work explores the benefits to the recipients of the peer engagement and overall program evaluation[126,127]; however, this study offers important insights into how and why women choose to train as a peer and the beneficial effects of this involvement.

Another subtheme reflecting patient action that emerged from the data analysis was that of resilience and adopting a survivor attitude. There is debate in the psychological literature about the definition of resilience and it has been traditionally defined as an individual's capacity to cope with stressful circumstances without developing any psychopathology[128,129]. However, for the purposes of this study, resilience is defined less stringently as the ability of individuals to cope or "survive" with adversity regardless of their physical or mental health. For participants in this study, being resilient included the development of strategies to cope with their chaotic lives. Facing each day one at a time helped participants to feel less overwhelmed. Fostering this attitude would be an effective way for family physicians to provide support to vulnerable, drug-using women.

Another patient action described by participants was taking ownership of their circumstances and recognizing that only they could make substantive changes in their lives. This reflected a need for others not to impose management options on participants. Family physicians should recognize that each woman is unique and will need to approach her addiction in whatever way she is able. Finding common ground is an effective tool family physicians can use to support their patients' choices while still ensuring that their decision is informed[110]. The findings also revealed how making health a priority was another patient action used by participants to gain control over their lives. In a population that is often perceived as not establishing health priorities, this was an important finding.

This study also described the many creative ways in which drug-using women prepared for physician visits. Describing the strategies vulnerable women use to increase the effectiveness of a physician visit and the likelihood of having their health needs met have important implications for family physicians and other care providers working with drug-using women. For example, participants made it clear that they did not like to be high during a medical visit and went to great lengths to ensure they would not use drugs prior to a visit. Participants did not want to show up to the doctor's office high in part because they did not want to appear like the stereotyped "crack-user". Health and social service providers would be apt to support women in this endeavor and recognize the importance of this strategy to their self-esteem.

Participants also spoke about the importance of being respectful of their family physicians if they expected respect in return. The importance of reciprocity has not been reported in the literature despite the abundance of literature exploring drug-users need to feel respected[1,14,46]. Participants recognized that part of mutual respect was abiding by the rules of an agency and accepting consequences when these rules were broken (e.g. being banned for a short period of time). Enforcing appropriate behaviours also nurtures the development of institutional transference by ensuring that all patients feel safe and respected.

Deciding what part of their drug-use history to reveal to physicians was another patient action that helped protect participants from mistreatment. Physicians need to recognize this as a coping strategy for drug-using women and inquire about drug use in a gentle and non-judgmental manner. It is also important for family physicians to tell patients why such personal questions are important. Participants revealed that they were usually forthcoming with their drug use history when they felt it was relevant to the visit. Participants also described ways in which they sought out non-judgmental care so as to not expose themselves to unnecessary discrimination and mistreatment. Thus, this study described what stigmatized, drug-using women expect of their family physicians by revealing the specific actions participants took to increase the control they had over the medical encounter.

2.5.3.3 Physician action

Participants did not settle for just any type of medical care - they had high expectations of their physicians. Just as patients took specific actions to help facilitate the formation of a patient-physician relationship, so too did physicians. There were three physician actions described as helpful by participants: adopting a harm reduction philosophy, providing quality care and going the “extra mile”.

The importance of working from a harm reduction philosophy was described as being extremely important to participants. When family physicians saw beyond the traditional abstinence-based treatment for addictions, participants were more likely to disclose information to their physicians and feel valued for who they were. Participants expected their family physician to be skilled and knowledgeable about drug-use and comfortable in working with drug-users. This finding suggests that it is important for family physicians to receive adequate training about harm reduction and its role in treating persistent drug use – particularly in stigmatized populations. There is currently little teaching about harm reduction in medical schools and family medicine training programs. Having newly trained family physicians that are knowledgeable about these principles would enhance patient care to vulnerable women who use illicit drugs.

Participants also expected their family physicians to provide them with quality care. This entailed being comfortable with procedures such as venipuncture, providing appropriate referrals and translating medical information in a way that was straightforward and accessible. Providing knowledge served to ease anxiety and empower patients narrowing the power gap between patients and physicians. Having an empowering patient-physician relationship allows marginalized women to express their concerns more readily and exert more control over decisions related to their health[47].

Lastly, another physician action described by participants as facilitating the engagement process and sustaining the patient-physician relationship was going the “extra mile”. Although participants did not feel this was an essential quality, family physicians who went above and beyond the “call of duty” to support their female patients were looked upon with appreciation and gratitude.

2.6 STRENGTHS, LIMITATIONS AND IMPLICATIONS

This was the first study to explore the process of engaging vulnerable, drug-using women from the perspective of the patient and the strategies these women use to facilitate the relationships they have with their family physicians. Important information about how these women access primary health care was also identified. This study also revealed the complex relationships among drug use, homelessness, sex work and violence. These findings suggest that these issues should not be studied in isolation. Furthermore, this study illustrated that, despite the multiplicity of complex problems facing this population, there are effective strategies which family physicians can undertake. Having a solid understanding of the patient-centered clinical method is one such strategy.

This study is limited by the geographical location of participants in Toronto, Ontario and particularly to Toronto’s inner city. Although attempts were made to recruit participants outside of Toronto’s downtown, including in Etobicoke and Scarborough, finding agencies serving large populations of women using illicit drugs was difficult. This could represent the large concentration of visibly homeless and sex workers in the downtown core; however, it is also possible that experiences of women using illicit drugs in the Greater Toronto Area are different. The difficulty in recruiting agencies to assist with recruiting also reinforces the rather specialized nature of programs for drug-users and the possible shortage of such services outside the downtown core. The lack of harm reduction services outside of Toronto's downtown core is especially concerning.

Although these results cannot be transferred to all vulnerable women using drugs, these results do provide new information and can serve as a basis for further research. Future research might include:

- Exploring the health of housed versus underhoused and unhoused sex workers
- Studying the health outcomes of drug users receiving harm-reduction centered primary care versus "standard" medical care
- Evaluation of various primary care delivery models including a comparison of health outcomes of vulnerable women receiving care from a specialized inter-disciplinary team versus regular care
- Exploring the effectiveness of involvement in peer-work activities on social and health outcomes such as housing, drug use, reliance on sex work and participation in disease screening and health promotion activities
- Studying the impact of patient-centered care to marginalized populations
- A quantitative study exploring the relationships between drug use, homelessness, and/or sex work to violence

2.7 CONCLUSION

This study set out to explore the process of engagement in the patient-physician relationship from the perspective of vulnerable women using illicit drugs. This group of women lived hard lives – lives complicated by extensive drug use, homelessness and sex work. These women faced many challenges in accessing primary health care; however, for those women that did have a family physician, flexible medical services offered in conjunction with social services facilitated engagement. Family physicians that had an understanding of the proximal and distal contexts of their patients' lives facilitated the formation of nurturing patient-physician relationships marked by a mutual respect. For those women with positive patient-physician relationships, continuity, listening, presence and trust were vital.

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CHAPTER 3

Family Physicians' Experiences of Engaging Vulnerable Women Using Illicit Drugs: "They came back today. That's the celebration"

3.1 INTRODUCTION

It is important for family physicians to understand the trend for very vulnerable women not to access health care and/or not to return for follow-up. This is contrary to women in the general population who access the health care system more than men[1-3]. For family physicians working in inner city settings, women who use illicit drugs are a hard-to-reach population for several reasons. Women may spend much of their day trying to secure their drugs and for many women this necessitates sex work[4]. Other barriers to seeking medical care include homelessness, lack of a health card, mental illness, lack of transportation, discrimination from health care providers and distrust of health care professionals and the health care system[5-12]. Thus, family physicians struggle with how to engage such disenfranchised women. There is high use of emergency departments and walk-in-clinics among this population[13-15]. However, some studies have found that despite this high utilization of emergency departments, homeless women have lower rates of outpatient visits[12,16,17].

This lack of continuity is of particular concern given the high morbidity and mortality in the population[5,9,11,18-23]. Homeless women, aged 18-44, using shelters in Toronto were found to be ten times more likely to die than women in the general population[18]. The two major causes of death in this age group were HIV/AIDS and drug overdoses[18]. This population also has low follow-up rates, poor adherence to medical advice, and lower rates of participation in health promotion activities and disease screening than women in the general population[8,24-26]. In addition, women who use drugs are more likely to have experienced trauma and suffer from post-traumatic stress disorder[8,10,20,27].

Caring for people who share their stories of trauma can often cause trauma in the care provider themselves. This phenomenon has been described in the literature as vicarious trauma or compassion fatigue. These terms are often used interchangeably; however, for the purposes of this study, the following distinctions will be made. Vicarious trauma is the natural and inevitable process which occurs as a clinician bears witness to the trauma experienced by his or her patient. By engaging in an empathic relationship with his or her patient, the clinician undergoes a transformation in his or her inner experience impacting the clinician's emotions and cognitive patterns[27,28]. Compassion fatigue, on the other hand, occurs when the clinician develops symptoms similar to post-traumatic stress disorder. The clinician is no longer able to cope with the cumulative stress and burn-out occurs[27].

There has been much research exploring vicarious trauma and compassion fatigue in health professionals working with victims of trauma and torture and some research exploring these phenomena in health care professionals working in hospital and mental health care settings[27-29]. However, no literature was found identifying the phenomena of vicarious trauma or compassion fatigue in family physicians working with people with chronic and persistent addictions problems, the homeless and sex workers. Therefore, the current study also sought to explore the experiences of family physicians who work with this population and to identify their coping strategies.

There is very little research studying the active role that family physicians can play in reducing the morbidity of these vulnerable women, particularly within the context of the patient-physician relationship[24]. The idea of studying the experiences of family physicians known to be advocates for vulnerable women in their communities is novel. Important feminist-based primary care research exists about the role of communication in the physician-patient relationship[3,25]. However, it is important to extend that research to include more marginalized women particularly considering their increased risk for morbidity and mortality. Research has demonstrated that continuity of care and having a positive patient-physician relationship can have beneficial effects on health[30-38]. Elucidating exactly how these objectives can be accomplished and encouraged in family physicians' relationships with women who use illicit drugs could have far-reaching health implications. Understanding how the role of the family physician is perceived by family physicians in positive patient-physician relationships may be useful to inner city family physicians trying to achieve such objectives. Engaging vulnerable populations such as women who use drugs is an important part of this process.

3.2 PURPOSE

This study set out to explore the experiences of family physicians providing care to vulnerable women using illicit drugs in order to better understand the process of engaging these extremely vulnerable women in the patient-physician relationship. Engagement refers to the initial contact of the patient with a health care professional and the health care system.

3.3 METHODS

3.3.1 CONTEXT

This study used the qualitative method of in-depth interviews. In-depth interviews are useful when exploring a relatively narrow research question and when the experiences and understanding of the participants are the primary interest, not the broader context of that understanding[4,39]. This method is often used to explore sensitive subject matters[4,40-43] where other qualitative methods such as focus groups would be inappropriate. In this study, researchers were seeking to explore the experiences of inner city family physicians caring for vulnerable women using illicit drugs; in particular, the process of engaging this disenfranchised population. In order to fully understand the process of engagement, it was necessary to explore the context in which this engagement occurred. Because this type of work had the potential to be emotionally difficult, understanding the impact on participants was important. Thus, in-depth interviews were the most appropriate choice of methodology to discuss the challenges and joys of caring for a traumatized population of women. Also, qualitative methods are an ideal method when studying complex problems such as working with marginalized populations[44-46].

There were no known risks to participants for participating in this study. Benefits included potentially enjoying participating in a process whereby they are helping other family physicians provide better care to a high risk group of women. As participating in in-depth interviews is often a reflective process, participants were also provided with an opportunity to reflect upon the work that they do.

3.3.2 SETTING

Inner-city Toronto and Ottawa, Ontario.

3.3.3 SAMPLE

Family physicians providing primary health care to vulnerable women who use illicit drugs and were known advocates for this population.

3.3.4 PARTICIPANT RECRUITMENT

Family physicians working primarily in impoverished areas of Toronto, Ontario and Ottawa, Ontario and were known to work with underserved urban populations were purposefully sampled. Recruitment was conducted in a variety of settings across Toronto and Ottawa (e.g. community health centres, shelter drop-ins, academic and non-academic family practices) in order to ensure maximum variation and richness of the data. Some of the participants were known to the researcher. Snowball sampling was used to obtain the names of other potential participants through personal contacts with family medicine departments, managers at community health centres, managers of harm reduction programs and other family physicians. Suitable family physicians were initially contacted by phone or email by the principal researcher. If they expressed an interest, they were screened to ensure they met the inclusion criteria. Inclusion criteria were as follows: family physicians that worked in inner-city Toronto or Ottawa and provided primary care to vulnerable women using illicit drugs.

Twenty-two family physicians were contacted directly and asked if they were interested in being interviewed. In addition, three clinical managers at three community health centres (representing nine family physicians) were contacted and asked if any of their family physicians would be eligible for this study. Of the thirty-one direct and indirect requests made, a total of ten family physicians were interviewed. Twelve family physicians did not meet the inclusion criteria and nine did not respond. Sampling ended when saturation was achieved (e.g. no new data were revealed or disconfirms previous data)[47,48].

3.3.5 DATA COLLECTION

The interviews took place in Toronto and Ottawa, Ontario. Each interview lasted between 45-75 minutes. Interviews were conducted by one researcher (SW). The interviews with the family physicians took place in their offices or homes and were recorded using two tape recorders. A semi-structured interview was conducted using an interview guide (Appendix IV). All participants were asked the same open-ended question to begin the interview (i.e. What is your experience of caring for women who use illicit drugs?). Probes were used as necessary. At the beginning of the interviews, participants were asked basic demographic information. Field notes were taken during each interview. Informed consent was obtained from all participants prior to each interview.

3.3.6 DATA ANALYSIS

Each interview was transcribed verbatim. The data were analyzed using an iterative and interpretive process. After each interview, the data were read independently by each researcher who identified pervasive themes. The researchers then met to compare and combine their respective analyses looking for key words, phrases or concepts. When common themes were identified, they were manually introduced into a coding template. Each theme in the coding template was assigned a numerical value and subsequent data used these numerical codes to identify common themes in subsequent interviews. The coding template was continually expanded, reviewed and revised as new themes emerged throughout the data collection. Upon reaching saturation, earlier transcripts were re-coded to ensure congruence with the final coding template. Once all the data were analyzed, dominant themes were identified and the coding template was condensed as some themes were identified as overlapping with others. This iterative method of theme identification and coding is consistent with phenomenological methods[48].

Appropriate pacing of data gathering and analysis occurred allowing for optimization of the iterative process[48]. There was a constant interaction between sampling, data collection, emerging analysis and theory construction[48]. This iterative process allowed for the data collection to be redirected in order to elicit, confirm and/or negate previous ideas. Theme saturation was achieved by the sixth interview. As this was early in the data collection and analysis process, four more interviews were conducted to ensure that no new themes were emerging and previous themes resonated with participants in the later interviews. This strategy is called member checking and involves asking participants if identified themes, concepts and interpretations are congruent with their own experiences[49]. If participants share different experiences, then further interviews and a re-visiting of the data analysis is warranted. Member checking increases the trustworthiness and credibility of a study[49].

3.3.7 TRUSTWORTHINESS AND CREDIBILITY

Trustworthiness and credibility are measures of reliability and validity in a qualitative study. Ensuring methodological rigour was achieved in this study by a variety of means. First, there was significant diversity amongst the sample population with respect to age, sex, experience, method of remuneration and practice setting. All these variables were considered to impact family physicians' ability to engage with the vulnerable patient population being studied and represented a range of experiences in dealing with challenging populations. Second, all participants were purposefully chosen because of their well-known commitment to working with marginalized patient populations. This was felt to be vital to studying the phenomenon of engagement in the patient-physician relationship. The third way methodological rigour was achieved was allowing the findings to lead the data collection and analysis. The interview guideline was adjusted as needed throughout the study to reflect emerging themes or new directions suggested by the previous interviews. Lastly, fellow researchers provided one another with checks and balances to ensure that they were being true to the data. The principal researcher worked in a similar practice to participants and, in some cases, knew them or worked with them either presently or in the past. This had advantages and disadvantages. Participants likely had an increased trust in the researcher because they felt she "understood" and she was "one of them". This implicit trust was likely beneficial for participants feeling comfortable enough to disclose their personal narratives of loss, stress and isolation. Being an "insider" also allowed for an interview guide to be created that was appropriate to this population of family physicians. The disadvantage of being so close to the participants both in terms of knowledge of person and of work-style was the potential for loss of objectivity and the introduction of self-indulgence[48]. Great lengths were taken to avoid these errors and it was felt that this was achieved in this study; in particular, by ensuring that reflexivity took place.

Reflexivity is the process of reflecting on your role and influence on the data collection and analysis[50]. This was ensured by having two co-researchers who did not work in the field of interest and who reviewed transcripts and analysis for indicators of bias (e.g. leading questions, introduction of personal experiences into interviews and into analysis etc.). Reflexivity is also an integral part of the immersion and crystallization process – a process whereby the researcher emerges him- or herself into the data and constantly reflects for new interpretations[50]. This process not only requires reflexivity but also solid data acquisition and congruence of researcher personality with methodology and time[50]. It was felt that all these conditions were met for this study.

3.3.8 ETHICS APPROVAL

Ethics approval was obtained from the University of Western Ontario's Health Services Research and Ethics Board (see Appendix V – Approval #13383E).

3.3.9 FINAL SAMPLE AND DEMOGRAPHICS

A total of ten family physicians were interviewed. The average age of participants was 42 (range 32-58). The average time in practice was 13.5 years (range 3.5-35). Six of the ten participants were male. Participants worked in a wide variety of practice-settings and were remunerated in a variety of ways. Half of participants worked in a Community Health Centre and all of these family physicians were on salary. One participant worked as part of a family health team and was paid through an alternate payment plan. Two participants had "regular" fee-for-service practices and spent part of their week working in a shelter. Two other participants worked in academic family practices and were paid under a blended model although the drug-using women discussed in this study accessed them through appointments in a fee-for-service model.

Participants differed in terms of how much of their practices involved caring for vulnerable, drug-using women (approximate range 5-50%). For example, two participants worked a few half days a month at a local shelter in addition to their more traditional family practices. Conversely, other participants worked solely with inner city populations and spent much of their time caring for the population under study. Some participants had more specialized interests such as HIV, homelessness, LGBT health (lesbian, gay, bisexual and transgender) and methadone/addictions.

3.4 FINDINGS

3.4.1 OVERVIEW

Three broad themes emerged when participants were asked the question: "What are your experiences in engaging vulnerable women who use illicit drugs?". The predominant theme was that of the patient-physician relationship. This relationship was shaped and influenced by the two other themes – the distal and proximal contexts. Participants described how distal and proximal contexts impacted the patient-physician relationship differently depending upon the level of a woman's engagement. There were two phases of the patient-physician relationship: the engagement phase (Figure 3.1A) and the maintenance phase (Figure 3.1B). During the engagement phase (A), distal and proximal contexts were predominant and mediated participants' ability to engage with this population. In the engagement phase (A) the following subthemes emerged: policy, "the system", access, women's context, physician context, and gaining trust. Once participants engaged with a woman and made the transition to the maintenance phase (B), the support provided by the patient-physician relationship served to mediate some of the barriers within the distal and proximal contexts and thus supported the provision of ongoing primary health care to this population of vulnerable women. Within the maintenance phase (B), the following subthemes emerged: advocacy, “the system”, the social determinants of health, women’s context, physician context, continuity of care, “meeting people where they’re at”, and creating a safe space.

FIGURE 3: Process of Engaging Vulnerable, Drug-Using

Figure 3.1A: The Engagement Phase

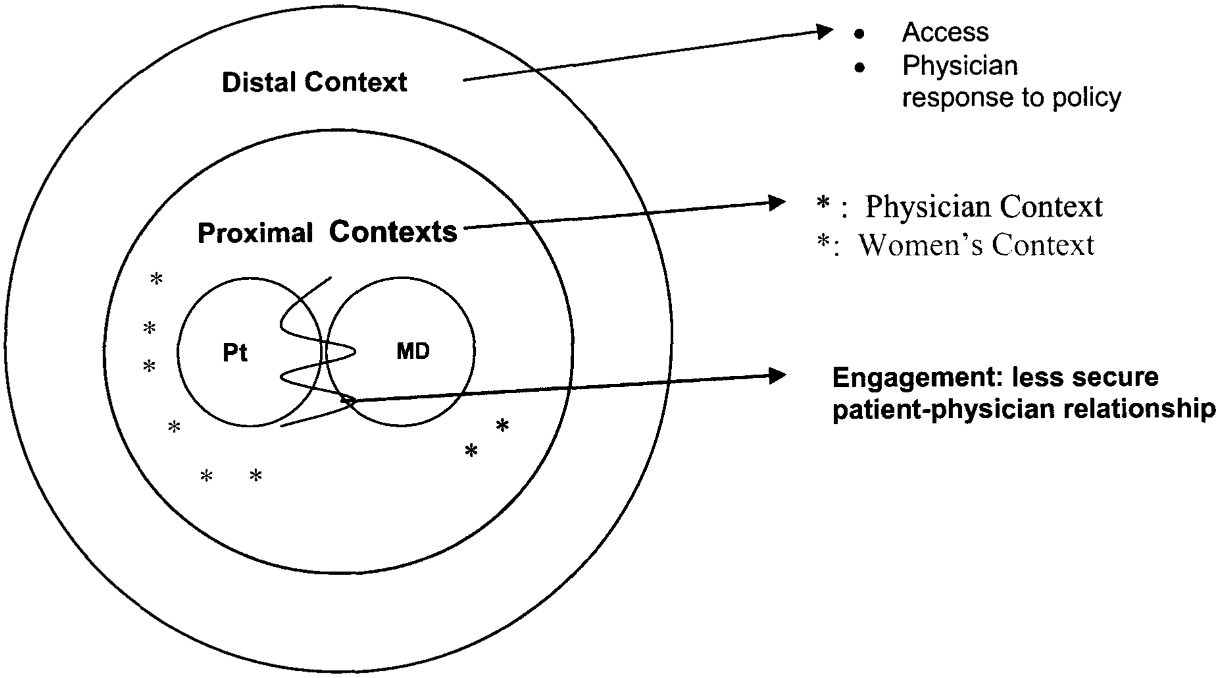
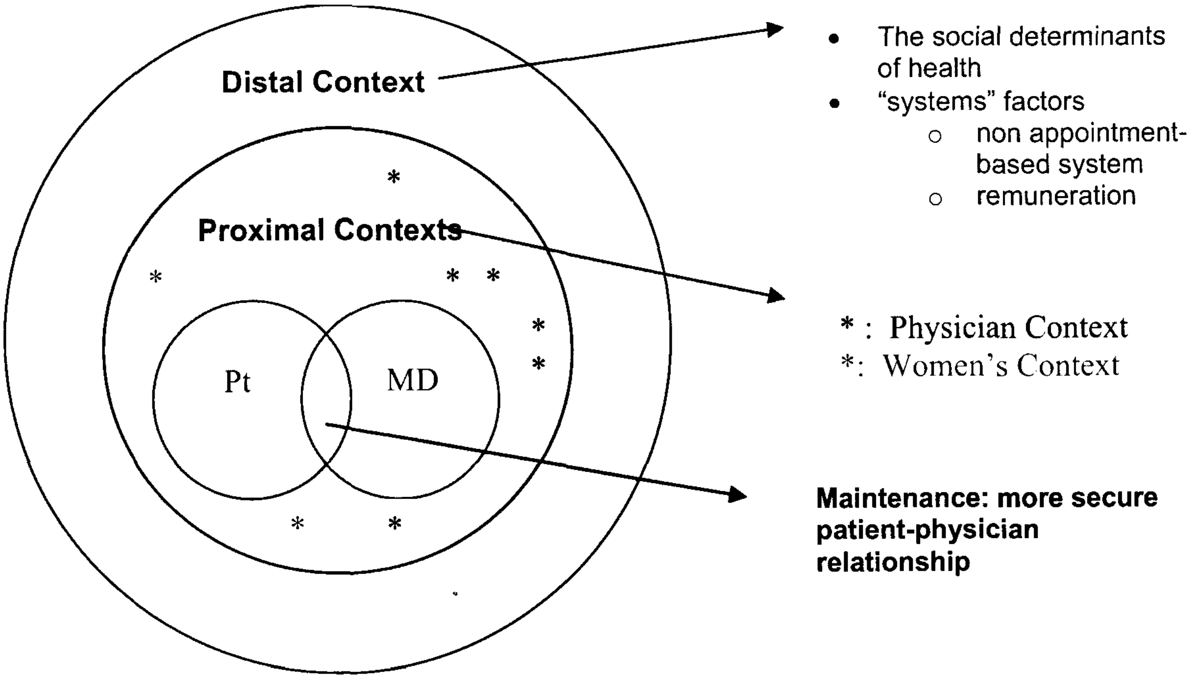


Figure 3.1B: The Maintenance Phase



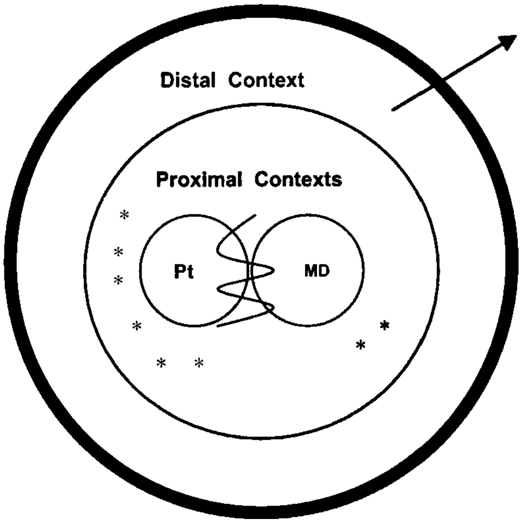
3.4.2 A: THE ENGAGEMENT PHASE

During the engagement phase, distal and proximal contexts played a large role in determining whether or not participants were able to engage vulnerable, drug-using women. During this phase of the patient-physician relationship, participants treaded lightly and worked hard to establish trust.

3.4.2.1 The Engagement Phase (A): Distal Context

The distal contexts of women's lives was a dominant theme discussed by participants. Subthemes during this part of the engagement phase were: access and physician response to health care and social services policy.

Figure 3.2 The Engagement Phase (A): Distal Context



A: Distal Context:
- **access**
- **physician response to policy**

3.4.2.1.1 The Engagement Phase (A): Distal Context: Access

If women were unable to access the primary health care system then participants were unable to engage with this population. Therefore, access was a dominant theme expressed by participants. How primary care health services were structured and organized played a large role in determining a woman's ability to access these services. Participants discussed many strategies to overcome the barriers to access including: flexibility and creativity of programming, teamwork, forming community links and institutional transference.

Flexibility and Creativity of Programming

Participants stressed that the services they provided and the clinics in which they worked must be flexible and creative. For example: *"In terms of engaging, there has to be some flexibility…people often tend to walk in…without an appointment. So, even squeezing them in for five/ten minutes. Or, even if someone else will see them…".* In an effort to meet the diverse needs of this population, many participants offered a variety of ways to access their services: "*…drop-in, a certain component of outreach, and appointments …home visiting…as appropriate….".* This flexibility was described by a participant as having "*…a sense of porousness to the clinic…"* where a patient would be made to feel welcome at any time and staff would go out of their way to meet their basic needs: "*…the women have learned that it's okay to just show-up – someone's going to take them in… they have felt welcome …someone has attended to them …given them some basic need [e.g food, transportation fare]."*

Many participants identified the need to offer multiple and targeted services at the clinics where they were delivering primary health care as an important aspect during the engagement phase. This idea of "one-stop shopping" was articulated by the following participant who ran a weekly medical clinic out of a women's shelter:

> *"...they're [women] at the agency anyway because the agency has other things that ... they like, like a place to visit, some food, a place to get a bath. A place to handle their money... And by the way a doctor comes once a week. So that's how you get them come back."*

This theme was also noted by participants working in community health centres where there are often multiple programs focusing on vulnerable populations. Examples of programs described by participants included: harm reduction programs (i.e. needle and crack stem distribution), meal programs, identification replacement clinics, peer training, chiropody and social work including crisis workers and case management. The following quotation illustrates the importance of offering a diversity of programming for targeted populations: *"...we have a housing worker people can go to. And we help with violence against women... the harm reduction program...."*

One theme that was reiterated repeatedly was delivering social and health care services concurrently. For instance, a few of the community health centres ran drop-in clinics with women-specific programming where women could access a nurse-practitioner and/or family physician: "*...a drop-in for women only was started...with the possibility to access a physician...a women-only space where they could have access to any kind of teaching... STD testing... crack kits, condoms.*".

Some participants described creative or “out of the box” methods of delivering primary health care as a way of engaging women, both at the patient and program level. In an effort to engage really hard to reach women, particularly sex workers, organizations established programs which were original and often fun. One agency offered cosmetic and aesthetic programs: *“…there was somebody who …wanted to cut hair… an aesthetician…we’re collecting women’s clothing… high heels – strappy stuff. For women who are in the sex trade…”.* In summary, participants expressed that having flexible and creative ways to access primary health care was a vital strategy to engage vulnerable women using illicit drugs.

Teamwork

Collaborative and interdisciplinary team care was seen as a way to engage and provide services for vulnerable women using illicit drugs. Working in teams enabled agencies to provide the flexible, multiple and creative programming described above. Due to the diverse needs of this population, having staff from multiple professional and non-professional backgrounds enabled a variety of services to be offered. For example, a participant recognized that some women were so disenfranchised that they would never see him. Thus, he relied on the long and trusting relationship he had established with his nurse colleague to provide medical care to a particularly vulnerable woman: *“…there are some [women] who just won’t see a doctor, so I do …consultations at arms length…”.*

Having other team members involved in the provision of primary health care also helped when the team needed to go that "extra mile" for a patient: *"Sometimes you have to go the extra mile and ... fax a prescription...or find them a detox bed ...Just a staff that's prepared to do that without saying 'I don't have time...'".* Needing to have more than one person "on board" was seen as very important in meeting patients' needs. For example, a participant described providing prenatal care to a young woman using crack cocaine whose life was very chaotic. She missed appointments yet would "drop-in" unexpectedly. This quotation illustrates how the team helped to maintain continuity:

> *"...having a team is really key. I think you need to have – and not just a team in terms of clinicians – 'cause my nurse practitioner knew her very well, and so back and forth we would go. But we also involved the nurse that...was at the [clinic]."*

Thus, the chaos in this patient's life made it difficult for just one individual to meet her health care needs. By providing care with a team, this woman's ability to access primary health care was increased.

A collaborative approach was also seen as necessary when caring for a population whose needs were often complex and multiple: "*They don't just need to be coming in and seeing a doctor.*" Therefore, participants identified how these diverse services offered by interdisciplinary teams were an essential method of increasing and sustaining access and thus engaging this vulnerable group of women.

Forming Community Links

Staff at other community agencies played a key role in linking women to participants and bridging the gap in service provision. If a woman trusted a service provider at a social services agency, that trust could be transferred to the physician/clinic where the referral was being made. *"Well it's mostly the agencies that do that [engage women]…so that's why I go in where I go [shelter] ... they'll come and see me because their worker has brought them…"*. A participant described how by simply making herself visible in the community: *"…So just really trying to BE in the community"* through outreach, establishing partnerships and promoting her program, she was able to form trusted relationships with community partners, who in turn, would refer women.

Institutional Transference

Creating safety within the institution where women received their primary health care facilitated their access to needed services. Participants used the term "*safe space*" to describe this idea of a welcoming, non-judgmental atmosphere and the establishment of institutional transference. *"… when women come to us they sense that it's a safe place, both in terms of confidentiality and with the gentleness and sensitivity with which they're treated."* When women felt safe, they could let down their guard and be themselves: *"... this agency is like a home away from home... a place where they could ... hang out and be themselves and not be on their guard."* Participants also noted that because street-involved women *"…don't have a lot of other stable connections, they do identify with the clinic where they have their care as a place that's very safe."*

Thus, participants believed that when women went to an agency or clinic and saw "other people like them", they felt welcomed into that space and felt less ashamed and judged of who they were and their circumstances.

3.4.2.1.2 The Engagement Phase (A): Distal Context: Physician Response to Health Care and Social Policy

A theme which emerged during the engagement phase was participants' response to health care and social policy; particularly, how current public policy determined what health and social services were available and accessible to vulnerable women using illicit drugs. The failure of public policy and subsequent implications on patient care frustrated many participants and motivated many to assume an advocacy role on behalf of their patients.

Implications of Public Policy on Patient Care

Participants frequently expressed their frustration with the lack of response from the "system". Dealing with living examples of failed public policy led to feelings of cynicism and exasperation:

> *"Well I think it's hard to not think a huge chunk of it [the work] is tragic…when you think about people's lives and the challenges… And the lack of response from the system… like not understanding … how people can't … want to do something about it."*

All participants discussed how the lack of appropriate and affordable housing was detrimental to the wellbeing of their patients and that making health a priority when patients had no place to sleep was simply unrealistic. A participant recounted how he had to think of the following list of things before he could begin to tackle his patients' health problems: "*…have they just lost their housing, are* *they under threat of eviction, are they overrun with bed bugs?... And [patients] won't get anything else done until that gets taken care of.*"

New expectations for chronic disease management mandated by the Ontario government provided a new source of frustration. Some participants felt the guidelines were impractical for patients with complex needs:

> *" ... there are expectations that you will do chronic disease management. Which I think everyone should be doing... that's fine...but you got to adapt these. It's a very different reality in that ... we have to make them work for our...population, and that's tough."*

A lack of appropriate resources was commonly encountered by participants. In particular, the lack of timely addictions services was noted by participants.

> *"What makes me angry is not their [patients'] behaviours, it's the way our society has chosen to react to those behaviours - the fact that it's so hard to get a patient in for appropriate treatment..."*

A participant had become so disillusioned with the lack of addiction resources in her community that she had essentially "given up" referring her patients to these resources. She saw it as a waste of her time and energy. She stated that she would happily redirect her energies back into these referrals but only if "... *we could get them into a program for addictions right away ...*".

The following participant expressed frustration and astonishment when, as a newcomer to Toronto, she learned that there were few coordinated services for pregnant, substance-using women: *"Man, Toronto is supposed to have it all figured out. And they don't....from a pregnancy point of view, there's not a whole heck of a lot. And you just think 'That's just ridiculous. It's 2007.'"* Thus, there was an enormous sense of frustration and anger with the lack of a coordinated and properly resourced response from “the system”.

Advocacy

The direct impact of health care and social policy on the day-to-day lives of patients led to a strong component of advocacy in the work of these family physicians. For some, advocacy was simply an extension of their clinical work while for others, medicine was an avenue to carry out broader interests in social justice and public health.

Participants gave examples of the patient-level advocacy that they did on a daily basis. Many participants helped their patients navigate the health and social services system: “*How can you help them work the system? Because often they are overwhelmed by it…and, don’t know how to advocate for themselves.*” Another participant discussed how helping a patient apply for a provincial disability income could significantly improve quality of life: “*These individuals all live in grinding poverty… one of the things that we can do … to immediately change their life is to…try to get them on ODSP [Ontario Disability Support Program].*”

Helping women who had children in the child welfare system was something many participants did: “*Either advocating on their behalf for visitation rights or challenging them when CAS [Children’s Aid Society] has said: ‘This is a bare minimum and you’re not meeting it.’*” A participant recalled his encounter with his patient when she had not been using drugs for two weeks and wanted his help to see her children:

> *"Do we need to be in the room with you when you…make the phone call? Do you need us to say 'She's right here with us…and as far as we can tell hasn't used drugs for this length of time…'."*

This participant recognized how crucial his support was to his patient and how his power as a professional would lend credence to his patient's case. Participants discussed how their status and power helped them to advocate on a broader systemic level: *"It is very powerful to be able to walk in and… say: "I have daily front-line experience working [with]…the most vulnerable… in our society"*. Because patients' stories informed how participants advocated, the advocacy they did was given credibility.

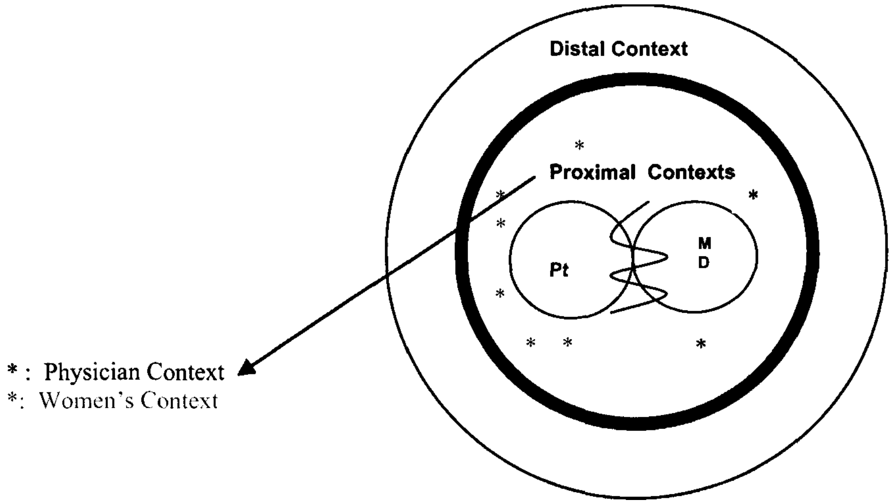
A participant discussed how having the funding pulled from his agency's harm reduction program greatly influenced how and for what he advocated: *"If we get shut down…the service to that client gets lost. So we need to be able to find ways [to advocate] that we are sustainable in … a hostile political environment."* A precarious balance therefore existed between systemic and community-based advocacy and participants had to ensure that advocacy efforts did not jeopardize patient services.

It was clear from the emotional narratives told by these participants that bearing witness to the horrors lived by their patients was a motivating force to demand policy makers ensure equitable and appropriate public, social and health care policy.

3.4.2.2 The Engagement Phase (A): Proximal Contexts

Proximal contexts in the lives of both women and physicians were themes which emerged from the data analysis; however, it was the proximal context of women's day to day lives that played the more prominent role in the engagement phase.

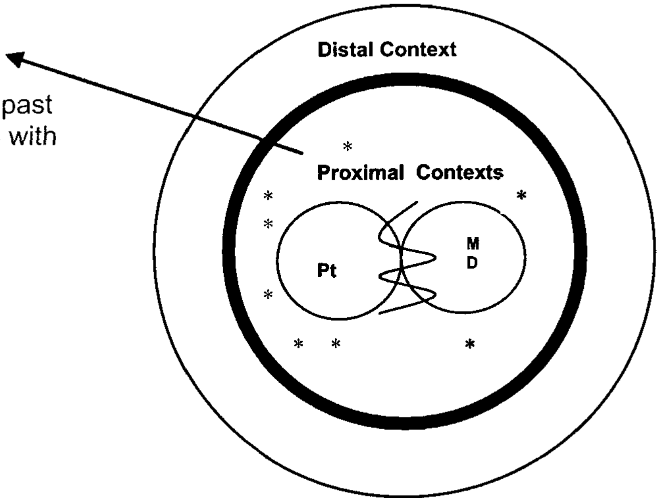
Figure 3.3 The Engagement Phase (A): Proximal Contexts



3.4.2.2.1 The Engagement Phase (A): Proximal Contexts: Women's Context

Understanding how women's daily lives impacted their overall well-being and coping strategies greatly influenced how and if participants were able to engage with them. Sub-themes discussed by participants included: chaos and recent and past experiences with trauma and violence.

Figure 3.4 The Engagement Phase (A): Proximal Contexts: Women's Context



Proximal Contexts:
Women's Context:
- Chaos
- Recent and past experiences with trauma

***** : Physician Context
*: Women's Context

Chaos

Chaos was a major feature in the lives of the women for whom participants provided care. Surviving from crisis to crisis was the norm for these women. The lives of many of patients were summarized as: "*Crisis, violence, trauma, loss* ...". Barriers participants faced in providing primary health care were described as:

> *"...they don't want to see doctors, there's no continuity, they double doctor...lose their medicine. They don't have housing, they don't have money. They're in jail. It's hard for me to follow-up with them. ...pregnancy, sexually transmitted diseases..."*

Another commonly recurring sub-theme raised by participants was how difficult it was to provide primary health care to a population which was often unable to follow-up or follow-through with prescribed management plans due to their chaotic lives. Participants frequently encountered specialists who refused to see patients anymore because they had missed too many previous appointments. This was especially frustrating when a significant amount of time and energy was invested in arranging investigations or specialist appointments: *"And it's frustrating if you've written the third consult letter to try...and make the phone call and got the earlier appointment because it was urgent, and they don't show."* This lack of follow-up had implications because participants often lost track of their patients. Thus, encounters with patients frequently occurred with great intensity for short periods of time and then the patients would disappear for extended periods leaving the physician wondering what happened to them and hoping that they were safe: **"...***they come in a lot...[and] only stay for a minute...they become a large part of ...my daily practice because you just see them every few days".*

The chaos interfering with a patient's ability to follow-up and follow-through with recommended management plans was described by some physicians as competing priorities:

> *"... So, it's just about where does the medical side of health fall in terms of their priorities? And generally it's not all that high. And that's even in situations where a woman is actively using, has significant complications from that drug use, may have an open abscess, may have Hepatitis C...[or] AIDS. "*

Participants understood that when the basic necessities of life were not being met, that it was unrealistic to expect their patients to place their health problems "high on the list".

There were, however, some situations where priorities shifted and health became more important for women using illicit drugs. Some participants described how pregnancy changed a woman's outlook on her life and her substance use.

> *"...I find that at this particular moment the conversations that I have with them [pregnant women] focus more around their health as opposed to other ... determinants of health...They're asking questions about and quite interested in learning about... what's happening with their body."*

Pregnancy thus became a "window of opportunity" to make positive changes in some women's lives.

The complexity of care required for this population was also increased due to the prevalence of mental illness: *"...there is some degree of co-morbid mental illness pretty much universally. Whether it's a mood disorder, anxiety issues or...full blown psychotic disorder.*" Mental illness therefore presented yet another barrier to engaging this population and perpetuated the crisis-driven lives led by these women.

Recent and past experiences with trauma and violence

Participants also described the role that violence played in their female patients' lives. Stories of women coming into the office having been assaulted were common and illustrated the lack of safety in the lives of these vulnerable women:

> *"...the picture that comes to mind first is...of the battered woman... who [is] REALLY heavily street-involved in the sex trade...absolutely homeless... involved with men who abuse them... whether they're their partners, pimps or johns...".*

The link between drug use and selling sex for drugs often provided the underlying context for this violence. Participants described how drug-using women were placed at increased risk for violence because their access to drugs was often dependent on their male partners. For instance, some women were only allowed to use their drug with their partners or needed their partners to inject drugs for them. Alternatively, their male partners may have forced them into sex work to secure their drugs, as this next quote illustrates: *"…there are women who[se] substance use is very dependent on…a male partner. So, they don't have direct access to their substance…They might be in sex trade work to supplement the male partner's habit."* Moreover, women were often forced into extraordinarily risky situations in order to secure their drugs and subsequent high. One participant told the story of a female patient who was a sex worker and in a violent relationship with a male partner who was in and out of jail:

> *"And when that person was in jail, there was a sense of relief…and then the person would come out of jail, there would be… really violent beatings. Loss of all her teeth at one point…and having the jaw wired shut. And…pain issues. And then trying to break away... [the] cycle of violence, stalking, abuse … that story is common."*

The violence was usually persistent and extensive such that it was a "*… bigger barrier than the drug…".*

Participants also noted the significant histories of past trauma or violence experienced by their female patients using illicit drugs: "*…you're dealing with people who have been so incredibly victimized."* One participant openly wept as she recalled how upsetting it was for one particular patient to talk about her trauma history: "*And having to ask her about her past, which you KNOW is quite painful for her… to talk about…but then understanding her a bit more and learning a bit more about her".* Despite this difficult process, having this information enabled participants to have a richer understanding of their patients and their backgrounds.

Participants also observed that growing up in the child welfare system was common among this population of women: *"It's pretty...consistent across the board that these women [have] had early histories of trauma, sexual abuse. Probably very chaotic families of origin. Lots of contact with foster care and Children's Aid."* The cycle of being in the child welfare system was often perpetuated as many women had also lost custody of their children. Participants described different strategies for helping women cope with these losses. One participant explained how his clinic served as a repository for memories for women whose children were in the custody of child welfare. This was necessary because women were so transient and had no safe place to keep important documents or personal belongings:

> *"...when they have the children we'll take photographs and we'll have them write letters. And they can't necessarily send the letters... we've done tapes where they've done messages for their children... We'll be the safe keeping place for them just because they're so transient...."*

Participants also reported that another consequence of repeated and pervasive violence was feelings of shame – shame at being a drug user, shame at being homeless and shame at simply not being able to present themselves physically the way they would hope they could. *"... they've had really bad experiences – of stigmatization and judgment. And there's a lot of trust issues."* One participant noted that the more vulnerable, street-involved women in his clinic were often judged by other low-income women in the clinic.

> *"So we had a lot of issues with women judging other women... The problem was, in raising their own self-esteem, they were pushing other women down...So we...had to change the mix of women that attended that clinic..."*

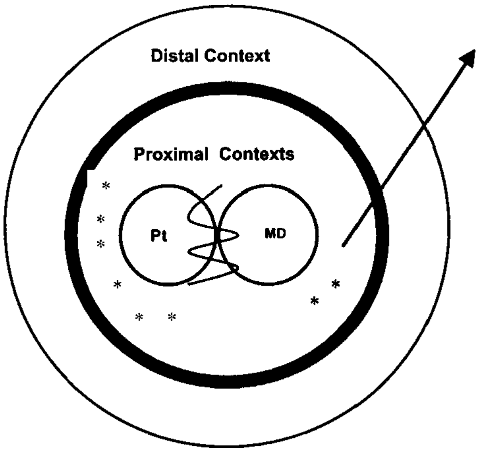
Thus, sources of women's shame involved not only the health care system and health care professionals but also other women who might be accessing health care in the same location.

Therefore, during the engagement phase, the data analysis revealed that chaos and recent and past experiences of trauma and violence played large roles in the lives of these vulnerable women and posed significant barriers to engaging in the patient-physician relationship.

3.4.2.2.2 The Engagement Phase (A): Proximal Contexts: Physician Context

The context of physicians' lives did not play as significant a role during the engagement phase and will be explored in detail in the maintenance phase (B) (distal context: section 3.4.3.2.2.).

Figure 3.5 The Engagement Phase:
Proximal Contexts: Physician Context



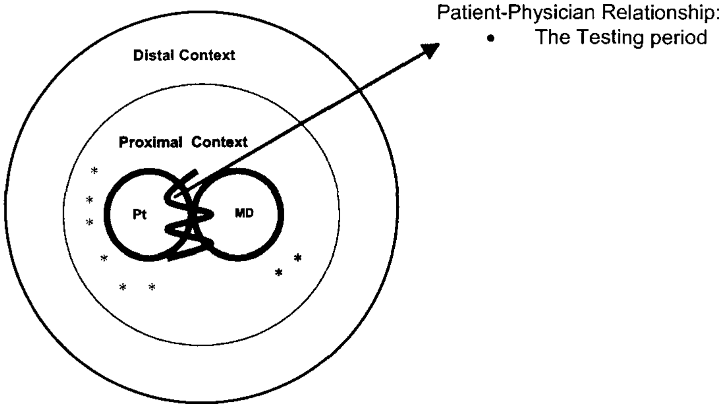
Proximal Contexts
Physician Context:
- Little role in engagement phase

* : Physician Context
*: Women's Context

3.4.2.3 The Engagement Phase (A): The Patient-Physician Relationship

Participants celebrated the strong and meaningful therapeutic relationships they were able to build with their vulnerable female patients who were using illicit drugs. Participants' narratives about the relationships they formed were emotional and powerful as they struggled to meet even the most basic of patients' primary health care needs. One major sub-theme was identified within the patient-physician relationship as important in the engagement phase: the testing period.

Figure 3.6 The Engagement Phase: Proximal Contexts: The Patient-Physician Relationship



3.4.2.3.1 The Engagement Phase (A): The Patient-Physician Relationship: The Testing Period

Participants described how trust was the foundation of the patient-physician relationship, particularly with a population that found it so hard to trust. Multiple visits or multiple opportunities for engagement were reported as necessary before any relationship was established. Although this was maybe the case for any patient-physician relationship, participants believed this was especially true in this population. This phenomenon was described by participants as a “testing period”.

Building trust was a very slow process: *“I find I go much slower…trust is the big thing. That relationship – you need to really build that before anything comes from it.”* In fact, this testing period could take years:

> *“I’ve seen people at ... [agency X] who ... it’s taken five years to see a doctor. And they see me walk by all the time… So they might have seen me walk by 200 times before they decide ‘Maybe I’ll go see the doctor.’ Yeah, so it’s very hard for some of them to develop trust.”*

Many participants felt that one of the contributing factors to this lengthy process of trust-building was that female, drug-using patients were “*wary of hospitals*” and the health system in general. This lack of trust was often due to: *"...bad experiences with the health system...[and]bad experiences in their lives which I think is absolutely universal which...brings a barrier to engagement."* This lack of trust in the health care system and health care providers led many women to avoid the health care system. *"And so they wouldn't go to a hospital. And they wouldn't seek medical attention....".* This reinforced how crucial it was for participants to take things slowly: *"I'm a pretty soft touch at the beginning...I purposely give them the space and the control over the interview to figure out where they want to go, or where they don't want to go."*

For participants, presence was another method of establishing trust during the testing period and was a crucial feature of their relationships with vulnerable women using illicit drugs. Creating a presence that was calm and relaxed within the office was a strategy participants employed to try and deflect the chaos patients brought with them into their visits:

> *"...if you can get into that... peace and serenity space ... having that from the time you walk into the room with them allows them to calm down and try to be in touch with you and try to lose some of the chaos around them. And find a safe place for them to talk about what they need to talk about. And just know that ...that it's safe and they're okay."*

Thus, having a serene and calm presence helped participants decrease the level of crisis in patients' lives thereby contributing to an overall feeling of safety.

Many participants described scenarios with patients where, despite not always being able to accomplish many medical successes, they felt their mere presence was significant to their patients. *"Sometimes I've done great things medically for people...But just knowing that for all their ... suffering I'm ... here* *and they can show up and know that that's a home base…And different than anything they've ever had before."* This presence was also meaningful to participants:

> *"But for the moment I derive a great deal of pleasure from some specific individuals ... who I enjoy just 'cause of who they are, and who I feel really benefit from my presence in their life. Not even so much necessarily the medical care I provide."*

Because this population of women had past experiences with abusive relationships, many participants reported that crucial to establishing trust was ensuring that patients felt secure and respected: *"…the sense that the people that they interact with and who work here have a sense of respect and a non-judgmental attitude."* This theme of non-judgment was pervasive during the engagement phase: *"They feel welcome. They feel that people recognize that despite their drug problems and other issues they're sort of 'Okay people'."* Participants described the need to accept their patients at face value and while they may not endorse their patients' lifestyle, participants were still accepting of these women:

> *"I think this was kind of important for her to actually her feel like there was somebody who didn't necessarily approve of some of the choices that she'd made but was kind of willing to accept her at face value."*

Also, to care and value these vulnerable women as worthwhile human beings regardless of their appearance or life choices was important to participants:

> *"... I am wanting to know and to listen to their stories of pain. Hopefully without judging them…but that common humanity I think is very important to impart to the person receiving care so that they don't feel just that they are the recipient. That they feel that …they are a human being ... who is worthwhile."*

In addition, trust was often established indirectly through word of mouth. When a patient had a positive experience, she would tell her peers that a particular family physician and/or clinic was “okay” and “could be trusted”. Because life on the street is an *“oral culture”* patients often served as recruiters. Participants reported that trust was gained *“…partly by word-of-mouth. So they [other women] talk to other people who say ‘…go see that doctor. He’s okay.’”*

During the testing period, participants noted that flexibility was also important in establishing relationships with vulnerable women using drugs:

> *“I think it would be safe to say that flexibility of setting…allowed that relationship to initially get established. And then, there’s an identified person to place institutional identity where one would go for crisis care.”*

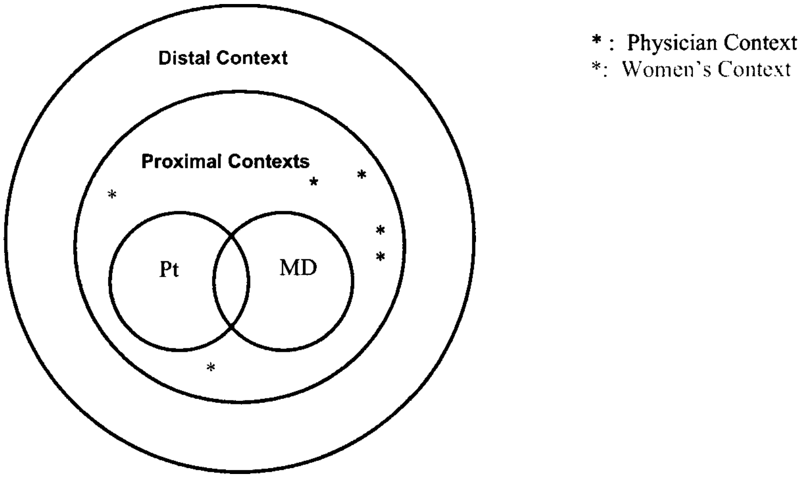
Proving to patients that they were not going to abandon them was also described as critical to forming a trusting relationship: “… *they’re just testing you out, looking for your boundaries, like…‘I know you’re going to come down on me…you’re going to like flip out’…showing them that you’re going to stick through it.”* Thus, trust became the core foundation to continuity of care.

In summary, participants were caring for a population of traumatized women who lived very chaotic lives and found it very difficult to trust health care providers. As such, there was often a period where women “tested” their family physicians to ensure that it was a safe place to receive primary health care. Participants described various ways that trust was established thereby helping to engage this vulnerable group of women: going slowly, presence, non-judgment, word of mouth and flexibility.

3.4.3 B: THE MAINTENANCE PHASE

Once participants had engaged with their female patients who used illicit drugs, the next step was maintaining that relationship. Although distal and proximal contexts still posed significant barriers during this phase, it was the patient-physician relationship which played the dominant role in determining whether or not women stayed connected to their family physician.

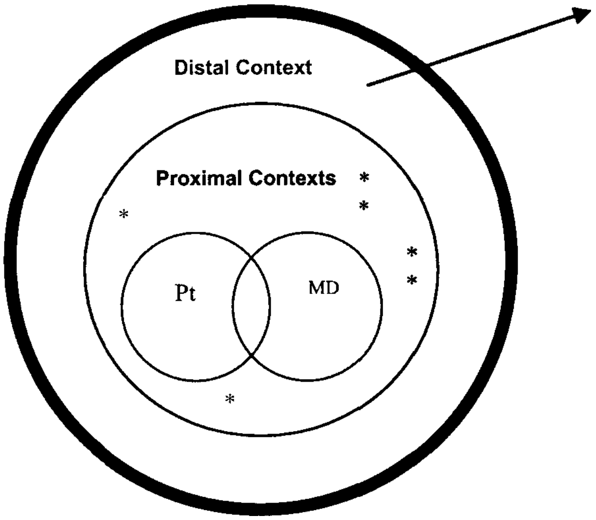
Figure 3.7 The Maintenance Phase (B)



3.4.3.1 The Maintenance Phase (B): Distal Context

The distal contexts participants identified as important during the maintenance phase were different than those identified during the engagement phase. The two factors identified as important by participants were: the social determinants of health and “system” factors.

**Figure 3.8 The Maintenance Phase (B):
Distal Context**



Distal Context:
- the social determinants of health
- "systems" factors
  - non appointment-based system
  - remuneration

3.4.3.1.1 Maintenance Phase (B): Distal Context: The Social Determinants of Health

Participants gave vivid and heartfelt accounts of how their female patients were surviving the struggle to meet their basic needs. Not only did participants have to deal with their patients' acute and chronic medical illnesses but also the consequence of living in what was often abject poverty:

> *"...Where are you going to get something to eat? Where are you going to lay your head?...How are you just going to get from Point A to Point B? Like these are truly the most basic needs of anyone and that's what you're dealing with."*

Participants described how many of the women they cared for were either homeless or underhoused: *"...drug users and women are all marginalized... and homeless...".* This often meant that medical visits were occupied with trying to secure shelter beds and sort out where a patient's next source of income was going to come from: *"Like they have so many other issues...that they're dealing with... like where are they going to sleep... their shelter or their money...".*

Patients often did not have a way to afford their medications and this was another factor participants had to take into account when providing care to this population: *" I've got to think about whether people can afford their meds."*

Lacking these social determinants of health pushed women to the margins of society making it more difficult for participants to maintain a therapeutic relationship. Participants noted that this population of women were: "*...far outside the mainstream of the system...".* Thus, poverty and struggling to meet the basic needs was an overriding theme raised by participants during the maintenance phase.

3.4.3.1.2 The Maintenance Phase (B): Distal Context: "The System"

Just as there were "system" factors which served as barriers to engagement, there were also "system" factors which facilitated maintenance of the patient-physician relationship. Two such "system" factors were described by participants: non-appointment-based systems and remuneration.

Non-Appointment-Based Systems

A prominent "system" factor during the maintenance phase was the frustration participants experienced with the traditional appointment-based system: *"... the appointment model that we almost all work [in] – it just doesn't work....".* Appointments were seen as a barrier to vulnerable women being able to access health care: *"... my family practice is not set up...to serve people who* *have chaotic lifestyles…It's based on set appointments, you need to show up on time…you've got to be very organized."*

One practical aspect to being able to function in most appointment-based systems is that patients are expected to call in to book an appointment. Since most of their patients did not have phones, clinics requiring appointments: "*…effectively screen out very vulnerable women who have chaotic lives ….*". Due to patients' inability to keep appointments, participants also noted how an appointment-based system posed "*challenges to continuity of care…*". One participant contrasted his current academic practice with previous employment at a community health centre which had an interdisciplinary team using a mixture of drop-in, outreach and appointments:

> *"… everyone is there ready to engage a client at a moment's notice… …it's like night and day in terms of being able to service people with complex issues…I think there's lots of space for people practicing in academic family practice like I'm in to shift the way that we practice to better meet the needs of this population."*

Providing set drop-in times allowed more flexibility for women and eliminated the problem of "no-shows" for participants.

Remuneration

Remuneration was reported to be a major determinant in how flexible participants could be in maintaining the patient-physician relationship with vulnerable women who were using drugs. Although a few participants felt more "bound" to this traditional format because of their fee-for-service remuneration, most participants were being paid by some alternate method (e.g. salary, alternate payment plan, etc.). As illustrated above, "no-shows" were an enormous problem and had financial implications for participants working under a fee-for-service model: "*If someone doesn't show up, you don't get paid. Which is why many times family doctors will… stop seeing someone if they don't show up two or three times.*" Some participants working solely under a fee-for-service model simply accepted the financial penalty they saw as inherent in working with this population. For example, one participant simply volunteered her services at a local shelter because most of her patients had lost their identification or were not eligible for provincial health benefits.

Alternatively, another participant tried to involve his patients when deciding if an appointment-based system would work for them. Early on in the relationship, he discussed the pros and cons of his practice set-up and discussed the consequences of not showing for appointments. If they no-showed more than the decided upon number of times, he would ask them to pay a small fee (usually a few dollars).

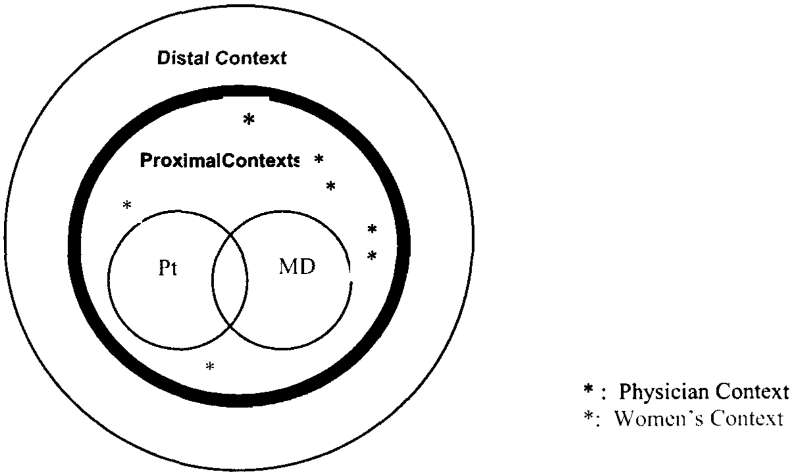
> *"Well, certainly the fee-for-service model makes it tough. So, one of the conversations I have very early on with my patients [with] chaotic lives is…that I work in an appointment-based system. And, that I do have certain expectations…"*

Thus, the manner in which a participant provided services as well as how he or she was paid could either facilitate of hinder her or her ability to maintain their work with this population.

3.4.3.2 The Maintenance Phase (B): Proximal Contexts

Whereas the context of women's lives played a more significant role during the engagement phase, once a woman had been engaged, participants identified how the context of their own lives became very significant when trying to maintain long-term relationships with this crisis-driven population.

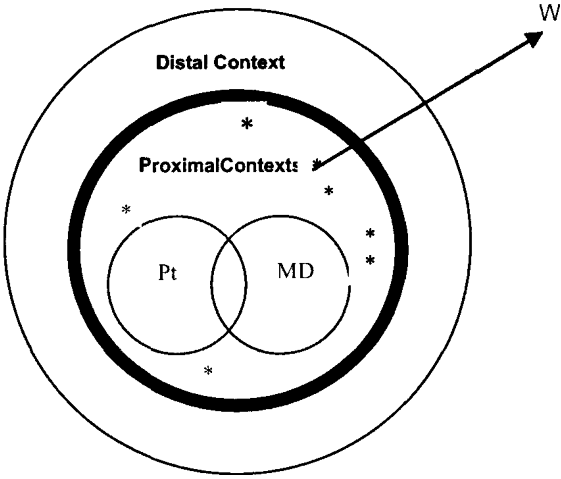
Figure 3.9 The Maintenance Phase (B): Proximal Contexts



3.4.3.2.1 The Maintenance Phase (B): Proximal Contexts: Women's Context

Participants were a significant source of support for women and the patient-physician relationship could help women cope with the chaos in their lives. Once the patient-physician relationship was established, it could serve as a modifier of this chaos. As such, the context of women's lives will not be discussed in the maintenance phase, recognizing however, that it is no less significant in the lives of these women.

Figure 3.10 The Maintenance Phase (B): Proximal Contexts: Women's Context



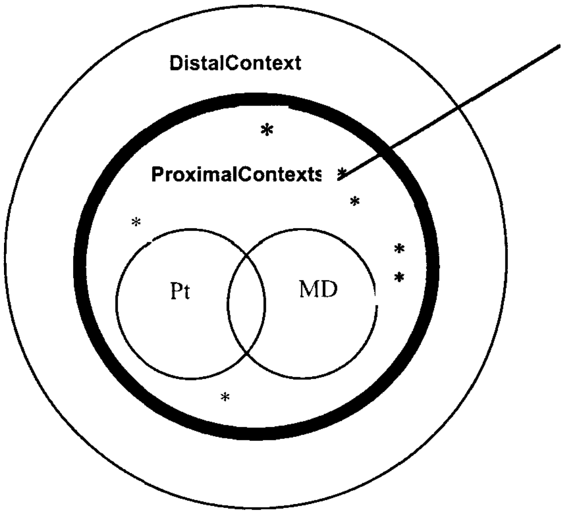
Proximal Contexts:
Women's Context:
- Less prominent role in maintenance phase

* : Physician Context
*: Women's Context

3.4.3.2.2 The Maintenance Phase (B): Proximal Contexts: Physician Context

Participants brought their own experiences to their everyday work. How participants placed themselves in relation to their fellow medical colleagues, how they viewed their work and the emotional impact of their jobs were all factors contributing to maintaining the patient-physician relationship. These sub-themes included: *emotional impact and adaptation and evolution*.

Figure 3.11 The Maintenance Phase (B): Proximal Context:



Proximal Contexts:
Physician Context:
- Emotional impact
- Adaptation and evolution

* : Physician Context
*: Women's Context

The Maintenance Phase (B): Proximal Contexts: Physician Context: Emotional Impact

The emotional impact of caring for this population was a predominant theme articulated by participants. They shared the challenges, sorrows and joys they experienced as they struggled to care for this needy population. The psychological impact of the job was apparent in the accompanying responses – participants found this to be a difficult topic about which to speak and many became quite emotional. The major sub-themes identified were as follows: hearing about tragedies and death, dealing with difficult behaviours, relationship to non-inner-city health colleagues and the positive rewards of the job.

A: HEARING ABOUT TRAGEDIES/DEATH

Within the framework of understanding the patient context and having established a relationship, participants had an emotional response to their patients' stories. Their day-to-day work was described as frustrating and challenging and many participants discussed how, at times, it was hard not to get "caught up in the chaos".

> *"Some of them are so troubled to begin with, and disenfranchised…So how fleeting their relief from suffering is when they get it…I try not to go through those roller-coaster rides with people, but try not to be too cynical…so, it's hard."*

Nearly all participants described the emotional impact of witnessing the overwhelming tragedy and premature death experienced by the women discussed in this study. "*… you're traumatized by them.*" Patients' losses became participants' losses. Other participants recalled female patients who had died. The following participant had a series of pictures on her wall of patients in her practice, many of whom had died. One of the pictures on the wall was of a patient whose story she recounted:

> *"I have a picture I'm looking at right there ...She'd contracted HIV and Hep C, lived on the street, and died just last year. And her main partner in life had died about two years before of an overdose... She was 37 when she died."*

This next participant described how heartbreaking it was to bear witness to someone who was destroying herself and how he was unable to make changes to her situation:

> *"I just think back to a woman that I saw...HIV, active crack use multiple complications of AIDS ...I just don't know if I've seen anyone like that... just on this path to the end - but, what a painful path to be going through....".*

Death for vulnerable women using illicit drugs was often premature and violent. Participants reflected on how devastating and emotionally draining it was to have one of the women they cared for become another "statistic" on the news – brutally murdered:

> *"...when they talk about a sex trade worker being killed and it's splashed across the front page of the papers, we check...to see if it was someone who was known to us... You listen to your radio in the morning ...and it's someone that you know."*

A participant had lost so many of her patients that she was constantly waiting to get news of another patient's death:

> *"...the people who seem to be my dearest clients- like they've just been dropping...And now that many of those people are gone it's been hard to build through the grief... to recreate those connections with people...I can think of a couple of people who I have...held onto who have stayed alive, I still just wait for the call that they're dead."*

Dealing with the constant loss and subsequent grief was so emotionally and physically exhausting that this participant could no longer invest the same intense commitment with her current patients.

B: DEALING WITH DIFFICULT BEHAVIOURS

Dealing with difficult patient behaviours was another sub-theme which emerged. The chaos in women's lives would occasionally manifest itself as difficult behaviours which participants both witnessed and managed. Participants frequently described intense and emotionally charged interactions with angry, psychotic, and demanding patients. "*...sometimes the interactions can be incredibly brutal...There can be racial slurs...clients have had to be barred...*". At times, participants reported feeling scared and unsafe. This became a concern for one participant's partner: *"...there have been a couple of times when you can feel really unsafe; and that's scary, right? And so then you can come home and your partner... they get really mad. And then you end up calming them down."* Another participant recounted her experiences with difficult behaviours: *"...when you get death threats from patients...or when somebody steals your prescription pad...and sometimes I have to fire people from my practice."*

Almost all participants talked about the challenges in dealing with patients who were on opiate medications or were drug-seeking: "*...it's very frustrating when people try to take advantage of me to get drugs. That bugs me... And that leaves a bad taste in my mouth."* Coping with drug-seeking behaviours in a clinical setting where many patients have legitimate chronic pain problems was described as extremely challenging. Some participants discussed strategies they developed to cope with these stressful clinical situations. For example, many participants used urine drug screens to ensure that patients were taking prescribed opiates and not selling them for illegal drugs: *"...more problematic is the person who is getting it [prescribed opiates] and selling it. And so starting to do urine screens when possible."* The therapeutic relationship was a tool helping participants during these stressful situations as summarized by the following quotation: *"...chances are, you are confronting that behaviour in the context of learning everything else about the person...But, it is partially the relationship that makes that management for people with drug-seeking behaviours less stressful."* In addition to the patient-physician relationship, participants used other coping mechanisms when dealing with such behaviours. These included using de-escalation techniques, and making boundaries and limits of services clear and specific.

> *"...it may just require an airing out. And letting that fully happen ... and then just doing some of those principles of de-escalation...and then moving on. And, being quite specific and very clear about what can be done and what can be offered."*

Support from other team members was also mentioned as important: "... *there were a couple of instances where I felt physically threatened. The people that were there around me at the time really helped ... helped me feel safe."* Taking on "good cop, bad cop" roles was a strategy used by one family physician and nurse practitioner team:

> *"Sometimes if you have someone else on the team that's the soft ... touch for this one visit cause the last visit was really tough. So*

> *[nurse] doesn't talk about x, y and z; and I'll be the one that'll talk about this, or whatever that is."*

Thus, the team approach helped to preserve relationships with patients with challenging behaviours and mental health problems.

C: RELATIONSHIP TO NON-INNER CITY HEALTH COLLEAGUES

Another recurring sub-theme raised by participants was feeling isolated from the mainstream medical community. Participants' used language such as: "fringe medicine", "ghettoized", "off the wall", "remote", "on the edge" and "an outsider" to describe this phenomenon. The following quotation describes the experience of one participant who felt judged because the neighbourhood where he practiced had a "bad reputation": *"I even had someone say: '**Couldn't you do any better**'? So, I mean, just by the fact of having chosen to work here, in many people's eyes, makes me seem quite fringe...".* Participants also expressed how they felt isolated from the greater medical community:

> *"And when you talk about what the challenges are that you're dealing with, right? ... People's eyes glaze over. They have no idea ... what you're talking about... They're very focused on things that I think are often quite superficial, so I don't feel a lot of connection. And I find that can be somewhat isolating."*

Lastly, although participants reported feel isolated from the greater medical community, many described working in an environment with like-minded colleagues: *"...one of the other things I would say is that while I might perceive myself as an outsider to ...medical community at large, I work in really supportive environment."* Thus, support was derived from working in an environment where other staff had similar interests.

D: POSITIVE REWARDS OF THE JOB

Notwithstanding the powerful narratives of tragedy told by participants, they all described the great joy, humour, inspiration and professional rewards associated with their work. It was these stories of the positive rewards of the job that propelled participants to return to the challenging work each day. The positive rewards of the job included celebrating small victories, the relationship, the complex medicine, professional rewards and working in a team.

Even when reflecting upon stories of outrageous despair, participants were still able to find meaning in their work and celebrated the small successes achieved by their patients. This next quotation recounts the experiences of one participant's patient who was murdered. Yet, just before her murder, her health care team helped reconnect her with her children living in child welfare: *"...we were actually able to add some quality of life even though she [had] a violent death..."*.

Participants stated that women "*...tell it like it is*". It was this rawness of character that was so appealing to participants. The women participants were caring for were living on the edge - there was no time to waste or beat around the bush and social pretenses were often thrown out the window. "*There's not a whole lot of layers of artifice.*" The following quotation summarizes these sentiments:

> *"Well people are ... totally real. I mean it's just completely unpretentious. And I think that's ultimately what really turned me on about the work. Like sitting in a [drop-in] ... people were NUTS... The people were CRAZY and it was just fabulous. Like they were just themselves in all their craziness... there's [an] easy kind of playfulness. And there's also a casualness."*

Ultimately, participants felt immense satisfaction at having built a trusting relationship where their patients valued them and saw them as a significant source of support: *"There's something very nice about being PART – not the cause, but just being part of bringing a little bit of peace or joy or break to someone's life whose life is so…rotten."* For the following participant, providing care to pregnant, substance-using women provided a unique opportunity to reach out to this vulnerable population and support them in making changes in their lives:

> *" … they want to be good mothers and they want to take care of their babies and they want to … put their best forward. And so I find that this is a time that is quite unique in terms of being able to reach them… I think that's one of the nicest parts. And that they value your … opinion at that time as well."*

Participants talked about the value of the relationship and how forming strong relationships with their patients became one of their most important goals. In fact, participants had to rethink what dimensions of the patient-physician relationship and their subsequent management outcomes needed to be valued and fostered. Thus, the relationship itself became the most important outcome measure used to determine the impact of their interventions.

> *"…You meet these beautiful people and…you get a chance to connect with people one on one. You learn their stories. They trust in you enough to share their stories with you and it's a really respectful…place to be at….".*

Participants recognized that without an established relationship women received very little health care from a medical doctor. Thus, the depth and intensity of the relationship was often a proxy measure of how ready and able a woman was to address her health care needs. Therefore, participants celebrated when a woman engaged with them. "*They came back today. That's the celebration…the goal is to engage.*"

The complexity of the clinical work was another reason participants enjoyed their jobs. "*An interesting day is seeing interesting medical problems…because women with drug addictions and mental health problems often have medical …problems that are much more advanced…*". Many participants described their work and workplaces as frenetically-paced and unpredictable – yet, that was clearly part of the attraction:

> "*…it's an utterly crazy, chaotic place …the whole agency was …addicting in that way. It was a very high energy place…Lots of people with major life crises being tackled there. And I think that's what kind of attracted me to it.*"

Participants also described how the juxtaposition of social and clinical sciences was very appealing: "*I like the superimposition of the social sciences and health…and then the ability to translate that the other way. Like, big level advocacy and political involvement…*". In summary, participants described a vast array of emotional experiences from feeling traumatized and overwhelmed to moments of intense joy as they reveled in the rewards of fulfilling patient-physician relationships.

The Maintenance Phase (B): Proximal Contexts: Physician Context: Adaptation and Evolution

Participants were open, thoughtful and eloquent as they reflected on how their work had impacted them and how they had adapted and evolved in response to the challenges their work constantly presented. The sub-themes described within the broader theme of adaptation and evolution were: practice style, coping techniques, modification of expectations, harm reduction, training and motivation and value system.

A: PRACTICE STYLE

Participants described the experience of evolving from a "rescuer" to someone who simply witnessed the suffering of their patients. Many participants described how difficult it was not to intervene in their patients' lives and "rescue" them. One participant felt such an obligation to one of his patients that he became her financial trustee helping guarantee her rent to prevent her from being evicted:

> *"So I interceded and said 'I will guarantee to pay back her back rent if you don't kick her out' … and right now she's living in a nice one bedroom apartment, and she's been there for 15 years…It feels like some responsibility but that's my job…".*

However, most participants felt they needed to set limits and boundaries and recognize that they could not "fix" everything.

> *"It's a subtle shift… where you go from what's wrong with this person? Why won't they just do what I tell them to do? To understanding that that's not where they're at. And you're not meeting their needs…I think that's just an experiential thing... It's very difficult to work with the clients that we work with …without coming to that understanding."*

This evolution from being a "rescuer" to someone simply "bearing witness" served as recognition that participants' roles were not to "save their patients" but to put together some of the broken pieces and try to first engage in a relationship and then maintain it.

Participants noted however that being able to distance themselves from their patients' problems and recognize that they were not responsible for "saving" or "changing" their patients' behaviours was a survival skill learned through experience and necessity.

> *"But just not ...overly enabling people. So...when somebody is in crisis, meeting the immediate needs but not putting everything I have into that, so that when they leave at the end of the day I'm not just in a heap... a mess. Rather saying 'Okay, what are they really asking from me today?' rather than ... 'How can I be the saviour?'"*

Coming to terms with her powerlessness made it easier for the following participant to not enable her patients and support them to make changes in their own lives when they were ready and able, thereby empowering them.

> *"...you're dealing with people who have been so incredibly victimized that I think...it was hard not to see the victim and just want to help...and I guess it's the realization...that no matter how much suffering people have been through it's still only them who can change it."*

Participants made it clear that the ability to distance themselves from a patient's chaos and dysfunction and be more of an observer was not an indication of being jaded or cynical. *"And that was harder at the beginning for sure. It's just...totally different. And I don't think it has to do with becoming desensitized. It's just simply coping."* Thus, setting appropriate boundaries and recognizing one's own limits was not only an evolution of practice style, but also a way of coping with the stress of the job.

B: COPING TECHNIQUES

Participants also reported intentional strategies used to cope with their challenging jobs. Coping techniques described included: use of team, not owning problems, exercise, advocacy and faith.

Having emotional support from the colleagues with whom they collaborated was a dominant theme discussed by participants. When the daily grind of the work took its toll, participants turned to their fellow team members first and foremost for support: *"We… have regular team meetings where we'll discuss cases…It's very practical case management. But other times it's just for psychological support for the caregivers, because it's taxing sometimes working with these clients."* Support from team members also decreased feelings of isolation: *" [feeling] not so isolated …I'm kind of part of some group that would support each other…".* Team structures varied considerably depending upon where participants worked. Some participants worked in settings where there were formal team meetings and debriefing allowing for opportunities to discuss complicated cases. *"At the end of the day we debrief – every day. So, that's been a fantastic piece…".* Some participants also described taking opportunities with an immediate team member during a busy clinic to simply "vent" – a quick moment to process a troubling case allowed participants to continue to work until a more formal occasion arose: "*In the back, the nurse and I check in on a regular basis... Sometimes you just need to close the door in the middle of the clinic…And we debrief about it, right there, right then."* Sometimes something as simple as a drawer of chocolates gave team members occasion to take a moment to reflect and chat: *"You just keep the drawer full of chocolate or* *candy…on a bad day, they'll just come to the door and say: "Okay, I just need to use the drawer….".* Having team members who were like-minded was a significant source of support for one participant: *"… there's a spiritual piece to the team which is fantastic…our mandate is health, respect and safety…the respect for both the clients that you're working with and also just for yourself…".*

Working in a team environment also allowed for personal development. Team debriefing allowed for rich learning opportunities for one another. For example, the following participant felt his colleagues role modeled and helped him to learn "*…how to express compassion in a reasonable way and how to challenge yourself when you are not in that sort of mode*". When there was sufficient trust within a team, mistakes could be discussed and suggestions for change made: *"What's been really good is that even when we've made mistakes, we've been able to say: 'Yep. We messed up. That's our fault. We messed up on that part.' That's been great."* Support from management was another resource some participants were able to rely upon to deal with workplace stress. Participants reflected how feeling valued for the work they did was very important. Management could also actively make participants' jobs easier by giving time for professional growth and development: "*We're given staff development time, so it's important, so I certainly can do what I need to do."*

Because deaths and the subsequent grief formed a significant part of the work for participants, attendance at funerals was also noted as a significant way of coping with loss: *"…It certainly helps me to process the natural grief that there is at losing people".* One participant described how his agency held a yearly memorial for all the patients that had died. Because many street-involved women do not have families and formal funerals are uncommon, many fear that they will not be remembered after they die. This memorial was therefore intended to honour and celebrate patients' lives: "*It allows the community to come together to grieve…so that when it's their turn that they too will have a place in terms of being remembered.*" Although these memorials were not easy for staff, they allowed for a celebration of memories: "*It's difficult because it brings back some of the sad stuff but at the same time it allows us to sit down as a team and remember…with laughter and tears.*"

Exercise was another coping strategy used by participants to cope with stress. *"I run to and from work every day…to…get myself mentally prepared…and then 20 minutes on my way home to try and leave what I do at work…and I am ready to be with my family...".* Finally, for some their faith was a means of coping: *"…my faith is very important in my coping with that [sad stories]".* Therefore, participants used a variety of coping techniques to help mitigate the stress that came with working with this challenging and complex population.

C: MODIFICATIONS OF EXPECTATIONS

Because participants recognized that there may be unique aspects to working with this challenging population, many participants reported clinical tools they employed to maintain engagement with drug-using vulnerable women. One such clinical tool was modifying the expectations of what their patients were able to accomplish. *"So you set your sights on an achievable level and you don't expect somebody to suddenly stop using them [drugs], go get a PhD and work and live happily ever after."* For example, following suggested diabetes guidelines proved to be difficult for participants. A participant stated how his expectations with respect to diabetic management were quite different for a street-involved woman using drugs as compared to someone in his middle-class practice:

> *"Her sugars are coming down from 30 to 15. In my practice here in [middle class area] 15 would be intolerable as a glucose. I'd want to get from 15 to 7. With her I'm thrilled because it's down from 30 to 15. So yeah, my expectations are different."*

Being more aggressive with pharmacotherapy in this population was a reality faced by participants as many of their female patients using drugs had poor access to food and therefore could not make healthy food choices: "*We can send people to the dietician. But if you live in a shelter it's like the reality is totally different. You skip A, B, and C and you go straight to drugs."*

Participants defined success differently when working with vulnerable women using illicit drugs.

> *"... it takes a different kind of framework to measure your success in this field as it does in a field like palliative care for example where you are not necessarily looking for cure... If your only measure of success is going to be those patients who have full recovery... you are probably going to be pretty disappointed in this work."*

Thus, modification of expectations for this physician and other study participants was also a coping strategy.

D: HARM REDUCTION

Another clinical tool participants used when caring for this population of women was harm reduction. Although patients' experiences and definitions of harm reduction differed, participants stressed the central role harm reduction played in both the individual relationships with patients and in the agencies/clinics where they worked. Realizing that many of their patients were not in a place where they were ready to abstain, participants felt obliged to encourage and support their patients to be as safe and healthy as possible while using drugs.

> *"... She's been using for the last 15 years. She's not going to stop until something drastic happens... I try to encourage her to reduce the amount ...it's part of accepting people for who they are...trying to provide medical ...and psychological care...while they're stuck in their addictions."*

As illustrated above, harm reduction was associated with acceptance and non-judgment of patients. Harm reduction also assisted in setting more realistic and achievable goals - a more mutually satisfying experience for both the patient and the physician. For example, the following participant noted that when his patients injected fewer drugs, they were more likely to maintain their housing:

> *"... maybe they were ... injecting four times a day and now [it's] one time a day, or they weren't able to maintain stable housing but now they can even though they are continuing to use – that... would still be a success."*

A central feature of harm reduction was seen as being able to take a drug history and speak openly and frankly to patients about their drug use. A participant noted: *"...this is a population that has a very well-attuned B.S. detector."*

Another recurring theme raised by all participants was how a lack of adoption of a harm reduction philosophy impacted patient care to this population and served as a barrier to engagement and maintenance: *"...they [colleagues] don't particularly embrace a harm reduction philosophy... and then[patients are] confronted with that ...[and] that safe space [has]...been destroyed."* Participants also described that just because they (or their team) had embraced a harm reduction philosophy did not always mean that this philosophy was shared by other colleagues at a clinic or agency. *"But, I have run into, not necessarily physicians, but some of the nurses who have been less tolerant of the clients."* Participants also recounted how their patients would also be discriminated against by other health care institutions who did not share the same philosophy: *"... [the patient]...had shown up in emerg – immediately characterized as a drug seeker, as someone who was just a burden on the system."*

One participant described his experience of trying to start up a methadone service within an academic teaching practice and encountering significant barriers because of perceived implications this his patients might have on the rest of his colleagues and the clinic.

> *"...staff were not prepared to do urine drug screens...nurses wouldn't want to see these patients... they would give them my direct pager number...it was made clear: 'Fine, you can do this, but we're not going to help you.' And it's not something you can do on your own.'"*

The mistreatment he and his patients received forced him to leave that particular practice.

Participants made it clear that working from a harm reduction philosophy was crucial to both the engagement and maintenance phases of the relationship with drug-using women. If women did not feel safe to talk about their drug use, they would likely not return. *"...if people knew that I was only interested in having them stop...they would not come back..."*.

E: TRAINING

Another sub-theme raised by participants was that of training. Very few participants had training in medical school or residency that prepared them for their careers in inner city medicine. They either felt that: "...*we were never trained with any of this*" or that their training had been very limited: "*I definitely felt fairly ill prepared by my training to come and do this kind of work."*

Most participants adapted by learning on the job: "*I've learned from doing the work, and from...networking in the community....*". Some participants even felt that the skills necessary for their jobs were skills that were difficult to teach and that simply had to be acquired by experience: "*I'm not sure that there would be anything other than just spending a bunch of time just doing it to actually to kind of get you there?"* Relying on peers and mentors for "on the job" training was another way participants gained experience: *"...I had mentors that I worked with... that...I've modeled my way of practicing on and learned a lot from..."*.

For a participant, despite having received no training in caring for substance-using pregnant women, she was still seen as "the expert" while attending a workshop about the subject. She felt this illustrated the large gap in training in this area: "*...I didn't understand why it felt like you were kind of reinventing the wheel ... that I would be the one with the most experience, when I had none.*" Another participant explained why she felt it was important that all family physician trainees receive training in this area: "*…SOMEHOW making this interesting for family doctors is really important. Because those few people they see…It matters that they get cared for properly.*"

F: MOTIVATION AND VALUE SYSTEM

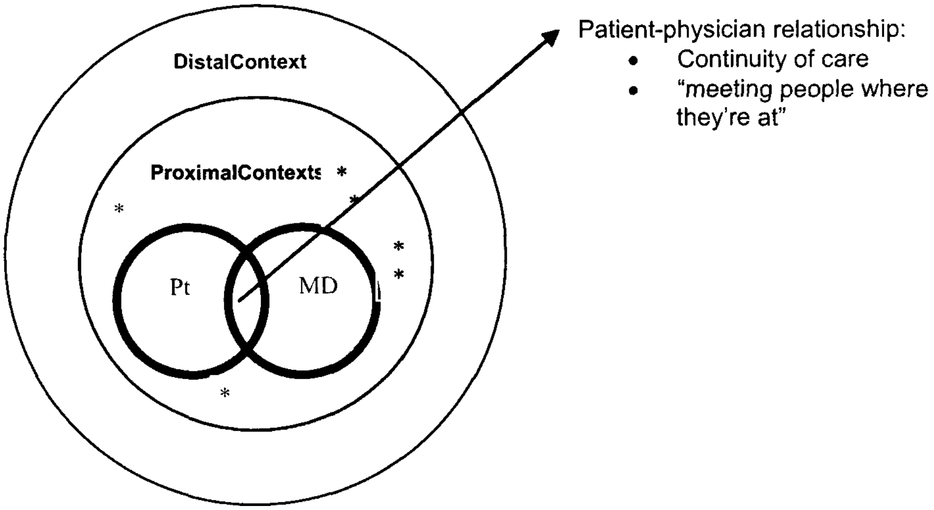
Participants' personal values greatly influenced their decision to pursue working with this and similar populations. An interest in social justice and issues affecting vulnerable populations informed many participants' decision to enter medical school: "*I've always had an interest in social justice type issues.*" Another participant, after spending time working overseas in a developing country, realized there was a need among Toronto's urban poor: "*I mean my interest in…poverty and the world's misallocation of resources led me to look into going into Bangladesh. Which, when I came to Toronto made me realize that 'My goodness, the urban poor are right among us.'*" The following quotation clearly illustrates a participant's commitment to his methadone practice and this marginalized population because he knew that despite the hurdles to see the work as mainstream, he knew it was effective:

> *"The numbers needed to treat for methadone are about one in two. It's one of the most effective things that I do as a family doctor. There's very little else that I can prescribe in terms of medications that are more efficacious… But, it's still perceived by many colleagues as…substituting one addiction for another…And, I…still get [a] little defensive about that. But [I've]…been doing this work for ten years and I don't expect to see myself in another ten years not working with these sort of challenging populations…I believe in it, and that's going to have to be enough."*

3.4.3.3 The Maintenance Phase (B): The Patient-Physician Relationship

During the maintenance phase, the patient-physician relationship was identified as a predominant sub-theme. Once women had initially engaged with participants, three strategies were described as critical to maintaining this engagement: continuity of care and "meeting people where they're at".

Figure 3.12 The Maintenance Phase (B): The Patient-Physician Relationship



3.4.3.3.1 The Maintenance Phase (B): The Patient-Physician Relationship: Continuity of Care

Being able to identify a person as "their doctor" and/or "their team" was a common theme identified by participants. Continuity of care, however, looked different in participants' inner city practices than in a traditional middle-class practice because crisis defined many of the patient encounters. Patient visits tended to be "*in the context of some sort of physical or mental/emotional or social crisis.*" There were often intense and frequent visits over very short periods of time followed by long periods of absence.

> *"They come in a lot. And it may just be for a moment. They may only stay for a minute…they become a large part of your daily… practice because you just see them every few days."*

Despite the fact that many participants were providing primary health care in a drop-in setting to a transient population, they all felt strongly that they were still providing comprehensive primary health care and identified continuity of care as an integral component to this. *"…But that we endeavor to provide that quality of care depending how much… you can avail yourself of… or want to avail yourself of. But I think that [continuity of care] matters…it matters a lot."* Being reliable and having a predictable schedule helped to maintain continuity of care: *"So the continuity is because I come to these places EVERY week…So people know that I'm pretty reliable… it's not a part-time thing. I'm there."*

Some participants felt that continuity of care was especially important when providing health care to a population of patients who had experienced recurrent loss and abandonment:

> *"It's very important that it's one person who is involved with them for a long period of time because many of these folks have been abandoned ... they can't learn to trust unless there's a sustained period of time invested in them."*

Thus, in stark contrast to these women's frenetic, transient and unpredictable lives, participants sought to provide a stable and consistent setting where women could come and receive primary health care thus helping to maintain the patient-physician relationship. The following participant recalled a challenging patient who was HIV positive and involved in sex work who had since died:

> *"…and I worked with her probably for about six or seven years… over the years we developed a really strong working relationship …she would actually start coming in for her appointments and was*

> *actually starting to address some of those high-risk behaviours…in the end, I think what she would have said was that I became a very important caregiver for her."*

Despite patients' numerous social and medical problems, having an identified person as their family physician could serve as a significant source of support for women.

3.4.3.3.2 The Maintenance Phase (B): The Patient-Physician Relationship: "Meeting People Where They're At"

Finding common ground or, as participants described it "*meeting people where they're at*" was viewed as critical to maintaining relationships with vulnerable women. This idea of "not pushing too hard" was illustrated by the following scenario where the participant was trying to figure out just how much she would be able to accomplish with her pregnant patient from the moment she walked in the room:

> *"… was [it] going to be a visit where I could push ahead in terms of getting…all the things you're supposed to get done? Or just a reassuring visit…and…backing off and not talking about substance and her relationship …just literally "What's your weight?"…and then out the door cause that was all she could manage for the day."*

This delicate dance of deciding when to back off and when to push forward suggested that participants were constantly reading patient cues to determine "what the patients could handle" at any given moment. Having the patient set her own priorities rather than following a physician-driven agenda was a theme raised by many participants. In the following quotation, a participant recalls answering a patient's question about drinking chamomile tea while pregnant when the family physician really wanted to talk to her about the effects of smoking crack on the fetus: *"And in your head you're thinking 'Oh, my goodness. You're using crack cocaine and you're asking me about chamomile tea?' but it was a legitimate question on her part. Like that's what she wanted to hear about, so that's what I talk[ed] about."* Another participant articulated this theme as follows: *"...finding [out] what are their concerns, their priorities. And working with those, because they might not necessarily be [what] my priorities are. And my priorities might have to go down to number 10 on the list."*

This theme is described by another participant who related a situation where a patient who was HIV positive did not want to take anti-retroviral medication despite her CD4 count being dangerously low. He stated that putting aside his agenda and having an open discussion with her was much more difficult than writing a prescription that he knew she would not take:

> *"Because it's always so easy just to write the script and say 'Here, take this – like yesterday!' As opposed to backing up and realize that okay, what she's really saying is 'No, quality of life and if and when I go [die], I need you to make sure I am comfortable.'"*

Thus, listening to patients' needs and hearing their concerns was not an easy task yet could empower women by giving them control over decision-making processes.

3.5 DISCUSSION

This study explored the experiences of family physicians known to be advocates for vulnerable women using illicit drugs. The process of engaging this marginalized group of street-involved women from the perspective of the family physician is an unexplored area of research. In particular, exploring the experiences of family physicians identified as providing exemplar care to this challenging patient population was a method which led to rich data collection thereby identifying strategies which facilitate and hinder engagement. The process of engaging this high-risk population was best understood in two phases: the engagement phase (Phase A) and the maintenance phase (Phase B). During the engagement phase, distal factors such as social policy and the organizational structure of the health care system and proximal factors such as women's chaotic lives and comorbid mental illness largely determined whether or not a woman was able to access the health care system and subsequently engage with participants. Thus, at this stage, the patient-physician relationship was tenuous. However, once that engagement occurred and the patient-physician relationship transitioned to the maintenance phase, the distal and proximal contexts in women's lives were, to some extent, mediated by a strong and supportive patient-physician relationship. The proximal factors in physicians' lives were dominant during the maintenance phase.

3.5.1 DISTAL CONTEXTS

Providing patient-centered care requires an understanding of the contextual factors which give meaning to the health and illness of an individual[51,52]. Understanding of such contextual factors leads to a richer understanding of the patient, as a whole person, and helps explain changes in their health status. For example, changes in context can lead to exacerbations of chronic disease states[53]. Participants clearly had a good understanding of the struggles faced by their patients and how these struggles impacted women's ability to be healthy and access primary health care. Participants identified factors comprising both the distal and proximal contexts of women's lives. The impact of the distal context will be explored first.

3.5.1.1 Distal Context during the Engagement Phase

There were many factors outside the domain of the patient-physician relationship which affected participants' ability to engage vulnerable women using illicit drugs. These factors comprised the distal context and included: physician response to policy and access. Participants discussed how various social and health care policies created barriers to engagement. They also felt frustrated with the perceived lack of response from the "system". They felt that many of the problems facing their patients were a result of failed public policy. This was a significant source of frustration and cynicism. This frustration and cynicism, however, was often turned into positive energy in the form of advocacy.

3.5.1.1.1 Advocacy

Analysis of participants' narratives revealed an intricate interplay between front-line primary health care, public policy and advocacy. When social or health care policies were impacting their patients' health – either directly or indirectly – participants felt obligated to take action. Advocacy efforts were not seen as an "add-on" but rather an integral and core component of working with at-risk women. Advocacy also seemed to be a natural outcome for this group of family physicians whose work was congruent with their motivations and value systems. For many participants, an interest in social justice determined their reasons for entering medical school and they felt a moral and ethical obligation to ensure that all patients received equitable access to health care and the social determinants of health. When a patient arrived hungry and with no place to sleep, they felt a duty to respond to these most basic needs – just as much as they felt it necessary to respond to patients' medical needs.

Advocacy took many forms. For instance, all participants gave examples of the individual-based advocacy done in their offices every day helping their patients navigate the social welfare system, reconnect with their children in custody and access specialist services. Some participants were involved in advocacy on a much broader systems level imploring policy makers for equitable and appropriate public, social and health care policy.

These findings are in keeping with many medical school curricula and medical organizations that purport advocacy to be every physician's duty[33,54-57]. In a study of community-responsive family physicians in Toronto, advocacy was vital to being community-responsive[58]. Just as our study found, these family physicians advocated at both the individual and systemic levels[58]. Gruen and Brennen argue that physicians are ideally placed to advocate for changes in the determinants of health where there is clear causality and where the socioeconomic factors directly affect patients' health (e.g. smoking, interpersonal violence)[59]. They argue that advocacy which all "global" citizens can undertake (e.g. social justice) is not as effective for physicians to participate in because the causality is not as clear. They also argue that it is questionable whether these activities are within the expected duties of every physician. Clearly, participants in our study felt their advocacy for social justice was valuable work and time well spent. The skills necessary for this broad-based advocacy work were not likely learned in medical school. Whether or not participants felt that their broad-based advocacy work was something that all physicians should do was unclear and requires further study.

3.5.1.1.2 Access

Without strategies to assist women to access health care services, participants were not easily able to engage women. Strategies identified by participants as helpful during the engagement process were: flexibility and creativity of programming, teamwork, forming community links and the presence of institutional transference. These findings are consistent with previous research in the United States indicating that the primary health care delivery system (e.g. process and structure) are just as important as insurance status in determining adherence to cancer screening[60].

Participants in our study worked in settings unlike those of most physicians. Participants worked, along with others in the organizations in which they were employed, to create services and programs structured to best meet the needs of this population. This meant being flexible, creative and being able to respond to crises. For example, in an effort to engage sex workers, organizations established programs which were original and fun such as hairdressing services and peer training programs. Peer programs have been shown to be an effective means of engaging and empowering vulnerable populations including drug users, sex workers and people suffering from mental illness[61-65].

Previous research has identified accessibility, comprehensive care and coordination of social and medical services as key priorities for primary care services for vulnerable women[5,16,17,66,67]. Similarly, in our study, participants noted that providing multiple services at one site and linking social and health services were essential strategies used by agencies to engage women. The current study was able to provide further insights into why this was important. Participants felt that if women used the social or harm reduction services in an agency, the women would come to trust the institution and the staff and would be more likely to participate in primary health care services.

This phenomenon has been described as institutional transference. Institutional transference occurs when patients have a positive reaction to an institution where they receive their care and their feelings of trust are placed in an institution rather than an individual[68]. Women needed to feel safe the moment they walked in the door of the place where they received their health care. Agencies worked very hard to create this “safe-space” characterized by non-judgmental staff and helping women feel a sense of belonging. This is in keeping with results from a study in the mental health literature which found that agencies with patients reporting high levels of institutional transference reported higher levels of patient satisfaction[68].

Working in teams with allied health professionals was also identified as an important method for engaging high risk women. If medical and social services are to be provided concurrently, as our findings suggest, then this requires collaborative and interdisciplinary care. In our study, social services staff provided mental health and social supports both for crisis and ongoing care. Outreach workers also helped to recruit hard to reach women and connect them with nurses and family physicians in clinics. Nurse practitioners were also integral players on interdisciplinary teams providing much of the primary health care to this population. Teams were defined broadly by participants and often included non-health care professionals such as outreach workers and staff working in harm reduction clinics. Delivery of primary health care through teams is now becoming standard of care[69]. Collaborative interdisciplinary teamwork enhances patient care because, as McWhinney notes: "No one profession can meet all of patients' needs."[52](p394). Despite the challenges of teamwork, collaborative interdisciplinary care can be rewarding. It offers opportunities to capitalize on others expertise and helps to sustain the capacity of individual team members by providing one another with much needed emotional support[69].

3.5.1.2. Distal Context during the Maintenance Phase

During the maintenance phase, the distal contexts that were prominent included the social determinants of health and "system" factors. The system factors included the implications of an appointment-based system and remuneration.

The knowledge that most of their female, drug-using patients could not meet basic needs such as food and shelter had a profound impact on participants. First, it helped to inform physicians that meeting any medical need would be difficult when their patients were constantly hungry and not able to find safe shelter. Second, it also fuelled many participants' advocacy work.

A significant source of aggravation and cynicism for participants was the constant battle with "the system". Many participants struggled to provide care to this population within a health care system that they viewed as structured to screen out extremely marginalized populations. This was illustrated when participants discussed their frustration at trying to work within an appointment-based system as appointments were clearly identified as a barrier to engagement and thus providing primary health care. Similarly, participants felt that a fee-for-service payment system hindered access to vulnerable populations and had negative implications for participant remuneration. Thus, the manner in which a participant provided services as well as how he or she was paid could either facilitate or hinder her ability to maintain engagement with this population. Interestingly, how participants were paid did not seem to affect the amount of work they did for their patients (or time involved). For instance, all participants appeared to make advocacy a part of their work – whether they were paid for their time or not. There is little research with regard to the method of remuneration affects a physician's willingness to advocate for their patient – either on an individual or systemic level[33]. However, in a study exploring remuneration methods of physicians providing care the homeless in Toronto, Canada, physicians were reimbursed for only 50 percent of patient encounters[70].

3.5.2 PROXIMAL CONTEXT

During the engagement phase, the proximal context of women's lives predominated but appeared to have a minimal influence from the perspective of the family physicians' context. The stability provided by the patient-physician relationship during the maintenance phase served to mediate some of the chaos and crises that marked the lives of participants' patients. During the maintenance phase, the barriers that made up women's proximal context became slightly less overwhelming allowing women to begin to take care of their health and ultimately feel more empowered to take charge of their lives. Thus, during the maintenance phase the physician context predominated.

3.5.2.1 Proximal Context during the Engagement Phase

Participants identified two factors comprising the proximal context of women's lives: chaos and recent and past experiences with trauma and violence. Chaos marked the lives of these family physicians' patients. This chaos made it difficult for their drug-using female patients to look after their medical needs. Facing competing priorities is a phenomenon that has been identified previously in the medical literature regarding this population[8,16]. Despite being at the highest risk for illness and injury, these women's high need for health care does not determine vulnerable homeless women's use of ambulatory services, in part, due to these competing priorities[16]. Our study provides new insights into this phenomenon from the perspective of family physicians.

Violence was another proximal context described by participants as impacting engagement. Drug-using women experience violence in many forms including intimate partner violence and violence as a result of sex work involvement and study findings confirmed this prior work[71-74]. Participants also reflected upon the impact that childhood abuse and neglect had on their drug-using patients. Previous studies have found high rates of post-traumatic stress disorder among street-involved women and participants confirmed this[8,10,20,27]. These findings suggest a need for adequate training of health care professionals who work with drug users to be able to identify violence and manage its physical and emotional consequences.

3.5.2.2 Proximal Context during the Maintenance Phase

Two subthemes emerged reflecting physician context: the emotional impact of the work and adaptation and evolution of practice with this patient population.

3.5.2.2.1 Emotional Impact

Within the framework of understanding the patient context and having established a relationship, participants had an emotional response to their patients' stories. Participants' day to day work was described as frustrating, and many participants discussed how difficult it was not to get "caught up in the chaos". Nearly all participants described the impact of witnessing overwhelming tragedy and premature death. Death is an inevitable and natural part of life and it comprises a significant part of family practice. Helping patients and their families at the end of their lives can be a rewarding component of the profession's work[75]; however, the types of deaths encountered in participants' inner city practices contrasted greatly from those in "everyday" family medicine. It often involved overdoses, murder, exposure to the elements, HIV/AIDS and suicide.

Therefore, participants described intense emotional responses to the trauma they witnessed in their patients' narratives. This phenomenon has been described as vicarious trauma[27-29,76,78]. Vicarious trauma is the normal and expected emotional response which occurs when an individual's job involves an empathic engagement with people who have experienced or are currently experiencing trauma. Traditionally, this phenomenon has been described in professionals working with victims of torture; however, it is increasingly recognized in paramedics, child protection workers and social service workers[76]. Our study adds to this literature by describing this phenomenon in a group of family physicians working with vulnerable women using illicit drugs.

Vicarious trauma is distinct from burnout in that it is specific to the field of trauma and it is a normal part of the work. Compassion fatigue, on the other hand, is not inevitable and can be prevented. Compassion fatigue has been defined as burnout in the lives of helping professionals as a result of "being confronted with powerlessness and disruption"[29] (p231). Burnout results from the traumatic stories of a client affecting the care provider in negative ways paralleling "the impact of the trauma on the client"[29] (p231).

There are multiple strategies to deal with vicarious trauma. These can be implemented at the individual and organizational level. The majority of strategies used to cope with vicarious trauma should be dealt with at an organizational level. Managers have a duty to warn all employees of the potential for vicarious trauma and compassion fatigue[76]. Organizations also have a duty to ensure a safe workplace or risk increased staff disability and poor performance. Of note, many of the participants in our study described feeling unsafe and had to deal with aggressive patients. Feeling unsafe in the workplace is highly correlated with the development of compassion fatigue[76]. Our study confirmed previous research demonstrating that debriefing with team members is a useful form of dealing with vicarious trauma[76]. Our study also confirmed Bell, Kukarni and Dalton's findings of the importance of effective supervision in dealing with workplace stress. The values established by an organization set the expectations of how the workplace and how workers should deal with stress and subsequent vicarious trauma. Normalizing the experience of vicarious trauma is important[76,78]. It can encourage employees to access organizational structures to prevent compassion fatigue such as vacation time, limiting caseloads and overtime[76,78].

Another significant emotion felt by participants was that of feeling like the "outsider". Participants described their work as "fringe" and even "radical". Providing continuing medical educational opportunities geared towards family physicians working in the inner city may help to decrease this sense of alienation. Moreover, making topics such as drug use, homelessness and sex work part of core medical curricula will also help to de-stigmatize these topics among new graduates.

Despite the work being frustrating and emotionally challenging, the rewards of the work for participants came from the joy they received in the day to day interactions with patients. Thus, the patient-physician relationship is not just good for patients. Our study demonstrated that the patient-physician relationship had positive outcomes for providers as well. The relationship was sustaining for participants and helped to mediate the other challenging aspects of the work. Participants often told vibrant stories of their hectic and emotion-filled days with humour and delight. Many family physician participants found strength in the relationships they had with their patients. Because these relationships were often difficult and labour-intensive to establish, when that engagement occurred, it was particularly meaningful.

Providing patient-centered care may have direct benefits on physician satisfaction[79]. Our study does not elucidate whether participant satisfaction with their work arose from being patient-centered and having high rates of patient satisfaction or whether there are unique rewards when working with this particular population.

3.5.2.2.2 Adaptation and Evolution

Participants also shared strategies they used to cope with hearing stories of adversity and hardship. In particular, participants identified how their practice styles had evolved over time, as they acquired clinical experience. How they approached their work often determined their risk for vicarious trauma. In addition to providing basic medical care, many participants realized that their role was not that of a "rescuer" or "saviour" but more of a witness to suffering and to be present during times of crises. Thus, participants were able to cope with the feelings of powerlessness which often accompanied this challenging work.

Another coping strategy included being able to make meaning out of seemingly senseless actions such as murder through memorials and attending funerals. Attending patient funerals has been described in previous studies as an important coping mechanism for physicians[80,81]. Some agencies held memorial services for patients – an activity which is not the norm in family practice with the exception of palliative care[80,81]. Other coping strategies mentioned included were not owning problems, exercise, faith and teaching. Similar strategies have been described elsewhere in the literature[78,82-84].

Family physicians should recognize their own limitations when needed and access the skills of other professionals, including those within and external to their team. Varying caseloads can also help to reduce stress and exposures to vicarious trauma[76,78]. Family physicians should also recognize risk factors for developing vicarious trauma: being young and inexperienced, lengthy exposures, and working with patients who have difficulty trusting and who face institutional barriers[76,78].

Another strategy participants used to prevent compassion fatigue was to be involved in political advocacy and social justice issues. Bell, Kulkarni and Dalton report that participating in advocacy can instill a sense of hope and empowerment because there is an increased belief that an individual can influence change[76]. As the changes seen in day to day practice were not large, participants found other avenues to seek out more sustained change. The front-line work carried out by participants affirmed and clarified their political and moral convictions which further validated their work. This phenomenon has been described as vicarious resilience.

Similar to vicarious trauma, vicarious resilience is the process whereby a helping professional can be empowered through his or her interaction with a patient's story of resilience in the face of adversity[29,78]. Although the participants in this study did not specifically describe this phenomenon, they did articulate elements that contribute to the process of vicarious resilience. These included: developing hope and commitment, witnessing and reflecting on human beings' immense capacity to heal, developing tolerance for frustration, developing boundaries and articulating personal and professional positions towards politics[29].

Working from a harm reduction philosophy was another clinical tool used by participants to maintain the patient-physician relationship. This approach was seen as critical to the work performed by participants. Harm reduction is an effective public health measure[85-91]. Although some participants felt that other colleagues viewed harm reduction as “fringe” and “radical”, their description of how harm reduction worked in their daily practices epitomized the principles of patient-centered care. Harm reduction principles placed the patient at the centre of medical care – patients were asked how ready or able they were to stop or cut back their drug use and when it was clear that they could not stop using, participants still remained their patients’ clinician, advocate and healer. Taking a harm reduction approach places more power back in the hands of patients allowing them to regain some control over the decision-making process[27].

Participants stated that the keys to effective harm reduction implementation were being non-judgmental, accepting patients at face-value and being compassionate. To most participants, harm reduction was simply a common sense strategy to mitigate the health consequences of behaviours while not necessarily condoning the behaviours themselves. Therefore, harm reduction served as a means for participants to accept their patients at face value which was vital to maintaining the patient-physician relationship with this high risk population. For many participants, harm reduction was also a pragmatic and preventative health strategy – since many of their patients could not abstain participants would avail to keep their patients as healthy as possible in the meantime.

Another significant finding of our study was that participants learned to modify their expectations of patient outcomes. This strategy was a practical clinical tool allowing participants to better cope with the participants’ current inability to place their health care needs as a priority. Modifying expectations also assisted participants to find common ground with their patients and be realistic about their own abilities[69,92].

Of note, many participants felt their medical school training inadequately prepared them for their work with women drug users; however, some also expressed doubt as to the benefit of additional training, identifying experience as the best teacher.

3.5.3 THE PATIENT-PHYSICIAN RELATIONSHIP

One of the key findings of this study was the two-phase process of engagement and maintenance. Participants identified the challenges of encouraging vulnerable, drug-using women to see a physician. Other literature has identified similar challenges to engagement[24]. However, the current study found this early engagement to be only part of the process necessary to providing care to these women. Once that early engagement had occurred, the work had just begun – convincing women to return posed another hurdle and the ultimate transition to the maintenance phase of the patient-physician relationship. Participants identified creative and effective strategies used to support women so that they would return for follow-up and maintain this once tenuous relationship.

3.5.3.1 Patient-Physician Relationship during the Engagement Phase

During the engagement phase, the focus was forming a sufficient level of trust with the patient so that she might return for a follow-up visit. During these first encounters little may be accomplished from a "medical" perspective other than meeting a basic acute health need. This tenuous time in the patient-physician relationship was called the "testing period". Mistrust of health care providers is common among marginalized populations and reinforces the need to take time and allow for trust to be established[10,93]. Key characteristics of the testing period identified by participants were as follows: taking time, presence, being non-judgmental, use of word-of-mouth referrals and flexibility.

Our study supports previous research which found that vulnerable populations placed particular importance on the patient-physician relationship[6,16,33,66,67]. As in our study, factors within the patient-physician relationship such as trust, compassion, respect and good communication have been previously identified as priorities for primary health care for low-income women[66,67]. Our study reinforces the importance of a non-judgmental stance and extending respect for stigmatized populations but for the first time from the perspective of the family physician.

Another important aspect to the patient-physician relationship identified by participants was the creation of a safe space. Central to the creation of the safe space was presence. The ongoing presence of a physician allowed patients to "test" the relationship and establish trust over a long period of time. Presence has been identified as an essential feature of the patient-physician relationship[52,94]. As Loxtercamp notes: "...with human presence and the comfort of words, we can help bridge a gulley where the road washed out"[94] (p227).

3.5.3.2 Patient-Physician Relationship during the Maintenance Phase

Our study provides new insights into the unique aspects of continuity of care in vulnerable women who use drugs. O'Malley, O'Malley and Forrest suggest that the patient-physician relationship is the "link in the chain" without which other critical aspects of primary health care such as continuity of care cannot function[67]. Our study was also able to elucidate some of the factors that affect continuity of care in this population. Continuity of care appeared different in these family physicians' offices – visits were often crisis-driven, brief and intense. This is in stark contrast to most family physicians' offices where acute, chronic and wellness checks predominate patient visits. Miller, in a 1992 qualitative study, identified three types of clinical encounters: routine, ceremony, or drama[95]. "Routine" visits were characterized by brevity and use of a biomedical model[95]. "Ceremonies", on the other hand, were more ritualistic, often involving the "convenantal" such as when a physician treats a patient with Vitamin B12 injections for their chronic pain[95] (p294). Lastly, Miller describes "dramas" as complicated, intense, and often involving conflict, non-adherence, or the delivery of bad news[95]. The current study findings suggest a fourth type of clinical encounter: "routine drama". "Routine dramas" were repeated visits that, although brief and frequent, were driven by constant and repetitive crises that often went unresolved. Study findings also suggest that routine visits were less frequent in study participants' practices than in regular family practices.

In most visits with street-involved women, participants were often trying to "convince" their patients of the importance of their health and health-related behaviours. Thus, participants were often waiting for the “golden opportunity” when their patient was “ready”. The abandonment these women had faced in their pasts also provided the context for the critical role the participants played in these women’s lives and hence affected continuity of care. Once a relationship had been established between participants and women, it was clear that participants felt an enormous obligation not to “fail” these women.

Continuity of care allows for family physicians for be better advocates for their patients[33] and help them navigate through a health care system that has often failed them. Continuity of care is not just important because it helps to maintain the patient-physician relationship, but it also has an important impact on health outcomes[33-38]. Previous research has identified that having a continuous relationship with a care provider was the biggest predictor of adherence to cancer screening for low-income women[60].

Continuity of care has been identified in previous research as being highly valued by vulnerable women[5,6,16,67] and improving their access to health care[16]. In a population-based cross-sectional study by Lim et al, a probability sample of homeless women demonstrated that continuity of person was more strongly associated with improved access than was medical insurance[16]. Continuity of care has also been shown to improve health outcomes in low-income populations. For example, continuity with a single health care provider increases rates of adherence to pap tests, mammography, clinical breast exams and fecal occult blood testing[60].

Saultz and Albedaiwi, in a review of 30 articles on interpersonal continuity and patient satisfaction, found a consistent and significant positive relationship between these two factors; however, one outstanding question was whether or not this was only true for patients who sought out relationships with a family physician[38]. The current study suggests that this may not be the case. Many of the participants in this study actively "recruited" their female patients by attending drop-ins and liaising with outreach workers. As such, participants often targeted patients who were not initially interested in receiving health care services. Over time coupled with a family physician that was both patient and persistent, an ongoing relationship was established. It is still unclear whether continuity of care plays a role in the initial decision of marginalized, drug-using women to seek out primary health care and requires further enquiry.

In addition to continuity of care, our study also identified specific strategies used by family physicians to communicate with extremely marginalized women. For example, "meeting people where they're at" was described as a way of finding common ground with women. Finding common ground is a strategy used in the patient-centered clinical method whereby both the physician and patient come to a mutual understanding of the problem, roles and management plans that are most appropriate to the patients' needs[92]. Finding common ground has been described as the "linchpin" in the patient-centered clinical method[92]. Without a thorough understanding of the patients' illness experience and the context in which this suffering occurs, a mutual understanding and agreement of the problem, goals and management plans will not be possible[92].

3.6 STRENGTHS, LIMITATIONS AND IMPLICATIONS

This was the first study to explore strategies to engage vulnerable women using illicit drugs from the perspective of family physicians. As such, new and important information was obtained not only about ways to facilitate and hinder access to primary health care for this marginalized population, but also the joys and sorrows that these family physicians experience in their day-to-day work. Although these results are not generalizable to all family physicians working with this population, these results do provide new information and are thus transferable to similar vulnerable populations.

Our study is limited by the limited geographical location of participants to Toronto and Ottawa, Ontario. Although attempts were made to interview participants outside of Toronto's downtown, it was difficult to find family physicians who were either willing to participate and/or who fit the inclusion criteria. This reinforces the rather specialized nature of this work.

Future research might include:

Access

- Confirmation of findings from other health care professionals working in similar settings
- Functioning of collaborative, interdisciplinary teams serving vulnerable, drug-using women
- Quantitative study of different primary care delivery systems for vulnerable populations (e.g. Community Health Centre, shelter-based, family health teams etc.) and their impact on: access, patient-

centeredness, continuity of care, health outcomes (e.g. hospitalizations, preventive services etc.)

- Comparison of drop-in clinics versus appointment-based clinics and their impact on access and continuity of care

Continuity of Care

- Exploring whether or not continuity of care is important to marginalized women when seeking out primary health care

Vicarious Trauma

- Interview family physicians who have left the field to see if compassion fatigue/vicarious trauma played a role in them leaving this area of medicine
- Similar research with non-physicians doing similar work
- Quantitative study using formal tools to quantify the extent of psychological trauma physicians (and other professionals working in this field) experience
- Ways to prevent compassion fatigue in the workplace and their effectiveness
- Prevalence of vicarious resilience and its impact on compassion fatigue

3.7 CONCLUSION

This research reinforces the role that the patient-physician relationship has in sustaining both patients and a group of inner city family physicians in challenging circumstances and serves to inform the work of health care providers working with marginalized women using illicit drugs. This study also provides new insights into the processes of the patient- physician relationship from the perspective of the family physician. Participants articulated what aspects of the relationship they felt supported and grounded a positive patient-physician relationship when working with an extremely hard to engage group of women. Furthermore, participants elucidated some of the systemic factors and the structural systems which served to facilitate or hinder engagement of this vulnerable population.

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CHAPTER 4:

GENERAL DICUSSIONS AND INTEGRATION OF FINDINGS

4.1 INTRODUCTION

Marginalized women, including those who use illicit drugs, have low-rates of primary care usage and high rates of morbidity and mortality[1-7]. As marginalized women descend down the socioeconomic ladder, they are less likely to access health care, particularly primary health care. Furthermore, this occurs just as their health becomes more precarious. This study sought to explore this phenomenon from the perspectives of both vulnerable women using illicit drugs and inner city family physicians who care for this population.

4.2 METHODS

In order to capture the phenomenon under study, individual in-depth interviews with vulnerable women using illicit drugs and family physicians who care for this population were conducted. Findings from each study were then compared and contrasted to develop general recommendations and outline possible policy implications related to the process of engagement.

4.3 INTEGRATED SUMMARY OF FINDINGS

4.3.1 OVERVIEW

There was strong congruence between findings in these phenomenological studies of the experiences of vulnerable women using illicit drugs and family physicians. There were several findings in both studies which helped to elucidate the process of engagement. First, both women and family physician participants identified barriers to accessing primary health care for women who use drugs. Although there is an abundance of literature exploring the barriers faced by marginalized women[1-3,5,6,8,9], the current studies' findings highlighted the enormous obstacles faced by these women from the perspective of both drug-using women and family physicians. There was much overlap between the groups' perspectives. A new finding relates to the health-seeking behaviours of drug-using women. This population of women behaves in ways which serve to both facilitate and hinder access to primary health care. Furthermore, actions undertaken by family physicians that facilitate and hinder these women's access to primary health care were identified. Lastly, the central role of the patient-physician relationship in the process of engagement and maintenance was another theme identified in both studies.

Both women and family physician participants identified proximal and distal contexts such as drug use, chaos, violence and lack of the social determinants of health as barriers to primary health care. How primary health care was delivered to this population of marginalized women was another theme which emerged from the analysis of both sets of data. Early on in the engagement process, when mistrust was common among women participants, the proximal and distal contexts of women's lives made the formation of a strong patient-physician relationship challenging; however, once trust was established, both groups of participants recounted stories of strong and sustaining patient-physician relationships. Respect, being non-judgmental, presence and continuity of care were described as important to both women and family physician participants.

Thus, the three dominant themes that arose when comparing the findings of both studies were: 1) women's contexts, 2) physician context, and 3) the patient-physician relationship. Medical education and continuing medical education were identified as paramount throughout the analysis of both studies hence suggestions for improvements are integrated into individual sections of this chapter.

4.3.2 FACILITATING ENGAGEMENT: HOW TO HELP WOMEN PATIENTS

There were many strategies identified to assist vulnerable, drug-using women to engage in the primary health care system. These strategies related to both the proximal and distal contexts of women's lives. Contextual factors which led to strategy identification included: drug use and the role of harm reduction, sex work, housing, violence, stigma, and chaotic lives. Having an understanding of these contextual factors allowed for recommendations to be made about health care and social services policies.

4.3.2.1 Drug Use and Harm Reduction

There was synergy of participants' accounts of the physical, psychological and social impacts of using illicit drugs. Participants in both studies recognized how pervasive drug use led to difficulties in making health and wellness a priority.

Harm reduction was a strategy identified by both study groups as a means of decreasing drug-related harm. Both women and family physician participants described how being non-judgmental was central to harm reduction philosophy. Not only did harm reduction programs provide vital information to women participants about their health, safer drug use and community resources such as drug treatment programs and social services, but they also served as an entry for women into the health care system. Thus, the role harm reduction programs play in the engagement process is an important finding.

Harm reduction is a spectrum with abstinence and methadone maintenance treatment at one end and needle and crack stem distribution and safe consumption sites at the other. Primary health care services should reflect this spectrum. Despite the controversy surrounding Canada's first safe-injection site, InSite, studies have concluded that use of a safe-injection facility decreases morbidity and mortality and is cost-effective[10-18]. In addition, since homelessness was a large determinant of whether or not the women participants had a safe place to use drugs, and as homelessness continues to be an ongoing epidemic in Canada, safe consumption sites are a necessary and life-saving public health measure[15,16,19]. Considering the chronic underfunding of harm reduction programs and considerable controversy which still surrounds harm reduction principles, the collective findings of the two studies add to the current wealth of evidence-based literature outlining the important role of harm reduction in public health policy. Evidence, not ideology should inform policy for harm reduction facilities[20].

Given the extremely high prevalence of mental illness and other physical health problems in substance users, it is important to note that addictions can be rarely treated in isolation[1-3,21-24]. Findings indicate that women drug-users in inner city Toronto present with multiple and complex problems. In the primary health care setting, these were usually dealt with concurrently. This reinforces the need for social service supports and interdisciplinary care when providing primary health care to this population of vulnerable women.

4.3.2.2 Sex Work

The impact of sex work on women's lives was noted by participants in both study groups. When women participated in sex work, the risk for violence, illness and further isolation increased substantially. Sex-work harm reduction is an emerging concept[25]. Due to the dangers involved in sex-work and the complex structural reasons that perpetuate these dangers, working with sex workers to minimize the harm involved in their work is an important primary health care and public health strategy.

A sex worker harm reduction approach can also help to reduce the dangers involved in sex work[25]. Peer-directed programs (e.g. harm reduction services, sex-worker directed peer work) were consistently identified as vital to such harm reduction strategies. Enhancing the capacity of and investing in new peer programs for sex workers should be a priority. Peer programs build capacity among marginalized populations by fostering individuals' strengths and empowering them to make decisions that are best for them[25-31]. Although there is literature about this topic, much of this is from a social services and public health framework. Hence, further exploration of the role of peer work within the primary health care setting and its direct effects on health is warranted.

Clinicians working with sex workers can do the following to help women stay as safe and healthy as possible: 1) regular screening for sexually transmitted infections (STIs), 2) providing tips on how to detect STIs in their clients, 3) enhancing skills to negotiate condom use, 4) encouraging women to always let a friend know her whereabouts, 5) encouraging engagement in lower risk sexual acts such as oral sex, and 6) cultivating regular clients[25,31-33]. The collective study findings suggest that the overall best strategy to minimize violence for sex workers is providing safe and affordable housing. This will be further discussed below.

4.3.2.3 Housing

A lack of affordable housing for vulnerable women using illicit drugs was identified as problematic by both family physicians and women participants. While women described the lived experience of being homeless, family physicians emphasized the need for better housing policies. Study findings suggest that housing provided stability for women and reduced their drug use and experiences of violence. Stable housing is particularly critical to sex workers because of the challenges they may face in adhering to strict shelter rules[34]. Shelters may only allow residents to stay during night-time hours. Despite some shelters making accommodations for shift-workers, sex work is often not seen as legitimate work. Thus, unless shelters for women become more flexible, they will remain an unsuitable interim solution to homelessness among sex workers.

There is currently a housing crisis in Canada. In fact, homelessness in Canada has been declared a national disaster reflecting an urgent need for the federal government to re-institute a national housing strategy[35,36]. Current study findings support the need for a national policy providing subsidized housing. Many of the stressors and health problems faced by the women participants could be drastically reduced if women had access to safe and affordable housing. The findings also point to the need for social housing to be able to cope with the multiple and complex needs of previously homeless tenants such as mental illness, drug use and poor physical health.

During times of unprecedented financial surpluses in Ontario in the late 1990s there were significant cuts to social housing and to regulations that protected tenants[37]. As a consequence, vacancy rates for affordable rental units in Canada are very low and even if rental housing is available it is often of very poor quality[37]. As such, people often have to rely upon unregulated and illegal substandard housing such as basement apartments and rooming houses that don't meet standard building codes[37]. Thus, policies that protect tenants are also urgently needed.

4.3.2.4 Violence

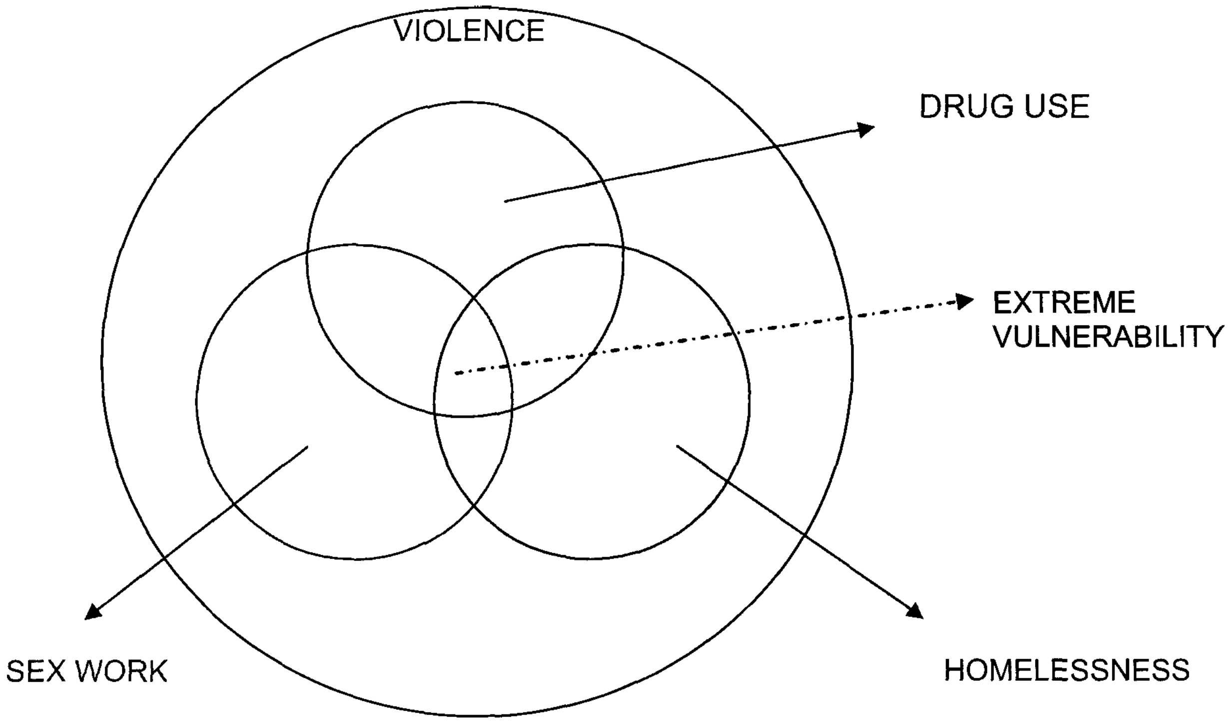
Violence was another common theme identified by participants in both studies and played a central role in the lives of these vulnerable women. Drug use, homelessness and sex work appeared to increase both witnessed and experienced violence (See Figure 4.1). Experiences of violence also appeared to perpetuate drug use, homelessness and sex work. Being exposed to all three of these "risk factors" could lead to extreme vulnerability and further marginalization and stigmatization. This is a significant finding as this is the first study to explore these complex, inter-dependent relationships and to suggest subsequent policy changes. The role of violence needs to be understood by family physicians providing care to vulnerable, drug-using women. Physicians need to recognize the gendered nature of violence[38]. Failure to do so disconfirms the experience for women and minimizes their reality[38]. The patient-physician relationship can validate women's experiences of violence and empower them to make change. Helping a woman make sense of her experiences and providing a safe and supportive connection outside the abusive relationship can provide a woman with a connection that strengthens her "conception of herself as survivor" [38]. As Candib writes:

> *A clinician willing to make a long-term connection with a battered woman can offer a consistent, caring, nonabusive, and nonsexual relationship at a time when no other relationships have these qualities. Offering a relationship rather than neutrality stand in sharp distinction to the distance and non-involvement of the systems approach*[38]. (p.78-79)

The violence experienced by the marginalized women, as documented in both studies, appeared to be different than for women in the general population. Violence was often present in both their intimate relationships and in encounters involving sex work clients or the drug community. This violence resulted in a state of chronic chaos exacerbated by multiple acute crises. Thus, traditional woman abuse screening tools, which identify predominantly intimate partner violence, may be inadequate for this population[39]. Further study exploring effective methods of screening for both woman abuse in long-term relationships and acute episodes of physical and sexual assault are warranted. In addition, caring for vulnerable women experiencing violence warrants further study as the findings suggest that stopping activities that place women at high risk for violence such as drug use and sex work were difficult to eliminate as it represented their way of life at the current time.

A harm reduction approach to violence may provide a useful framework for clinicians. Exploring ways to minimize violence with their women patients is a pragmatic solution for family physicians and is the model used for many agencies serving sex-workers[25].

Figure 4.1: Violence and vulnerability



4.3.2.5 Stigma

The women participants spoke about how they felt demeaned by a health care system that saw them as worthless and lacking will power. These experiences were corroborated by the family physician participants who had witnessed their colleagues mistreat this population. Ultimately, there was resounding synergy between women's personal experiences of stigma and the family physicians' first-hand accounts of the attitudes and behaviours of their colleagues. Proposed strategies to decrease stigma include: 1) decriminalization of sex work, 2) empowerment of stigmatized populations through education, and 3) education of perpetrators of stigma, including health care professionals, by addressing drug use and sex work as public health problems as opposed to individual defects[25,40]. Further study exploring effects of: 1) early exposure to stigmatized populations in medical school on attitudes and 2) using a public health framework to teach about drug use and sex work is warranted. A public health approach is beneficial because it serves to de-stigmatize and decriminalize such behaviours[25].

Our study also found that significant organizational planning was often necessary to respond and adapt to complexities such as stigma. For example, women judging other women in the waiting rooms was identified as a barrier to engagement. This is a new finding and reflects a need to have organization planning strategies to overcome this stigmatization of women. The implementation of such strategies reaches far outside the patient-physician relationship. These are not “typical” problems encountered by family physicians and reflect the unique challenges faced by family physician participants.

4.3.2.6 Chaotic Lives

Having chaotic lives was identified by both groups of study participants as a barrier to engagement. Ways to mediate this chaos were suggested by both family physician and women participants. Whereas family physicians spoke about ways to provide more flexible and creative programming, women participants articulated how having drop-in times was often easier for them than appointments. Thus, agencies that provide services to street-involved women need to consider ways to provide easy access and flexible services.

Currently in the city of Toronto, services to homeless people and drug users are offered primarily at community health centres, shelters and drop-ins for at-risk populations. Although this study did not set out to compare and contrast these services and subsequent differences in patient outcomes, further study on this topic is warranted so that delivery of primary care services is based on solid evidence.

One of the unique aspects of providing care to drug-using women is the method used by social and medical services to actively recruit women to engage with "the system". The idea of having health care and social services "search out patients" is very different than the regular primary health care system that is designed to wait for people to present to them. This difference reinforces the crucial role that social services play in engaging vulnerable, drug-using women and the need for adequate funding for outreach workers and case managers.

4.3.3 FACILITATING ENGAGEMENT: HOW TO HELP FAMILY PHYSICIANS

Just as the women participants described the many actions they took to facilitate their access to primary health care, family physician participants also identified strategies to foster the process of engagement. Such actions included: 1) advocacy, 2) teamwork, 3) methods of remuneration, 4) changes to primary health care delivery, and 5) coping strategies.

4.3.3.1 Advocacy

The family physician participants had established long-term relationships with their patients and assumed the role of advocate. The experiences of women participants necessitated this action of family physicians. Thus, whereas family physicians described the importance of advocacy, women participants expressed their gratitude for family physicians who went “the extra mile”. Given their high rates of morbidity and mortality, vulnerable women who use illicit drugs are therefore more dependent upon their family physicians for access to the broader health care system and often require an advocate who will help them to navigate this system[41,42]. Just as women participants identified the barriers they faced in navigating a health care system that they saw as complicated, family physicians described the importance of advocating for their patients. Women participants also described a significant lack of social supports illustrating the importance of having “someone on their side”.

Physician advocacy did not just benefit patients. Advocacy work was sustaining and re-energizing for many family physician participants and validated their work and contributions to their community. Unfortunately, advocacy is time- and energy-consuming and poorly remunerated[43]. Given the benefits of participating in advocacy for both patients and physicians, workplaces and physician remuneration models should give thought to providing protected time for family physicians to carry out advocacy activities. Family physician participants described how advocacy prevented cynicism and helped them cope with feelings of burn-out. Advocacy is a skill that requires fostering and medical students need to be provided with the knowledge of how to be an effective advocate[44]. As such, advocacy needs to have an integrated presence in the medical school curriculum. Physicians are granted significant status in our society and thus are in a unique position to be effective advocates[43,45].

4.3.3.2 Teamwork

Teamwork was identified as an important means of engaging vulnerable, drug-using women. Women's experiences of helpful relationships with allied health professionals corroborated family physician participants' statements that non-physician team members played a vital role in care provision. In particular, both studies identified the important role of outreach workers in bringing women in from the community to agencies where they could receive primary health care.

Thus, family physician participants could not do this work in isolation. One of the critical roles of these non-physicians is to help build trust[46]. Findings suggest a need to fund primary health care services that provide interdisciplinary and collaborative care. This requires a significant shift in resource allocation to non-physician services (e.g. nurses and nurse practitioners, mental health and addiction services, social workers, and harm reduction and peer programs) and an integration of these services with primary health care. In addition, study findings suggest that social service professionals well versed in issues related to drug use, homeless and sex work are essential.

Study findings also confirm the complex health and social needs of this population of women. Enhancing the capacity of primary health care professionals to care for complex health problems in a primary care setting is warranted. The East Toronto Hepatitis C Program, which provides education to and treatment for drug-users infected with Hepatitis C, is a good example of how community-based, interdisciplinary and "one-stop shopping" models of care increase engagement, increase adherence and minimize need for tertiary care[47,48]. Providing collaborative, interdisciplinary care was important in engaging women into the primary health care system and sustaining this access over time.

4.3.3.3 Remuneration

How physicians are paid impacts their ability to provide the flexible and creative services described above. Findings from both studies suggest that a fee-for-service payment model is a barrier to primary health care for vulnerable, drug-using women. Just as the chaos in women participants' lives made it difficult to make appointments, family physician participants noted how their method of remuneration impacted upon their ability to provide drop-in services and work within an interdisciplinary environment. Ontario's primary method for paying physicians is fee-for-service, although there is a significant trend towards more blended models[49]. As such, most family physicians in Ontario, unless salaried, are not remunerated for visits with non-insured patients, missed appointments, team meetings or advocacy work. Despite this, family physician participants had high levels of participation in these non-remunerated activities.

These findings corroborate findings of another study examining physician remuneration in four Toronto shelters and drop-ins for homeless people[50]. It revealed that these physicians saw fewer patients in a given day and were not always compensated for individual patient encounters. This was usually because of patients' lacking the proper identification. Certainly, the findings of the current studies indicate that because of reduced patient volume, high volume of work outside of direct patient encounters and the high number of patients lacking evidence of health insurance, physicians who work with marginalized populations would benefit from improved remuneration methods. Thus, just as patients require "out of the box" program delivery, family physicians also require creative remuneration methods. Whether or not fee-for service remuneration methods pose a barrier to easy access and interdisciplinary teamwork is an area that deserves further quantitative study.

4.3.3.4 Coping Strategies

Analysis of the family physician study data revealed the phenomenon of vicarious trauma and possible compassion fatigue and the subsequent coping strategies used by these physicians. Whereas women participants recalled experiences of horrific violence and its physical and psychological sequelae, family physician participants described the emotional toll of working with such traumatized patients. This is a new and important finding. There is little research exploring this phenomenon in the primary health care setting. Given the impact of compassion fatigue both personally and professionally, workplaces would be wise to ensure that staff members are aware of the risk factors, symptoms and strategies to prevent and cope with vicarious trauma and compassion fatigue.

There are multiple strategies to deal with vicarious trauma that can be implemented at the individual level, but the majority of strategies should be dealt with at an organizational level[51]. Managers have a duty to warn all employees of the potential for vicarious trauma and compassion fatigue[51]. Organizations also have a duty to ensure a safe workplace or risk an increase in staff disability and poor performance. Of note, many family physician participants described feeling unsafe and had to deal with aggressive patients. Feeling unsafe in the workplace is highly correlated with the development of compassion fatigue[51]. Current study findings confirm previous research demonstrating that debriefing with team members is a useful form of dealing with vicarious trauma[51]. Findings also confirm Bell, Kukarni and Dalton's findings of the importance of effective supervision in dealing with workplace stress[51]. Above all, the values of an organization set the expectations of how the workplace and how workers should deal with stress and subsequent vicarious trauma. Normalizing the experience of vicarious trauma is important[51,52]. It can encourage employees to access supportive organizational structures[51,52].

The model of vicarious resilience could serve as a useful framework for family physicians working with patients exposed to trauma and/or violence[53]. How conscious physicians are of the impact of their work and their ability to reflect and adapt to the challenges presented to them will, in part, help to mediate the risk of developing compassion fatigue[53]. Family physicians should recognize their own limitations and use the skills of other professionals, including those within and external to their team when needed. Varying caseloads can also help to reduce stress and exposures to vicarious trauma[51,52]. Family physicians should also recognize risk factors for developing vicarious trauma: being young and inexperienced, lengthy exposures, and working with patients who have difficulty trusting and who face institutional barriers[51,52].

It is possible that there is a parallel process of marginalization as experienced by family physicians who work with severely marginalized women. It is possible that as women patients become more disenfranchised and isolated, the family physicians providing care to them also become more marginalized from "mainstream" medicine. If this is true, then there are implications for how we train and support physicians working with similar populations. This process merits further exploration.

4.3.4 THE PATIENT-PHYSICIAN RELATIONSHIP

The patient-physician relationship was influential in the lives of both women and family physician participants. While both study groups experienced this relationship differently, it remained significant in the lives of all participants.

4.3.4.1 Continuity of Care

Given the high levels of abandonment experienced by the women in this study, a strong patient-physician relationship is arguably more important to these women than the general population. Strategies to encourage engagement and maintenance of the relationship could have important implications for the health of these women. Study findings suggest that continuity of care was one such strategy. Women participants felt valued and cared for when they had long-term relationship with their family physicians, and family physician participants articulated the importance of continuity of care. Some women had been with their family physicians for over two decades. Having a consistent relationship characterized by compassion and respect validated the women's sense of self-worth.

4.3.4.2 Presence and Trust

Another theme where there a strong congruence in the two data sets was that of presence and trust. It is easy for family physicians to get lost in the mire of despair, sickness, and complexity of their daily work with this study population. The obstacles faced by these women in attaining wellness and stability often appeared insurmountable and there was a risk of losing sight of the small victories that were so cherished by the family physician participants. Findings from both studies identified that a strong patient-physician relationship characterized by presence and trust was beneficial to both family physician and women participants. For a stigmatized population of women, the need to feel "human" and valued was enormous. Family physician participants recognized the role presence played in valuing their vulnerable patients. The medical encounter provided women participants with a safe and brief respite from the chaos that characterized their lives. Presence has been identified as a key component of patient-centered care[54-56]. As Loxterkamp stated: “So here is the physician’s balm…his patient asked only that he be there, to talk when she could not manage the pain alone” [54](p227).

Trust has been described as the “kernel of caring relationships”[56]. Women participants spoke about their previous negative experiences with health care providers and their subsequent mistrust of the “system”; family physician participants described the slow process of the “testing period” whereby trust was established as women felt increasingly safe and understood within the relationship. Trust involves a sharing of power. When power is shared, a mutual understanding between patient and physician can occur thus fostering empowerment and self-efficacy. When there is power sharing in relationships, both parties make themselves emotionally vulnerable. The family physician participants illustrated the challenging task of balancing one’s objectivity and protecting one’s inner emotional resources while remaining open to emotional reciprocity. When physicians are able to successfully navigate this connection, there were great rewards for both family physician and women participants.

4.3.4.3 Listening

Wanting a physician who listened to their stories of suffering was identified as important by women participants. Family physicians also spoke about the importance of allowing their patients to “tell their story”. Although the importance of listening is not a novel finding, this is the first study to articulate the crucial role of listening to a population of stigmatized women from the perspectives of both patients and family physicians[9,38,57]. Listening to patients' narratives about the illness experience is a critical part of the patient-centered clinical method[58]. Listening and hearing patients' stories legitimizes their experiences and allows for the development of empathy – physicians begin to imagine what it is like to enter another person's experience[38,55,57]. Attentive listening is a learned skill and something with which many physicians have difficulty[55]. Attention to this skill in medical training is essential and should be emphasized in medical education and medical curricula.

4.3.4.4 "Meeting People Where They're At"

Physicians are generally trained to provide patients with information and expect their patients to follow-through with their recommendations. This can prove to be difficult because patient and physician agendas tend to be different[55,59,60]. "Meeting people where they're at" requires a relinquishing of physician power and recognition that patients may be at varying stages of readiness for change. Both groups of participants described the importance of acknowledging a patient's readiness for change. The Stages of Change model has been found to be an effective intervention tool for addictions; in particular, working with patients who are not ready to quit[60]. Whereas women participants described how: *"you gotta want to help yourself first…"*, family physician participants identified the importance of *"working with …their priorities"*.

Candib points out that when medicine replaced the paternalistic action of "telling patients what to do" with the concept of patient autonomy, it was with the assumption that patients are equal to their physicians and able to free themselves from subjugating societal forces[38]; however, in reality, patients are not equal in the patient-physician relationship and may not be able to navigate the relationship with full autonomy. In order to make fully informed choices, patients need to be able to fully communicate their needs, fears and expectations to their physicians[9]. Patients, and women patients in particular, may have difficulty doing this[9,61]. Thus, the autonomy framework fails to take into account the oppressive effects of chronic illness, violence and chaos faced by women study participants.

"Meeting people where they're at" recognizes that women patients need to have control over their health-related decisions yet enables physicians to provide input and guidance. Ultimately, "meeting people where they're at" was an effective example of how finding common ground requires power-sharing within the patient-physician relationship and an acknowledgment of the participants' context[59].

4.3.4.5 Implications

The collective findings suggest that "any primary health care" is not necessarily good care. A primary health care system that is designed to support patient-physician relationships and promote continuity of care would improve health outcomes on many levels. How organizations structure themselves can either facilitate or hinder continuity[41]. Continuity of care can be encouraged through providing targeted and flexible programming for drug-using women by interdisciplinary primary care teams. In addition, offering concurrent social and medical services along with peer programming can help to establish institutional transference and increase the likelihood that women feel sufficiently comfortable to return for follow-up and maintain their engagement with primary health care providers.

4.4 CONCLUSION

The collective findings of both studies suggest that vulnerable women using illicit drugs face many barriers to engaging in the patient-physician relationship and the primary health care system. Existing literature already provides a wealth of information about the context of vulnerable women's lives. The current study findings offer new and important information about the role of the family physician and the patient-physician relationship in the process of engagement; in particular, that engagement is a two-step process characterized by engagement and maintenance phases. Study findings suggest that there are many strategies which could assist vulnerable women using illicit drugs to overcome barriers. These strategies include: 1) providing safe and affordable housing, 2) increasing harm reduction programs for drug users and sex workers, 3) investing in peer programs, 4) having policy and programming guided by women's strengths, 5) delivering flexible and creative primary health care with a focus on concurrent social and medical services, and lastly 6) recognizing the vital role of the patient-physician relationship and fostering continuity of care. In order to make these strategies a reality, action on the part of policy makers and medical educators is required.

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APPENDIX 1: LETTER OF INFORMATION FOR WOMEN

"Engaging women who use illicit drugs: helping family physicians care for vulnerable women"

You are being asked to participate in an interview as part of a research project to learn about:

- the experiences of women who use illicit drugs and how they get their health care and
- the experiences of the doctors who provide primary care to a similar group of women

This is being studied so that doctors can take better care of women in situations like yours.

The interview will take place at a location and time that is convenient for you and will take approximately 45-60 minutes. The interview will be tape recorded. Our discussion will then be taped and typed out. You will be asked not to use your real name in any of our conversations (you can use a "fake" name). If any personal identifying features are mentioned on the tape, it will not appear on the typed document. The content of all interviews will be typed out anonymously. Published results will have no identifying features. The papers and tapes will be kept in a locked file cabinet at the offices of the researchers. At the end of the study, the tapes and papers will be destroyed. All participants will be compensated with a $10 food voucher and 2 TTC tokens for their time and inconvenience.

Participation in this study is voluntary. You may decline to participate, decline to answer any questions or withdraw from the study at any time with no effect on your current or future care. There are no known risks to participating in this study except that some of the discussion may bring up some difficult feelings. If you would like to talk to someone about any feelings raised during the interview, you will be provided with a list of resources about where you can go to talk to someone. The benefits of participating in the study include helping doctors better understand women in situations like yours so they can provide better care. Sometimes, women also find it helpful to talk about their experiences.

If you have any questions about your rights as a research participant or the conduct of this study, please contact the Director of the Office of Research Ethics at (519) 661-3036 or email: ethics@uwo.ca.

Other questions may be directed to the local researcher, Dr. Susan Woolhouse at: 955 Queen Street East, Toronto, ON, M4M 3P3, Tel: 416.461.2493.

This is not an industry sponsored study and is part of a Master's thesis for the researcher Susan Woolhouse, MD. A copy of the letter of information will be given to you for your records.

Thank you for considering participating in this study.

Regards,

Susan Woolhouse, MD, CCFP

Researchers:
Susan Woolhouse, MD, CCFP; South Riverdale Community Health Centre, Toronto
Judith Belle Brown, PhD, Professor, Department of Social Work and Family Medicine, Chair, Centre for Studies in Family Medicine, University of Western Ontario
Amardeep Thind, MD, PhD, Associate Professor, Department of Family Medicine and Epidemiology and Biostatistics, University of Western Ontario

Affiliations:
Centre for Studies in Family Medicine, Department of Family Medicine, University of Western Ontario, London ON

APPENDIX II: INTERVIEW GUIDELINE: WOMEN PARTICIPANTS

1. Demographics: age, ethnicity, gender (TG?), orientation?, income, housing, DOC, last use, problems with health?, last seen MD, regular MD?, education level, # of children, relationship status
2. How has your drug use impacted your life?
3. How has your drug use affected your ability to see a doctor?
    a. Can you describe the place where you see your doctor?
        i. Are there other services (needle exchange, meal, social services, shelter etc) at the place where you see your doctor?
        ii. How did you find a doctor? What that easy?
        iii. What made it hard to find a doctor? Who helped you find a doctor?
        iv. Does anyone help you get to the doctor?
        v. What makes it hard to get to the doctor? (TTC, priorities, food etc)
        vi. Is the need or desire to get high more important than the need to see the doctor?
4. How has your drug use affected your health?
    a. Can you describe what it is likes to be high?
    b. Using drugs can be dangerous. Do you worry about overdosing? Is death or the thought of dying part of your reality?
    c. Some women tell me stories that make it seem like they are barely surviving – is that what it is like for you?
5. Sex work is a reality for many women who use drugs. Can you describe how sex work has affected your health?
    a. Does working at night interfere with when and how you can access the doctor?
    b. Do you feel comfortable talking to your doctor about sex work?
6. When you've been pregnant, have you seen a/your doctor regularly?
    a. Does being pregnant change your priorities? Does keeping healthy become more important?
    b. Did using drugs ever impact your ability to care for your children?
        i. Did a doctor of health professional ever call CAS on you?
7. Can you describe the place where you see your doctor?
8. Why do you go to the doctor? What does the doctor help you with?
    a. When is the last time you have you seen a doctor or nurse for a pap or breast exam?
    b. Has there been a particularly difficult time that your doctor has helped you get through?
    c. What makes it hard to stay healthy?
9. Do you often feel unsafe? Is violence a part of your life? Does this make it hard to make your health a priority?
10. If your doctor asks you to get something done – like an xray – how do you do that?

   a. What about getting to a specialist? How is that difficult?
   b. Have you ever just shown up at your doctor's office without an appointment? What happens?
      i. Do you get in trouble? Do you have to pay?

11. Have you ever shown up to your doctor's office drunk or high? What happens?
    a. How does your doctor make you feel about your drug use?
    b. How does your doctor talk to you about your drug use?
12. Do you feel safe when you are with your doctor?
    a. Have you ever felt unsafe when at the doctor's office?
13. Is there anything else that you think is important to tell me in terms of how doctors could help women who are in situations like yours?
14. Is there anything else that you think is important to tell me in terms of how health care services are provided? What would be the ideal way to set up a clinic serving women who are using drugs or in the sex-trade? Do you have ideas? Are there other services that should be offered in the same place?

APPENDIX III: LETTER OF INFORMATION FOR FAMILY PHYSICIANS

"Engaging women who use illicit drugs: helping family physicians care for vulnerable women"

You are being asked to participate in an individual interview as part of a research project which will study:

- the experiences of women who use illicit drugs in accessing primary health care and
- the experiences of the family physicians providing the care to these women,

in order to better understand the process of engaging extremely vulnerable women

We are interviewing family physicians in Toronto's inner city who work with populations who face barriers to health and health care and who are known to take a particular interest in serving marginalized populations. By understanding the experiences of family physicians who are able to engage high risk women (in this case, women who use illicit drugs), we hope to better understand the process of engagement.

The interview will take place at a location and time that is convenient for you and will take approximately forty-five to sixty minutes. The interview will be tape recorded. Our discussion will then be transcribed and typed. If any personal identifying features are mentioned on the tape, it will not appear on the typed document. The content of all interviews will be transcribed anonymously. Published results will have no identifying features. The transcripts and tapes will be kept in a locked file cabinet at the offices of the researcher. At the end of the study, the tapes and transcripts will be destroyed.

Participation in this study is voluntary. You may decline to participate, decline to answer any questions or withdraw from the study at any time.

You may be asked for access to your clients for inclusion in other study interviews. Your clients will be assured that their care will not be affected by either declining or participating in this study.

There are no known risks to participating in this study. The benefits include helping family physicians understand how to provide better care to a high risk group of women and also being able to better understand why and how family physicians provide this care.

If you have any questions about your rights as a research participant or the conduct of this study, please contact the Director of the Office of Research Ethics at (519) 661-3036 or email: ethics@uwo.ca.

Other inquiries may be directed to the local researcher, Dr. Susan Woolhouse at:
955 Queen Street East, Toronto, ON, M4M 3P3.

This is not an industry-sponsored study and is part of a Master's thesis for the researcher Susan Woolhouse, MD. A copy of the letter of information will be given to you for your records.

Thank you for considering participating in this study.

Regards,

Susan Woolhouse, MD, CCFP

Researchers:
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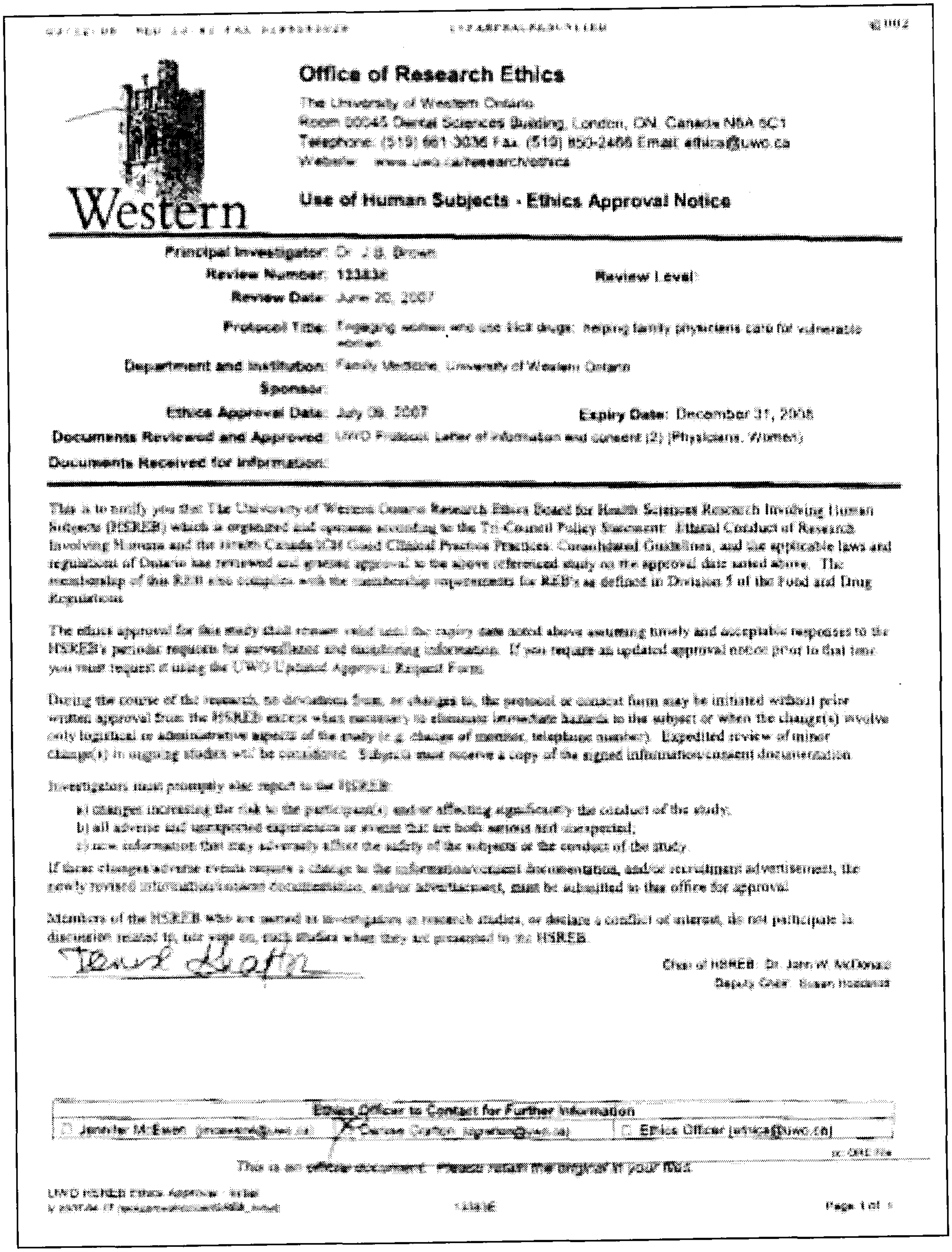
APPENDIX IV: INTERVIEW GUIDELINE: FAMILY PHYSICIANS

1. Demographic information
    - Age, gender, yrs in practice,
    - Can you describe your practice? (academic, solo, CHC; collaborative; all "inner city vs mixture")
    - How long have you been caring for vulnerable women?
    - Salary structure (FFS, blended model, APP, salary)
2. What is your experience of caring for women who use illicit drugs?
    - How did you choose to serve this population?
3. Can you share with me some of the joys of caring for these women?
    - What are some of the memorable stories?
    - What makes caring for these women enjoyable or rewarding?
    - What sustains you in your work?
        - "I imagine some of the work is difficult – what makes you go back day after day?"
4. Can you share with me some of the sorrows of caring for these women?
    - What are some of the tragedies?
    - What makes a difficult or bad day for you?
    - What role does compassion play in your work?
        - Are there times that it's hard to be compassionate?
    - Does the stress of the work ever affect your ability to function either at work or in your personal life? In what way?
    - Can you describe some of the ways that you cope with dealing with such constant tragedies?
5. What are some of the things that you do to engage these women? (How do you get women to come back and see you?)
    a. How do you talk to women about their drug use?
        i. Can you tell me about the role that harm reduction plays in your practice?
    b. Can you describe some of the reasons that it is difficult to engage this population? (e.g. have women follow-up and have regular care)
    c. How does gender affect the degree of disenfranchisement, if at all?
        i. Why are women more vulnerable?
6. In doing the work that you do, do you find it hard to identify with your physician colleagues who are not doing inner city health work?
    a. Do you see yourself as an outsider? Can you tell me more about that?
    b. Can you relate with your colleagues who are working in a more traditional practice setting (can they relate with you)?
7. Can you describe some of the ways you modify your practice when caring for this population? For example, when developing a diabetic treatment plan?
    a. How are expectations of clinical outcomes modified? (for example, with the diabetic?)

    b. Seeing as follow-up and follow-through are such a problem, how do you deal with complexity of illness?

8. Can you describe how you cope with difficult behaviours such as verbal or physical abuse?
    a. Where does drug seeking behaviour fit into this?

APPENDIX V: ETHICS APPROVAL



Office of Research Ethics

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Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. J.B. Brown
Review Number: 13183E **Review Level:**
Review Date: June 20, 2007
Protocol Title: Engaging women who use illicit drugs: helping family physicians care for vulnerable women
Department and Institution: Family Medicine, University of Western Ontario
Sponsor:
Ethics Approval Date: July 09, 2007 **Expiry Date:** December 31, 2008
Documents Reviewed and Approved: UWO Protocol, Letter of information and consent (2) (Physicians, Women)
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. John W. McDonald
Deputy Chair: Susan Hoddinott

Ethics Officer to Contact for Further Information		
☐ Jennifer McEwen (jmcewen@uwo.ca)	☒ Denise Grafton (dgrafton@uwo.ca)	☐ Ethics Officer (ethics@uwo.ca)

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