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## Identifying Barriers and Accessibility Recommendations for Individuals of the Vancouver's Downtown East Side Community in Accessing End-of-Life Care

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### Abstract

**Overview:** End-of-life care for the individuals of Vancouver's Downtown East Side (DTES) community is an essential area of health care practice that aims to bring dignity to highly marginalized and vulnerable individuals. This study was completed in conjunction between the University of British Columbia's (UBC) School of Social Work and May's Place, a hospice operated by The Bloom Group located in DTES. The purpose of this qualitative study was twofold: to examine the barriers individuals of DTES community face in accessing end-of-life care, particularly at May's Place, and to identify recommendations on making end-of-life care services more accessible to the same population. This study utilized the frameworks of biopsychosocial-spiritual theory and trauma-informed practice to ensure the information collected reflected all aspects of individuals' lives, and held the values of collaboration and transparency. Previous literature showed the main categories of barriers marginalized and vulnerable populations experience in accessing end-of-life care: a lack of trust in health care providers caused by previous negative experiences, a lack of appropriate services, a highly vulnerable lifestyle where survival needs are prioritized, and substance use. **Methodology:** The target population included professionals within British Columbia's Lower Mainland who are currently employed or have been employed within the past five years, for a minimum of six months, in either the field of end-of-life care or with an organization servicing the DTES community. Due to their high vulnerability, service users and Indigenous individuals were outside of the approved ethics clearance and excluded from this study. The recruitment method utilized was non-probability sampling, more specifically, purposive and snowballing. The study had a sample size of six participants, all of whom consented to participate in audio-recorded semi-structured interviews (five in-person; one via telephone). There were no foreseen risks with this study; however, a list of supportive resources was available to participants upon request. At the end of each interview, participants received an honorarium for sharing their time and knowledge. To analyze the data, the student researchers employed the use of thematic analysis (Braun & Clark, 2006). All transcripts were transcribed verbatim before two rounds of coding were completed (descriptive and thematic coding; Braun & Clark, 2006; Saldaña, 2013). The student researchers developed the final themes through consensus in using an inductive and semantic approach (Braun & Clark, 2006). **Results:** The data yielded five major themes: Barriers to Accessibility, Strengths of May's Place, Accessibility Recommendations, Sense of Responsibility, and Other Organizations and Cities. Participants corroborated existing literature in identifying previous negative experiences with health care staff, a lack of appropriate services, and substance use, as obstacles in individuals accessing end-of-life care. Participants also identified a range of personal barriers that could contribute to one's ability to access appropriate end-of-life care. In terms of current strengths of May's Place, participants provided positive feedback regarding its physical location, policies and practices, and staff. As for recommendations, participants highlighted the need for the further implementation of harm reduction practices, appropriate training and staffing levels, increased collaboration between health care providers, and offered specific suggestions for May's Place. Of note, all participants demonstrated a sense of responsibility in creating solutions to better serve this patient population. Lastly, participants provided information of other organizations and cities that are working from harm reduction approaches in serving marginalized and vulnerable populations during the end of their lives. **Discussion and Limitations:** The student researchers believe the results of this study demonstrates that these chronic barriers are consistent across multiple geographic locations and are not being addressed by current health care systems. Despite the strong sense of responsibility displayed by health care providers, they continue to work in conditions that cause moral distress by not being able to provide appropriate care to their patients. Limitations of this study includes concerns with the research design, reliability, and validity, particularly with section bias and instrumentation. Therefore, it is recognized that these results may not be transferable outside of May's Place or DTES community. **Future Directions and Conclusion:** The student researchers believe it would benefit May's Place to continue implementing more robust harm reduction practices, and to give further thought on how to increase collaboration among health care providers, perhaps through the use of a blended model. In closing, this research study demonstrates the vital need for further research and changes to current practice to ensure individuals of DTES community have access to inclusive care and a dignified end of life.

**Keywords:** End of Life Care, Hospice, Vancouver Downtown East Side (DTES), May's Place



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## Introduction

In 2013, the Ministry of Health released the Provincial End-of-Life Care Action Plan for British Columbia, which examines the priorities and actions for the provincial health care system in providing end-of-life care. End-of-life care refers to the support an individual receives when they are terminally ill, and their death is imminent; it often focuses on respecting individuals' decisions within the last three months of their life and emphasizes providing comfort care as opposed to concentrating on medical treatment (Ministry of Health, 2013). End-of-life care is intricate and diverse, but when a person has a higher level of marginalization and vulnerability, appropriate care can become even more challenging to deliver. End-of-life care is particularly relevant to the field of social work, as it is an area practice in which social workers are often involved, especially when it pertains to marginalized and vulnerable populations receiving just and fair treatment.

This qualitative research study aims to delve into the complex reality that the individuals of Vancouver's Downtown East Side (Vancouver's DTES) community are facing in accessing appropriate end-of-life care. Situated in Vancouver, British Columbia, May's Place Hospice (May's Place) has been providing end-of-life care to individuals of Vancouver's DTES and other surrounding areas since October 1990 (Vancouver Coastal Health, 2017). May's Place, which is the first freestanding hospice in Western Canada, aims to provide physical, emotional, and spiritual care to individuals who are suffering from advanced and terminal illnesses, specializing in providing care to individuals who are facing challenges with mental health and substance use disorders (i.e. alcohol and/or illicit substance addiction) (The Bloom Group, 2019; Vancouver Coastal Health, 2017). The hospice works from a harm-reduction approach by having a needle disposal box available in each bedroom and allowing individuals to use substances off of the hospice grounds (Li, 2014). Currently, May's Place is hoping to expand its facility from a six-bed to a ten-bed resource in partnership with Vancouver Coastal

Health, who presently provides some operational funding (Li, 2014). This research study was completed in conjunction between the University of British Columbia's (UBC) School of Social Work and The Bloom Group as part of a masters level research course; all funding for this study was provided by The Bloom Group. The research team included the student researchers, a UBC professor acting as the primary investigator, and The Bloom Group project sponsors. The purpose of this research study was twofold; it aimed to examine the barriers individuals of Vancouver's DTES community face in accessing end-of-life care, particularly at May's Place, as well as attempted to identify potential recommendations on how to make services more accessible for this same population.

## ***Conceptual and Theoretical Framework***

For the purpose of this research report, "end-of-life care" refers to the medical care a person receives once they have received a palliative diagnosis and is within an estimated three months of their death. This definition was chosen to reflect the time in an individual's life when they are typically able to access hospice care. The population of interest is defined as the "individuals of Vancouver's DTES community" as a way of using a person-centered approach to encapsulate all individuals' who identify Vancouver's DTES as their home community, regardless of where they are on the housing continuum or if they live transiently. The term "marginalized and vulnerable" is used to reflect the complex social locations of the individuals of Vancouver's DTES community (i.e. possible low socio-economic standing, substance use, mental health) that create barriers for individuals to access care. Lastly, the student researchers use the term "harm reduction" to encompass all practices that focus on reducing risks associated with substance use and do not require individuals to be abstinent.

Biopsychosocial-spiritual theory and trauma-informed practice were the two primary theoretical frameworks used to conduct this research study. These two approaches were intentionally chosen to honour the values and mission of May's Place, as well as stay true to the student researchers' practice

orientation. Utilizing a biopsychosocial-spiritual theory, the student researchers hoped to gather information regarding multiple areas of individuals' lives that may impact their ability to access end-of-life care (Saad et al., 2017; Sulmasy, 2002). Using trauma-informed practice as a guide for this research ensured the values of safety, transparency, and collaboration were present at every point in the research process (Fallot & Harris, 2008; Purkey et al., 2018; Raja et al., 2015).

### **Literature Review**

To narrow the research reviewed for this report, the student researchers chose to focus on literature that spoke of the barriers individuals who are experiencing homelessness encounter when accessing appropriate end-of-life care. The literature included scholarly, peer-reviewed articles, which were primarily qualitative research studies utilizing semi-structured interviews and focus groups, as well as Canadian provincial and federal legislation. Explored below are the four main identified categories of barriers to care, along with how this research study aims to address gaps in knowledge, ending with the research questions for this study.

#### ***Health Care Experiences: Contributing to a Lack of Rapport and Trust***

A lack of rapport and trust between patients who are homeless and their health care providers can be a significant obstacle to overcome. It has been expressed that individuals who are homeless often feel disempowered, disrespected, and discriminated against during previous experiences within the health care system (Hudson et al., 2016; McNeil & Guirguis-Younger, 2012a). Individuals who are homeless have also expressed fears of judgment, alienation, and stigmatizing attitudes from health care workers regarding their lifestyle (Håkanson et al., 2015; Klop et al., 2018; McNeil et al., 2012; Reimer-Kirkham et al., 2016; Stienstra & Chochinov, 2012). Furthering this, it was suggested that even though health care providers recognize individuals who are homeless have a high level of vulnerability, there appears to be a lack of acknowledgment and validation of their patients' complex situations (Stajduhar et al., 2014). This has led to feelings of shame, which resulted in

individuals choosing not to seek medical care at the end of their life (Hudson et al., 2016; Stajduhar et al., 2019). It is also essential to recognize that many individuals who are homeless have faced previous trauma, which may have included negative experiences within the health care system. For example, Indigenous individuals may have a lack of trust in institutions from the trauma and legacy of the residential school system and Indian Hospitals (Stienstra & Chochinov, 2012).

#### ***Lifestyle: A High Level of Vulnerability***

Individuals who are homeless regularly experience compounding social disadvantages and oppressions which can limit their ability to access necessary health care (Stajduhar et al., 2019). A unique aspect of providing end-of-life care to an individual who is homeless is the understandable tendency of that person to need to focus on survival needs, such as finding daily nutrition and shelter (McNeil, Guirguis-Younger & Dilley, 2012; Song et al., 2007); this could realistically make it difficult for someone to concentrate on receiving health care for a terminal illness. A terminal illness may also not be a pressing concern for individuals who are homeless, as death is often normalized due individuals witnessing many deaths of their peers (Hudson et al., 2016).

#### ***Intersectionality with Substance Use: A Harm Reduction Approach***

Delivering appropriate end-of-life care to those who are homeless requires compassionate and flexible thinking in order to fill identified gaps of knowledge (Shulman et al., 2018). In completing the literature review, the student researchers recognized there is a gap in the literature regarding the amount of research exploring this topic in the context of Vancouver's DTES community, as well as limited discussions about how to improve end-of-life care for this same population. At the request of May's Place, this research study was completed in the form of a program evaluation, with the further goal of gathering information on their current services to fill an additional, specific gap in knowledge. Therefore, in hoping to add data to this niche area, the following research questions were created:

1. *What barriers are individuals of the Vancouver's*

*Downtown East Side community facing in accessing end-of-life care at May's Place?*

*2. How can end-of-life care at May's Place become more accessible to the individuals of the Vancouver's Downtown East Side community?*

### **Methodology**

The student researchers would first like to acknowledge that the primary investigator, UBC Professor Barbara Lee, received approval for the completion of this research through the UBC Office of Research Ethics; the research was approved for the category of low-risk.

### **Sampling**

For this research study, the target population included all professionals within British Columbia's Lower Mainland who were employed in the field of end-of-life care or in Vancouver's DTES community. The sampling frame is the list of individuals from the target population who were initially contacted regarding the study (Schutt, 2014); this included professional contacts at: The Bloom Group – Cottage Place and May's Place; Vancouver Hospice Society; Vancouver Coastal Health – Vancouver General Hospital, North Shore Hospice, Three Bridges Community Health Centre Clinic, Pender Care Clinic, Robert and Lily Lee Community Health Centre, and Raven Song Community Health Centre; Fraser Health – Surrey Memorial Hospital, Burnaby Hospital, and Royal Columbian Hospital; Providence Health Care – St. Paul's Hospital and St. John's Hospice.

### **Recruitment**

The recruitment method utilized was non-probability sampling; more specifically, the study employed purposive sampling and snowballing. In using purposive sampling, participants were selected based on their knowledge about the study topic, their willingness to share their expertise, and their ability to represent a range of points of view (Schutt, 2014). Through the use of snowballing, additional potential participants may have been identified by other participants, as participants were encouraged to share information about the study with colleagues and contacts that may wish to participate in the study (Schutt, 2014). The student researchers are aware that some of the initial contacts from the

sampling frame forwarded the study information to further professionals.

The recruitment phase of this research study occurred approximately over a month. During this time, key contacts from the sampling frame were contacted directly by student researchers and the project sponsor, both in-person and electronically. The project sponsor then redistributed the study information approximately two weeks after the first round of distribution to foster further interest in participation. The prospective participants were provided with a study information package that included a copy of the Invitation to Participate, the Study Information Letter, and the Consent Form. Participants were instructed to directly contact the student researchers to express their interest in participating. When the student researchers were contacted by prospective participants, indicating voluntary interest, the student researchers electronically re-provided the study information package to ensure the prospective participants received all of the pertinent information. The student researchers then coordinated with the prospective participants to arrange interviews with explicit instructions to review the Consent Form prior to the interview.

### **Sample Size**

Upon the completion of the recruitment period there were seven identified potential participants. However, due to time constraints and conflicting schedules, only six of these potential participants were interviewed. The participants came from four different professional backgrounds and had a range of experience in providing end-of-life care and serving individuals of Vancouver's DTES community. It was explained to the student researchers that the professional community who care for this population is relatively small, and therefore, out of the respect of the participants and their confidentiality, no further demographic information will be provided. All six participants met the inclusion criteria to participate in the research study, in that participants had to be currently employed or employed within the past five years, for a minimum of six months, in either the field of end-of-life care or with an organization servicing

the Vancouver's DTES community. Due to a high level of vulnerability, service users and Indigenous individuals were outside of the approved ethics clearance, and therefore, were excluded from this study.

### **Data collection**

Student researchers conducted semi-structured interviews with participants that lasted an average of forty-five minutes. Of the six interviews, five were completed in-person and one was completed via telephone. All interviews were audio-recorded with the written consent of the participants. Prior to commencing each interview, the student researchers verbally reviewed the signed Consent Form with participants, which included information regarding the participants' ability to withdraw their consent at any time without consequence until a given date. The interview had nine questions, focusing on collecting information regarding professional experiences, barriers to accessibility, strengths of May's Place, accessibility recommendations, and promising practices including other organizations and cities; the interview guide can be found in Appendix A. While there were no foreseen physical, emotional, and/or physiological risks associated with partaking in the study, the student researchers acknowledged the subject may be sensitive and prepared a list of supportive resources that were available for participants upon request. At the end of each interview, the participants received a \$5 gift card to Starbucks as an honorarium to show appreciation for sharing their time and knowledge.

### **Analysis**

Thematic analysis was used as the overarching analysis framework for this research study, with the student researchers completing all six phases of this process (Braun & Clark, 2006). As the act of transcription has been identified by some researchers as a key phase of data analysis, the student researchers first familiarized themselves with the data by transcribing all interviews verbatim (Braun & Clark, 2006). The student researchers then completed two rounds of independent coding that examined each line of the data as a separate

segment. The initial round of coding is often described as the phase in which a general list of ideas regarding what is said in the data is created (Braun & Clark, 2006); to complete this, the student researchers used descriptive coding in which each line of data was summarized by assigning the segment with a word or short phrase that identified the topic of the data (Saldaña, 2013). In the second round of coding, the student researchers used thematic coding as a way to categorize and synthesize the amount of information collected (Ayres, 2008). This second round of coding allowed the researchers to move away from describing the topics identified in the data to establish common themes and ideas throughout the data (Ayres, 2008).

After the completion of two rounds of coding, the student researchers began to independently search for themes by refocusing on broader concepts and sorting codes into potential themes (Braun & Clark, 2006). The themes identified were founded on an inductive approach, which is characterized by the themes being linked directly to the data (Braun & Clark, 2006). At this point in the process of analysis, the student researchers came together with the data they had individually collected and coded, and continued to review the data to define concrete themes. These two phases included deciding which themes had enough data to support them and which could be combined, as well as naming subthemes (Braun & Clark, 2006). The final themes were derived using a semantic approach, meaning all themes were taken explicitly from the data, and not from examining underlying assumptions and conceptualizations (Braun & Clark, 2006). Lastly, the student researchers engaged in the final phase of thematic analysis, which is identified as writing the research report.

### **Results**

This study yielded five main themes: Barriers to Accessibility, Strengths of May's Place, Accessibility Recommendations, A Sense of Responsibility, and Other Organizations and Cities; the student researchers would like to acknowledge the first three themes that have several subthemes that allow for a greater in-depth exploration of the data.

## **Barriers to Accessibility**

### **Health Care System.**

**Past Negative Experiences.** Many participants shared that numerous individuals from Vancouver's DTES community have had previous negative experiences in institutions or facilities that prevents them from wanting to seek medical care, including going to a hospice. One participant articulately stated "a lot of marginalized patients... have had bad experiences with health care providers, and feel... not necessarily that the health care team has their best interest at heart". Another participant noted that if a person avoids accessing health care they will not be able to access end-of-life care, as this process requires being regularly connected to a medical professional or accessing hospital services. A further participant explained the overall mistrust of the health care system contributes to the creation of biases about what a hospice setting may be like, such as losing choice, freedom, and independence. Participants also took the time to highlight the unique, increased trauma Indigenous populations' hold that stems from colonization, residential schools, and previous harm from medical professionals. This results in a fear "where, you know, they've had these incredibly traumatic experiences in institutions and so anything that reminds them of that... they just don't want anything to do with."

**Coordination.** Several participants expressed concern that multiple health care providers are seeing the same individuals, but are doing so in silos. When a participant expressed concerns about the amount of communication May's Place has with other health care organizations servicing the same population, they also noted that: this isn't a May's alone issue, it's more of a question of why don't we have a more coherent system from the hospital that's in the Downtown East Side, with the hospice that's in the Downtown East Side, with all the providers and clinics that are in the Downtown East Side - it's not as coordinated at all as you would expect, as you may expect from the outside.

A further worry was voiced that this lack of coordination meant many individuals of Vancouver's

DTES community do not receive the planning they deserve around their end-of-life care, with numerous patients being discharged from hospitals to return to the streets or a line-up shelter without any sort of plan for follow up care.

### **Mainstream System for Non-Mainstream Clients.**

It was expressed by a participant that the health care system, policies, and regulations have been created by mainstream, middle-class individuals, without taking into account the values and needs of marginalized and vulnerable populations. From this, many services have been created, but are not necessarily what individuals of Vancouver's DTES community need.

**Housing.** Individuals living in Vancouver's DTES community often have to relinquish their housing, such as a bed in a shelter or unit in an SRO building, to be able to enter hospice. This can be a difficult decision for individuals to make, as it means they have to forgo the safety and comfort of their own home without having the opportunity to return. Participants provided feedback that May's Place can be off-putting to individuals, which creates further hesitancy in the choice to leave their own home. Unlike other hospices, participants reported that the exterior of May's Place can feel institutional, as it does not have the appearance of a home and is situated in a multi-level residential building; it also requires individuals to press multiple buzzers for entry, meaning patients residing there cannot have free access to their living accommodations.

**Lack of Home Care.** Several participants raised concerns about the lack of access individuals of Vancouver's DTES community have to home care during the end of their life. This includes access to resources such as shift care nursing, which are nursing staff that are responsible for providing the final acute care to individuals in the last 120 hours of their life when they are actively dying. This barrier was reportedly created by health authorities and agencies deeming homes in Vancouver's DTES community, SROs in particular, as being "not always the safest environments for health care workers" to attend. The safety concerns included bed bugs, general violence both inside and outside of the building, violence directed at staff, as well as unsafe

and unsanitary home conditions.

**Finances.** In particular, participants were troubled that when individuals are receiving income from the Ministry of Social Development and Poverty Reduction (MSDPR) “most of their cheque goes towards the hospice except....about... a hundred dollars they get back each month”. This leaves individuals with little money to purchase items they may want, “including things...related to addiction, but also like just the regular, you know, stuff that...a person might want to buy like food they choose to buy instead of the food they are given at the hospice”. It was also noted individuals have expressed wanting to have some available monetary funds, even if they do not spend their money.

**Barriers from Personal Life.** Several personal concerns were also identified as creating further obstacles to accessing appropriate end-of-life care. First, individuals may be discouraged by the routine implemented in hospice, as the expected schedule for meals, medications, and visits is often vastly different than their usual lifestyle and can be challenging to adjust to. Second, participants expressed that individuals of Vancouver’s DTES community are often concerned about their pets, and are not willing to go to hospice until a plan has been made for them. This is further complicated as May’s Place, similar to other hospices, does not allow patients to bring pets with them. As a participant stated, the “people that [they] come across in the Downtown East Side, they’re quite lonely, they don’t have many, like, supports and their pets become, like, a really big source of comfort....especially if [a person is] dying”. Third, individuals of Vancouver’s DTES community have previously told participants that they believe moving into hospice is signifying “giving up” or that “death is near”. This fear is compounded by the requirement to complete paperwork that clearly states a person is within three months of death, as many individuals may be in denial or may not want to know the extent of their prognosis.

**Substance Use.**

**Health Care.** When an individual, struggling with

a substance use disorder presents for health care, it was noted “getting people to understand their end of life in the context of their addiction can be quite difficult, so...there’s a lot of barriers around the health care providers that they meet and the kind of care they’re even offered”. This referred to the notion that individuals who use substances, whether that is alcohol and/or illicit substances, are not necessarily receiving specialized care; this can include physicians not being familiar or comfortable with palliative care in the context of a substance use disorder, which then may result in the under-prescribing of pain medication for symptom management.

**Subsequent Behaviours.** In recognizing that some patients require “a very high amount of opioid use or substance use, [the problem then becomes] the disruptive behaviours that go with that and whether that’s manageable in a hospice setting or not”. Participants raised the concern that it can be difficult to inform a hospice of expected behaviours, as individuals often act differently depending on their setting and whether they are actively under the influence of substances. In relation to the ability of May’s Place to be able to care for behaviours caused by substance use, a concern was raised that “[May’s Place] should have the expertise for that patient population and it feels like they don’t, and therefore, aren’t really offering anything that is unique to the patients”. However, while “there is a lot of push back around managing behavioural issues [at May’s Place]”, a participant felt it is for “very practical reasons”, referring to the hospice’s shortage of staff and security. There were further questions about how individuals could access their substances if they are immobile while in hospice, noting there may be concerns with “dealers or other people who [the hospice] may not want frequently coming to supply”, in addition to visitors wanting to use substances with patients.

**Strengths of May’s Place**

**Physical Location.** Participants shared that May’s Place is physically situated “exactly in the right place”, as it keeps patients connected to their community

and is located “right within the neighbourhood”. In addition, a participant stated they felt the inside of May’s Place provides a home-like environment that is clean, safe, and comfortable.

**Policies and Practices.** First, the hospice is a low-barrier facility that incorporates some harm reduction practices, including allowing patients to smoke cigarettes and tobacco on the patio. If patients would like to use additional substances, staff will reportedly assist individuals in getting outside. May’s Place has also seemingly formed an alcohol-management type program where nursing staff can help manage and supervise a patient’s alcohol access if needed. Second, the hospice provides short admissions for respite, which is a two week period where an individual can reside at the facility with the ability to come and go as they please. Third, participants appreciate the financial flexibility May’s Place extends to clients of the MSDPR. To provide context, an example was shared of individuals being admitted to May’s Place but choosing to leave shortly after their admission. When the individuals had to return to hospice in the following week, May’s Place reported the individuals’ official admission date as the second admission in efforts to allow them time to adjust financially. Lastly, May’s Place makes a conscious effort to promote their facility in the community via an online video tour that can be shared with individuals, arranging “visits for [individuals] to just tour the facilities and meet some of the staff beforehand and get an idea whether they want to go there or not”, and have previously provided a drop-in lunch on a referral basis for individuals with a terminal illness who may require future hospice services.

**Staff.** Staff were reported to possess strong psycho-social skills, are “quite open and creative”, and will work with patients to address their personal concerns. The following feedback was provided regarding staff members: [staff] actually do a marvelous job of welcoming people who aren’t necessarily socially appropriate or have good social

interactive skills... [staff] certainly don’t balk at the fact that people may look scruffy and might arrive with bugs on, [staff] are very good at sort of arriving and managing the bug situation so that it doesn’t spread to the entire facility and yet managing the person and helping them feel welcome. [Staff] do very good at relational building once the person’s there....they’ve got a wide...tolerance...for people who like I said don’t necessarily have good social skills.

In addition, the staff accommodate different lifestyles and behaviours through their de-escalation skills, including the ability to allow visitors who may be disruptive. May’s Place staff communicate with community partners, such as arranging debriefing meetings. The hospice staff takes time to build rapport with patients, including visiting potential patients in hospitals and building relationships with patients who have a prognosis longer than three months. The staff are also flexible with allowing patients to have some control of their daily routine.

#### **Accessibility Recommendations/Solutions**

**Implement More Harm Reduction Practices in Hospice.** Several participants highlighted the need for further implementation of harm reduction practices in hospice settings, including May’s Place, naming that “harm reduction onsite is a general [mindset], a general awareness, and a general preparedness”. Participants cited limiting the spread of disease, providing safe spaces to use, and preventing deaths caused by overdose as some of the reasons why harm reduction practices are needed. Most notably, participants spoke about how the goal at the end of an individual’s life is often not to gain sobriety, and recognized “if the person is at the end of life [and] they’ve had an intractable addiction problem, that is not going to go away at end of life”.

One recommendation, in particular, was to ensure marijuana is allowed to be consumed on hospice patios or balconies. A participant was “surprised to find out there’s no accommodation at this point for pot smoking... it’s legal and if you can smoke on a balcony, cigarettes and tobacco, licensing needs to



get on board there....because otherwise some of our guys are going to [leave]”. To potentially implement further harm reduction practices at May’s Place, participants recommended looking at the models of Insite and Crosstown Clinic, two harm reduction organizations within Vancouver’s DTES community. Participants suggested hospices create a designated safe space to allow for onsite substance use, such as a room with clean supplies aided by the development of signals among staff to represent when individuals are in the room. Alternatively, a participant felt that it may be more “realistic” for hospices to provide opioid replacement therapy, where individuals would receive medical-grade doses of the opioids that match their current level of substance use at regular intervals. While participants recognized there would need to be appropriate staffing levels and specialized training to achieve either of these practices, participants continued to speak at length about the importance of implementing further harm reduction practices.

**Health Care Professionals.** As previously stated, there were concerns expressed with the lack of training May’s Place staff appear to hold, which had participants calling for the need for specialized training, especially in the areas of harm reduction and behaviour management. Further advocacy for the improvement of trauma-informed care, particularly relating to Indigenous individuals, was provided, with one participant articulating the importance of this by stating the following: the whole awareness of how troublesome the health care system has been, you know, from Indian hospitals, which is painful to just even say, where people were literally tied down because the white system thought they were infectious and children, it was...it’s just so awful and it’s not too far in our past, it’s not like a 100 years ago, it really is just a few years ago.

In addition to appropriate training, participants noted it is vital for health care providers to have a passion for this area of practice. Participants identified what separated the staff attitudes were their beliefs in harm reduction, their ability to “walk beside the individual and support them with what

they need or what they recognize as their needs”, as well as their ability to problem solve and generate creative solutions to work around structural barriers. Participants also recommended having lower patient to staff ratios and security in hospices, if needed, to ensure staff and patient safety. In addition, they suggested having a staff member who is readily available to attend to a person’s individual needs, such as getting items from their home, completing banking, and sorting out legal affairs.

**Larger Health System Coming Together.** Participants advocated for increased collaboration between health care providers in order to better serve the individuals of Vancouver’s DTES community. Seemingly apparent suggestions, such as increasing communication between the community health care workers, hospitals, and May’s Place, were heavily reiterated. Participants also suggested that health care providers should have earlier conversations with individuals about what end-of-life resources are available in their community and stressed the importance of including the individual in their health care planning process by “making plans... not around them, but engaging them into the whole thing”. An additional suggestion was to ensure health care providers who frequently provide care to an individual identify when that person may need end-of-life care and notify other health professionals to become involved. Another provided recommendation to increase the collaboration between health care providers was through the use of a blended model. Participants identified that individuals should receive an overlap of care in hospice from their previous community and hospital care providers for a set period of time, as a way to utilize the existing therapeutic relationships as a bridging tool in building trust with patients’ transitioning to hospice. Finally, multiple participants called on the larger health care system to subsidize the cost of receiving care at a hospice for individuals who receive their income from the MSDPR, as a way to ensure they do not have to forgo nearly their whole cheque to receive care. Participants felt individuals should be offered more “a respectful experience... of life, where they don’t have to pay all of their cheque to die to be in a place that is

safe”.

**For May’s.** Participants provided the following recommendations specifically regarding accessibility at May’s Place. A participant suggested ensuring May’s Place is well marketed in Vancouver’s DTES community, as currently, it appears “clients have heard from other people, like in the neighbourhood and friends and whatever, that [May’s Place is] where you go to die” instead of believing it is somewhere “where you can be addicted and still get really great care and...where you don’t have to give up your whole monthly cheque, that type of thing, and maybe just a place you can rest and recover”.

Another recommendation was to encourage health care professionals from hospitals and the community to attend a tour of May’s Place as a way to strengthen relationships and guarantee that professionals properly know how to describe the hospice to their patients. Participants identified that providing community partners, including hospitals, with clear boundaries regarding what May’s Place can handle in terms of an individual’s substance use and behaviours would be useful to lessen the number of inappropriate referrals.

In terms of admissions criteria, some participants felt it could be valuable for May’s Place to look at widening their admissions criteria. The suggestions came in the form of allowing a wider range of prognosis (i.e. up to six months instead of three), offering general short stay admissions that only last for a few days, and having a few stabilization beds that would act as a step-down from acute care in the transition from hospital to home. Participants hoped the process for short stay would be made easier for individuals, including having no cost associated with their stay and a simpler paperwork process, as a way to encourage individuals to try the service. Participants would ideally also like to see a simpler paperwork process for all admissions.

Participants queried about the ability of May’s Place to allow patients to bring their pets on a case-by-case basis based on the type of pet, size, maintenance, behaviours, and allergies. If this is not possible, participants suggested allowing patients to have visiting hours with their pets as long as

someone is responsible for their care or implementing a pet therapy program run by volunteers.

The last recommendation for May’s Place was to connect with Indigenous communities, particularly Elders, as a way of building “like a sort of connection between May’s and some of our [Indigenous] clients”, as “First Nations awareness is an area of growth [for May’s Place]”. A participant suggested an Elder could facilitate “healing circles which are kind of like support groups, but, like, in a more like culturally... relevant sort of set up”.

### ***Sense of Responsibility***

All participants articulated a deep sense of responsibility in wanting to understand how to best serve the individuals they work with and stated this field of research was a vital part of that understanding. One participant spoke of preliminary research showing how marginalized and vulnerable populations do not wish to partake in Medical Assistance in Dying, noting that “their life is so hard, they spent so much energy trying to live, why would they want to die?” and that this population is “also a lot more comfortable with suffering”. Building on this, another participant stated the unmet need of providing appropriate end-of-life care to individuals of Vancouver’s DTES community has increased because “we’ve done such a good job of extending people’s lives..., and we’ve got an aging population in the Downtown East Side and we’ve got... a sicker population down there because of all the...brain injuries and things like that due to the opioid crisis”. A third participant shared they are currently “a little bit paralyzed about not knowing how to fix the problems” and they suspect their colleagues would “agree that [they] are not doing a good job in the big picture sense of serving [their] patient population”. Overall, participants continually expressed that they believe “everybody should have the option of dying with dignity... and [there’s] many examples of where that wasn’t the case in the Downtown East Side”.

### ***Other Organizations and Cities***

Several participants provided information on other organizations and cities that are providing unique care to their marginalized and vulnerable populations.

In Vancouver, British Columbia, participants named organizations such as St. Paul's Hospital, the Hazleton, Dr. Peter's Centre, the Portland Hotel, and the Community Transitional Care Team as organizations that are either currently or have previously provided end-of-life care to this population. Of importance, the participants chose to highlight these local organizations for their ability to implement harm reduction strategies in caring for their patients. Further cities were mentioned without participants providing information about the particular programs; these included Ottawa, focusing on the work of John Turnbull, Calgary, and Dalhousie. Additionally, one participant shared information regarding a low-barrier hospice in Toronto for individuals experiencing homelessness, which has flexible admissions criteria. Lastly, a participant spoke about the outreach services doctors are providing in Victoria, British Columbia.

## **Discussion**

As expected by the student researchers, some information examined in the literature review was corroborated by the data collected in this research study. In particular, substance use, negative experiences with health care providers, and a lack of appropriate services were confirmed as barriers for individuals of Vancouver's DTES community in accessing end-of-life care. This demonstrates these systemic barriers are consistent across multiple geographic locations, are longstanding and chronic, and are not being addressed by current health care systems. The bigger question then becomes, if the barriers are being consistently identified, why are they not being resolved? It is the student researchers' opinion that underlying these barriers, there is a concern of othering, disconnection, and lack of understanding from the larger mainstream society towards this population. This notion is derived from the data collected in this study that was further supported by existing literature; both acknowledge there are many health care professionals who lack an understanding on how to appropriately care for marginalized and vulnerable populations, further maintaining the mistreatment of this population by the larger health care

system and perpetuates feelings of being misunderstood, disrespected and discriminated against (Hudson et al., 2016; McNeil & Guirguis-Younger, 2012; McNeil, Guirguis-Younger & Dilley, 2012a). Perhaps this is further echoed by the controversy in the broader society regarding whether more time, effort, and resources should be spent improving end-of-life care for individuals of Vancouver's DTES community.

Unlike the existing empirical literature, this research study provides more specific information directly relating to the barriers individuals of Vancouver's DTES community face in accessing end-of-life care, and also some unique recommendations that are tailored to this community and the services being provided. Specific to Vancouver, the research findings for this study highlights the lack of collaboration and communication among many health care providers who serve the same individuals. This is particularly concerning as Vancouver has a large marginalized and vulnerable population who may not be receiving appropriate and essential care, which as the data suggested, could result in many individuals dying either in their homes or on the street without care. Building on this notion of not receiving appropriate care, there are further concerns with how interacting systems, such as health care/home care, welfare, and housing are not meeting the basic needs of individuals of Vancouver's DTES community particularly in relation to end-of-life care. This was highlighted in the collected data among the reoccurring conversations regarding the lack of home care available to individuals of Vancouver's DTES community, as well as financial expectations of entering hospice that leaves individuals with little personal monetary funds. Surprisingly to the student researchers, there were also a number of personal barriers identified by participants. This feeling of surprise speaks to the tendency to view end-of-life care as part of a larger, homogenized system, while perhaps being ignorant to the fact that death is a very individual experience. This demonstrates that the need for end-of-life care is robust and cognizant of an individual's biopsychosocial-spiritual needs ranging from the

micro to macro level.

The student researchers were pleased to see resemblances of the biopsychosocial-spiritual theory and trauma-informed practice interwoven in the accessibility recommendations offered by participants; notably these recommendations also ranged from micro to macro levels. Of the recommendations offered by participants, the student researchers particularly believe the further implementation of harm reduction practices is critical in creating an inclusive end-of-life care system that acknowledges and supports individuals' preferences and needs. The worthiness of further harm reduction practices was demonstrated by every participant in this study mentioning its effectiveness, and is echoed among existing literature that demonstrates how incorporating harm reduction practices in end-of-life care can foster open communication and trust, as well as elicit higher levels of satisfaction by care receivers and their families (McNeil et al., 2012; McNeil & Guirguis-Younger, 2012b; Podymow, Turnbull & Coyle, 2006).

### **Limitations**

There were several limitations to this study that impacted both the internal and external validity, as well as the reliability of the results. Regarding internal validity, both student researchers independently conducted semi-structured interviews, which created a concern of instrumentation (Lee, 2020; Mertens & Wilson, 2012); the student researchers acknowledged they likely asked questions in different manners which may have altered how participants responded, and therefore, could have impacted the data that was collected. This could have been amplified in the interviews that occurred in-person versus via telephone. In terms of participants, there was a significant limitation with regards to selection bias. As previously noted, service users and Indigenous individuals were excluded from the sampling pool due to having a higher level of vulnerability than approved by the ethics clearance for this study. The student researchers recognized this is a significant limitation to the study, as it is missing two important voices in Vancouver's DTES community. In addition to this, there was a notable

limitation in that no professionals employed at May's Place participated in the study, meaning their perspectives are not represented in the data. Furthermore, the unique attributes voluntary participants may possess, such as having a strong viewpoint they want to share, created an additional selection bias in this study (Lee, 2020; Mertens & Wilson, 2012). When completing the interviews, the participants may have modified their answers based on the knowledge that they are part of a research study, also known as the reactive effect (Lee, 2020; Mertens & Wilson, 2012). With regards to external validity, the student researchers acknowledge their own expectations of this research study may have created a limitation, which is referred to as researcher bias (Lee, 2020; Onwuegbuzie & Leech, 2007). In order to help mitigate the concerns mentioned above, the student researchers incorporated the process of member checking (Lee, 2020; Onwuegbuzie & Leech, 2007). This was accomplished by asking clarifying questions, as well as inquiring if the participants wanted to add anything further before ending the interview. The student researchers also provided the anonymous quotes used in this report to participants who requested this on their Consent Form, as a way to ensure the student researchers were accurately representing the data. In addition, the student researchers engaged in reflexivity as a way of critically analyzing the assumptions and biases they may have held throughout the study, both independently and collectively (Lee, 2020; Nobel & Smith, 2015).

In terms of limitations of reliability, with both student researchers participating in the coding process, there could be a concern of inter-rater reliability. To minimize the effects of this, the student researchers reviewed the emerging themes and reached agreement by consensus, in which both student researchers had to agree to each theme (Engle & Schutt, 2017).

Despite the attempts to lessen the limitations of this study, the small sample size added to the restriction of the generalizability of these results. With this, the student researchers acknowledge the

results of this study may not be applicable outside of May's Place or Vancouver's DTES community.

### **Future Directions**

An implication of this research study for the field of social work, similar to other health care professionals, is that social workers are often placed in situations that create moral distress and ethical dilemmas by not being able to provide adequate care to individuals. This means that care providers are often aware of what the right decisions may be, but they are unable to act on them due to structural constraints. A potential impact, both at the micro and mezzo levels, is that all research participants expressed wanting a copy of the report, with multiple participants stating they would like to share this research with their colleagues as a way to start conversations regarding their practice. The student researchers hope this research can assist in starting conversations within agencies, but also between organizations about how best to collaborate to properly serve individuals of Vancouver's DTES community in their end-of-life journey.

While there are many avenues of future research, the student researchers focused on two particular topics that may be of interest to May's Place. First, the student researchers recommend gathering additional information on how to further implement harm reduction practices into May's Place, starting with connecting with local community partners who are already practicing this approach, and inquiring how these practices could be utilized in a hospice setting. Second, the student researchers recommend examining how a blended model of practice could be implemented at May's Place. As previously noted, this model of practice, suggested by participants, recommends that individuals should receive an overlap of care in hospice from their previous community and hospital care providers for a set period of time, as a way to utilize the existing therapeutic relationships as a bridging tool in building trust with patients' transitioning to hospice. The student researchers believe this may be a worthwhile venture to increase collaboration among health care providers, and wonder if a blended model could assist in increasing patient capacity at

May's Place. The student researchers suggest collecting information from local, national, and international sources to determine if this model of care is implemented elsewhere and how successful it can be in assisting individuals in transitioning to hospice. The student researchers also provide the two following recommendations to May's Place. First, as a shorter-term goal, the student researchers recommend May's Place invests time in connecting with community partners, including local hospitals and community agencies, about how to improve working relationships and coordinate services. As previously noted, other health care providers are hoping to receive clarification from May's Place regarding their current capacities as a way to mitigate inappropriate referrals. Multiple participants also called for May's Place to review their admissions criteria and process to see if it could be more flexible and simplified as a way to increase patient capacity. In saying this, the student researchers also believe if May's Place is going to have wider admissions criteria, it is vital for all staff members to be appropriately trained in specialty areas, such as substance use, behaviours, harm reduction, and mental health, in order to provide appropriate care to this patient population. Second, in recognizing this will take more work and time, the student researchers recommend May's Place incorporating further harm reduction practices onsite as a longer-term goal. As a way to begin this process, the student researchers suggest connecting with local community partners who are already practicing from this approach as a way to identify how current models of practice could be modified to a hospice setting.

Examining the wider scope, student researchers hope to see this research topic evolve from the micro-level of looking at how a hospice, such as May's Place, cares for individuals of Vancouver's Downtown East Side community, to a more mezzo and macro level. This would include examining how the health care agencies in Vancouver, British Columbia, including hospitals and community organizations, care for the same population, with the further hope that the larger health care systems in Vancouver will improve upon their attitudes and

ideologies while caring for this same population.

In upholding a trauma-informed approach, the student researchers recognize that service users and Indigenous populations need to be included in all future directions, as it could be extremely harmful to implement practices that are not formed in the true spirit of collaboration. This could include community based research methods, as well as adhering to the Ownership, Control, Access, and Permission principles, which is a guide to research created by First Nations to ensure colonization is not further perpetuated (First Nations Governance Center, 2014).

## Conclusion

End-of-life care for individuals of Vancouver's DTES community is a critical area of practice that aims to bring dignity to highly marginalized and vulnerable individuals. Regardless of this being a fundamental service, multiple systemic barriers inhibit individuals in receiving appropriate end-of-life care, such as past negative health care experiences and lack of coordination between health care services, the inapplicability of mainstream systems to marginalized and vulnerable populations, as well as a limited understanding on how to adequately provide health care to individuals with a substance use disorder. Outside of these systemic barriers, individuals may also have personal obstacles that impede their ability to access care. Despite this, many health care providers in this field are dedicated to finding creative solutions on how to make end-of-life care more accessible and appropriate for the individuals of Vancouver's DTES community. Participants advocated for the further implementation of harm reduction practices in hospices, specialized training and appropriate staffing levels, and increased collaboration between health care services. Lastly, participants also offered recommendations specific to May's Place. In closing, this study highlights the need for further research in this area of practice as a way to ensure all individuals have access to inclusive care and a dignified end of life.

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## Appendix A

### Interview Template

#### Before starting:

Review the consent form verbally. Inquire whether they would be willing to provide anonymized quotes and if they would like a copy of the final report upon completion. Below are 9 questions with possible follow up questions if the answers were not already covered.

#### Questions:

1. Can you please summarize your professional experience with either: May's Place and/or providing end-of-life care for the individuals of the Vancouver's Downtown East Side community OR working with individuals of the Vancouver's Downtown East Side community?
2. What are the key barriers for people who live in Vancouver's Downtown East Side in accessing End of Life Care?
  - a. How do these barriers relate to May's Place?
3. Through our literature review, we have identified a lack of harm reduction practices, mistrust of health care providers, lack of appropriate services, and having highly vulnerable lifestyle, as key barriers for the homeless population in accessing end-of-life care. What are your thoughts on this?
  - a. What is your take on harm reduction?
4. What strengths do you believe May's Place have in how they provide end-of-life care?
5. What are some potential recommendations that would make end-of-life care more accessible for people who live in Vancouver's Downtown East Side to access, especially at May's Place?
  - a. What are some obstacles for implementing these recommendations?
6. In the literature review incorporating harm reduction and collaborating with community resources have been some of the suggested recommendations to increase access to end-of-life care to people who are experiencing homelessness. What are your thoughts on this?
7. Are you aware of any promising practices being implemented elsewhere?
  - a. If so, please describe these to us
8. On a scale of 1-10, with 10 being the highest priority, please describe how important do you feel it is to spend time and resources in creating an accessible end-of-life care in Vancouver's Downtown East Side?
9. Is there any information you would like to discuss or add?