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Caring for People on the Margins: An Institutional Ethnographic Exploration of Community Palliative Care Work for People who are Precariously Housed

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Caring for People on the Margins: An Institutional Ethnographic Exploration of Community

Palliative Care Work for People who are Precariously Housed

by

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A THESIS

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Abstract

People experiencing homelessness have more barriers accessing healthcare than the general population. Challenges are worsened when people become ill and require end-of-life care (EOLC). Some barriers to EOLC for this population include discrimination, service providers who lack knowledge about homelessness, and fewer opportunities to voice care preferences. As part of a developing palliative equity movement, small teams have been created to provide better EOLC for people experiencing homelessness. While much research explores homelessness and healthcare, to date, none investigates the social organization of these teams amidst the mainstream system. This research addresses this gap by exploring how one of these small teams, the Community Allied Mobile Palliative Partnership (CAMPP), interacts with clients, structures their work, hooks into the mainstream healthcare system, and is institutionally accountable to a broader philanthropic funding structure in Calgary, Canada.

This project uses institutional ethnography (IE) as its guiding mode of inquiry. From the standpoint of CAMPP clients, IE promotes understanding of how this team's work is put together, produced, legitimized, and challenged while operating in the interstices of the mainstream healthcare system. With over 100 hours of observations, document reviews, and 21 client and service provider interviews, this research recasts the reader's view from taken-for-granted medical models of palliative care toward the social realities of people at society's margins and how the CAMPP team embeds these needs into their care model.

Grounded in client accounts, this project illustrates how the mainstream system is structured to create challenges for people facing economic marginalization warranting a service like the CAMPP team. Paying close attention to language, this study shows how CAMPP is

shaped by and reshapes the palliative care discourse to include social factors, mobilizing the widely recognized model of “harm reduction”.

Lastly, this project describes how the CAMPP team is funded and their perceptions of the sustainability of their program. This study has implications for policymakers, community programs, researchers, and people experiencing homelessness by making visible how teams like CAMPP provide care “at the margins” of dissolution while caring for people “at the margins” of society.

Keywords: institutional ethnography, palliative care, homelessness

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As my sister Chelsey would say, to make any progress in our lives, be it personal or social, we all stand on the shoulders of giants, and I sure have some giants in my corner. Thank you, all.

Dedication

I dedicate this dissertation to my mom, Wendy Jane Petruik. Stronger than anyone ever gave her credit for. Wiser and wilder than the world was ready for. I wish I knew then what I know now and for that reason, I will never stop learning.

This is to all the people, like my mom, that our health system should've reached in the way they needed but didn't, should reach in the way they will need but won't, and to those who devote their lives to making it better.

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List of Abbreviations

ARP	Alternative Relationship Program
CAMPP	Community Allied Mobile Palliative Partnership
CFREB	Conjoint Faculties Research Ethics Board
EMR	Electronic Medical Record
FTE	Full-time Equivalent
HCOT	Healthcare Outreach Team
HIV	Human Immunodeficiency Virus
ICHA	Inner City Health Associates
IE	Institutional Ethnography
OECD	Organization of Economic Co-operation and Development
PCOAT	Palliative Care Outreach and Advocacy Team
PEACH	Palliative Education and Care for the Homeless
PHCP	Palliative House Calls Program
PiT	Point in Time Count
PORT	Palliative Outreach Resource Team
RN	Registered Nurse
SOAP	Subjective, Objective, Assessment, Plan
TRC	Text-Reader Conversation
UK	United Kingdom
WHO	World Health Organization

Chapter One: Setting up the Project

We are on our way to the hospital to pick up Louis to take him to the local charitable furniture donation centre. We are going there because Louis gets discharged from the hospital tomorrow after a four week stay. He does not have any furniture or flatware, nor does he have the means to purchase it or move it into his new place. When we arrive, I see a man who looks to be in his thirties sitting in a wheelchair parked in a sunny spot of the sidewalk. As we pull up, the man waves as he sees Steve driving the van. Steve and I get out and he introduces me to Louis. He tells us that he couldn't wait to get out and enjoy some sun today. We all file into the van, and I sit in the back next to where his wheelchair is strapped in, a space where the original van seats were taken out to accommodate him. We start talking and I explain a bit more about my research and how I am interested in the work of CAMPP, and he says, "I wouldn't be here without these guys [CAMPP]" pointing to Steve. I ask what Louis means, and he explains that they helped him get out of a "terrible" situation. He explains that in his previous situation he was getting sicker and sicker and was unable to access support and he feared he would die in the basement he was stuck in. He further explains that he could not get up and down the stairs because of his wheelchair and had few people helping him take care of himself. I ask how he got connected with CAMPP and he says, "One day the ambulance came and the next thing I know Steve was there. I would have died that time, I think, if I didn't meet [Steve]. It's not just about getting to a hospital; it is about surviving outside of the hospital." I reflect on this as we drive to the furniture warehouse in a borrowed van from another non-profit agency and help him move his furniture into his new home. I am learning that the CAMPP team truly takes a different approach to palliative care. – Field Notes December 03, 2019

Introduction

In this thesis, using an institutional ethnographic approach, I explore the work of a unique team in Calgary, Alberta, Canada, called the Community Allied Mobile Palliative Partnership (CAMPP). The fieldnote excerpt from my ride-along visit with Steve from the CAMPP team and his client, Louis, is an example of how the work that the CAMPP team does as a palliative care service in Calgary, Canada, is described and valued by the people they serve. I highlight this fieldnote excerpt because the purpose of this study is to better understand what situations call for the CAMPP team's work from the "standpoint", as Dorothy Smith (2005) uses the term, of CAMPP clients.

Louis' situation is not unique when it comes to CAMPP clients. The CAMPP team's clients struggle with stable housing, are very ill, and require support to either help them die with less suffering or help them extend their lives beyond what would have been possible had they remained in their precarious situations without adequate support. Clients like Louis explain how the mainstream system does not work well for them, and the CAMPP team members recognize this as shown by their aim to address the needs that are not met elsewhere in the existing health system. The CAMPP team delivers what they describe as a "palliative approach to care" for people with life-limiting illness who are experiencing homelessness or precarious housing in the community. They operate in part by helping their clients navigate the mainstream health system and support them with their needs that fall beyond what it offers.

Part of this research explores how this program constructs "palliative care" in a way that is unique to the needs of the people they aim to support. The current project investigates how the CAMPP team's work is produced, how it is justified, the challenges in doing this work, the

Chapter One: Setting up the Project

tensions between the CAMPP team's approach and existing approaches, and the threats to this work in how the health and social care systems are currently organized and funded.

This project provides an in-depth look at the coordination of a small palliative care outreach team that is part of a wider palliative care delivery system in Calgary, Canada. According to clients that I interacted with in this study, until the CAMPP team came about, they were not receiving the support that they felt fit their needs. This project takes up this problem by discussing issues of organization and access to healthcare, responsabilization of care, operating within philanthropic funding systems, and more. There are many academic works that focus on healthcare and palliative care but few that focus on care for those who are in socially marginalized positions. However, this is the first study that takes an institutional ethnographic approach to investigating how this work is socially produced, constructed through language and shared discourses, the social context it functions within, and the tensions and challenges of this work from the standpoint of clients.

This chapter starts with a description of the background and context in which this small non-profit community-based palliative care team is socially and structurally situated within and alongside major institutions like the health system, the political system, and the non-profit social services and funding systems. I then introduce the "Palliative Equity Movement" that came from the broader "Health Equity Movement" from which CAMPP, along with several other Canadian grassroots, fringe, palliative care teams were born. Next is a section that positions me as the researcher investigating this work and how my experiences led to being introduced to CAMPP. Finally, I detail a description of the CAMPP team and finish the chapter by framing my research, the main findings, and conclude with a breakdown of the coming chapters.

Background and Context

The Canadian government mandates that provinces implement health insurance plans for Canadians that aim to remove financial barriers to access health services. The health care system is meant to be “universal” which means that all Canadians and Permanent Residents can apply for public health insurance no matter their income level. Universal health insurance covers essential medical visits, such as physician visits, hospital services including surgeries and prescription drugs while in hospital, and immunizations. This health coverage does not include dental care, vision care, or prescription drugs out of hospital. Already, we start to see the challenges with access and how this might affect certain groups differently. For instance, dental, vision, and prescription drugs are services Canadians require to maintain our health, but if you do not have personal insurance coverage or are unable to cover the costs yourself, you are unable to tend to these areas.

Additionally, for many Canadians, “accessing” healthcare is much more complicated than financial cost. “Access” to healthcare has been scrutinized in the Canadian healthcare literature which helps us understand that being *permitted* to access services does not always translate into *use* of services or obtaining services appropriate to one’s needs (McCoy, 2005; Pugh et al., 2019). Specifically, for the most socially marginalized individuals, including those experiencing homelessness or precarious housing, finding adequate and appropriate care is much more difficult. Additionally, “access” is more nuanced than simply walking through the doors of a doctor’s office. Canadian healthcare systems involve processes and policies that actively exclude some socially marginalized populations even after individuals walk through the doors, based on how the work is organized and the incompatibility of the work with meeting the needs of these groups.

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People with very low or no income, and who are precariously housed, have unique barriers to accessing healthcare because of their social circumstances. Some of these barriers include distrust of the healthcare system, lack of transportation, inability to take time off work for medical appointments, and prior negative experiences with health professionals (Cipkar & Dosani, 2016; Gaetz et al., 2017).

Further, the barriers that socially marginalized populations experience contribute to negative health outcomes associated with poverty and deprivation (Barnes, 2022; Clarke, 2021; Davies et al., 2019; Marmot, 2020; Player et al., 2020; Rowley et al., 2021; Traynor, 2019). For instance, people who are vulnerably housed or homeless have a much higher rate of chronic illness and a much lower life expectancy than the general population. This is due in part to being exposed to the elements, violence, increased anxiety, lack of facilities to tend to hygiene and other basic needs like regular meals or even enough sleep. The burden of illness is higher for people experiencing homelessness because of higher rates of chronic medical conditions, tuberculosis and HIV infection, and traumatic injuries (Zlotnick et al., 2013). These illnesses, in conjunction with severe poverty and inadequate access to health care, can also lead to high mortality rates among those experiencing homelessness (Canadian Observatory on Homelessness, 2021). On average, people who are homeless can expect to die approximately 30 years earlier than their housed counterparts (Hubbell, 2017; Marmot, 2004). However, despite the higher risk of illness and death, when people in marginalized social circumstances acquire a life-limiting illness and are nearing end of life, appropriate supports during and at the end of life, like palliative care, are challenging or impossible to find.

According to the Canadian Institute for Health Information (2018), fewer than 15% of Canadians receive palliative home care in the last month of life. This is a measure of the general population and given what is known about homelessness and access to health services, it is reasonable to surmise that few members of the homeless population figure into the small number of people tallied in this study. For people who are homeless, it is difficult to measure exactly how many people receive care nearing end of life but given that there is limited information about this (Cortez & Meyer, 2022), expectedly, this number is likely drastically reduced. Some Canadian palliative physicians recognize that people in socially disadvantaged positions often do not receive the care that they need and have responded by independently creating teams meant to address this gap in service. Further, these independent teams have risen out of and have reinforced what is starting to be spoken about in the literature as “The Palliative Equity Movement”.

Health Equality and Equity

Debates between terms like “equity” versus “equality” in healthcare exist in the literature. Often these terms get used interchangeably despite important differences (Yao et al., 2019). This discussion points out that “equality” does not address the social disparities in our society and that decision-makers and scholars need to take a step further to ensure that health services are “equitable”. They argue that the responsibility for health equity lies also with the service providers and healthcare decision makers. The EQUIP¹ Health Care (2020) distinguishes “health equality” from “health equity” by stating that,

¹ EQUIP is not an acronym but the title of a centre for research on equity in health care. See the website: equiphealthcare.ca for more information.

Health equality aims to ensure that everyone gets the same things in order to enjoy full, healthy lives. Like equity, equality promotes fairness and justice, however, it can only work if everyone starts from the same place and needs the same things.

Further, while it is untraditional to use a quotation by a participant in this study so early in the report, I felt it was fitting to share how one of the research participants in the current study described this difference between equality and equity. In his interview with me, he shared that “equality is like providing shoes for everyone; whereas equity is like providing everyone shoes that *fit*.”

Further, in the concept of “health equity”, there is an emphasis on the unique “needs” of people instead of a “one size fits all” approach to maintaining health or delivering healthcare. This is a criticism of the current approaches embedded in the mainstream health system which exclude specific, more socially and structurally vulnerable, populations. Our existing healthcare system is only one of the factors that can shape a person’s health outcomes, but not having access to appropriate healthcare when you need it most can be devastating. That is, while healthcare and access to it may not directly decide one’s health, *not* having access to it when it is needed can worsen health outcomes. Particularly, at the end of life when people need the most care, scholars have highlighted the importance of having access to support that is “appropriate” to one’s circumstances. That is, proper care can determine the quality of one’s last moments of life as well as how survivors grieve their loved ones who died (Elk & Gazaway, 2021; Klop et al., 2018; Luckett et al., 2014; Schneider & Dosani, 2021). Thus, equitable care has become a prominent issue in end-of-life care discussions.

Moving toward palliative equity. In the 1960s, Dame Cicely Saunders founded the St. Christopher's Hospice which sparked what is known today as the "Modern Hospice Movement". This movement started with her recognition of the need for better end-of-life care in the United Kingdom. The field of end-of-life care has since been burgeoning and while the UK leads the charge, other nations, like Canada, are still relatively youthful in their delivery, but making strong headway. With the Modern Hospice and Health Equity movements in full swing, they paved the way for what scholars and clinicians in the field now informally acknowledge as the "Palliative Equity Movement".

The first palliative care unit in Canada was created in Winnipeg, Manitoba, at St. Boniface General Hospital in 1974. Now, it is common to have palliative care units or hospices associated with most hospitals. This visibility of hospital-based palliative care in the last several decades demonstrates the influx of support from government and non-government bodies promoting the growth of palliative and end-of-life care in hospitals. However, according to Health Canada (2018), despite this rise in support, 75% of Canadians would prefer to die at home. With this, there has been a shift in Canada from the provision of end-of-life care in hospitals to the community via "home care" programs over the last several decades. Yet, even with this transition, still, only approximately 15% of people in the community who need it have access to palliative care in their homes (p. 5). As Stajduhar and colleagues write in their work highlighting how health system changes may be constraining home care nurses' abilities to enact care consistent with palliative care principles and philosophies, "the organization and delivery of home care is a major health policy issue in Canada" (2023, p. 76).

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Building home-based care services into the mainstream system does much to improve the care of patients in the community, but for reasons obvious in the title of the program, it does not address the needs of people who do not have stable or consistent housing. Contandriopolous et al. (2021) further point out in their literature review on home care in Canada, that the development of this work has evolved haphazardly and the definition of it is still unclear with some jurisdictions operating differently than others.

Relatedly, to promote improvements in palliative care, in 2019, the *Health Canada* department of the Canadian government put forward an “Action Plan on Palliative Care” that built upon the earlier “Framework on Palliative Care in Canada” which outlined five goals to address over five years:

- 1) Raise awareness and understanding of how advance care planning and palliative care can improve quality of life until the end of life.
- 2) Support health system quality by improving palliative care skills and supports for healthcare providers, families, caregivers, and communities.
- 3) Support health system quality improvement through enhanced data collection and research.
- 4) Foster improved access to palliative care for underserved populations.**
- 5) Improve access to culturally sensitive palliative care for Indigenous communities.

While all five goals are important and relevant to the current work to differing degrees, the fourth goal stands out as significant federal recognition that there are groups in Canada who are not receiving adequate end-of-life care. The Action Plan highlights the circumstances of people who are homeless, stating that this group needs “flexibility and an understanding of their lives”

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(p. 4). While this project focuses on equity that is based on housing and poverty, there are other significant intersecting areas of inequity. For instance, there is a growing body of literature and clinical recognition that acknowledges cultural inequity in palliative care delivery. This action plan addresses the fifth goal, focusing on improving access to culturally sensitive palliative care for Indigenous communities. While the action plan signals movement toward recognizing the need for improved care for these and all underserved populations, it is only one step in a long journey toward achieving equity in the delivery of palliative care. As Nelson et al. (2021) state, “although there is an increasing emphasis on the overall accessibility of palliative care for all patients, models are less well defined” (p.177).

There are substantial challenges that arise as the provinces and territories try to adapt to the mandated goals and actions within their unique contexts. One commonality among jurisdictions is the acknowledgement that people who experience homelessness are underserved. Beginning in 2014, groups began to take the matter of limited end-of-life care for people experiencing homelessness into their own hands. This resulted in the construction of four independent, palliative physician-led teams across Canada: The Palliative Outreach Resource Team (PORT) in Victoria, British Columbia; The Palliative Education and Care for the Homeless (PEACH) Program in Toronto, Ontario; the Palliative Care Outreach and Advocacy Team (PCOAT) in Edmonton, Alberta; and the Community Allied Mobile Palliative Partnership (CAMPP) in Calgary, Alberta.

Each of these teams functions adjacently to the mainstream systems in their respective provinces. They provide palliative services that started out distinct from the mainstream system. As Conway describes it, the mainstream system operates in accordance with assumptions around

the “middle-class” patient (Conway, 2013) and this is something these teams have tried to address. The “middle-class” patient involves practices in which “middle-class tastes, behaviours, and dispositions are presented as being universally relevant and the ‘norm’ by which practices of other social classes are judged, or simply not seen because they do not conform” (Richards, 2021, p. 5). These teams deliver “outreach” support to people located in the inner cities of their respective areas. The “outreach” approach means that the teams are mobile units, providing care in places where the mainstream system does not, such as on the streets, in shelters, and anywhere else in the community that they are needed. The current research focuses on the work of one of the programs in Calgary, the Community Allied Mobile Palliative Partnership.

My Position as the Researcher

The current dissertation project was inspired by events that occurred in my family early in my PhD program. Aligning with the methodological approach of institutional ethnography, this research is grounded in the real-life experiences of my family and me as we navigated a health system that, we soon learned, was not designed for many people who are nearing the end of their life. These experiences inspired me to question and challenge the current healthcare system language of “universality” in the context of people who are dying. As Dorothy Smith (2005) explains in her book *Institutional Ethnography: A Sociology for People*, “talking our experience is a means to discovery”, so with this, to help position myself as the researcher in this project, I will share part of my story and how it influenced my uptake of the current research.

My mother died in 2017 and her death signalled to me that there were immense underlying injustices within the health system. While I knew about many issues and problems within the system, I did not know their extent and how they disproportionately affected certain

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socially marginalized patients. My mother struggled with mental health issues and historically managed them using substances like alcohol and prescription pills. These issues sent her on a long journey through the health and social services system, placing us as a single parent family in precarious situations. At times we lacked stable housing and had to stay at friends' houses and one time in a women's shelter. Her life was wrought with challenges, including losing my father at age 35 to a heart attack in 1990, and several other close family members after that.

After suffering a stroke in 2010, she decided not to use alcohol anymore. We enjoyed seven sober years with her until 2017 when she was diagnosed with pancreatic cancer in the emergency department in an Edmonton hospital. Earlier that day, she was sent to the emergency department by her dentist because she was jaundiced and so he denied her treatment until she saw a physician. She encountered an emergency department physician who treated her poorly based on her clothing, hygiene, and their presumption that she used illicit substances. She was incredibly offended by this and felt shamed, as she was immensely proud of her seven sober years. This made her want to leave without receiving necessary tests. My sister and I were in attendance and managed to convince her to stay, yet the attitudes towards her continued, with me overhearing one nurse refer to her as an "odd duck". This encounter signalled to me what I had already known based on my professional experiences with clients, who told me that they were often judged by their appearance, and health care providers often made harsh judgements about them about their substance use. These judgements, whether they were substantiated or not, were associated with negative interactions and perceived moral inferiority. Witnessing my mother go through this affirmed these stories and impacted me deeply, knowing how my mother was made to feel in a place that she was hoping would help her.

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It was during this visit, after some tests and waiting many hours, that she learned that she had pancreatic cancer. She was not yet admitted to hospital, so we were waiting in a “casting room” not meant for patients since they did not have any available beds. This is where she was delivered the awful diagnosis. The physician came in, told her she had pancreatic cancer, and left without any guidance, answered questions, provision of sympathy, or explanation of next steps. I recall my mother looking up at me and stating that her aunt “had that cancer”, who she lost many years earlier. My sister and I wished we could offer her more comfort in that moment, but, without any information, and having little experience ourselves navigating such circumstances, all we could say was “let’s just wait and see”. This was only the beginning of her negative experience, as she had many undesirable encounters with the care providers in her short two-week trajectory toward death which ended uncomfortably in an acute care unit in an Edmonton hospital. It was her challenging experience from the emergency department to her death that inspired my interest into the world of palliative inequity.

How I came to know CAMPP. In 2017 as part of my doctoral course work, my Sociology of Health and Illness Seminar instructor introduced me to the CAMPP team after learning that I was interested in the intersection of dying and social marginalization. I contacted the founding palliative physician of the team, and he invited me to “ride along” with the team to get to know a day of their work. The “ride along” was scheduled for one year before I started my candidacy examinations and thus, I was unable to start my research at that time. I did, however, ask the team about the prospect of focusing my project on the work of their team and they were excited about the idea. After I completed my qualifying exams, I reached out to the team again and pitched a research idea. They allowed me to incorporate their team in the

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research project and after receiving approval from the research ethics board, I started my data collection with the team in 2019 and completed it in 2020.

The CAMPP Team

CAMPP is a three-person team: a palliative physician, a nurse coordinator, and a health navigator. The palliative physician attends CAMPP one day per week, usually on Tuesdays. They conduct the palliative assessments with clients and help with things that only physicians have the authority to do, such as signing off on treatments, interventions, and sometimes communicating with other health professionals and advocating for patients. The founding palliative physician also does much “behind the scenes” work coordinating research projects and soliciting donations and funding sources as well as contributing to the strategic planning of the program. The nurse coordinator does the bulk of the day-to-day organization of the work and client visits. They manage intakes of clients, administrative duties for the program, and client-facing work. The health navigator supports the team by focusing on client-facing work with an emphasis on helping clients “navigate” the health and social support systems.

The CAMPP team works closely with their partnering program, the “Healthcare Outreach Team” (HCOT) who works under a charitable organization called CUPS². Both teams work with people who are experiencing homelessness and who have severe health problems, but CAMPP specifically focuses on people with a life-limiting illness and who are expected to be nearing end-of-life.

² CUPS Calgary Society is a charitable organization located in Calgary, Alberta, Canada that assists adults and families in Calgary living with the adversity of poverty and traumatic events to become self-sufficient. Note: “CUPS” is not an abbreviation but the name of the organization (Petruik & Colgan, 2021).

The Current Project

My research focuses on the social organization of the work of CAMPP using an institutional ethnographic method of inquiry. It is my aim in this project to explore how the daily job activities of the people who choose to do this work are coordinated with and for individuals who require support. While there is much academic literature that focuses on care for people at the end of life, there is no research to date that focuses specifically on the social organization of this work for people who are living precariously at the social margins. Furthermore, this is the first research project to explore this type of work in this context from an institutional ethnographic lens.

To locate this knowledge, the current investigation is guided by the following overarching research question: “From the standpoint of clients, how is the work of the CAMPP team socially organized in the context of the wider palliative and end-of-life care system in Calgary, Alberta, Canada?” This question guided my data collection as I pieced together the activities, tasks, and language that are often taken for granted and not investigated closely but have become routinized. To explore this question, I collected observational data, interview data, and reviewed many program documents.

Main “news” from the research. This research gleans new insights from the day-to-day work involved in providing care for people experiencing homelessness who have life-limiting illness. However, it also opens a new terrain of understanding that scrutinizes the language and social organization of this care within and alongside the broader healthcare system. In this project, I use Smith’s (2005) generous concept of “work”, which means something different from ordinary understandings of it. A typical understanding of “work” might be one that

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involves tasks which a person is paid for doing and is separated from personal aspects of people's lives like family and relationships. Instead, Smith's notion of "work" expands this idea to include all aspects of life that involve what "people do intentionally (this does not mean they want to do it) that takes effort and time and is done under definite conditions" (Smith & Griffith, 2021, p. 41). In this project, I envisage taken-for-granted practices that the CAMPP staff members take up and reposition them through the lens of effort and intention. Further, using the institutional ethnographic approach, I also aim to make visible why and how "hooking in" to the mainstream healthcare system is troubled, attenuated, and ruptured for people experiencing homelessness who are nearing end-of-life.

Institutional ethnography allows us to look at the work of the CAMPP team within the broader institutional context. A useful aspect of IE is that it is flexible and does not need to be applied the same way in every instance. There is a common application of IE, where the institutional ethnographer explores the interconnectedness of work activities, locates a disjuncture that contributes to the subordination of a group or groups, and tries to help address the problem. However, institutional ethnography can be applied in many ways and in any setting where people connect with each other in the world. A unique aspect of IE is that it does not need to follow a prescriptive routine and researchers continue to widen the scope of IE and what it can investigate.

This study does not take the typical IE route, but rather uses IE to look at a particular coordination of activities in another way than how we typically look at them. While IE has been widely applied to healthcare settings (see for example, Corman, 2017; Diamond, 2009; Rankin & Campbell, 2006), the current project extends the focus on health care settings to a relatively

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autonomous community health care team. This study brings into view the translocal relations of coordination that open out from the experiences of these team members and their clients with a focus on how things come to be coordinated through what the people do as part of their everyday routines. This research examines a team that is creatively coordinating their work within the larger ruling relations of healthcare in a way that shifts common “taken for granted” approaches to health care to help their clients. These community-based professionals are not working *outside* of ruling relations, but have done work, which I start to show in my findings, that acknowledge constraints but adapts their practices in ways they can work within them and adjacent to them.

Another advantage of IE is that it expects the investigator to start in the “standpoint” of people for the purpose of uncovering the interconnections that result in disadvantages and oppression against specific groups. With this project, I start from the standpoint of CAMPP clients to understand their links into the healthcare system, what makes the work of the CAMPP team warranted for them and to make visible the areas of access to healthcare that are blocked for this group. An aim of this research is to walk beside the participants and document how they, along with the CAMPP team, coordinate their lives as they relate to their illnesses and social circumstances. While it is important to study the institutional relations that create disadvantages for some groups, in this research, I look at what seems to be working and how these practices are put together and how these practices are then marginalized by where they are positioned institutionally.

This research explores what matters, what works, and what does not work when it comes to providing healthcare for this socially marginalized group. The unique circumstances and needs

that social marginality imposes upon individuals who are homeless creates a tension between the policy that healthcare is accessible to all Canadians despite the ability to pay and the ways in which the experiences of this group demonstrate how they are functionally excluded based on how the system is organized. This study explores how healthcare professionals have come together with people in these precarious positions to try and construct a way for them to have the care that they need, despite the current systemic limitations.

This research shows that CAMPP's structure is based on the need to address a disparity in care for people experiencing homelessness. They do this by using specific processes that they intentionally create to organize their work in favour of serving this group. In this research, I found that some of the important daily tasks of the CAMPP team include planning and organizing the day, face-to-face client work, pivoting from previously held plans, and administrative duties. These tasks take skilled judgement which is guided in a purposeful way of working set up deliberately by the CAMPP team. The decisions that the team make throughout their day are shaped by their experiences working with a population who have specific needs: those who are very ill and experience vulnerable housing.

Shaping the way that the CAMPP team structures their work is an intentional use of the discourse of palliative care. They use this discourse in a specific way that differs from the way that professionals in the mainstream health system use it. At the start, the CAMPP team and those working within the mainstream palliative system negotiated the terrain of the existing palliative care landscape and their relative placements within it. The current findings show that both teams function within and perpetuate discourses that rationalize their respective work processes and practices. This research explores how, while both teams describe their work as

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“palliative care”, the term is functionally different when considered within the contexts and applications of their respective service delivery models. The teams operate within an overarching discourse of “palliative care” and speak much of the same language with respect to it; however, their activities connected with their language differ in application. Both teams bring up the concept of “harm reduction” as a recognized term in current healthcare services.

However, following the use of this concept through the CAMPP team’s work practices, it is evident that how the team coordinates their work permits them to engage in *specific* work activities that those in the mainstream system, for reasons that may be explored as an extension of this study but not fully covered here, cannot or will not do.

The CAMPP team can function because they work to obtain grants and donations that fund their work. The way that they are *able* to do what they do is by locating funding. The CAMPP team must piece together funds from several sources to accumulate enough money to stay in practice. This piecing together of funds is another side of work that the CAMPP team embarks upon alongside their client-facing work. In this research, I found that the team’s work is positioned within the wider philanthropic funding and accountability environment that exists in Calgary, Alberta. Since the founding palliative physician started the CAMPP team, they have been on a mission to find stable operational funding. The climate of philanthropic and grant-based funding is precarious and while the CAMPP team works to secure these funds, they also try to make the case for their position within the mainstream system where they would enjoy financial stability and security. However, the CAMPP team suspects that, in its current format, the mainstream system does not recognize the work that CAMPP does as effective, largely, as the CAMPP team surmises, because it is not measurable like the work that appears within the system currently. They further infer that if they were to become funded in the mainstream health

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system, the work that they do would have to follow the policies and practices of the mainstream system, effectively losing the distinctness that allows them to function in a way that is valuable to their clients. That is, the team describes CAMPP's work as outside of the mainstream system's standardized measurable activities, but they require the funding and stability to operate located within that system. The potential tension that the CAMPP team faces in their work then is how they can make visible what they do in ways that "count" to the larger mainstream healthcare organization to operate on a stable basis while also upholding their unique way of operating.

In the coming chapters, I delve deeper into these findings to comb through the work of the CAMPP team in the context of the wider institutional milieu. This will start to answer the question posed at the beginning of this research, "From the standpoint of clients, how is the work of the CAMPP team socially organized in the context of the wider palliative and end-of-life care system in Calgary, Alberta, Canada?"

Conclusion

While there is much scholarly literature that focuses on homelessness, another body of literature on palliative care, and a growing body of literature on how both are interconnected, to my knowledge, there is none that explore the coordination of this work from an institutional ethnographic lens nor that investigates the specific work activities of care providers who work on the fringes of the mainstream publicly-funded health system. It is my aim that the current research will build on the existing body of academic work in healthcare that takes an institutional ethnographic approach by expanding the way in which IE as a method of inquiry is applied to healthcare settings and the literature on homelessness and palliative care more widely. This

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research can also serve to inform future policy and practice decisions in both health and social service sectors on all levels of implementation.

In the following chapter, I explore the literature and context in which this work is situated. Discussing the important aspects of the literature that pertain to the current topic, I outline how the literature is organized to make assumptions about the work of healthcare professionals without looking at the specific work activities and without scrutinizing the social organization of it. In Chapter three, I outline the methodology of the current research before discussing the findings in Chapters 4-8. Chapter four will introduce three CAMPP clients, Harriet, Chapa, and Rowan and how they experience the health system given their unique social positioning. Building on the client accounts, chapter five investigates the CAMPP team providing a glimpse into their typical workday and how it is organized. From here, I move into chapter six where I explore the different constructions of the discourse of “palliative care” and how the CAMPP team organizes their work while working in the interstices of the mainstream health system. Chapter seven dives deeper into the work of the CAMPP team by making visible the common notion of “building relationships” that the team holds as important in their approach to palliative care. Next, to round out the discussion of this work, I will speak to the broader context of philanthropic funding and accountability and the challenges and tensions that the CAMPP team faces to work within it. The closing chapter concludes the dissertation with a summary of the work, the limitations of the research, the implications of the findings, and a discussion on the possible directions for future research.

Chapter Two: Background and Literature Review

Introduction

In this chapter, and extending into the following Methodology chapter, I provide an outline of the key ideas, concepts, theories, and relevant empirical literature surrounding the current research project. To situate investigation of the work of the CAMPP team, I begin with the current context of the healthcare system and what scholars and service providers identify as the problem of inequitable access to healthcare, particularly end-of-life care.

Speaking to the key changes to the Canadian health system first, I will then discuss the larger dominant neoliberal political context in which our healthcare system is situated and principal issues that arise from this political structure. Additionally, I will speak to alternate perspectives that scholars suggest as responsible for changes in our healthcare system since World War II. From here, I highlight the sociological exercise of recognizing “social factors” in relation to “health” and then transition into a discussion about the context of “homelessness” and “end of life care” in Canada.

Next, I describe the concept and history of “health equity” and how it has come about in scholarly work. I also outline how researchers, practitioners, and health advocates participate in a highly coordinated landscape of “palliative equity” advocacy work as constructors of this term and its associated care philosophy. I also revisit a brief discussion of the resultant non-profit community-based teams that have grown from this movement and the approach that they take up that differs from mainstream end-of-life care.

Most of the current scholarly literature involves quantitative studies that rely on survey data, clinical data, or statistical accounts. A body of qualitative studies also exists that focuses

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on the experiences of the potential users of services or the service providers. However, the focus of the current study is different. This study takes up an institutional ethnographic approach to explore the work of the CAMPP team from the *standpoint* of clients. The focus of the present project qualitatively explores how CAMPP's work is coordinated and carried out with specific attention to the pieces of work "hooking into" each other. This study starts in the experiences of clients, and this is the basis and justification for this research. However, while there are many IE studies that have examined healthcare and related topics to investigate possible "disjunctures" that occur in healthcare settings, in the present research, I explore how the CAMPP team has identified a disjuncture in the mainstream palliative care system and has gone to work to address it. This does not mean that the CAMPP team operates outside of relations of ruling or that the team could benefit from an institutional ethnographer investigating to locate a particular disjuncture *for* them. The CAMPP team, like all of us, operates within the ruling relations, but the CAMPP team participates in and moves through the ruling relations of the larger health care system in a way that is not built into the wider health care system structure. This project, within the scope of institutional ethnography, is interested in how the real happenings of people's everyday activities are coordinated to make up a social reality that we have otherwise not explored in this way.

This study makes visible how the CAMPP team still works within ruling relations but tries to actively work differently than the typical model to adapt to the needs of their patients. So, while many IE studies offer the service of locating disjunctures that are otherwise not visible to the key informants, this research study focuses on the coordinated efforts of the team, who while trying to address the tension that arises from our healthcare system, in its current state, not addressing the need of a highly vulnerable population, people who are homeless with life-

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limiting illness. This study, then, attempts to make visible how the team goes about doing their unique work, how they justify the work, how they legitimize it in the face of current mainstream palliative structures, and the challenges that they face trying to sustain the program within the ruling relations that govern how the mainstream health system is organized.

A Brief History of the Canadian Healthcare System

Healthcare is a dynamic system responsive to its socio-economic and political surroundings. Healthcare has transformed over time and continues to be shaped by people who are in the position to make decisions. In 1947, Tommy Douglas implemented Canada's first public hospital insurance plan in Saskatchewan. "This plan covered everyone in the province regardless of their ability to pay" (Germov & Hornosty, 2017, p.287). At the time of reform, Douglas also intended for a second reform of health service delivery that would focus on population health needs with an emphasis on the social determinants of health. The first stage of his plan became a reality, but his second vision, while much talk of the social determinants of health has erupted in mainstream health practice, has yet to be implemented via health care policy reform today (Martin et al., 2018). Martin and colleagues (2018) argue that for the Canadian health care system to resist being outdated, it needs to "revise the social contract between governments, healthcare providers, and the public to acknowledge the social determinants of health" (p.1721).

Before World War II, the concept of the "welfare state", a system where the government assumes much of the responsibility for the welfare of its citizens through health, social, and economic programs, was not typical in Canada. Following World War II, Canadian politicians focused on "human rights" through increasing expenditures on things like healthcare and social

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programs to help those in need (Germov & Hornosty, 2017). Today, the Canadian government offers residents a federally funded healthcare system that is managed individually by the provincial and territorial governments. This health care insurance coverage, however, does not include dental care, vision care, or prescription drugs out of hospital. Large numbers of Canadians do not have access to supplemental insurance that covers these services which leads to concerns about inequity between groups (Martin et al., 2018). The Canada Health Act defines five principles that govern the Canadian public health insurance system. The five principles are: public administration, comprehensiveness, universality, portability, and accessibility (Government of Canada, 2016). In this section, I focus on “universality” because of how it ties into the current research.

“Universality” is one of the principles that provinces and territories must abide by to qualify for federal funding for healthcare (Germov & Hornosty, 2017). “Universality” means that any Canadian or permanent residents can apply for public health insurance (Government of Canada, 2021) and that health services are to be available to all Canadians equally (Clarke, 2021, p.246; Germov & Hornosty, 2017, p.291). However, while Canada boasts a “universal” healthcare system, this concept has been debated among scholars, clinicians, and social advocates.

The concept of “universality” intends that *all* Canadians have access to the same coverage for their healthcare needs even without the ability to pay for them. However, over the last two decades, researchers have scrutinized the principle of “universality,” labeling it as somewhat of a misnomer for the actual realities that many Canadians face (Martin, Miller, Quesnel-Vallee, Caron, Vissandjee & Marchildon, 2018; van Staden, 2018). Particularly,

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Canadians in low-income brackets, racialized individuals, those who have mental health problems, and/or use drugs and alcohol often report negative experiences in the mainstream health system deterring them from care because they feel that the system is not “for them” (Cipkar & Dosani, 2016). For instance, people who are homeless have challenges accessing general healthcare as they have needs that are outside of what the mainstream system is built to address. Barriers for this population also include mistrust of healthcare professionals, perceived stigma and discrimination, competing priorities, difficulties registering with GPs due to lack of a fixed address or photo ID, and making and keeping appointments (Cipkar & Dosani, 2016; Hudson, Flemming, Shulman & Candy, 2016; Klop et al., 2018).

McCoy (2005) also scrutinizes the term “access” in a way that uses institutional ethnography to understand how access is shaped by real-time daily activities of people receiving care and by those providing care. In McCoy’s study, she explains how access can include the doctor-patient relationships including doctors’ interactional styles, ways of providing treatment options and treatment information, and ways of addressing the specific needs and life circumstances of patients living in poverty and social marginality (p. 791). Related to access is the notion of “eligibility”. With a “universal” healthcare system, all Canadians are “eligible” for services that are covered by Medicare. However, being entitled to coverage by being “eligible” does not mean that each person will receive the same care or enjoy the same access to care. In the US, DeVault, Venkatesh & Ridzi (2014) explain how eligibility is an institutionalized process that reduces individuals to a “text-based” rendering of themselves stripped of the complexity of their individual circumstances and context. In Canada, eligibility is assumed; however, when it comes to receiving care, things get more complicated. To receive care that one needs is dependent on whether the healthcare system offers support and whether one “complies”

or “adheres” to the spoken and unspoken rules of receiving it. In their critical paper, Mykhalovskiy, McCoy & Bresalier (2004) explore the problem of “adherence” and “compliance” where they describe “the matter of how well patients follow health advice (p.316). These authors make visible the complexities of “compliance/adherence” beyond the patient and into the multiple sites of medicine, public health, and community organizations. These are some of the debates about how the problem of “access” could be handled or approached. While much of the debates centre on how some believe that it is the responsibility of the state to ensure that everyone has “equitable” access to health services and others believe that the state should not be primarily responsible for individuals’ health, there are still others, such as the aforementioned authors, that say that the issue of “access” is too simplistic and that we need to widen our ideas of access beyond “universality”. Thinking about the healthcare system and the responsibility of “health” leads us to think about the way that our society is shaped politically and ideologically.

The Canadian healthcare system has undergone transformation over the last several decades. However, there have been debates in the literature about the impetus for this change. Some scholars refer to a key part of this transformation as resulting from “neoliberal” ideologies brought forth after 1979 when the United Kingdom’s Margaret Thatcher and her subsequent leaders implemented ideas of globalized free markets as a way to improve prosperity for all. Neoliberalism is a right-wing political ideology that highlights the “free market” economy and prioritizes individual freedom rather than a focus on collectivist values such as the rights of groups (e.g., unions). Scholars also argue that the “retrenchment” of the social welfare system in recent decades following more right-wing governments coming into power has been to blame for increased inequities in healthcare. For instance, Richards (2022) states that “neoliberal ideology views responsibility for poverty as belonging to the individual and resulting from people’s

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‘character-personality defects’ (Margaret Thatcher, 1978 cited in Jones, 2012, p. 64) such as being ‘work shy’ or showing bad money management. Meanwhile deep-seated structural inequalities or supply side issues in the job market are downplayed or denied” (p.9).

These academics argue that dominant neoliberal ideologies have contributed to changes in the way healthcare is delivered in Canada. That is, that the focus has moved toward a model that mimics a quasi-market orientation (Dawson & Dargie, 2002, p. 34-6) and a consumer-producer style rather than a system that operates based on the best interests of the patient. The argument is that these “market-based” strategies have caused significant changes in the way healthcare is delivered in Canada. While the principles, like “universality”, have not changed, it is the way in which this term is understood and carried out that has. Because of this, scholars have conducted research on how, underpinning the healthcare system based on neoliberal ideas such as cost-effectiveness and efficiency, harm is being done to patients, especially those on the socially marginalized end of the societal spectrum (Armstrong & Armstrong, 2010; Armstrong, Armstrong & Coburn, 2001; Clarke, 2021; Coburn, 2004; Germov & Hornosty, 2017; MacDonald & Wright, 2020; Rankin & Campbell, 2006).

It would align with the neoliberal approach to believe that it is not the main responsibility of the state or healthcare systems to ensure “health equity” among individuals in society. Rather, a neoliberal thinker may propose that it is the individual’s responsibility to access services since they are “universally” available to Canadians and if there are obstructions to this, such as poverty, that it is largely the individual’s responsibility to come out of these obstructions and not the responsibility of the health care system. Or it may be that these “obstructions” are not recognized at all in this alternate and, currently, more prevalent, way of thinking. Many scholars

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argue that this “neoliberal” ideology currently dominates the way of operation of our mainstream health system in Canada (Coburn, 2004; Hankivsky et al., 2014).

Those who critique neoliberalism may say that “health inequity” is a consequence of those in power intentionally pushing the responsibility of decreasing poverty onto individuals rather than the state. These groups further argue that structurally and systemically embedded policies and processes position certain groups in unfavourable conditions leading to unequal opportunities and disproportionate challenges.

Other scholars argue that more nuance is needed in the debate around health care transformation. That is, scholars such as Jacob Hacker contend that reform and change are not synonymous and that one can happen without the other, and likely, has. Hacker’s (2004) work argues that the literature has overstated the responsibility of neoliberal reform having caused large scale changes in Canadian health care. Rather, that while neoliberalism is a factor, in comparing countries with quite different health care structures, the change looks different and demands more nuance. He argues that, in Canada, change comes from erosion of the health care system from bureaucratic inertia, or “passive privatization”. Passive privatization is a concept that refers to the structural features of how healthcare is governed and financed in Canada that affect what can be accomplished by reformers which then mediates the impact of such reformer aspirations.

Because of these debates, in recent decades, scholars have used the language of “equity” over previous terms like “equality” regarding healthcare provision to highlight the importance of “access to appropriate care” over “equal access to care”. This distinction emphasizes that while all Canadians are “permitted” to use healthcare services in Canada (recall the principle of

universality), their social circumstances position them in such a way that the current healthcare system either does not reach them or does not meet their needs. These critics of neoliberalism argue that attention to social and structural factors is necessary, and that people's circumstances are often beyond individual control.

However, while healthcare is an important contributor to “health,” it does not tell the full story. Over the last several decades, there has been increasing recognition of what researchers call the “social determinants of health,” broadening our scope of understanding health and illness beyond the individual and the “absence of disease”.

Recognizing Social Factors Contributing to “Health”

In 1946, the World Health Organization (WHO) changed the definition of “health” to recognize that it is more than the “absence of disease or infirmity” (World Health Organization, 2022). The WHO definition of “health” today states that health is “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2022). However, it was not until the 70s with the LaLonde Report (1974) that Canada officially recognized health to include a social component (Germov & Hornosty, 2017). Following this, Canadian researchers found income and its distribution to be key “social determinants of health” (Health Canada, 2002, Mikkonen & Raphael, 2010).

The “social determinants of health” approach was built out of the need to understand why there were discrepancies in the degrees to which certain groups are healthy or ill. The World Health Organization (2022) defines the “social determinants of health” as “the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, live, work and age, and the wider set of forces and systems shaping the conditions of daily life.

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These forces and systems include economic policies and systems, development agendas, social norms, social policies, and political systems” (Overview section, para. 1). While there is some debate about what factors should be categorized as a “social determinant of health”, main factors that are widely recognized are: gender, racialization, Aboriginal status, income and social protection, disability, access to affordable health services of decent quality, employment and working conditions, unemployment and job insecurity, food insecurity, housing, basic amenities, the environment, social inclusion and non-discrimination, structural conflict, education, early life experiences, and the social safety net (Mikkonen & Raphael, 2010; World Health Organization, 2022).

Some researchers argue that there should be a differentiation between “primary” and “secondary” determinants of health (Segall & Fries, 2017). This is a way of capturing the difference in socioeconomic factors and behavioural practices. These individuals describe the primary determinants as the factors like education, environment, employment, income, and health services. Examples of secondary determinants include personal stressors, sense of control, self-esteem, and social involvement. The concept of the “social determinants of health” helps us think about health as more than something that exists in the body and widens our scope of understanding to see the relationship between our bodies and the social environment.

In the current project, while recognizing that many of these “determinants” intersect to shape the lived realities of people, the focus is largely on three of the determinants: “income”, “housing”, and “health services”. It is important to recognize that one cannot meaningfully extract one determinant from the others, as they are interconnected, but for ease of analysis and

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understanding, I highlight these three factors while recognizing that much work is needed in all areas of intersecting determinants.

An argument for the importance of focusing on income and income distribution as a social determinant of health is the concept of the “social gradient of health”. The “social gradient” was constructed by Michael Marmot (2004) and is described as the “graded association between socioeconomic status and population health” (Segall & Fries, 2017, p. 416). There is much work that shows a positive correlation between health outcomes and level of income: the higher one’s income, the better one’s health outcomes tend to be (Clarke, 2021; Davies et al., 2019; Marmot, 2020; Rowley, Richards, Carduff & Gott, 2021).

In several works, Raphael (2002a; Raphael, 2002b; 2004, Mikkonen & Raphael, 2010) explains how health depends on “available, accessible, and good quality nutritious food; clean, accessible, and available water; good transportation systems and infrastructure, including public transit; stable, safe, adequately compensated, interesting and fulfilling employment; safe, available, and appropriate, and affordable housing; and other essential components of life” which would include reasonable access to appropriate healthcare (Clarke, 2021, p. 89). This is what scholars call a “materialist” approach to understanding the “social gradient” of health (the link between health outcomes and income) (Clarke, 2021; Marmot, 2010; 2020). Further, the “neo-materialist” approach takes this one step further and recognizes the importance of relative distribution of material and social goods within a society as well as material resources as influencing health outcomes (Clarke, 2021). Where there are differential distributions of these goods, the argument goes, we will see corresponding disparities in health.

Related to the determinant of “income” is “housing”. There is a breadth of research on housing and the analytic project of “housing” has been explored in numerous ways in the literature. With the current project focusing on the provision of end-of-life health services to people who are homeless or vulnerably housed, the next section provides a brief history of the construction of homelessness in the literature and the current state of homelessness in Canada.

Constructing “Homelessness” in Canada

The language around housing has been contentious in the literature with some challenging the term “homelessness” in preference for other terms such as “unhoused” or “houselessness”. The argument for using the latter terms is that people without shelter often find a sense of “home” in places that may not be typical to those who have stable shelter (i.e., shelters or encampments, for instance). Alternatively, many people may identify “home” as a physical structure, but some may not subscribe to this notion, especially if they do not have a physical structure in which they regularly reside. For some, a “home” may be a city or a town, or it could be in reference to, not a place at all, but rather a feeling of being around certain people they feel comfortable with. It is important to note that the term “home” is subjective and personal to the individual. There are compelling arguments to use both versions of the term. For this project, however, I choose to use the term “homelessness” mainly because the people I interviewed chose this term in our discussions and I want to stay aligned with their choices and descriptions. Finally, in the literature, the term “homelessness” refers more to the personal experience of being unsheltered rather than the physical structure of the shelter itself. While I see value in all the terms, for the purposes of this project, I continue with “homelessness”.

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Homelessness is a social phenomenon that has long been studied by scholars in various forms. While this chapter does not provide a comprehensive review of all the literature on the topic, it discusses the main trends and historical checkpoints that have marked the scholarly literature with a focus on its construction as a social problem.

Ethnographer Erin Dej (2020) places the term “homelessness” under the metaphorical magnifying glass to question the *use* of the concept rather than take it for granted as so much social science and public health scholarship has. Dej argues that the term has taken shape to become a common term that has meaning and influence that should be scrutinized rather than taken for granted. As she elaborates, “[N]ot having a home is an identity marker (the creation of the “homeless” person) and is not innate, natural, or scientific” (p.27). Similarly, Dorothy Smith (1990) helps us see that identity markers like “homelessness” are actually produced and evolve through people’s ongoing concerted and coordinated activities (Nichols & Braimoh, 2018). Where categories like “homelessness” may on occasion prove useful, it is important to investigate and deconstruct the assumptions that underlie them and the lived realities that are silenced by the dominant narratives that construct them (Smith, 1990). With this, it is notable that even within the one term, there are many definitions that people adhere to depending on where one looks, with each definition wrought with their own criticisms. For this study, I will use the term put forward by the Canadian Observatory on Homelessness, which is widely used in Canada.

Homelessness describes the situation of an individual, family, or community without stable, safe, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it. It is the result of systemic or societal barriers, a lack of affordable

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and appropriate housing, the individual/household's financial, mental, cognitive, behavioural or physical challenges, and/or racism and discrimination. Most people do not choose to be homeless, and the experience is generally negative, unpleasant, unhealthy, unsafe, stressful, and distressing. (Gaetz et al., 2017, p.1)

Adding to this definition, the Canadian Observatory on Homelessness makes an important distinction in the dimensions of length and severity of experience including between transitional, episodic, and chronic homelessness, which all have varying factors that affect health outcomes, social status, relational interactions, and experiences. Transitional homelessness is short-term, usually lasting less than a month. Episodic homelessness refers to those who move in and out of homelessness, and chronic homelessness involves individuals who are homeless for a year or more and usually stay this way for a long time (Canadian Observatory on Homelessness, 2021). In the current study, most of the CAMPP clients were, prior to their involvement with CAMPP, within the latter category of chronic homelessness.

With all the variation in the ways we understand homelessness, it is extremely challenging to gather a precise estimate of how many people are “homeless” in Canada at a given time. However, Rossi (1990) and Hulchanski (2009) have been writing about homelessness in North America since the surge of “homelessness” in the 1980s as it became increasingly visible due to changes in government policies. In a keynote address, Hulchanski (2009) describes how these policies resulted in

...an increasingly deregulated society in which the ‘genius of market forces’ would meet our needs, in which tax cuts, made possible by cuts to programs that largely benefited poor and average-income people, were supposed to ‘trickle down’ to benefit those in

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need. The competitive economy required, we were told, wage suppression and part-time jobs with no benefits.

Hulchanski further states that the refusal to provide affordable housing combined with a disintegration of the public social safety net led to an unprecedented number of people losing their housing in Canada (Canadian Observatory on Homelessness, 2021). Hulchanski outlined that because of this, we, as a society, needed a word to describe this phenomenon and that word was “homelessness”. Hulchanski explains how the word differs from earlier uses of “homeless:”

...it was clear that homelessness referred to a poverty that includes being unhoused. It is a poverty that means being without required social supports. And it is poverty so deep that even poor-quality housing is not affordable. Canada has always had many people living in poverty. In the 1980s more and more people were not only poor, but also found themselves unhoused.

In Hulchanski’s view, homelessness describes a social phenomenon, a shared experience, brought about by complex social, economic, and political processes. For him, the focus is on social conditions, not an individual’s housing status.

According to the authors of *Finding Home: Policy Options for Addressing Homelessness in Canada*, eighty-seven percent of articles using the term “homelessness” between 1851 and 2005 were published between 1985 and 2005 (Hulchanski, Campsie, et al., 2009). Despite continued investigation since then, homelessness is still very much apparent in affluent societies like Canada (Eberle et al., 2001). In 2007, the City of Calgary implemented its first “Ten Year

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Plan to End Homelessness in Calgary, Alberta”. Fifteen years later, in 2022, Calgary still has major struggles with homelessness.

The City of Calgary conducted a ‘count’ of people who were homeless every two years from 1992 to 2008 (City of Calgary, 2008). For this ‘count’, their definition was that “homeless persons are considered to be those who do not have a permanent residence to which they can return whenever they choose” (p.1). In 2008, the Calgary Homeless Foundation oversaw the implementation of a 10 Year Plan to End Homelessness which aimed to ensure that all people who faced homelessness would have access to “safe, decent, and affordable housing as well as the resources and supports necessary to sustain that housing by the year 2018” (Canadian Observatory on Homelessness, 2018). At this time, the organization had the intention of collecting live data through homeless sector serving agencies, but they were unable to get this system running so in 2012, the Calgary Homeless Foundation returned to counting people who were homeless, and they referred to these as Point in Time Counts (PiT). In 2016, the first coordinated PiT count that included several communities across Canada took place, but Calgary opted out of that count because of their already occurring counts. It was not until 2018 that Calgary opted back in with all designated communities. However, these counts often only included those who were “visibly homeless”, not those who were close to homelessness such as those individuals or families who were one paycheck away from losing their housing. Like those counts prior to 2018, it also involved select communities that chose to take part. However, the catchment area for the survey has been growing. In 2016, there were 32 participating communities in Canada and in 2018, there were 61 communities. As of the 2022 Calgary Homeless Foundation’s point-in-time count, 2782 people experienced some form of homelessness in Calgary, Alberta (Calgary Homeless Foundation, 2022). However, these

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counts may offer underestimated predictions for the reasons listed above but also especially as the 2020 count was canceled due to a global pandemic and the count for 2021 involved altered methods of data collection (A. Tézli, personal communication, May 09, 2023).

Given the limitations of the definitions and measurements of homelessness, the current best estimate of total people who are experiencing homelessness in Canada is around 235,000 in any given year, with 25,000 – 35,000 experiencing homelessness on a given night (Employment and Social Development Canada, 2019; Gaetz, DeJ, Richter, & Redman, 2016). In the 2018 “Point in Time Count Report”, the investigators reported an estimated 5735 people in Alberta who experienced homelessness at that time (including unsheltered, emergency sheltered, provisionally accommodated and/ or identified as likely homeless with an unknown location), with an estimated 2911 individuals in Calgary, Alberta (The Calgary Homeless Foundation, 2018). According to the Calgary Homeless Foundation, the annual prevalence of homelessness in Calgary is estimated to be 18,250 Calgarians experiencing homelessness per year. However, again, the actual numbers are potentially much higher, given that many people who are precariously housed or unhoused people are not *visibly* without shelter; rather, they are *hidden*, staying with family or friends and out of the scope of the organizations that measure and count homelessness (Gaetz, Donaldson, et al., 2013).

People experiencing homelessness are a focus of much literature for various reasons including that they are at heightened risk for a broad range of acute and chronic illnesses (Brown et al., 2012; Hwang, 2001; Hwang & Burns, 2014; Morrison, 2009) with mental health and addictions being the most commonly identified health concerns among this population (Campbell, O’Neill, et al., 2015). However, the relationship between homelessness, mental

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health, and addictions is controversial mostly due to how mental health concerns and substance use are measured and reported in the academic literature. For instance, in 1990, Shinn and Weitzman argue that research results challenge the assumed link between mental illness, substance use, and homelessness, suggesting that serious mental illness affects only about one third of homeless single adults. Therefore, many works overstate the correlation between mental health and substance use among homeless individuals and could risk falsely identifying mental illness and substance use as “root causes” of homelessness, thus inadvertently individualizing the problem when there should also be more examination on structural issues such as the “growth of poverty, the erosion of funding for social programs, the destruction of low-income housing, and other contributors to homelessness that are not characteristic of individual victims” (Shin & Weitzman, 1990, p. 2). The association between mental illness, substance use, and homelessness can individualize the problem, when focuses on the wider contributions to the issues would hold others accountable in addition to the individual, which is often, intentionally, or unintentionally avoided in much of the literature.

Furthermore, people who are unhoused are often exposed to dangers that the housed population does not regularly encounter. For instance, the experience of homelessness is associated with a higher risk of illness or injury due to a range of factors including exposure to the elements, violence, and lack of access to facilities to manage their hygiene and safety. For these reasons, this population has been documented to be frequent users of emergency public systems, and to have higher mortality rates than same age individuals in the general population (Aldridge et al., 2019; Frankish et al., 2005; Morrison, 2009; Stafford & Wood, 2017). Also, the life expectancy of people experiencing homelessness is much lower than the general population (Geddes & Fazel, 2011; Hubbell, 2017). Cipkar & Dosani (2016) state that the mean age of

death for people experiencing homelessness is between 34-47 years. Others contend that adults who experience prolonged homelessness have mortality rates 3 to 4 times higher than the general population (Baggett et al., 2013; Henwood et al., 2015; Morrison, 2009). These higher rates of mortality in the homeless population then inspires the question, “how are people in these groups cared for at the end of life?”

People Experiencing Homelessness are not Receiving Palliative Care via “Traditional”

Methods. Overall, researchers suggest that access to palliative and end-of-life care is a problem in Canada with a scant 15-30% of Canadians receiving palliative care nearing the ends of their lives (CIHI, 2018; Henry et al., 2017). The problem is worsened for people experiencing homelessness. Studies show that, despite the alarming mortality rates of this population, generally, people experiencing homelessness do not receive the end-of-life care that they need (Barnes, 2022; Cipkar & Dosani, 2016; Reimer-Kirkham, Stajduhar, Pauly, et al., 2016; Giesbrecht, Stajduhar, Mollison, et al., 2018; Stajduhar, 2019; Traynor, 2019). Reimer-Kirkham, Stajduhar, Pauly et al. (2016) claimed that mainstream palliative care services are not responsive to the needs of those who are what they termed, “doubly vulnerable” – defined as individuals both in need of palliative care services and experiencing deficits in the social determinants of health that “result in complex, intersecting health and social concerns” (p.293).

Scholars have investigated the unique needs of persons experiencing homelessness who are nearing death and found that many have distinct concerns compared to the general population. Some of these concerns include a fear of dying anonymously, estrangement from people who are close to them, managing use of substances, and low finances (Sumalinog et al., 2017). Hankivsky and colleagues (2014) argue that the current “one size fits all” approaches to

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palliative care are tailored to a “standard person” and that this “standard person” is rooted in white, middle class, cultural and religious values which excludes a wide range of people who do not fit that mold, especially those who are socially vulnerable. De Veer and colleagues point out that for people who are dying and homeless there is often a delayed start to palliative care if they get it at all. This is due to the difficulties in recognizing the need for palliative care and individuals not having regular medical care that aids early identification. The authors also say that many individuals show ambivalence about receiving palliative care due to previous negative experiences with the health system. Further, they found that there is a lack of service providers or facilities to care for this population. These authors also point out that there is complexity with respect to pain and symptom management for this population due to the high prevalence of people who use drugs and the effect of this on tolerance levels for certain pharmaceutical drugs offered at the end of life.

Traditional models of palliative care also run in a way that hold assumptions about their patients that do not fit the typical patient who is homeless. For instance, traditional models of palliative care often do not acknowledge that patients may not have medication coverage, access to reliable transportation, or a stable residence. Healthcare providers also often assume that patients have a pool of informal supports such as family and friends who are willing and able help them with their care (Henry et al., 2017) which in many cases is not true, especially in socially vulnerable groups like those who are homeless. Caregiving is an important aspect to palliative care and comes up frequently in the literature.

Caregiving at “Home” and in the Community

Authors in the healthcare literature tend to differentiate between two types of caregiving or support: informal and formal. These works also tend to use the terms “caregiving” and “support” interchangeably. For current purposes, I will use “caregiving” to refer to both.

According to researchers in caregiving, informal caregiving refers to unpaid care providers with a tie of kinship or affection toward the care receiver (Novak, Northcott & Campbell, 2018, p. 322; Revenson et al., 2016). In contrast, formal caregiving is the paid support or care from professional caregivers such as doctors, nurses, social workers, and home care workers (p.318). Near end-of-life, the need for care often increases. The distribution of informal versus formal caregiving is controversial among scholars, policymakers, and the public. While many informal and formal caregiving tasks overlap, there is contention around which tasks “should” be left for informal caregivers as opposed to formal caregivers. Some policymakers argue that informal supports provide people with more control over their lives; however, researchers find that many older people report that these informal supports make them feel like a burden to their families, which can place tension on their familial relationships and friendships (Peckham et al., 2014).

Much of the literature focuses on the distinction between informal and formal caregiving for people nearing end of life. However, for studies that focus on caregiving and those who are precariously housed or homeless, the details are more nuanced. Some studies have specifically explored what caregiving looks like outside of the mainstream health system and for those in socially marginalized situations. In an empirical ethnographic study, Stajduhar, Giesbrecht, Mollison, Dosani et al. (2020) find that people who are made structurally vulnerable because of homelessness, poverty, racism, criminalization of illicit drug use, and mental health stigma are often cared for by “chosen family” who also face structural vulnerabilities themselves. Their

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study attempts to change the lens in which people in society view caregiving and palliative care by highlighting the differentiated needs and social supports that exist outside of what our mainstream system “expects” of their patients and their social supports.

The emphasis of family and caregivers is embedded in the definitions of palliative care, including the focus on the importance of family and caregivers in the priority of the practice. Therefore, it is no wonder that there are many studies that focus on caregiving and familial roles in the palliative care literature and that this literature is expanding. In Canada, one of the main attributes of palliative care provision involves support for family, caregivers, and significant others (Luckett et al., 2014; National Consensus Project, 2018). This is built into many palliative care frameworks embedded within mainstream health systems. Internationally, “the most common models of palliative care are aimed at supporting home-based end of life care, ‘optimizing’ the use of specialist palliative care, avoiding futile treatments and providing support for family care givers and community health professionals” (Luckett et al., 2014, p.5).

Some scholars who have critiqued the social organization of caregiving in the health services sector describe how much of the transition is fueled by “neo-liberalism”. This ideology as discussed earlier, includes “massive budget cuts, privatization, outsourcing of contract employment, and increased reliance on market relations as a mechanism for the distribution of resources” (McCoy, 1998, p.415). Aligning with the notion of “neo-liberalism” are the aims of “new public management”. “New public management” is expected to increase efficiency, reduce costs, and improve the quality of services, while reducing direct government involvement (Rankin & Campbell, 2006). Some academics critique the transition from formal care to informal care as a political cost-saving strategy that relieves public healthcare from the

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responsibility of caring for the sickest individuals (Armstrong & Armstrong, 2010; Armstrong, Armstrong & Coburn, 2001). They argue that this is a part of a larger move toward caring for people in the “community” rather than in hospitals. While this strategy is often advertised as based in preferences of people receiving care, critics argue that this causes problems for groups who do not have access to informal care and unfairly distributes the burden of care on women (Sinha, 2013) and on non-profit community organizations (Armstrong & Armstrong, 2010). Furthermore, the “new public management” approach also leads to formulations of “accountability” that bind the way care is delivered in ways that are limiting and can negate professional autonomy, judgement, and move the patient out of focus of service providers’ priorities in place of administrative duties (Corman & Melon, 2014; DeVault, Venkatesh et al., 2014; Rankin & Campbell, 2006).

For individuals who are homeless or vulnerably housed, social supports, and thus informal care, are often fewer or more fragmented than those in the general population (Eyrich et al., 2003; Solarz & Bogat, 1990; Johnstone et al., 2016; Padgett et al., 2008; Shinn et al., 1991). Therefore, this group faces the likelihood of not receiving enough care when they are nearing death. Many researchers that explore end-of-life preferences find that many people, if given the choice, would like to die “at home” (Gomes et al., 2013; Hakanson et al., 2016; MacWilliams et al., 2014). This is the argument that often pairs with the decision to move more health services into the community and out of the hospital. The issue with this becomes whether the supports are available for people to die comfortably at “home” and what “home” itself refers to and if supports are available there. This leads us to a discussion about how individuals who are homeless or vulnerably housed at the end of life would define a “good death” and if one is possible.

What is a “Good Death”? Hint: It is not the Same for Everyone

Harris (2017) characterizes death as a “social issue” in her chapter on what she calls an “egalitarian perspective” on dying and death. This perspective recognizes that those members of society who are differentiated based on social identities like socio-economic status are also those who face adverse consequences when they approach death. These consequences include but are not limited to types of access and care they receive. There are also individual differences embedded in the social context and Harris (2017) argues this is often overlooked by clinicians and health providers. With differentiated experiences at the end-of-life that are based on social identities and contexts, some people experience deaths that are worse than others.

Differentiations in dying and death experiences lead to distinguishing what a “good death” may look like, or if one is even possible. While there has been a growth in literature focusing on the “good death”, like traditional conceptions of palliative and end-of-life care, the focus is on the general population, and tends to exclude those in socially compromised situations. In Corpora’s (2021) study, she uses the notion of a “good death” to point out the privilege that goes along with it and how individuals with multiple marginalized identities face differences in experiencing a “good death”. Therefore, while the idea of a “good death” is something that may function to ease the discomfort of existential stress, she argues that it is reserved for those who have the privilege of reaching it, not for the socially marginalized.

Relatedly, there is much debate in the literature about whether our society is a “death denying” society. Historically, scholars argue that it is obvious that western societies “deny” death through avoidance of it, as demonstrated through the growing institutionalization of death, moving out of everyday sight and from the responsibility of families to professionals (Becker, 1973). However, others disagree, saying that death is ever present in our lives, with the

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possibility that we are obsessed with death as evidenced by the popularity of death-focused media such as some movies, video games, and other entertainment mediums (Novak & Wilson, 2022). Still others offer the distinction between death denial and death “taboo,” contending that the reality requires consideration of the nuance and that we do not outright “deny” death, but rather parts of it are “taboo” in lived reality; we keep it at a “safe distance” through engaging in it via entertainment and media (Walter, 2017).

The avoidance of death-related discussions on a societal level could be a reason that the health sector has historically paid less attention to the importance of end-of-life related services. Or in the case of palliative and end-of-life care, it could be because dying is seen as a “failure” of the dominant biomedical healthcare system. As MacDonald & Wright (2020) explain, there is a “counterculture stance and practice in palliative care because it runs opposed to many tenets of biomedicine which focuses on curative interventions” (p.63). However, recently, in Canada, some argue that there is a movement toward more death and end of life care related discussions. For instance, in 2022, state funding was offered to palliative care related issues in Canada based on the *Federal Action Plan on Palliative Care*, which affirms this assertion (Healthcare Excellence Canada, 2022).

The palliative and hospice movement of the 1960s, which expanded to Canada in the 70s, shifted the focus of end-of-life care from prolonging life for the sake of life, to providing “better deaths”. However, the idea of a “good death” originates long before this, with some saying that it dates to the Stone Ages (Kellehear, 2007). While the language of the “good death” is more recent, ideas about improving people’s last days and the experiences of those who are bereaved are not recent. Allan Kellehear (2007) states that in hunting and gathering economies, where

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people's lives were short and death came quickly, the focus was on transitioning the spirits of the dead from one world to the next. He goes on to mention that this evolved into the "pastoral age" where people were living longer and experiencing slower deaths allowing for anticipation; the emphasis was on preparing for death and the afterlife (Northcott & Wilson, 2017, p. 113).

Kellehear notes that it then transitioned into the third age of "the city" – by which the "good death" became a death that could be controlled and that was managed by professionals. This leads us to the present time, which Kellehear describes as the "cosmopolitan age" and says that this age has a mix of "wealth and poverty and long and short life expectancies" (Kellehear, 2007, p.7 in Northcott & Wilson, 2017, p.113). He further argues that a "good death" is nearly impossible at the present age of dying and that even "well-managed" deaths in our society are rarely achieved.

Northcott & Wilson (2017) add to this argument by asking, with the grief that accompanies death, "can death ever be ideal"? There is no clear answer to the question. So, while a noble goal, the notion of the "good death" is contested in the literature, with some critics stating that a "good death" is a construct that we can achieve, while others argue that it is too variable and is highly individual in meaning, changes over time, and based on personal values and perspectives as well as social, historical, and cultural contexts (Krikorian et al., 2020).

However, returning to the exclusion of the unhoused population in constructions of the "good death", it is significant to note that much of the literature that speaks to the "good death" involves a heavy focus on "preferences" at the time of death including the location of death. Corpora (2021) suggests that, since the palliative and hospice movement, there has been a tendency for "good deaths" to be associated with shorter hospital stays so that one could die at

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home more comfortably to improve the quality of life (and death) patients and families. A “good death”, then, in Western societies often refers to one that is “painless, taking place at home, and surrounded by family and friends with some element of acceptance of one’s demise” (Corpora, 2021, p.773). Other preferences for a specific dying process are also highlighted in the literature, including the preference to be without pain during the dying process, emotional well-being, treatment choices, dignity, family, and good quality relationships with healthcare providers (Meier et al, 2016).

However, the notion of “preference” can get more complicated for stigmatized and vulnerable persons with advanced illness since they are often excluded from consideration during the construction of typical care models. As several researchers in this area explain, individuals who are homeless or vulnerably housed often spend their final days in settings that have limited resources, expertise, and support, and their preferences and wishes are often ignored (Chidiac et al., 2021; Reimer-Kirkham et al., 2016; Stajduhar, Mollison, Gleave et al., 2017). As Davies and colleagues (2019) show, people who are more socio-economically deprived may have inferior “access to and knowledge of services and/or tend to communicate their care preferences less” (p.3). Another study looked at the experiences of patients with serious illness in an urban public hospital and their concerns, preferences, and perspectives on improving palliative and end-of-life care and found that effective communication and paying attention to preferences is something that this socially marginalized population valued (Dzul-Church et al., 2010).

Hubbel (2017) investigated end of life concerns reported by individuals experiencing homelessness and found that the main concerns were fears of dying alone or unnoticed; fear of dying violently or painfully; uncertainty about identification or disposition of one’s body;

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concern about receiving inadequate healthcare because of their homeless status; and concern about unhonoured preferences. Therefore, while researchers tend to agree on the importance of people communicating preferences and for these to be honoured at the end-of-life, for persons experiencing homelessness, the concern is that the preferences will be ignored or unknown altogether. Hubbell also points out that, for this population, traumatic life experiences on the street and in healthcare systems may shape end-of-life care preferences for this group in ways health professionals may not expect or understand, which may produce barriers to satisfying preferences even with the intention to do so.

Relatedly, Song et al. (2008) created a form called “Honouring End of Life Preferences” for understanding the preferences at end-of-life for persons experiencing homelessness, further demonstrating the value placed on preferences in relation to the idealized version of death. Similarly, in British Columbia, Canada, the Equity in Palliative Care Collaborative (2021) developed tools to help understand the wishes of socially marginalized individuals to help them plan for the end-of-life. Others found that men who were homeless who completed an advance directive through a shelter-based intervention were more likely to have their detailed care preferences documented or used during later hospitalizations (Leung et al., 2017). Thus, there has been an increase in work trying to understand preferences at the end-of-life and improve the consideration for them in the homeless population.

Many studies show the importance of “home” as a preference for location of death. However, this causes problems for individuals who do not have typical definitions of “home” and it is further complicated by the different constructions of home including, but not limited to Indigenous conceptions of home and the inextricable relationship to the land. Additionally,

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Hankivsky et al. (2014) showed the complexity of the issue around providing palliative care in the home and how “home” as a site for palliative care was intertwined with access to outside formal supports, spiritual beliefs, housing security, and associated costs that go with caring in the home. Caring at home is obviously complicated for people without access to stable housing. Therefore, these studies align with what Nelson and colleagues concluded in their study that providing a one-size-fits-all approach to palliative care may limit patients’ access to important resources that are better aligned with their personal beliefs and preferences (Nelson et al., 2021).

Yet another scholar, Sarah Elizabeth Coward (2018), explains in her dissertation research investigating the meaning of “home” for people experiencing homelessness, “the participants’ constructions of ‘home’ and ‘not home’ were not focused on a singular feature, unlike the broader social constructions of ‘home’” that often refer to dwellings (p. i). Therefore, mainstream conceptions of end-of-life preferences that are modeled after people who are not in precarious housing circumstances, and do not consider other cultural conceptions of “home,” exclude considerations of what people in precarious housing situations need or want.

Klop and colleagues (2018) find that people experiencing homelessness nearing end-of-life have physical, psychological, social, and spiritual concerns. Their physical concerns are about serious illness and physical distress. Their psychological concerns are about the fear of death and dying. Their social concerns are about becoming a burden to others and their spiritual concerns are hardly mentioned but they describe them as consisting of fears of the unknown. Individuals have concerns about care including that they expect their end-of-life care to be poor (p.9). The study participants frequently mention barriers related to receiving healthcare, such as end of life care not being a priority and living on a day-to-day basis, the absence of social

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relationships and support from family, only having small networks, and themes about health-related and other behaviour, such as the limited insights homeless people have into their own health. This study reports more barriers than enablers for participants, but the greatest enabler for this group is the importance of religious beliefs and their spiritual experience. This study states that the “attitudes of healthcare providers towards persons experiencing homelessness” is also a major theme (e.g., building trusting relationships). That is, the treatment of people experiencing homelessness and the need for pragmatic and flexible approaches from staff is said to be an enabler to a more “desirable” end of life. Feelings of being ignored, discriminated against, and disrespected by healthcare providers and a lack of trust are often mentioned as barriers. Additionally, lack of knowledge and skills of professionals (e.g., inexperience in determining when a patient is nearing the dying phase and meeting the palliative care needs) are barriers. And finally, the complicated organization of care is a barrier (e.g., minimal access to palliative care) according to this study.

Further, Hubbell (2017) explains that people experiencing homelessness also lack opportunities to communicate end-of-life preferences. Another study found that flexibility and preference for place of death were driving patient and family factors for satisfaction (Vernon et al., 2022).

Previously in this chapter, I noted a shift from providing end-of-life care in the hospital to “the home”. Some of this shift comes from the belief that most people *prefer* to have their last days carried out at “home”. This has given rise to what we know today as the vocation of modern-day home caregiving (Buck, 2011 in Corpora, 2021). While the shift seems to align with preferences, it becomes problematic when state-funded social and healthcare programs, like

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the mainstream health system, and the palliative services offered within them, make assumptions about the ability of families to care for people at home or in the community. For instance, in many provinces, we have what are called “Home Care Services”. Embedded within the title of these services is the assumption that one has a stable shelter to call “home”. In some instances, people do not have their own lodging or the places they call “home” are not within the “eligible catchment area” of the services provided. Contandriopoulos and colleagues (2021) point out in their systematic review that the literature on home care and its effectiveness is limited and that 18% of the papers they found mention unmet needs that home care should address. They also note that there is minimal scholarly work that points to what is needed to implement future change and improvement in home care delivery.

Vernon et al. (2022) argue that traditional Western perspectives tend to input assumptions when patients’ preferences are not a textbook match to the current models, leading to an increased potential for implicit biases in the delivery of care (Nelson et al., 2021). As a response to this discrepancy between services and client needs, a study of US hospice leaders found that tailoring hospice and palliative care outreach within communities to better engage vulnerable and key populations is key to improving inclusion in hospice and palliative care (Hughes, Vernon, Kowalczyk & Basco-Rodillas, 2021). This approach often involves addressing cultural beliefs, treatment preferences, and differences in health literacy when designing programs and communications.

The construction of the “good death” undergirds our societal idea of what it means to care for people “well” at the end-of-life. It even provides the foundation for how we conduct research with individuals who are excluded from the “good death” language by inspiring

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investigators to understand what people in precarious housing situations “prefer” when they are nearing end-of-life. “Preferences” around dying and death are viewed in North America as a key component to a “good death”. However, even the focus on “preferences” assumes that as mortal beings, we should have control, understanding, acceptance, and knowledge about aspects of dying and death that are available and accessible to us. Asking individuals who are socially marginalized about their preferences to increase the chances of a “good death” may not get at what researchers may think it gets at. “Preference” can be a limiting concept if one is not accustomed to the comforts of those who are housed, faces frequent discrimination, or has inadequate access to basic necessities on a regular basis. Furthermore, as Hart et al. (1998) explain, the notion of a “good death” could be a term that legitimizes another form of social control within which socially approved dying and death are characterized by normalized behaviours and choices.

As this ideology of the “good death” dominates, Hart et al. (1998) describe how we should remain critical as we determine whose interests this prevailing ideology of the “good death” serves and how the choices of the dying are facilitated or constrained by this ideology. While this is an older study, it holds true today as we make assumptions in scholarly and clinical settings about what preferences at the end of life commonly look like, excluding some of the most socially vulnerable groups. This leads us back to the discussion about what “equity” in healthcare means and how this relates to discussions of end-of-life care.

The “Health (In)Equity” Problem in Healthcare

In recent years, there has been a movement toward recognizing the problematic relationship between people who are homeless or vulnerably housed and mainstream healthcare systems. Scholars have studied this problem using the term “health equity” or “health inequity”.

“Appropriateness” of care is part of what undergirds the burgeoning concept of “equity” in the literature. While the main tenets of the concept are agreed upon by scholars and others who work in this field, the exact definition varies according to who is speaking or writing. According to Javanparast and colleagues (2022), the concept of “equity” draws attention to “disparities in health between population groups that are avoidable, unfair and unjust” (p.2). The EQUIP Healthcare Program (2020) out of the University of British Columbia has a more detailed definition of health equity.

Health equity focuses on ensuring and treating those who require care in ways that are appropriate to **what they need** to enjoy full, healthy lives. It aims to remove unjust and unnecessary differences, requiring us to consider the possibility of making different arrangements for resource allocation, or social institutions or policies. [Emphasis in original]

Similarly, the United States Center of Disease Control and Prevention website (2022) describes “health equity” as, “the state in which everyone has a fair and just opportunity to attain their highest level of health.”

As mentioned in the Introductory Chapter, scholars have begun to speak more about “equity” beyond the previously discussed concept of “equality”. That is, advocates have argued

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that “equality” is not sufficient to address the social disparities in our society and that decision-makers and scholars need to take a step further to ensure that health services are “equitable,” meaning that individual social circumstances should be accounted for when considering healthcare delivery.

Naomi Richards (2022) identifies this as the “equity turn” in healthcare. She highlights how reports and visions for national healthcare have begun to put forward “equity-driven agendas” because of the recognition of health inequities and the rise of recognition for what are called the “social determinants of health”. She also highlights how dying and death scholars and care providers take up this project and begin to feature palliative care in this “equity-focused” work. However, while she highlights the presence of this trend, she also notes that with respect to caring for the dying, this is not a new concept.

Richards (2022) notes that much of the literature about health and palliative equity speaks of it as a new phenomenon and focus for scholars and healthcare providers alike, but that in fact, it has *returned* care of the dying to its historical roots. She reminds us that the original palliative care patients were the “dying poor” in the late 19th and early 20th centuries. Considered “proto-hospices” (Golden, 1981 in Richards, 2022), there were accommodations set up for the “dying poor” that were charitable or philanthropic organizations. The “roots” of palliative and end-of-life care originate in the UK with the rise of “proto-hospices” and the first “modern hospice” in the latter half of the 1900s. Richards’ work prompts reflection on the deeply entrenched and historical marginalization that people in poverty face, including at the end of life, as well as the cycles of its examination over time. In Canada today, authors take up the cause of “palliative equity” and speak of it as a novel approach not yet embedded in the current systems of care,

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perhaps because, in Canada, we have not had the same long history that the UK has in this regard.

“Palliative Equity” in Canada. Originating in the United Kingdom, beginning in the voluntary sector outside the UK’s mainstream health service, Dame Cicely Saunders founded the first known modern hospice, St. Christopher’s Hospice in the 1960s. This set off what is now known as the modern hospice movement. Relative to our UK counterparts, palliative and end-of-life care are youthful in the field of medicine in Canada. The term “palliative care” did not emerge in Canada until the mid-1970s and originally was serving primarily cancer patients, later expanding to all people with “life-limiting illness” (Government of Canada, 2018). In Canada, hospices had their start in the hospital setting with the establishment of the first palliative care unit in Winnipeg, Manitoba, at St. Boniface General Hospital in 1974.

According to the federally released “Framework on Palliative Care in Canada” (2018), palliative care is,

[A]n approach that aims to reduce suffering and improve the quality of life for people who are living with life-limiting illness through the provision of: Pain and symptom management; Psychological, social, emotional, spiritual, and practical support; and Support for caregivers during the illness and after the death of the person they are caring for.” (p.4)

In this definition, palliative care is an approach that can be provided at any stage of an illness. End-of-life care, by contrast, focuses specifically on the care provided to an individual when they are in the last few weeks or months of life. Thirdly, “hospice care” is a type of palliative care but is meant to provide care that intends comfort for the patient without curative intent and often

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happens within the last six months of life. This is distinct from palliative care because palliative care is care provided to the patient intending to improve comfort but can be with or without curative intent. Often these terms are used interchangeably and there are further delineations within each sub-category.

Recently, some palliative care researchers have taken up “equity” language which involves recognition of the “social determinants of health” and how they influence health outcomes including access to appropriate palliative care. Many healthcare and social service providers feel that mainstream palliative care services are inaccessible to people experiencing homelessness and especially inaccessible to those who also use drugs (Huynh et al., 2019; MacKenzie & Purkey, 2019; McNeil & Guirguis-Younger, 2011; Stajduhar & Mollison, 2018). Additionally, some scholars document that people who are unhoused often have complex and diverse end-of-life care needs and typically die outside of the mainstream end-of-life care system (McNeil, Guirguis-Younger & Dilley, 2012). Dahlin et al. (2022) report on the history and evidence of structural racism, the role of social determinants of health, and roles of nurses in improving “health equity” to ensure people are getting the care that they need. They go further to offer strategies on how to supply more “equitable palliative care” through developing more culturally sensitive practices and communication skills and recommend that healthcare providers learn about the elements of social determinants of health to perform assessments as part of every patient assessment.

Other scholars also zero in on specific social determinants of health such as the cultural aspects of care that contribute to palliative inequity and the challenges in understanding their impact. For instance, Hussain, Koffman and Bajwah (2021) state that it has not been possible to

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completely disentangle how much racism or racial discrimination versus other social determinants of health, such as deprivation, cause health disparities, or to what extent they result from policies or practices of exclusion that mimic racism. While investigators may not be able to perfectly tease out or control for one social determinant of health over the other in all cases, Hussain et al. (2021) point to evidence that those from minority ethnic groups are less likely to receive adequate assessment and treatment for pain (Calanzani et al., 2013; Pinhero et al., 2019), agitation, and psychological distress (Gardner et al. (2018), and they are less likely to receive adequate information to manage their illnesses (Clark et al., 2016). Rethorn, Garcia, Cook & Gottfried (2020), however, state that “viewing social factors in aggregate rather than individually may offer more precise estimates of the impact of social determinants of health on outcomes” (p.1). Further, Javanparast, Anaf, and Tieman (2022) state that considerations of the “social determinants of health are integral to achieving ‘health equity’ and that increasing research and evidence on the social determinants of equity in palliative care” (p.3) are necessary.

This emphasis on the social aspects of care has been expanding in Canada with a focus on housing vulnerability and poverty as two key determinants affecting “palliative inequity”. Some scholars argue for a reorientation of palliative care that explicitly integrates the premise of “health equity”. For instance, Dahlin and colleagues (2022) take up this language in their study on health equity stating that “patients who are doubly vulnerable by serious illness and social determinants of health need increased engagement by palliative clinicians” to achieve equity in palliative care (p.218). The language in the literature matters as scholars coordinate our knowledge of what we understand to be “facts”. These studies cast our gaze to the social components that shape individual health experiences at the end of life and have led to a new cohort of care providers that offer palliative care “outside” the mainstream health system.

Toward Providing Equitable Palliative Care. Across Canada, teams have started to respond to inequity in palliative care in mainstream health service models. Starting with a team in Victoria, British Columbia, Canada, in 2011, a group of downtown service providers began an informal collaboration to improve access to, and quality of, palliative care for people who are nearing end-of-life and who live on the street or have unstable housing. In 2013, this collaborative, known as the Palliative Outreach Resource Team (PORT) paired up with Dr. Kelli Stajduhar from the University of Victoria to help PORT document the experiences of people who are homeless and living with life-limiting conditions in Victoria (Stajduhar & Mollison, 2020). Similarly, in 2014 in Toronto, a palliative physician, Naheed Dosani, began a program called Palliative Education and Care for the Homeless (PEACH) which serves people experiencing homelessness in Toronto's inner city. Following this, a program in Calgary came about called the Calgary Allied Mobile Palliative Program (CAMPP) in 2016, which later changed their name to the Community Allied Mobile Palliative Partnership in 2022. Soon after, Cara Bablitz began a similar program in Edmonton, Alberta, called the Palliative Care Outreach and Advocacy Team (PCOAT). Also, the Ottawa Mission's Diane Morrison Hospice in partnership with the Ottawa Inner City Health is committed to caring for people experiencing homelessness while needing end-of-life care.

According to the leaders of each of these programs, what differentiates their services from other mainstream palliative care services is their approach that works as a type of “scaffolding” for people's connections with health services and life necessities. All teams are funded differently, with most being funded by grants. The PEACH team, however, has secured ongoing sustainable funding from the Ontario Ministry of Health via an arms-length organization called the Inner-City Health Associates (ICHA). The other teams have separate funding partners

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that contribute to their programs. A major distinction for the teams is that they operate under models of “harm reduction”.

Harm reduction models have been around for decades, becoming more well-known in institutional settings in the 1980s and 1990s (Boucher et al., 2017). An assortment of conceptualizations of the term “harm reduction” exist and evolve as the academic literature expands. Harm Reduction International (2022) conceptualizes harm reduction as referring to,

policies, programmes and practices that aim to minimise the negative health, social and legal impacts associated with drug use, drug policies and drug laws. Harm reduction is grounded in justice and human rights. It focuses on positive change and on working with people without judgement, coercion, discrimination, or requiring that people stop using drugs as a precondition of support. (Harm Reduction International, 2022, Who We Are section, para. 1-2).

However, others argue that there is more to the discussion. For instance, Boucher et al. (2017) argue that with all the varied definitions of harm reduction that exist, people with lived experiences are often left out of the process “despite calls to include their voice in recommendations for harm reduction service delivery and implementation” (p.3). Furthermore, these authors point out that there are differences between harm reduction as a concept and harm reduction programs and services. In this study, I take up part of this tension as we bring to light how the nuances in understanding can contribute to differences in program delivery, structure, and implementation when I discuss palliative care as discourse and how CAMPP takes up the conceptualization of harm reduction in organizing their work.

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Furthermore, it is important to highlight that, while common understandings of harm reduction philosophy imply that patients are not required to abstain from using substances to access the services, this does not mean that all individuals who experience homelessness and require end-of-life care use substances or would be classified as having a dependency (Aleman, 2017; Schneider & Dosani, 2021). Rather, these models undergird the outreach teams' approaches regardless of their prospective patients' history with using drugs.

There has been a rise in the research that focuses on the role of "harm reduction" in palliative care. McNeil & Guirguis-Younger (2011), who studied illicit drug use as a challenge to the delivery of end-of-life care services to people experiencing homelessness, call for further investigation into the role of harm reduction in end-of-life care settings to address challenges and barriers preventing homeless illicit drug users from accessing end-of-life care services, such as competing priorities (e.g., withdrawal management), lack of trust in healthcare providers and social care settings, including non-disclosure of illicit drug use, pain and symptom management, interruptions in care, and lack of experience with addictions. Buchanan et al. (2003) argue that much of the opposition to "harm reduction" approaches to end-of-life care tends to revolve around moral values around substance use despite the evidence to support harm reduction approaches that improve health outcomes and quality of life for the people in care. This is problematic as it can lead to individuals who are homeless who also struggle with mental health and/or substance use challenges facing barriers to care from institutions and healthcare providers, for reasons including strict abstinence-based policies, risk and safety management, and limited implementation of harm reduction techniques (Schneider & Dosani, 2021).

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Podymow et al. (2006) describe how harm reduction strategies can support end-of-life care for people with a heavy burden of disease, psychiatric conditions, and substance use. They found that those working with people experiencing homelessness within large urban areas should consider integration of comprehensive health services using a harm reduction strategy.

Following this, McNeil, Guirguis-Younger, Dilley et al. (2012) contend that more comprehensive harm reduction services may be needed in end-of-life care settings to engage underserved populations of people experiencing homelessness, especially as a point of referral and alternate source of end-of-life care for this population.

In addition to these authors, still others argue that harm reduction strategies and palliative care are strongly paralleled, highlighting that both methods have similar priorities and approaches (Stajduhar, Giesbrecht, Mollison & d'Archangelo, 2020). However, while, there have been arguments for this approach to be embraced, health care providers are often not trained in this approach and the medical model of service delivery still dominates. Hawk et al. (2017) paraphrases Marlatt (1996) saying that, "harm reduction as an approach stands in opposition to the traditional medical model of addiction which labels any illicit substance use as abuse, as well as to the moral model, which labels drug use as wrong and therefore illegal." For these reasons, the mainstream system as it exists is not equipped to deal with populations who may encounter these issues or accommodate service providers who work under these philosophies.

Conclusion

There have been major changes and restructuring in Canada's health system over the last several decades, including our understanding of what "health" and "care" mean. It was not until

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the mid 20th century that Canadian officials recognized social factors contributing to health, and we are now at a stage where the health system, while making efforts in the direction of social care, is still falling short for those who live on the extreme social margins, namely, those who are homeless or vulnerably housed.

Canada's mainstream health system makes consequential assumptions about its patients based on how it is structured. One assumption is regarding "access". A foundational principle of the Canadian health insurance system is to provide Canadians with "universal" health insurance so that access to healthcare services is not limited by one's ability to pay. However, as it stands, the system as it is carried out is not fulfilling its intended mandate. Universality assumes that all Canadians will have the means, desire, and skills to "fit in" with the system the way it is organized. If the system is physically available, the assumption is that people just need to get there. However, as scholars have described, "access" means much more than just being permitted to obtain health services; it includes the context in which people live, the approaches of services providers, and as we will learn more in this dissertation, the organization of care that either does or does not make people and "the system" a mutual fit.

Because of this lack of "fit", scholars, healthcare providers, and social advocates have started to promote the notion of "health equity". Ensuring that services "fit" the needs of the people is of primary concern. Individuals facing extreme poverty are exposed to worse health outcomes than the general population. Their risk of mortality is also higher and so this population often needs more healthcare support than the general population. With fewer social supports or resources, individuals in this socially precarious situation are left even more vulnerable in a society that places the responsibility of one's health and healthcare firmly on the

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individual. Recent programs have emerged to address this gap in health services at the end of life that take up a different approach to care, a “harm reduction” approach that focuses primarily on the unique needs of this socially marginalized population.

While there has been a growing body of work examining “harm reduction methods” of approaching end-of-life care for people experiencing homelessness, to date, most have approached this research using methods that focus on the “experiences” of the individuals delivering services or potential clients of the services. While important, these investigations exclude a detailed inventory of the work activities that go into this innovative approach to care provision and how this work is socially organized amidst the wider health services delivery system. The current project builds on experiential research and takes up this latter analytic project by using an institutional ethnographic method of inquiry, as I will outline in the following Methodology chapter.

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In this chapter, I expand on the description of the CAMPP team provided in earlier chapters. I also speak to the intention of the current research to take up the standpoint of clients. Next, I outline the guiding research questions that informed the project, discuss the approach I took to examine the CAMPP team's work, Institutional Ethnography (IE), and lay out the methods that I used to collect the data. This chapter also discusses the analytic approach that I took to understand the data and my experience with the research ethics process.

This study focuses on the work and practices of a small group of people organized as the Community Allied Mobile Palliative Partnership or the CAMPP team. The standpoint that the current study takes is that of people experiencing homelessness with life-threatening conditions who are experiencing injustices related to the mainstream healthcare system. In this project, I examine the issue through the access point of exploring the work of the grassroots organization in Calgary. I am specifically interested in what is involved in the provision and social construction of appropriate end-of-life care to highly marginalized people who are not well-served by the healthcare system. To explore this, I focus on the work and institutional positioning of the CAMPP team. In this work, I use pseudonyms for all individual participants in the study.

The CAMPP team was formed in October 2016 after "Charles" recognized a disparity in the way his homeless clients were cared for in the hospital palliative care unit where he worked. After he had recognized this problem, a colleague introduced him to a nurse who helped him form the CAMPP team. Together, they planned to deliver services directly to the population that Charles noticed was not getting proper treatment from the mainstream health system.

The CAMPP team is primarily funded by grants and donations and operates outside the mainstream health system in a non-profit organization called CUPS. They have a partner team that they work closely with called the Healthcare Outreach Team (HCOT) who work with people who have high medical needs and who are homeless. The HCOT team is also grant-funded through operational funding of their parent organization, CUPS Calgary Society. Charity Intelligence Canada (2023), verified by the publicly available CUPS 2022 Annual Report, concludes that CUPS is a charitable organization whose funding is mostly from grants with less than 1% of their funding coming from government. While it may occur that they cross paths with the same clients, the HCOT team is not specifically funded to work with palliative and end-of-life care clients like the CAMPP team does. It is the work and practices of the CAMPP team that the current project focuses on to better understand alternative approaches to end-of-life care for people experiencing homelessness. Some of the names and identifying information of the people and programs in this project have been changed to help protect their anonymity.

Guiding Research Questions

This research explores the work of the CAMPP team in the context of a larger movement toward equitable delivery of palliative care in Canada. In this project, I explore the team's day-to-day activities of caring for people, their work processes, and the interfaces they have with the larger social and healthcare system. Through this, I explicate how the work of this team is socially organized. This study is guided by one main research question and five interrelated sub-questions:

- 1) How is the work of the CAMPP team socially organized in the context of the wider palliative and end-of-life care system in Calgary, Alberta, Canada?

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- a. How do people experiencing homelessness interact with CAMPP?
- b. What does CAMPP do to care for people with life-limiting illnesses who are homeless or precariously housed?
- c. How does care provided by CAMPP hook into the mainstream health system, other health and social care agencies, services, and organizations?
- d. How is CAMPP made institutionally accountable and how is their work legitimized within this accountability structure?
- e. How does the way CAMPP's work is organized, coordinated, and made accountable shape their daily work activities and service delivery?

This study takes an institutional ethnographic approach to inquiry. Therefore, the research questions are meant to guide the inquiry and are not prescriptive. By exploring these questions, I provide an account of how the CAMPP team puts together their work in the context of the wider health and social care system to help meet the needs of society's most vulnerable, people who are homeless and nearing the end of their life. In the following section, I discuss IE and what it helps to make visible in the social world.

Institutional Ethnography (IE)

What is IE? Institutional ethnography is often placed in the "Methodology" section of a thesis because that is where it best fits given the traditional layout of a dissertation. However, Dorothy Smith, the creator of IE, refers to it as more than a methodology. She refers to IE as a "new sociology," one that originates from her feminist background and comes toward the discipline differently than how "traditional sociology" has in the past. That is, IE does not theorize about a social world that exists "out there", rather, IE is firmly rooted in the ontological position that our

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knowledge about social happenings can be found directly in what people are doing, thinking, seeing, and imagining. The interest of IE is to make explicit what is not directly visible to us in our everyday lives. Institutional ethnographers do this by tracking the interactions, actions, activities, and tasks of people and relevant texts to create a type of “mapping” that outlines how the social is organized. In this way, IE guides our strategy of collecting and understanding data; therefore, it encompasses *both* a methodology and a theoretical approach to understanding the social world.

IE is called a method of inquiry because it is not on its own a methodology (Devault & McCoy, 2006). IE allows us a way to dive into the lives of real people and inquire before asserting theoretical assumptions. IE is different from traditional ethnographies in that it pursues analysis on multiple levels of social organization through collection of data at multiple sites and “beyond what informants at the local level may know” (Campbell & Gregor, 2002, p.81). IE is equipped to make these pieces of social interface visible beyond what local informants know, including staying sensitive to common language that informants use and may take for granted in their everyday activities.

Additionally, institutional ethnographers often hold a specific intention for their projects. That is, IE is commonly a social advocacy project because it endeavours for some kind of social change that comes from examining taken-for-granted social practices that favour certain groups over others. Further, IE confronts relations that occur within institutions between people that cause, or in this case address, social inequities.

Why did I choose IE? Because I view the experiences of the CAMPP team as shaped by institutions and coordinated by texts and societal practices, I chose to use Institutional

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Ethnography (IE) as my guiding mode of inquiry for the proposed study. This means that I am committed to the assumption that any “knowledge” that we can derive about the CAMPP team’s work will come from ethnographically examining their *actual* daily and nightly work of caring for persons experiencing homelessness. My use of the words “actual” or “actualities” when I explain the position in which I examine the CAMPP’s work are relatively “empty terms” (McCoy, 2008, p.705). These terms are “empty” because they refer to what I will be focusing on without committing to concepts, names, definitions, and operationalizations to preconceived ideas and meanings.

Rather, my aim in this project is to discover concepts and categories that the members in the setting use in their work, while also taking note of my own perspective as an IE researcher and the lenses I use in my observations. The goal is to do so without falling victim to a kind of “relativism” where we deconstruct our own descriptions, as this is not the analytic goal of IE (McCoy, 2008). Additionally, IE positions the researcher as part of the research, and this aligns with the IE notion of a “social ontology” which understands knowledge to be constructed by people in their actual daily lives and activities rather than focusing on social organization as something that happens “out there,” located in an intangible theoretical world. Furthermore, IE places researchers as part of the project, not to be understood as objective observers or “outsiders” looking in on some situation or phenomenon. Instead, IE asserts that researchers shape and are shaped by the project, and this adheres to my values and understandings of the social world and research projects. Additionally, like IE’s philosophical underpinnings, I also believe that in *doing* research, researchers are inherently contributing to the social organization of it.

IE's Social Ontology and Concept of Standpoint. Institutional ethnographers take up an analytical project that requires a specific orientation to the phenomena they investigate.

Ontology refers to one's "theory of reality" and for IE, the theory of reality is embedded in real life happenings of individuals. Developed from Marxist materialist philosophy, Smith criticizes ideological reasoning of traditional sociology because traditional sociology has tended to replace the actual with the conceptual (Smith, 2005). Furthermore, IE purports that there is no social world without people and so "social ontology" directs the attention of institutional ethnographers to what people are doing in their everyday and every-night lives. This specific orienting helps the IE researcher know where to direct their attention. When Dorothy Smith describes the "ontology of the social", she explains that the findings of IE research "are in and of the same world that [they] investigate" (Smith, 2005, p.52). As McCoy (2021) writes, "in this ontology, the social happens in the ongoing, coordinated, mutually adjusted activity of people" (p.38). That is, McCoy explains, that for Smith, the "social" is viewed as a "process" in the materialist ontology of IE. This ontology assumes that as people we are always in our bodies in a time and place but never isolated from social relations in "extended chains of action that reach forward and back in time, and extend geographically" (McCoy, 2021, p. 39).

For Smith, a central tenet for IE is that its discoveries are firmly rooted in everyday happenings which can be cartographically tracked to explain widely dispersed social organizations of things. IE aims to make explicit the act of knowing and functions as theory *and* method because it undergirds the theoretical conceptualization of the study but also guides how the data is collected. IE is a *method* of inquiry that uses people's everyday experiences as a lens to investigate social relations that make up larger social institutions (Smith, 1987, 2005).

However, when institutional ethnographers speak about "social relations", we intend the term not

as the object of study, but as what we use to do the “looking” (G.W. Smith, 1995 in Smith & Griffith, 2022, p.68). IE researchers are interested in the interactions and intersections of people and their work which make up “social relations”. Therefore, the “ontology of the social” refers to how IE researchers orient to their analytic project grounded in the place of social reality and real happenings, attending to interchanges that make up social relations. As Smith and Griffith (2022) explain, the interests of institutional ethnographers enter into and organize what we bring into focus, but these decisions always develop from the standpoint of those we learn from through our research.

Standpoint is another orienting concept of IE that helps direct our attention to the beginning of the inquiry and is not meant to be a conceptualization of *some object out there*. We begin from “standpoint” to open possibilities of interesting investigative threads to follow. This is the starting place of the research interest and is not meant to refer to the taking up of one’s “perspective” based on their social positioning. Standpoint helps us begin to look for how people’s experiences of their worlds can be opened up as they intersect with relations “reaching beyond the immediacy of their experience” (Smith & Griffith, 2022, p. 77). In this study, we are starting from the standpoint of clients who receive care from the CAMPP team. We are interested in how CAMPP goes to work on their behalf in the context of the wider social and healthcare system. We begin to see how the worlds of people experiencing homelessness and who have life-limiting illnesses live in the world and navigate their health and illness situations and how their experiences are shaped socially. From there we see where the need for CAMPP came from and how this team was crafted, and their work is constructed to address this need. Related to Smith’s notion of a “social ontology”, in the next section, I discuss three other key

conceptualizations that help us put a social ontological approach into practice: *discourse*, *texts*, and *work*.

“Discourse”, “Texts”, and “Work”. IE avoids drawing heavily from theory since it is premised in being grounded in individual daily and nightly activities. However, it does draw from special *concepts* to help guide the researcher’s attention. Three concepts that IE researchers have used and refined over the course of IE’s evolution are: *discourse*, *texts*, and *work*. These three interrelated concepts are meant to orient the researcher’s data collection and help with focusing on specific happenings during the investigation. As Smith and Griffith (2022) write, “the institutional ethnographic conceptual practices are not theories, but they are indeed an activity that is actually performed” (p.29). Aligning with the “grounded in reality” approach, institutional ethnography also bases its conceptual practices in physical happenings. That is, the concepts are based in active participation by the investigator, not a “high-level” theoretical approach to explaining aspects of social life. For Smith, theoretical concepts are meant to express actual social relations (2006, p.56) and orient the researcher in real time to real activities done by real people.

Discourse. The concept of discourse is relevant to the current project as we explore how the participants in the research engage in, are shaped by, and shape discourses around caregiving at the end of life. Smith uses the term *discourse* in a way that builds from Michel Foucault’s (1970, 1972, 1980) use of the term. Foucault describes discourse as “regulating how people’s subjectivities are coordinated, what can be uttered, what must be excluded, what is simply not made present, what can be spoken or written and heard and understood by others [and how] it is discursively determined” (Smith, 2005, p. 18). Smith states that Foucault’s conceptualization is

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helpful as it supports our understanding of the social world by giving us a way to think about how the social world is systematically produced, ordered, and disseminated. However, for Smith, to avoid resignation to “blob ontology” (2005, p.56), institutional ethnography should focus on the social which is located in how people’s activities or practices are coordinated. That is, “individuals are there; they are bodies, they are active, and what they are doing is coordinated with the doings of others” (p.59).

Coherent with this design, Smith’s notion of discourse is also inherently produced in actual sites by actual people; its activities and components can be seen in real time and are mediated through texts. IE uses the concept of discourse as a tool to recognize social relations in which the work of many is coordinated. Discourse in IE functions as an orienting concept to direct attention to text-mediated social relations of coordination (L. McCoy, Personal Communication, June 09, 2022). Discourse is ever-changing and can be opened up by people’s experiences. That is, recognizing happenings in our everyday lives that are common and fueled by taken for granted understandings of what “should be” can show how discourse is alive and active in our everyday lives. For instance, in their earlier work, Smith and Griffith talk about a “mothering discourse” that they explored based on their own experiences of feeling like a “defective parent” because of how schools, large influential institutions that they had affiliations to through their children, did not incorporate the needs and demands of single mothers in their taken for granted understandings and expectations. Internalizing this discourse of “motherhood”, Smith and Griffith recognized that they were assessing themselves against what it meant to be a “good mother” according to the discourse. These authors explained how they were being shaped by and actively participated in the “mothering” discourse as they tried to “measure up” to the

expectations of the school despite the specific challenges they faced as single mothers compared to “traditional” families who had more supports and resources.

Furthermore, beyond accessing discourses through experience, Smith and Griffith (2022) also describe discourse as an “organization of relations among actual people engaged and active in actual local settings...whose activities and work, are coordinated *textually*” (p.34; emphasis added). That is, common texts, either physical or digital, coordinate our interactions and act as vessels by which messages are carried and interpreted to contribute to discourse. Discourses are often coordinated through texts which brings us to the next important concept.

Texts. In the current research, I have analyzed texts to understand how members of the CAMPP team operate and make sense of their work, shape, and are shaped by discourses around caring for people at the end of life in the context of North American healthcare. Texts are an important part of the institutional ethnographer’s “toolkit” for investigation. They refer to material objects that carry messages and can be reproduced many times so that different people can read the same text in separate places at different times (Smith & Turner, 2014). Understanding the social world for IE often involves investigating the creation and reproduction of texts that become recognizable to people as integral components of institutions. For IE, texts are an active participant in our social world as they “coordinate and concert people’s activities across time and space” (Smith & Turner, 2014, p.3) and bring us beyond studying the “local” in ethnography.

To get at what Smith calls the relations of ruling or the relations of coordination and control in the places where we wish to focus, we often need to account for the texts involved in these processes. Now more than ever, “technology permits our ability to reproduce texts so that

they can be widely distributed such that copies of texts can show up in different places at the same time” (McCoy, 2008, p.703). Because of this, practices are reproduced across multiple sites. Institutional ethnographers strive to make visible how people put together their everyday/night lives and how their practices are mediated by such modes of knowledge – often in the form of texts. Institutional ethnographers are always interested in what people are doing and how these doings are repeated over time to create routinized practices across time and place. Therefore, institutional ethnographers should seek out people who are doing the work because they are knowledgeable about the work they are involved in; Smith (2005) describes this as “work knowledge”.

Once texts are (re)produced and taken up by people in the world, they are activated. This activation transforms the text from its original version to a dynamic two-sided one involving the reader’s whole life of experiences, ideas, and understandings. Smith refers to this as a “text-reader conversation” (TRC). A TRC involves how one comes to the text and engages with and activates it. While the reader engages intimately with texts, activating them through their own lens of discovery, the text itself remains unchanged in the physical sense. However, the reader is changed by the text; and the interpretation of the text is shaped by the reader. For instance, in Susan Turner’s ethnography, she explicates how a text can be read differently when she observes a public meeting where elected officials were planning a ravine development proposal. In her study, Turner explores a “sequence of naturally occurring talk in which a visual text is central to a city council ‘making a decision’” about the ravine (p.197). In Turner’s study, she shows how IE helps orient us to what we take for granted as processes that go on internally for people, like reading, but that are actually visible and socially organized. Texts are significant in IE because they are key constituents in coordinating our world, making ideas replicable beyond the local.

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We engage in a dialogue with texts when we read them or write them and this creates something that can be picked up by another person who, whether they see it the same way or not, engages with the same text, (re)producing a relation in the social world. It is a sequence that gets started and perpetuated by the act of engaging with a text, whether it was written or read. In Smith and Griffith's (2022) most recent book they explain, using Susan Turner's model of the "work-text-work sequence", how texts "that can be seen as activated at one moment in a social relation hook up at the next in a sequence as they are activated in someone else's work" (p.53). That is, through engagement with texts, social relations become observable because we can track how we coordinate with them and how our social realities can be organized to construct a social world that affects real people. In this research, I explore texts that the CAMPP members engage with, are transformed by, and transform in their day-to-day activities working with people experiencing homelessness nearing end of life.

Not all uses of texts need to be made visible in work processes because of some problem they may contribute to. In IE, it is important to show that texts are coordinators of interpersonal activity and can ground our understanding of how the social work is coordinated. In this study, I build on this conception of texts as coordinating lives and activities and how the dynamic two-way relationship between the text and the reader can shift the use of the text. While in some cases, the implementation of texts is rigid, in this study, we will see how the CAMPP team uses texts that are modeled from and reflect mainstream health care uses of texts, but they use them differently to try and support their approach to the work and the goals they are trying to achieve.

Work. The final key concept that I want to bring to light in this section of the chapter is *work*. Work is a concept that IE investigators use to orient to what people are doing that is

intentional, takes effort and time and is done under definite conditions (Smith, 2005, Smith & Griffith, 2022). In IE, we are not meant to take “work” as we would in its regular definition as we understand it, namely, as being something that we do for compensation to support our livelihoods. For IE, the concept of work could be related to paid compensation; however, the intention is to view work through a generous conception of the term that allows us to open up the possibilities of how activities are coordinated socially by people who may not recognize them as work because of how they are positioned or taken for granted in our society. This concept is important for this project as I use this specific, yet generous, understanding of it while investigating the activities and operations of a small independent team that provides care for people who are vulnerably housed or homeless and who struggle with life-limiting illness. In this study, work also includes what people living in homelessness at the end of life are doing — to survive, to engage with treatment, with CAMPP. From the standpoint of these people, it is clear how the approach of the CAMPP team shapes the conditions and possibilities of their work in important and helpful ways.

How this Project fits Within the Larger IE Landscape

Like this project, many IE studies focus on professional workplaces and approach the inquiry from the standpoint of workers in clinical settings with the wider agenda of explicating ruling relations that serve to marginalize specific people and groups. For example, Corman (2018) investigated the hidden work of the person in the “front seat” of an ambulance in paramedic work. This study takes the standpoint of the clinical professional working in the often “taken-for-granted” role of the front seat driver in an ambulance call. Corman not only explains the importance of paramedic work but also highlights the nuances of what the actual work is,

how the work is delivered, and how it is organized by institutional technologies such as dispatching systems, medical control protocols, and the “electronic patient care record”.

Other authors explore nursing work in the age of electronic health records and how these texts rule the types of things nurses come to “know” about their patients and how the texts organize the ways care is delivered (Campbell & Rankin, 2017). Still other IEs focus on the standpoint of the person or people receiving services or the “clients/patients”. For instance, Nichols and Braimoh (2018) explore the standpoint of youth in urban centres and how they are systematically excluded and oppressed due to social processes and the organization of programs that are intended to help the youth and families in these neighbourhoods. In this study, the authors examine social housing in low-income communities and how youth who live there are exposed to enhanced police surveillance as additional police officers are assigned to these areas which then heightens levels of criminalization and distrust among these social housing environments. While the distribution of police officers in these areas is explained as a way of enhancing protection, “extensive policing of low-income neighbourhoods and social housing shapes increased involvement in the youth justice system, diminishes social and labour market integration, and creates a deep sense of social and political exclusion among those who live [there]” (Nichols & Braimoh, 2018, p. 162).

The institutional ethnographer Debra Brown (2006) explores the organization of the child protection system. Brown provides a critical investigation into how mothers involved in the child protection system are set up in ways that require them to follow a core set of competencies and pass “risk assessments” to fulfill the organizationally created criteria of a “good mother”. However, she found that these expectations were not always aligned with how the mothers

themselves would define “good mothering”. As these examples show, IE can be carried out in a multiplicity of settings and can explore institutional practices from the standpoint of whatever group the researcher is interested in.

Commonly, IE focuses on large scale institutions such as the healthcare system and on components of them that are engrained in the mainstream operations, such as nursing or paramedic work. Typical IE studies help us see how well-meaning people’s work in places like hospitals is distorted in relation to what the people they provide services for need because the workers are answerable to a larger system of institutional accountability processes. While the current study also focuses on healthcare, it is unique in that it shifts the focus to how people, namely those of the CAMPP team, find ways around larger systems, to run in different ways that meet the needs of people who are missed by others in the mainstream healthcare system.

While IE does not take people themselves as the object of analysis, it does focus on the work of people. This does not mean that we are not interested in people, we are, but it is the experiences of the people that are our starting point, not what we are *ultimately* interested in. What we are *ultimately* interested in is how people’s experiences are linked together, shape, and are shaped by these linkages. People’s experiences are a starting place and a resource in IE, but not the final analytic object (McCoy, 2008). We want to move beyond what any one person can see based on their experience and generate a wider understanding of how the social is created from people who connect up to one another.

What this study focuses on, based on the standpoint of individuals who are socially marginalized, is the wider organization and coordination of the services that the CAMPP team provides to this group. This study aims to make visible how the CAMPP team, a small,

relatively autonomous healthcare program, finds problems with the larger mainstream health system in its delivery of palliative care to people who are homeless or vulnerably housed and operates on the borders of the mainstream health system and the non-profit social services sector. This project examines how the team works with people who have not had a positive history getting help from the mainstream health services system, so they help navigate the resources available that span both health and social sectors. They struggle to operate because of the unstable funding environment that their work is embedded in and so they must shift and transform to both adapt to, but resist, mainstream discourses and approaches that are well-recognized and taken for granted.

That is, this IE takes a slightly different approach than IE studies that have come before it because the present project examines how the team identified a tension within existing healthcare system and this study investigates how the CAMPP team goes to work to address it. The current project looks at how the team coordinates their work, organizes it within the constraints of the systems that hold them accountable, and navigates the challenges associated with being a relatively self-directed healthcare team that operates differently from the mainstream healthcare system.

Accessing the Standpoint of CAMPP Clients

Despite its name, institutional ethnography is not a study of institutions per se (Smith, 2006, p.2). Instead, it is the mode by which we can make visible the happenings of an institution through mapping interactions and interfaces between real people (who make up the institution) in real time. For IE, the “institution” is different from how we may typically understand the term. For instance, a popular use of “institution” is described by Goffman (1961) as, “a social

establishment...buildings or plants in which activity of a particular kind regularly goes on” (p.3). This is distinct from the way in which Smith describes “institution”. McCoy (2008) writes, “an institution in IE refers to the way clusters of ruling relations [are] interconnected around a specific function, such as healthcare, child protection, or television news” (p.703). For IE, the use of the term “institution” is more about the positioning of it and how it is socially put together than it is the study *of* it as if it were a bricks and mortar establishment to be observed in its entirety. The importance of institutions in IE is to examine their happenings from the “ground up” rather than take the institution as a whole for granted. Institutional ethnographers are interested in the inner workings of the institution. IE aims to keep the object of study in the actions of real people and trace the web of interactions that serve to make up the pieces of the larger institution. Smith views an institution as a set of happenings that work together to shape experiences of people. Additionally, for IE, institutions are not restricted to one place like a hospital or a school and cannot be contained to one place since social relations by their very nature, exist translocally, and those translocal relations across space and time are the analytic object of IE.

In IE, we begin the investigation by locating a standpoint of a group of people in an institution. “[The analysis] begins with some issues, concerns, or problems that are real for people and that are situated in their relationships to an institutional order” (Smith, 2005, p. 32). In this study, the starting problem is the perceived inadequate provision of palliative care for people who are homeless or vulnerably housed. As mentioned in chapter two, individuals experiencing extreme poverty who are homeless often do not have access to appropriate care along the entire healthcare delivery spectrum up to and including end of life. These concerns

fueled the development of grassroots organizations which aim to bridge the gap between the people who require health services and the services they need but are not getting it.

IE has an inherent goal to advocate for a problem in the world. In this case, the problem is the difficulty hooking into the mainstream palliative services that people experiencing homelessness face because the system is ill-suited for their specific needs. This calls into question the notion of access for specific populations to mainstream healthcare because it is not just a matter of whether service is offered or denied, but whether a person can engage with it and whether it is delivered in ways that work for them. The standpoint that the current study takes is that of the homeless person facing a life-threatening condition who is experiencing this injustice. I investigate this problem from the standpoint of clients via the access point of exploring the work of the grassroots organization in Calgary, Alberta, Canada called CAMPP, the Community Allied Mobile Palliative Partnership.

An Emergent Design

Institutional ethnographic research does not call for a specific and detailed formula of its methods, although much planning is involved in carrying out a study of its type. Broadly speaking, IE follows a traditional research process in that it starts with a proposal, recruitment, data collection and then moves to analysis, write-up, and dissemination. However, the finer process details appear as the research progresses. DeVault and McCoy (2002) explain,

There is no one right way to conduct an IE investigation; rather, there is an analytic project that can be realized in diverse ways. IE investigations are rarely planned out fully in advance, identifying research sites, informants, texts to analyze, or even questions to pursue with informants...[T]he process of inquiry is rather like grabbing a ball of string,

finding a thread, and then pulling it out; that is why it is difficult in advance to specify exactly what the research will consist of. The researcher knows what she wants to explain, but only step by step does she know who she needs to interview, or what texts and discourses she needs to examine. (p.755)

As is typical with IE, in this project, I decided much of the research direction by choosing “threads” of investigation to pursue. When I began talking with people who were clients of the CAMPP team, a co-creation of the way forward began to develop. My research took this approach which followed a general plan including a starting place and an outline of how I predicted the research would proceed. While there were guiding research questions that broadly oriented my focus, the specific threads of interest emerged during the observations with the CAMPP team. As the data collection progressed, more threads of interest and questions emerged, and I went back and forth between the data and analysis to unravel a more complex and nuanced understanding of the work.

Methods

Engagement and Recruitment. I contacted the CAMPP program in January 2018 via email and informed them that I was interested in potentially studying their work for my dissertation project. The team’s lead physician invited me to ride along with them for a day to get a better idea of the team and how they operated and conducted their daily activities. While this instance was not a part of my data collection, the purpose of the ride-along was to meet with the team and introduce my interests and potential project while gaining a better understanding of the program. I met with the CAMPP team again in October 2018 to speak more about my project and ask them if they would be interested in being a part of my research project. We confirmed that the project

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would go ahead, and we made a tentative schedule of the research-related ride-along visits with the team where I would begin the observation stage of the research.

In IE, it is common for researchers to start by learning about the experiences of the people whose standpoint they are taking up for the study. In this study, I am orienting to the standpoint of the CAMPP clients. However, because of the nature of the CAMPP services, and the population they serve, it was impossible to start by talking with clients. I had to access clients through the CAMPP team because they had built the trust and rapport with their clients which is something that takes a long time to develop with the people they worked with. I did not have this same relationship with the clients and, furthermore, by nature of the study, I would not have known who the CAMPP clients were without asking the CAMPP team themselves. The clients consisted of any person who CAMPP identified as being one of their present clients. Potential participants were those people who I met during a previous ride along visit and who agreed to be contacted by me outside of CAMPP team members being present. It was made clear to clients when asking if I could contact them, that their response would in no way affect their relationship with CAMPP members or the services they received. Their involvement was entirely voluntary, and they could retract consent to be contacted or consent to participate at any time during the data collection process of this project. Once they agreed to be contacted, either by consenting after being asked by a CAMPP team member or by myself during a ride-along, I would try to reach them by telephone outside of a CAMPP visit. Method of contact was by phone and if they agreed to be contacted, I would call and re-introduce myself and the project and ask if they were still interested in participating in the research project via a face-to-face interview.

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Once clients agreed to be contacted, the CAMPP team member would pass along their contact information to me. We made it clear to the clients that agreeing to be contacted did not mean they were agreeing to take part in the interview. I scheduled interviews at locations of their choice. Some clients were difficult to reach given their precarious housing situations and some did not have access to their own telephones. Because some clients did not have their own phones, the contact information provided was often for a friend or for the front desk of where they were staying at the time, so the person answering was not always able to locate the client. I did not always receive a call back so would often have to call multiple times. After five attempts at contacting the client, I would stop and assume that this was a decline to participate in the study. I wanted to make sure I was not excluding difficult to reach clients by not trying hard enough to contact them, but I also did not want them to feel pressured or coerced. Therefore, I chose five attempts and at the fourth attempt, if I was able to leave a message, I stated that there would only be one final attempt. Once I reached the client, I would provide more information about the study and answer any questions they had. If they were interested, we set a date and location for the interview.

The service provider recruitment was like the client recruitment, but differed in that, after the interview, I asked service providers if there was anyone else they thought I should speak with and if so, would they connect me with them. Many of the service providers mentioned others they worked with who would have experiences relevant to this study. I also met many service providers when I was riding along with the CAMPP team and so for most of the people, during a ride along I would ask them if they would be interested in speaking with me either then or later. If they agreed, we would arrange a time to meet. Other times, members of the CAMPP team would provide me with the name of somebody and if their contact information was publicly

available, I would reach out via email or by phone and ask if they would be interested in speaking with me about the study. If their contact information was not available, a CAMPP team member would reach out first and ask if they would agree to be contacted. If they agreed, then we would schedule a time to talk and then a time to conduct the interview if they consented to participation.

Observations. The ride-along trips with the CAMPP team started in Fall of 2019 and continued until late winter of 2020. Data collection continued more informally after that as I began the analysis of the data and re-entered discussions with CAMPP members for clarification which occurred at multiple points as I was writing. The purpose of the observations was that I was orienting to what made up their work with clients, their work in the office, how they spoke with other service providers, their clients, and each other. I was interested in the sorts of things that were taken for granted in their day-to-day activities, including the language they used to refer to their work or work-related activities, slang, and the texts that they used in relation to their work. As Smith (2021) writes, “attending to the language as it comes to play in observations we make...shows us how the particularities of any actual work can be discovered as it articulates sequences of actual activities as local language practices” (p.76). It was by paying attention to these things that I could better understand how the CAMPP team members put their work together with and for their clients and how these institutionally embedded processes organized their work and the experiences of their clients via institutionally mandated sequences.

The observations helped me to know CAMPP’s work so that I could construct a map of the interactions and processes involved in caring for individuals who are homeless at the end of their lives. The observations ranged from two hours to seven hours at a time. The length of the

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observations depended on the judgement of the CAMPP members and whether they felt that my presence would interrupt their work with clients. I attended on Tuesdays most weeks, but occasionally attended other days of the week if they were engaging in novel work or had time to accommodate my presence. In total, I completed approximately 100 hours of observations with the CAMPP team, attending ride along visits, attending their meetings, and engaging with them after formal observations was completed; occasionally I was present during their phone calls with clients and other service providers. The observations involved various activities including traveling to meet with clients at shelters, hospitals, on the street, at clinics, at supportive living buildings, and many other locations. Occasionally, the activities were simply sitting in the office observing the team while they carried out their administrative tasks such as entering notes from the work they did with clients into their agency database or updating other files and filling out forms.

Throughout the observation phase, I wrote “reflective memos” and “descriptive field notes” (Emerson, Fretz & Shaw, 2011) which included my ongoing thoughts and insights, personal reactions and moods, as well as analytic in-process memos during and after the observations.

Written accounts of what I saw in the “field” are a necessary part of ethnographic research. Emerson et al. (2011) use the term “descriptive fieldnotes” to describe the process of capturing experiences and observations. They explain, “there is no one ‘natural’ or ‘correct’ way to write about what one observes...different descriptions of similar or even the same situations and events are both possible and valuable” (p.6). I remained aware that my observations and interpretations of them are a product of the environment I am in, my state of mind, feelings, and

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attention at the time, but remain credible and rigorous and can be read as an accurate account of the situation from my position as researcher. I kept detailed hand-written notes in a pocketbook that was easily concealable so my writing would not be distracting for the CAMPP team or their clients. Having a small notebook also helped when I had to carry it in my pocket if the environment was inappropriate for notetaking. When I finished my ride-along visits, I typed up my observations in a Microsoft Word document and saved the notes in a password protected file on my personal computer. I made a concerted effort to type them up soon after my ride-along visits, so the observations were “fresh” in my mind. I organized each observation note by including headings for different components of the ride-along. For example, I included a section where I would have “threads” and “hunches” for follow-up to ensure I was building my understanding and recalling questions I had in earlier observations.

Before each scheduled ride-along, the CAMPP team and I would partake in a negotiation to ensure that we (myself and CAMPP) were still being sensitive to the client’s needs and appropriateness of having a third party attend the visits.

I also took part in the everyday happenings of the CAMPP program service delivery by observing and being a part of the program physically and socially. In this way, I was a participant actor in the field with the purpose of gaining an intimate understanding of what went on in the environment. Emerson et al. (2011) explained that “immersion [of the researcher into the field] precludes conducting field research as a detached, passive observer; the field researcher can only get close to the lives of those studied by actively participating in their day-to-day affairs” (p.3). As an active observer, I was introduced to clients and service providers on the ride

along, spoke with people, and in some cases assisted the CAMPP team members in small tasks like passing items to them, navigating situations with clients, or holding doors open.

I engaged in a “participating in order to write” approach (Emerson et al., 2011, p.24) which brought “together the connections between writing, participating, and observing as a means of understanding another way of life” (p.23). Participating as an observer meant that I was not trying to be objective and separate from the environment that I was observing. Instead, I was very much a part of the environment and the interactions that were occurring. The first time I would meet a client or service provider during a ride-along, the CAMPP team, usually the CAMPP nurse or the health navigator introduced me and my role with the team. They would usually say something like, “This is Courtney, she is a researcher from the University of Calgary, and she is studying our work, do you mind if she observes us while we are here?” Most of the time this was met with affirmation and welcoming, but occasionally I was asked to stand outside if the client explicitly said they were uncomfortable with my presence or if the team members sensed that they did not want anyone else in the room.

As an active participant, I also became part of the interactions and in some cases during ride-alongs, I did my best to make myself useful in situations where there was an extra hand needed. On one occasion, we helped a client move into a new place and we were at a donation centre for furniture. I helped pick out furnishings for the client’s new home and helped load the van with furniture. These interactions helped establish rapport with clients and service providers and unintentionally helped initiate deeper conversations about client circumstances.

Interviews. The main aims of the interviews were to identify and track the social relations of how people come to access health services when they are very ill and experiencing

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extreme social marginality and how their care is organized. Following the direction of DeVault and McCoy (2006), I was curious to understand how people's lived experiences took shape within institutional relations of health services. To discover this, I needed to let the social relations appear through the conversations and not assume what they were prior to data collection. However, researchers always have their own experiences, and, in my case, I came with experience working in health and social services. Therefore, I came with "insider" knowledge and had to ensure that prior knowledge did not hinder my capturing of the details of the work that I was investigating. The prior experience in the field also helped with building rapport with the people that I was talking with. I understood and was familiar with some of the experiences the participants spoke of which grounded my knowledge, but I had to be cautious not to "sweep over" vital details that could easily be taken as common knowledge based on shared experience. It became an important part of the interview and observation process to keep checking in with myself that I was not "skipping over" pieces of the conversation based on my own assumptions or experiences within the health and social services systems and to let the people I was interviewing and observing explain to me or show me how their experiences came to be.

I was committed to navigating my way through the many alternative possibilities of which "threads" to follow to make deliberate choices to ask questions that helped explicate these institutional processes. I chose "analytic threads" to follow, since it is not the goal of IE to map the entirety of the social relations of an institution, but to identify, and make visible, subsets of ruling relations involving the activities of individuals that make up organizations and the discourses they (re)produce (Smith, 1987). These relations are organized to shape the experiences of individuals and that was the focus of my research. That is, one of the purposes of

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IE interviews is to explicate how people's lived experiences take shape within institutional processes (DeVault & McCoy, 2006, p.25) and this is what guided my process.

Interviewing to understand how people are embedded in, shaped by, and help shape institutional processes involves ensuring that the purpose of the interview is not to collect information about the individuals themselves. However, this is often unavoidable and can become inextricable with the information investigators are looking for since we are talking extensively about the happenings of people's lives. However, the analytic goal as McCoy (2006) advises is "to make visible the ways the institutional order creates the conditions of individual experience" (p.109). As the researcher, I did not extensively plan the interview questions ahead of time but came with a set of topics to explore and through listening to the descriptions of the informant's experience, we engaged in a dialogic conversation to "identify specific institutional sites, work processes, or discourses for further investigation." (p.109).

The discussants are expert knowers of their own experiences that we can learn from and by asking them questions about their relationship with the larger institution, the interview can elicit valuable information that they themselves may not be able to see outright. My goal was to use the information that I collected from the interviews and the observations to explore how the institutional relations go to work to not only inhibit some individuals from accessing adequate health services from the mainstream health system, but also to discover how this then translates into warranting the services of the CAMPP team and also how the relations shape and are shaped by the work of the CAMPP team.

I completed interviews with the CAMPP team members, people who received services from CAMPP, and people who worked adjacently to CAMPP as service providers in other

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organizations. I completed twenty-two interviews in total. Three of the interviews were with clients and 19 were with service providers including the CAMPP team members themselves. All the interviews were included in the data analysis, but not all the interviewees are represented in the selected quotes. All the interview data, however, contributed to the knowledge building and final product.

While most of the interviews were scheduled, one-on-one interviews, I often asked the CAMPP team members or others present clarifying questions about what they were doing and why to gain a detailed understanding of the work. I classified these as informal conversations, and they were conducted in addition to the one-on-one interviews. I spoke with CAMPP members one-on-one throughout the observation process and informally during the entire data collection process including during the write-up stage to clarify important pieces of information. I spoke many times with each of the CAMPP team members and sent them messages or called them to ask clarifying questions as they came up.

When I was speaking with CAMPP members and the service providers and administrators that worked adjacently to the CAMPP team, I was specifically looking for the actual work processes of the participants' work, if they were external to the CAMPP team, how their work connected up with CAMPP, how all respondents spoke about their work, and the concepts they used for work processes or work-related activities or experiences. I often started with the question, "Can you describe your work as it pertains to people experiencing homelessness who are living with life-limiting illness?" If I was speaking with administrators that were responsible for organizing funding or other "behind the scenes" activities related to the operations of CAMPP, I started the interview differently. I would often ask what their role was

in relation to the CAMPP program, and based on their answers, would follow threads of interest that pertained to how the CAMPP team was organized; all depending on what stage of the research I was in at the time of the interview. I probed for further explanation about any work-related concepts that the interviewees seemed to take for granted or the processes that they spoke about to understand how these things were pieced together. I also triangulated the descriptions and data provided in the interviews with other pieces of information including texts and/or observations of the phenomena they described. In this way, I built a map of how the work was organized.

The CAMPP team received agreement from five clients to be contacted. Unfortunately, one client died before I had a chance to contact him. Of the remaining four clients, three agreed to be interviewed. All interviews were meant to be in-person interviews, but due to a global pandemic that occurred part way through the data collection process, I submitted a modification to my ethics application to conduct telephone interviews instead to protect the health of everyone involved. I completed three in-person interviews with clients, three in-person interviews with service providers and 16 telephone interviews with service providers. All interviews were audio recorded and transcribed verbatim. All interviews were unstructured but guided by topics and probing questions. I provided the CAMPP team, interested service providers, and clients with information sheets if they wanted to learn more about the project. All interviewees read and signed consent forms prior to the interview.

When I spoke with clients, I was interested in how they described their own experiences as a client of the CAMPP and as a person in the world living with a life-limiting illness in a position where they are socially marginalized. I was interested in what they had to tell me about

how they managed their lives including their illness and any care that they received in relation to it. I was interested what it was like for them to live with the illness they had in the position they were in having little financial resources. I asked questions related to the types of circumstances that led them to interface with care workers including the CAMPP team. What came into view were specific tasks, processes, and activities that the CAMPP team engaged in that differed from typical interfaces that clients had within mainstream care delivery systems.

Reviewing Texts. I also paid close attention to the replicable texts that arose in my observations and interviews. Dorothy Smith and Susan Turner (2014) explain that texts “are material objects that carry messages...and are never separate from how they coordinate people’s doings. They must be conceived as occurring in definite actual settings of people’s everyday/every-night living.” (p.5). This quote highlights the material aspect of texts for institutional ethnography and how they show up in our lives and help link people up to one another. However, texts are not active on their own. As people, we activate them through writing them, reading them, and sharing them.

Because texts, when activated by individuals, coordinate people’s actions, the institutional ethnographic research process in this study included the presence of texts that I found or was alerted to in the ethnographic setting. Therefore, I collected documents such as referral forms, program reports, grant proposals, client intake sheets, and other relevant documents to better understand how the work of the CAMPP is organized. For example, I noted if the CAMPP program staff used assessment forms, handed out brochures, or used computer programs to keep track of clients. All of these are examples of textual formations that are a key part of the social processes involved with the CAMPP team’s work. Tracking texts allows us to

observe and make visible how individuals exchange knowledge in an institution and how people make processes and ideas replicable.

Analytic Approach

The analysis of the data began when I started observing the team. My observations guided the decisions to explore specific threads of interest. It is in this way that the data “builds on itself” as the project progresses. The purpose of an ethnography, as Atkinson (2017) writes, is to “reconstruct a given social world in conceptually rich ways that uncover the orderliness of everyday life, the skillful work of social actors...[Ethnographies] are complex accounts that reveal something of the complexity of the social world” (p.13). The aim of the current analysis is to help reconstruct portions of the work of the CAMPP team in a descriptive way that uses the collected pieces of data and analytically positions it in a way that warrants new perspectives around how that work is shaped institutionally.

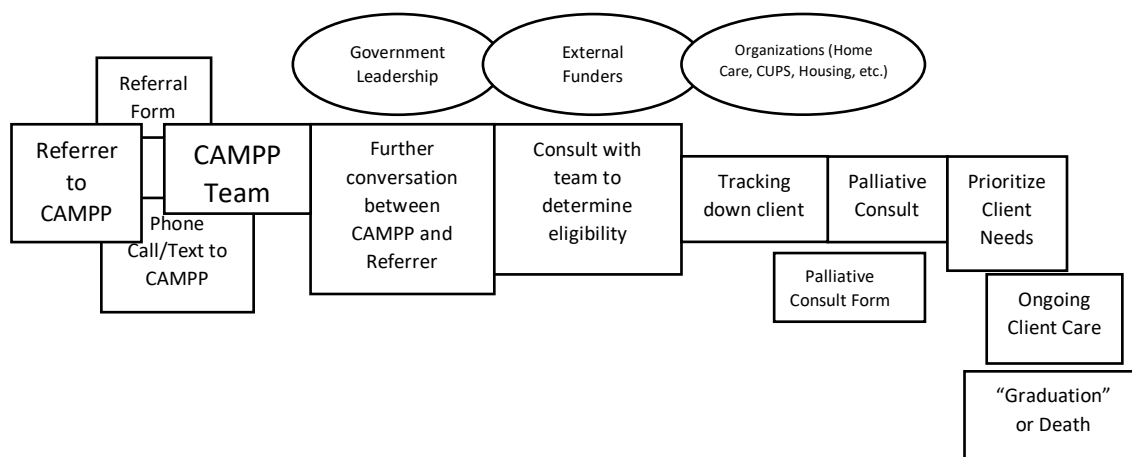
I wrote up the data as a compilation of ride along visits, interviews, and interactions with CAMPP, clients, and adjacent service providers. While I did most of my analysis manually, I also used NVIVO 12 Qualitative Data Analysis software to organize and index the data. As Rankin (2017) describes,

Indexing is a way of thinking that may help to avoid the common mistake of drifting toward ‘thematic analysis.’ The practice of indexing is a way to discover linked practices going on in society. It is a strategy that can be used to stay grounded in IE’s core materiality as opposed to developing themes and categories that are abstracted from the data and that leave the particularities behind. Indexing is a tool that can be used to cross-reference across work processes, people, and settings. (p.6).

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I started with observations and throughout the data collection period, I maintained close relations with the observation notes by reading and re-reading them, making notes where I noticed the data linking together. In this way, I followed threads of interest that I examined in deeper ways as the data collection and analysis progressed. These threads of interest also guided the questions I asked the interviewees. Beginning just before the interviews, I created a kind of process map (Figure 1) of the CAMPP team's work that visually demonstrated a broad level idea of how the CAMPP team operated and what external and related people interfaced with the work of the CAMPP team. A simplified version of the map is below.

Figure 1 - CAMPP General Process Map



While quite simple, this map helped me organize the interactions CAMPP had with those outside of their program as well as the sequences of action that occurred between them.

In IE research, mapping is a rigorous, data-based practice of tracing text-mediated work processes in ways that makes visible specific activities, texts used in them, and policies and discourses also at work. Many IE researchers use mapping as a helpful analytic tool and their maps vary in size, type, and level of detail. For example, Susan Turner (2001) is known in the

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IE literature for creating a mapping procedure that helps us reveal a visual depiction of relationships between local and translocal experiences of people and their work processes. In her study, she mapped the translocal work processes that produced a municipal land development decision in her neighbourhood. My mapping process was largely made of sticky notes posted to my wall which I could move around and draw links between to help me visualize the processes. I inserted pieces of information such as explanations of what went on at every step on a sticky note and put it in the proper position on the map. This also helped organize how I would write up the data. If I found that there was a piece of information but was unsure of where it fit, I would leave it off to the side and reposition it when things became clearer. This map helped me to visualize the larger picture of the CAMPP team's work without missing important pieces of analytical information.

IE is unlike other qualitative methods as it does not rely on a preconceived "theming" or "coding" process that the investigator engages in and must adhere to. Instead, it is a process of exploring topics or categories in the data that one notices and follows throughout the research process that are important to the work of the players and then mapping this work onto a broader institutional framework. While it is tempting as a researcher to try and capture as much institutional processes and information as possible, it is not the work of the institutional ethnographer to map an entire institution. Rather, the investigator must make choices about what pieces of the institution they should examine. Starting in the data, "zooming out" then back in and piecing things back together is how we start to understand the nuances of the social organization of the "institution". As Campbell states, "[T]he analysis begins in experience and returns to it, having explicated how the experience came to happen as it did" (Smith, 2006, p.92).

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In this project, I treated the data as the entry point into understanding the broader social relations of the institutional setting of the CAMPP team's work. Once I started to see threads of interest, I created an analytical category chart and started to "index" sections of my notes into these categories. I also did this with interview transcripts. Once I understood what my categories were (e.g., tracking referrals and use of the referral form, common language and concepts that the team and others use, funding and accountability related issues, etc.). I sorted through the notes and began drawing links between processes that I had not spotted before. This strategy helped me see things more clearly and ask myself more questions about work processes and concepts. This process is unlike theming as one would do in other types of ethnographic exploration. Instead, these categories were "buckets" that related to pieces of the data that would be of interest to an institutional ethnographer like the types of things that the participants are carrying out as work whether they identify it as such or not, or things that participants may take for granted in their work or their understanding of it. These categories also included pieces of data that illustrated specific work processes or common institutional language. I was not creating themes based on my assumptions of conceptual links – the links had to come from observable data. Indexing is a low-level way of organizing my data that is not interpretive coding. All the findings resulted in this level of organization before I was able to meaningfully draw links and relationships between the data chunks.

Throughout the data collection process, I wrote "ethnographic chunks" that were heavily descriptive of time, place, and context. They also illustrated interactions between people during a ride along. After these processes, I began writing up my analytical findings. Even throughout the writing, the analytic process continued as I identified areas that I had not previously

considered prior to the writing stage. The analytic process truly began at the outset of the data collection and continued through the writing stage.

I completed data collection once I no longer needed to check in with participants to verify aspects of the data. I would have liked to speak to more clients; however, based on the context at the time involving an emerging global pandemic, and the small number of individuals available for the study, I was unable to. Once I completed the data collection, all names and identifying pieces of information were changed or omitted to protect the identities and privacy of the participants. The CAMPP team and the organization that they are housed within, CUPS, are the only names in the project that are shared explicitly, although I changed the names of the CAMPP and CUPS team members to pseudonyms along with all other names in the study.

Research Ethics

I submitted my research ethics application in July 2019 to the Conjoint Faculties Research Ethics Board (CFREB) and the application was approved on October 4, 2019. While this approval was eventually granted, the process was delayed because of concerns raised by the ethics board about the vulnerability of my research participants. In this section, I will describe part of the ethics process as it pertained to my study and the disjunctures that were systemically produced during the research ethics application process. It is relevant to discuss this here for two reasons: first, it is part of the IE mode of research inquiry to pay attention to institutional processes that remove important context from people's "real life" situations, leaving people voiceless and disempowered, which happened during this application. Second, these disjunctures threatened the ability to conduct this research which aimed to improve the lives and

deaths of people experiencing homelessness who are very ill, potentially furthering the marginalization of this group.

During the ethics application process, I faced two significant challenges. First, my research involved people who were classified by the ethics board and the Tri-Council Policy Statement Regulations as “vulnerable” based on their status as homeless and/or vulnerably housed and experiencing life-limiting illness (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2018). Because of this, I was called to a full research ethics board meeting. At this meeting, I was questioned about two main things: how I was going to gain consent from the prospective research participants who were homeless and ill and, further, how I was going to assess the individuals’ “capacity for consent”.

In my original ethics application, I explained that, in my study, the people that the CAMPP team serves were not the focus of my study. While this group is present in my study, they are not the analytic focus of the project. This meant that I would obtain consent from the CAMPP team for conducting my observations as their *work* was my analytic focus. When it came to clients, however, the board identified the issue of *how* I would ask for permission to observe the work without CAMPP’s involvement. A concern from the board was that they did not want clients to feel coerced to participate in the study as they might feel that way if the CAMPP team was present when I asked for permission. The board voiced that the clients may be concerned about their ongoing care if they refused to participate. This was an understandable concern, however, I felt that their proposed solution was problematic. The board requested that I

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observe the CAMPP team without documenting anything about clients, positioning me in an impossible scenario.

We understand that you want to follow the CAMPP staff as they are interacting with clients, and that you are not planning to ask for consent from the clients initially. As we discussed, we should be able to approve this, however we do need to emphasize that you cannot make any observations on the clients themselves without full informed consent from the clients. So, the observations at that point would only include the CAMPP staff. Before you make any observations of clients, you will need to get informed consent from them individually [without the presence of CAMPP]. – Email from CFREB Analyst 2019

The problem with their request was that I could not reasonably conduct my observations, imagining that the CAMPP was working by themselves when what they *do* is work with clients. It did not make sense to keep their clients out of my data, and it would have been unreasonable to document the CAMPP team doing their work as if they were in rooms talking to themselves. Additionally, while I acknowledged and agreed that client consent was needed and important to carry out the research, based on the board's expectations, it would not work to do this without the CAMPP team being involved at all. Based on the type of work the program does, and why they do it, it was not be feasible to reach clients ahead of time, without the team, to ask if it would be okay if I attended the visit.

The CAMPP team works exceedingly long and hard to build relationships with their clients, which I did not have at the outset of my research. I could not reasonably or respectfully expect clients to speak with me about their very personal experiences with healthcare without the

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relationship with the CAMPP staff there to facilitate the meeting. Therefore, the only way it would work is if I attended the visit and asked for permission at the outset and if the client declined, I would remove myself from the visit and wait in the car. The board eventually agreed to the following:

The focus of the observations is on the work that the CAMPP team provides and not the clients or their experiences. I will be taking notes on the work of the CAMPP team. I will not be collecting any personal information about the clients. During the ride-along observations, I will necessarily see the CAMPP staff work with patients and interact with other professionals while doing their jobs. The following protocol with respect to informing patients about the research is similar to one used in a previous study with paramedics by Michael Corman, which was advised by Emergency Medical Services (EMS). I will rely on the professionals, in this case, the CAMPP team, to use their discretion to determine, on a case-by-case basis, when the researcher should stay well back, out of ear/eyeshot, and when it is appropriate for the researcher to approach with the team. Unless the situation is an emergency, the usual procedure will be that in cases where the CAMPP team allow me to approach the client together with them, they will introduce me as a researcher who is studying their work and ask the client if it is okay if I am there while the team meets with them. If the client affirms my presence, I will stay. If they do not, then I will leave the location and wait for a CAMPP member to let me know they are finished so I can meet them at their next location. In asking clients to accept or decline my presence, it will be made very clear that their decision will in no way influence the care the clients receive from CAMPP. – Excerpt from Approved CFREB Application 2019.

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The second issue that came up after we agreed on this solution to gaining consent to be present in the observations when CAMPP was working with clients, was the board's concern with determining "capacity to consent" of participants. The wording that the board put forward to me was,

It will be important to have an independent assessment of capacity to consent for all clients. This assessment should be conducted by someone who is qualified to conduct it but is not a participant in your study. Please let us know how you plan to assess capacity to consent in your revised application. – Email from CFREB Analyst 2019.

The board's concern about "capacity to consent" was based on the overrepresentation of "mental and cognitive challenges" in homeless populations. While the overrepresentation may be true, in my view, questioning the "capacity to consent" based on homelessness is unjustified. While it is important to stay cognizant of who one is interviewing, the state they are in, and whether or not they are fully informed of the consequences and benefits of participating in the research, assuming insufficient capacity based on whether or not they have a home, and/or that one has some kind of mental health issue severe enough to deteriorate their capacity to consent to speaking with a researcher is problematic given that this population is already stigmatized based on their social position. The assumption should be that they have capacity, just as we would assume for any other adult population, unless they otherwise indicate differently. Assuming that individuals without stable shelter would be less competent because mental illness is overrepresented in this population greatly underestimates and widely overgeneralizes a large and heterogeneous population's abilities. There are many individuals with mental health issues that would be absolutely capable of consenting to research. In fact, I would go as far to say that

positing that a researcher should expect decreased decision-making capacity and therefore implement a tool or enlist an outside professional to determine decision-making capacity of the participant based on their housing status and assumption of mental illness (without knowing anything about the type of illness), but who is otherwise living as an independent adult (who has been able to consent to care from the CAMPP and presumably other service providers), reifies and reinforces social stigmatization and marginalization, and further undermines the goal of “protecting” the individuals that the said mandate was put in place for.

After numerous drafts and discussions, the finalized wording that the ethics board approved stated that,

All participants are presumed to have the capacity to consent as per broadly shared principles of informed consent. People will not be assumed to lack capacity because of their [homeless] status or appearance. However, it is possible that, when I meet with a client for a planned interview, I may observe signs that the client is at that moment severely intoxicated or disoriented for some reason. In that case, during the informed consent process, I will ask a short series of questions to help determine capacity to understand and agree to participate in the research. These questions have been derived from a template created by researchers at the University of West Virginia. This form will be included with the consent form of the participant when storing the documents. If the participant is deemed unable to consent, and they do not have a surrogate decision maker, then I will not include the individual in the research but will speak briefly with them and not outright reject them, but simply not use their data or proceed with the formality of the interview. – Excerpt from Approved CFREB Application 2019.

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It is notable that I was never even close to compelled to use the University of West Virginia tool in any of my interactions with clients.

It appeared in this case that the procedures in place for the ethics board to ask questions about consent and care are often based on populations that are different than those involved in my study. It is important for boards to ensure the safety of participants involved and, of course, to be diligent in ensuring that people are protected from investigations that may exploit or harm them. However, the process in place that existed for *other* research projects did not fit mine and further, posed potential harm toward the population they aimed to protect.

These are some of the challenges that I came up against in this project because of the population involved in the study. I found that using IE in a research ethics process that was not designed to work with studies of this type complicated the application process because the people working within the system did not recognize the analytic object of my study. This delayed the study as we went back and forth trying to fit my wording to the pre-set template that asks questions in such a way that makes it difficult to explain the study in the way it is intended. Importantly, I found that this misalignment also risked undermining the interests of the population in question. The CAMPP team spends vast amounts of time and energy building relationships with their clients and for a researcher to request “access” to informants’ personal lives when they have experienced trauma at the hand of large institutions before, in large part the justification for the CAMPP work to begin with, without a pre-existing relationship or someone they trust to introduce them, is disrespectful and potentially harmful. It would be unethical to attempt to contact individuals without having the support and introductions from the CAMPP team.

Second, and most importantly, the research ethics process upheld assumptions about the potential decision-making capacity of only the portion of the population in the study who were not professionals. That is, I was not asked to assess the capacity to consent of the service providers; only those who were clients of said providers. While mental and cognitive health challenges may be overrepresented in this client population, it does not predetermine that the individuals in my study should be questioned about their capacity to consent. This was further reinforced when none of the individuals I proposed to interview warranted my use of the University of West Virginia capacity to consent tool. This concern about homeless individuals is stereotypical and calls into question their abilities as adults to participate in a research study. This is obviously problematic because it, at worst, could prevent meaningful research and reify stigmatization, and at best delay research that could be used to inform and improve the end-of-life care situations of this group.

The research ethics board members understandably, and for important reasons, act as gatekeepers to the research process. While it is imperative to hold researchers to account and ensure the protection of participants in the research, this must be balanced with the recognition that people also have the right to make decisions for themselves whether they are in a group that is overrepresented by challenges or not. Too much heavy-handed gatekeeping on behalf of people that are viewed as vulnerable and potentially incompetent is paternalistic, subordinating individuals by constraining them under the guise of "protection". This can drastically delay or prevent important research from taking place that serves to improve the conditions of the people they are trying to protect. The ethics board's institutionally embedded process upheld preconceived models for understanding research that did not match what I was proposing and held assumptions about the population that were, in my estimation, authoritarian and unjustified.

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I feel that discussing the issues that came up during the research ethics application process and their implications is important to inform future board members, researchers, and other interested parties about the consequences and risks that could come from their own stated intention of preventing risk.

Conclusion

In this chapter, I provided a summary of the CAMPP team and a description of the how the current research takes up the standpoint of clients. I also outlined the guiding research questions informing the project, detailed my investigation approach to the CAMPP's work, described my data collection methods, discussed my analytic approach and my challenges and experiences going through the research ethics process. In the next chapter, I move to the first of four chapters outlining the research findings.

Chapter Four: What Works, What Matters, And What Doesn't: Accounts of Clients as Recipients of Healthcare

Introduction

Charles is a palliative physician in Calgary who developed the CAMPP team. He recognized that many of his patients who were homeless or vulnerably housed did not get the care they needed via the mainstream health system. He noticed that this gap in care existed because the help that this group needed did not fit with the existing healthcare model. He observed that the current services were designed in ways that either did not account for the unique circumstances of this group, or outright excluded them for not being able to meet the expectations of the providers within the care system (e.g., regularly attending appointments on time, abstaining from substances during hospital visits, having familial supports to rely on, etc.). Charles and the colleagues he consulted recognized that navigating mainstream health services is difficult for people who are homeless or vulnerably housed, in part because many reported having strained relationships with healthcare providers and barriers to connecting with health services.

Typical barriers that people served by the CAMPP team experience include transportation to and from medical appointments, fear of judgement from healthcare providers, lack of coverage for medications, no family doctor, lack of social supports, among many others. People often come to know about the CAMPP team through a service provider either at the hospital or from a social services community programs referral. More discussion about this process comes later in the thesis.

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The intent of this chapter is to ground later discussions by beginning from the experiences of three people who are CAMPP clients. In their own way, each person tells of their experiences negotiating interactions with the healthcare system as they provide accounts of their experiences working with the team. The interviews provide three distinct accounts that help us learn what it means to be a person who requires the support of the CAMPP team. The focus in this chapter is on the organization of healthcare (both mainstream healthcare and CAMPP services) for people with life-limiting illnesses as viewed from the standpoint of people who are homeless or vulnerably housed and living in poverty. As a reminder, “the notion of ‘standpoint’ anchors the research in the relevancies of a particular group” (DeVault & McCoy, 2006, p. 17). By taking this lens, the researcher’s analytic focus is not directed toward the interviewees as objects of inquiry whose meanings and actions are to be explained, but on the institutional organization of these experiences. Further, one of the purposes of IE interviews and what taking the “standpoint” of clients does is help “explicate how people’s lived experiences take shape within institutional processes” (DeVault & McCoy, 2006, p.25).

In this chapter, the individual accounts offer us the knowledge of people’s experiences which help us see the kind of work that is required of them, how they become reluctantly pulled into relying on the health system, how the mainstream health system is set up in ways that create challenges and barriers for them, and what services they find helpful and useful to them. A main analytic goal of this chapter is to “make visible the ways the institutional order creates the conditions of individual experience” (McCoy, 2006, p. 109) and this will be illustrated through accounts of how these individuals engage in very specific types of work to survive and will introduce us to the specific ways of working that the CAMPP team engages in to support them.

First, I reintroduce the term “work” as it is meant to be used in this context. For this project, “work” is used in the same way Dorothy Smith (2005) uses it to refer to “anything that takes up time, uses effort, and is done with intent” (p. 229). It is meant to orient the reader to what people are doing as they participate in institutional processes and can also encompass activities that are not hooked into institutional processes. “Work” is widely used in the IE literature as a metaphor directing our attention to everyday practices that people engage in that demonstrate what relations their labour produces (Bisaillon, 2012). When we think about work in this way, we are orienting ourselves to activities that people themselves may not normally think of as work because of how typical they are to their daily lives and practices. However, a key task of the IE researcher is to observe what study participants may view as taken-for-granted and describe it in relation to the activities of the people they are connected with and how their efforts produce or activate something in a sequence of processes within a larger system of activity.

For the clients in this chapter, we see that they engage in a type of work like that which is explained by Smith, Mykhalovskiy and Weatherbee (2006) as “lifework”. Smith et al. (2006) describe the work that goes into being a person with HIV/AIDS and how people who are HIV positive or who have AIDS have to radically revise their lives and expectations in ways that force them to live differently. The authors explain that the way that these individuals engage in a process of organizing and reorganizing their everyday lives under conditions of their disease can be viewed as work. For instance, by nature of having the illness, these individuals are pushed to commit to ongoing participation in the healthcare system to extend their lives (p. 167).

Furthermore, Smith et al. (2006) state that people with HIV/AIDS put much time, thought, and energy into their daily living, navigating multiple intersecting systems. This

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“lifework” is aptly named as it is something that their lives depend upon. We will see in the coming accounts how CAMPP clients regularly engage in similar acts of “lifework” to sustain their lives. This work involves not just the work it takes coordinating with healthcare services, but also the work that they do daily including, but not limited to, finding shelter, trying to find a place to tend to their hygiene, communicating with care providers, managing appointments and medication, locating food, finding transportation, and keeping safe from violence and the elements.

Like Smith et al.'s (2006) research participants, people who are both very ill and homeless/vulnerably housed are pulled into a particularly demanding kind of work which is not just practically complicated given their life circumstances, but for many, is also emotionally stressful because it involves repeated contact with medical settings in which they have had prior bad experiences. People who are homeless often are assumed to have histories of using substances. There is an associated stigma with people who use drugs in our society and that permeates the health system, making it difficult for this population to seek medical care. As McMahon (2009) states in her article, people who do not have homes and who are assumed to use substances are often deemed by many services as “hard to engage”. If people do seek care and are people who use drugs, this can complicate medical care because regulatory requirements about opioid use, for instance, may not fit the needs of people with histories of substance use, who might require higher doses due to higher tolerance (McNeil & Guirguis-Younger, 2011). Because this population has unique medical needs that also include frequent medical visits, hospitalizations, medication fills, medical equipment, and managing treatment regimens, they must take part in other forms of work to sustain their lives. This work involves physical,

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organizational, emotional, and interactive work, and is provoked by institutional processes that they are hooked into.

It is important to consider that individuals do not engage in this work seamlessly but that they are in very painful situations which can push them to resist this work. That is, there is a limitation to the notion of work in that we can risk overemphasizing rational and purposive action on the part of individuals and underestimate the toll that physical and emotionally difficult circumstances can have to prevent this work from occurring. For example, people in these situations may feel panicked about seeing a doctor if they have had prior bad experiences. Bad experiences may have caused them to avoid the situation or lash out in emotional distress. It is because of these specific instances that we must also understand the broader experiences of people in these circumstances more generally. By using both the concepts of work and experience to frame our understanding, we can account for the context of people's lives that help us understand the myriad situations they must navigate, react to, and get support for because of being very ill and homeless/vulnerably housed.

I met with Rowan, Harriet, and Chapa in their homes, at their request. All participants had faced homelessness when they encountered the CAMPP team, but at the time of the interview were living in a form of subsidized housing. All had severe, long-term, life-limiting illnesses and had been CAMPP clients for at least one year or more. While they had these things in common, they also had unique circumstances that positioned them differently in relation to the health system. This created distinct challenges for them depending on their situations, resulting in warranting the CAMPP team's unique approach to care.

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Two of the three interviews were similar to what one might expect a typical day-to-day conversation to look like: two people talking over a hot drink in chairs facing one another. These interviews involved sit-down conversations where the participants talked about their experiences and lives. However, the other interview, the one I start this chapter with, unfolded differently. This interview started off typically then developed into an urgent occasion of *doing* “lifework”, making dramatically visible the precarity of this person’s connections to what they needed to survive as well as the importance of the work that the CAMPP team takes up in helping to link their clients to critical resources.

The individual accounts in this chapter will demonstrate how clients must navigate the many intersecting processes that exist across various institutions (i.e., healthcare system, social services system, and private companies) and how this translates into work, concerns, needs, issues, and preferences related to their care. The aim of this section is to ground later chapters that focus on the work of the CAMPP team within the knowledge of the people who are marginally positioned in relation to the broader health system. This section orients readers to three individual contexts that show how CAMPP services come to be needed and how they are viewed by some of their clients.

Rowan’s Account: “I Can’t Afford to Breathe”

Our interview took place in Rowan’s apartment in the early afternoon of a sunny but frigid winter day. I walked up the stairs to the third floor and down a dimly lit hall to a red door on my right. The door was held open by a small garbage can. I could hear a television playing inside. I approached the door and I knocked gently. I heard the person inside respond by saying “hello?” I asked for Rowan, and he asked me to come in. He was sitting on the edge of his bed,

and he looked over his shoulder and waved me in. I had met Rowan twice before during my ride-along visits with a CAMPP team member. I re-introduced myself just in case and he nodded and said "yes, yes, I remember." He slowly stood up and told me that I could sit on the chair on the opposite side of the room near the window. The suite was a small unit that consisted of a bathroom on the right side when you walk in, a small coat rack on the left-hand side, a small kitchenette further down across from a single-sized bed. The room had a large window fitted with dark orange curtains and there was a small television playing in the background. There was not much space to move around the room as Rowan's items took up much of the space. There were clothes, plastic bags, empty food boxes, and other items strewn about the floor and pushed up against the baseboards. I walked over to the chair to have a seat. I pulled out my notepad and audio recorder and placed my bag on the floor beside me.

I knew from my earlier visits with the CAMPP team that Rowan was a 70-year-old man who had a severe chronic respiratory illness. He was very friendly with a low and raspy voice that I assumed was a result of his medical condition. Rowan was connected to an oxygen tank that was secured to a dark blue walker with black wheels and handle grips. There was a long, thin, transparent tube that draped down beside the tank to the floor and up around his neck and head and into his nose. Part of the tube dragged on the floor beside Rowan, and I found myself worried that he would step on it or trip over it. He must have noticed my wary face looking down at the floor at his tube because as I was doing so, he said, "It's okay, it's pretty sturdy." Rowan had two oxygen machines: a larger one and a chargeable portable one. He was connected to the portable one because he found it easier to get around. The larger machine was for when he slept so he could charge the smaller machine. Rowan sat on the edge of his bed across from me and asked, "Shall we start?"

Courtney: So, how did you come to know about CAMPP and work with Lee and Stephen?

Rowan: Before I lived here, I was in the hospital and staying at the local shelter, when I came here. Before that, I was in Saskatchewan for about 10 years...A worker helped me get housing from the hospital then connected me up to Steve. I was in the hospital and a worker met me there, if I remember correctly, and then eventually put me in touch with Steve. She introduced me to Steve.

We spoke for a few minutes about how Rowan was introduced to the CAMPP team, and he quickly moved into talking about some struggles he was having that he was seeking support for from the team. He previously had his oxygen tanks removed by the vender, and a recent phone call had him worried.

Rowan: I was taken off oxygen 3-4 months ago and that put me in the hospital for 10 days. I called Steve yesterday because I got a weird phone call from the oxygen company, so Steve is phoning them for me. I have COPD, that is cardio-obstructive pulmonary disease, a combination of emphysema and bronchitis. I have had it for quite a while, and I have been on oxygen for about 3 years. Ever since I came here, well no, it was when I was in the hospital, and I got home here I needed oxygen and they came and took it all out so I ended up back in the hospital because they called an ambulance, and I couldn't breathe. They never told me they were gonna come and take my oxygen, I came home and no oxygen. They said it wasn't paid for; it was freaky.

Courtney: What was the process of getting it back?

Rowan: I had to go to the hospital again. You know what an ambulance is worth?

\$385.00 one way. I have [health insurance coverage], but it sure costs the system.

There are nurses and orderlies and doctors and they gotta be paid, they are not working on welfare. What does the nurses make? Probably 50 bucks or better 100 bucks an hour.

As the conversation unfolded, I came to understand the process through which Rowan's oxygen supply was paid for and maintained. The process involved periodic tests and authorizations from his doctor, and if those did not happen in time to get submitted to the government to ensure continuous payment to the private oxygen supplier, the device was repossessed. Going to the emergency department was the quickest way for Rowan to get the test and authorization, and get his oxygen back, but as he pointed out, the cost to the healthcare system was high, which raised the question of whether a more forgiving and flexible process might be of benefit not only to Rowan but to the system.

Rowan: Yeah, it doesn't cost me, but I have to pay for my meds. I am not on AISH [Assured Income for the Severely Handicapped is a government subsidized program providing monetary benefits for people who are prevented from supporting themselves financially based on a handicap or disability] because I am 70 but [health insurance] pays some and it pays a bit but I gotta put out money each month. I just paid a big bill at the pharmacy. The last bill was \$179.00 and because I don't have much money right now 'til I get paid, I gotta wait until I get my old age pension

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around the 27th or 28th. That is still two weeks away. Today's the 11th. So, a couple weeks yet.

Because of Rowan's age, he is on a provincial supplemental health insurance plan for people over the age of 65. Because of the way our "universal" health insurance system is set up, this means that he pays up to 30% of each prescription up to a maximum of \$25.00 per medication and the rest is paid for by the government. He pays the difference at the pharmacy. He finds it difficult to keep up with these payments given that he is on several expensive medications and a limited income. A challenge is that the insurance coverage for the oxygen expires intermittently and requires the client to continually update the insurer with their oxygen levels to secure their eligibility. Normally, this is managed through appointments with Rowan's respirologist who takes his oxygen levels which are then provided to the health insurance program which, depending on if he meets the requirements, approves the cost of the oxygen machines, and sends the funds to the oxygen vendor. Rowan explained to me that it was hard to keep track of all his medical needs like appointments and medications and this was what Steve from the CAMPP team often helped him with. I asked him how he managed his medications, and he said that the pharmacy provided him with a bubble pack that had all the week's meds sorted and that all he had to do was go to the appropriate day and time and pop the bubble and take them. What he did struggle with, however, was his oxygen.

Rowan: Oxygen is a challenge. My challenge is to keep breathing [coughs] or I will be in trouble.

When he mentioned that he also struggled with keeping track of his medical necessities, he was not just *describing* his challenges with his oxygen in the past; rather, he was actively navigating

them as we were talking. He was also talking about other appointments and responsibilities he had coming up, thinking ahead to errands he needed to run, drawing on his knowledge of the kinds of challenges and help available to him carry out these tasks.

Rowan: Do you think I should phone them again? Because I need [the oxygen] if I am going to the Safeway or Walmart. I can't walk there, but I hit the food bank and it's right next door, and they are really helpful, and they will bring it right over for me because I am pushing oxygen. They help me quite a bit, so I don't have to pick up the heavy canned foods. They carry that for me. If I need to get to and from medical appointments, then Steve helps me and will meet me here and go with me in the cab. It is hard to keep track of all the appointments. If I don't write it down, I will forget it. I need to get my income tax done on the 16th and I have to go to the wellness centre.

In asking me, the researcher, if he should phone the oxygen vendor back after he received the strange phone call, he was actively engaged in the work of pursuing outside support.

I took note that by asking the question, he was involved in the work of navigating how to move forward with his problem. Before I responded, he spoke about how oxygen helped him when he went to the grocery store, but that he sometimes circumvented this need by accessing the conveniently located food bank next door. The people working at the food bank helped him by bringing food to him since he was "pushing oxygen". When I clarified what "pushing oxygen" meant, he said that he had to physically push the wheeled oxygen tank around everywhere he went and was therefore limited in what else he could carry. From my experience working in social services and having familial experience accessing food bank support in my

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childhood, I knew that the food bank did not always have food available and sometimes the selection was limited in nutritional value. I recall an instance when I was a child when we accessed the food bank and received thirteen packages of pudding mix but no ingredients to make the pudding. Relying on the food bank meant it was likely that, on occasion, Rowan had to also access grocery stores. However, he needs help with transportation to and from the store and with carrying his groceries.

Rowan also explained how he had trouble keeping track of his appointments and that he needed to write things down. Later in our conversation, he asked me for help in looking for a phone number which he had written on a torn off corner of a cigarette carton. The room had many papers and items laid about on the tables and floors and so it was quite challenging to locate a tiny white piece of cardboard with a scribbled down phone number on it. I started to see how difficult it was for him to keep track of the many people that he interfaced with regularly and depended on to manage his medical and social conditions.

To our surprise, as we were talking, someone knocked on the door. It was a representative from the oxygen vendor company. I saw Rowan's mood change from upbeat and smiling to worried and concerned. Rowan reluctantly invited the oxygen vendor inside.

Rowan: [to the oxygen vendor] I need both of these machines. I just went outside for 10-15 minutes, and I had to come back in just to breathe. So, I need the big one, but I need the small one too if I need to go shopping, I wouldn't last to make it to Safeway or Walmart even by taxi...you can't just take them. Do you want me to phone your company?

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Vendor Representative: Yes, you should phone them then. Do you have the number?

Rowan: Yes. [sighs] (Makes call to oxygen company)

As Rowan was making the call, I turned to the vendor representative and asked him what was going on. He explained to me that Rowan needed to go to the hospital to get a blood test because he did not qualify for government-funded oxygen anymore and that he needed the blood test to qualify. He told me that he needed to take both of Rowan's machines away because they were no longer paid for. During this conversation, I heard Rowan on the phone with the oxygen company,

Rowan: Why? Why didn't they forewarn me? Who told me what? They are gonna try and change that, my worker is going to arrange this, listen I cannot go without oxygen. I go outside for 15 minutes, and I can barely breathe! What are they gonna do? Take my machine away? I can't pay today; I don't get paid until the end of March. I've got about \$58.00 in the bank. So, I gotta go without? Can I keep the small one? Well then why did you quote me yesterday at \$275.00? Well, that is very nice but ya see, I am in a dilemma here. I don't get paid for two weeks...why didn't they tell me that? So, you want me to have to go back to the hospital? I don't want to have to go back to the hospital!

Although Rowan explained to the person on the phone from the company that he did not have the funds to pay for the machines and would not have them for two weeks, they were unable to negotiate with him since their professional obligation (both the representative who was present and the person on the phone) was to secure payment for the tanks or remove the tanks, not

accommodate Rowan's funding timelines. This was not an expense that he had budgeted for as he normally had this cost covered through publicly delivered health insurance. He attempted to negotiate with the vendor to see if he could keep only one of the machines, but they refused to allow it.

Vendor Representative: It is unfortunate that this happens, but [pause] it happens.

Rowan's physical and social living conditions made it extremely difficult and sometimes impossible to meet the expectations of each of the interfacing institutional work processes of the multiple people representing organizations. His relationship with one system was dependent on the other and he became stuck in between them without the power to make decisions about his own health. He attempted to negotiate with the vendor representative and the person on the phone to meet his medical needs, but he did not have the money to satisfy the request of the vendor and he was unable to obtain the money for the oxygen from the government program because he did not have updated respirologist tests that would determine his eligibility for government subsidy. Rowan's next respirologist appointment was in two weeks and so for the next two weeks, he did not have access to funds to cover the cost of the oxygen machines nor did he have updated tests to confirm his eligibility for coverage.

Rowan expressed difficulty in managing his appointments and the expectations of the various professionals that gatekept his access to the technology that he required to breathe. He attempted to track his appointments by writing things down but had a challenging time keeping track of where he placed his notes. He mentioned that he called Steve when these things happened but, in the case of the respirologist, he did not foresee that he would require extra support since he was sure he had it written down. Since he missed the appointment, Steve helped

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Rowan reschedule the appointment and agreed that he would attend the next appointment with him.

Rowan: Steve is coming with me to my respirologist appointment in two weeks in a cab and I have \$58.00 to my name for two more weeks until I get paid and so if they take my oxygen, I can't afford to breathe.

The missed appointment resulted in the rescheduling of the appointment which activated a sequence of processes that resulted in more challenges for Rowan. Rowan relied heavily on a device that aided him with oxygen flow, and the encounter with him illustrated a regular interface with multiple institutions: the healthcare system, a government benefit program, and the system of private oxygen vendors. Each institution had their own standards, procedures, and processes as their priorities that Rowan was expected to navigate. He was also expected to be knowledgeable and comply with the interests of the institutions regardless of whether he was familiar with them or how they worked. As a patient (of the health system), a client (of the social program), and a consumer (of the vendor), he juggled each role and worked to find what he would deem a positive outcome in his best interest: the ability to keep his oxygen.

On the day of our interview, however, the need for his oxygen payment was imminent and after talking to the oxygen company and not reaching an agreement where he could keep either tank, he had to problem-solve. Rowan asked me to call Steve from the CAMPP team on his behalf because his voice was "running out" due to his respiratory illness. I called Steve and he told me that he would start "calling around" to help solve the problem in a way that did not involve Rowan going back to the hospital or losing his oxygen. After a few minutes, Steve informed me that the vendor would leave the smaller tank, but for the time being, would have to

confiscate the larger tank. Rowan was dismayed since the smaller tank did not hold a battery charge for very long, but he was relieved that he would have access to oxygen and that, for the time being, he would not have to return to the hospital.

This interview was unique in that it had a mix of the typical interview format where a researcher and a participant discussed various topics that the participant knew about. However, the interview was interrupted by real-time events that made visible the work processes that interfered with the daily happenings of Rowan's life which activated the need for outside support in managing his medical needs.

Rowan's respiratory illness embedded him within multiple work processes originating in different institutions. Each institution's processes were activated through Rowan despite Rowan's social and physical marginality which positioned him precariously to manage the competing interests on his own. Rowan did not want to rely on the system's embedded default "fix" of having to go to the hospital for immediate blood tests which would gain him approval sooner, because this would be physically arduous for him and extremely costly to the health system. Instead, he worked to seek support from others including from Steve and me to navigate the various systems and to ensure that his medical needs were met.

Harriet's Account: "Because We Were Homeless, We Were Treated So Badly"

Harriet and I had met several times before our interview when I attended ride-alongs with the CAMPP team. Because of this, I picked up what I knew to be her and her husband's preferred order from Tim Horton's. When I arrived, she extended her arms to greet me with a hug and apologized that she could not stand up because her pain was particularly bad that day. I thanked her for seeing me despite her pain. Harriet wore a glowing smile, and her chocolate

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brown hair was styled atop her head in a loose bun. She was wearing long-sleeved sweater and sweatpants with slippers on her feet as her legs dangled off the side of the bed a few inches from the floor. She is not a particularly short person, but I noticed that the bed she had in her room was taller than a typical bed and later found out that it was a bed that helped her get in and out via remote control. She explained to me that a bed like this was necessary for her due to the pain that she experiences from her illness.

Her husband was home when I arrived; she asked me to wait to start the interview until after he left as he was just gathering a few items before going to the store. Her husband walked over to give her medications and explained to me that he always made sure she had her meds, but that it could get tricky because so many of the pills “look alike”. She held out her hand for the medications and said, “He takes good care of me”. They smiled and exchanged a kiss and then he left the apartment. I was struck by the comment her husband made about the medications “looking alike” as I recalled an earlier ride-along where Steve supported Harriet with organizing her medications. In this instance, Steve selected certain pills out of their bottles and placed them in a container with the first letter of the day of the week on it. He then took another pill and broke it in half and placed it in the same container. He held a few of the bottles up close to his face to read the words on the side and placed them back down without taking a pill out. Once he was done, he explained to Harriet what he had done and when to take the pills.

Harriet explained to me that she had just moved into this suite and was previously homeless in Calgary for many years. She stated that she was first introduced to the CAMPP team because a hospital staff member connected her with the team and Lee, the nurse coordinator from the CAMPP team, came shortly thereafter to meet her.

Courtney: I know we have spoken a bit about CAMPP before, but can we start with the story of how you met them?

Harriet: I think the hospital reached out to CAMPP for me because I was dying. I was in the hospital, and I was dying, you know. I was near death. So, they reached out to Lee, and he came to see me at the hospital...I was dying, and I was homeless. He was lovely, and I am telling you, Courtney, after that everything just started to add up.

Harriet explained that at the time of meeting the CAMPP team, she did not want to seek medical care even though she knew she needed it, because she had a negative history with the mainstream health system. Harriet felt that when she encountered health professionals, they often undermined her trust by the things they would say to her or by their actions towards her. She expanded on this by talking about a situation where she was staying in the hospital and a medical professional made her feel bad based on how they treated her and her husband.

Harriet: All I knew is that I needed somebody to come to me and [the CAMPP team] just did... Every hospital I stayed in; they would never let [my husband] stay with me. You know, because we were homeless, we were treated so badly. At the [Calgary hospital], all the husbands get to stay there with their wives, or their wives with their husbands, and mine was the only one that was not allowed, literally not allowed to stay there...And CAMPP had come and taken [my husband] to the cafeteria and bought him something to eat, some food and the nurse, I can't remember her name, but the nurse, the head nurse, she literally gave him a garbage bag to go sleep outside because it was raining...and he had to sleep outside. It was very horrible the way homeless people are treated.

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Harriet observed other couples being treated differently from her and her husband and felt that the health professionals behaved this way because of her homeless status. She pointed out that during this time she recognized that she needed help because the hospital system was not working for her and the CAMPP staff stepped in to fill this gap. At this time in Harriet's life, she was frequently in and out of the hospital and, as she states below, was doing "whatever she had to" to survive, but at a certain point she got too sick to continue managing on her own.

Harriet: I became ill, otherwise I would've done whatever I had to do, ya know? I was doing things to pay my rent and then I became even too ill to do that...so I became homeless, and I didn't know what to do. When I was on the street, ya know, it got to every two days I was back in the hospital, every two days by ambulance...There was a time when [the CAMPP team] came every single day, Courtney. There was not one day they did not come to see me. It was in the beginning, they did not believe I would live more than two weeks, and it has been almost one year. It is miraculous.

For Harriet, the CAMPP staff member's repeated visits were a significant factor in her living well beyond the two weeks that were initially expected. The current health system is not organized in a way that accommodates for the close and repeated follow-up work that the CAMPP team engages in with their clients. Yet, for Harriet, CAMPP's approach played a major part in improving her life to a point where her life expectancy improved. Below, she outlines yet another negative experience that she had with the health system while being homeless and how it shaped her relationship with healthcare professionals prior to working with the CAMPP team.

Harriet: The hospitals want you out straight away because you are homeless, too.

One doctor I was with because I was rushed by ambulance to the [name of hospital], the doctor said, "Do you, do you not have coverage?" and I said no, and my husband was standing there. I said no, the card hadn't gone through or whatever, and my husband explained why, and she said, "well I won't get paid." She said those exact words. "If you do not have coverage, I don't get paid" ...So you know, this is a reason why also that homeless people are very deterred from the system. Ya know, they are so frightened.

In this instance, Harriet explained how the physician made her feel that by working with her, the physician would be giving away a "freebie". As a citizen of Canada and resident of Alberta, Harriet is entitled to hospital healthcare, which means that the doctor should be paid for treating her, and she would not receive a bill—money should not need to be discussed. However, because Harriet was homeless, and this social status positioned her uniquely within this text-based structure of authorization within the health system, she appeared to the doctor to be a "freebie," which the doctor made visible to Harriet. She stated that she understood this to be the case because she did not have the card with her Alberta Health number on it which acts as the "pass" for her to be covered based on provincial insurance. In Harriet's case, she came from out of province and had not yet gone through the institutional process of becoming an official "Alberta resident" who would be covered, even though the principle of health care insurance coverage is Canada-wide, and she likely had the benefit card from her previous province.

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Harriet found it difficult to get this organized given her health condition and lack of understanding about how to complete the health insurance application process. Harriet explained that these types of hospital encounters were frightening to people in her position because people who needed care could not be confident that they would get adequate (or any) care if the system was not reimbursed.

Harriet's experiences influenced how she viewed the health system and the people that worked within it as not valuing her as a patient. Her anecdotes help us to understand how and why she and others in similar positions might be deterred from the system out of fear. This can become incredibly problematic, as an avoidance of the system can lead to worsening illnesses. This was the case for Harriet because she waited until the illness progressed to such a degree that it resulted in an inevitable reliance on the system and a pattern of frequent hospital admissions. Becoming reliant on a system she feared was incredibly uncomfortable for her as she did not feel recognized as a welcome or deserving patient.

Harriet's two stories highlight the way she experienced dis-entitlement in the alleged universal healthcare insurance system. The second story was about the text-based entitlement that authorized the monetary exchange that occurred between the province and the medical professionals. At that time Harriet, did not have that entitlement securely logged in the system. Her earlier story is about a more moral entitlement, which she saw played out in the options and treatments offered to some couples but not hers.

As an experienced patient, Harriet knows what would work for her, and this is shown in her statement above, "all I knew is that I needed somebody to come to me and [CAMPP] just did." Harriet recognized the approach that the CAMPP staff took in caring for their clients and felt it was helpful to her; she explained to me that having the CAMPP team in her life was one of

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the main reasons she was alive today. She also noted another part of what made the CAMPP a unique service that worked for her:

Harriet: All this stuff, all the crap we deal with in the hospital is something we never experienced with CAMPP... They don't give a shit what you do or what you're doing. They are never going to leave you. And they told me that, and you know what? They never have. They're still here. And I've told them to go fuck their hats, like literally, ya know, just go fuck off and they still come back. Of course, I apologize, I don't mean it.

Harriet expressed that it was a vital component of the work of CAMPP that they persisted in coming back despite her attempts to push them away by telling them to "fuck off." In her experience, this persistence as part of care did not exist in the larger health system. She expressed that she did not *mean* to act that way, but that sometimes her stressors put her in a negative mental state where she did not want to see anyone. This did not mean that she wanted to terminate services, but that her reactions were harsher than she intended; she valued this type of persistent care because it was not something she had ever received from care providers in the mainstream health system, and it made the difference in her health outcomes.

Harriet's illness made it inevitable that she connected with the healthcare system. However, her previous interactions with the system were so negative that she ended up experiencing unnecessary suffering that led to what she thought was going to be the end of her life. She recognized that she needed help and that she sometimes pushed it away based on her previous experiences, but that the persistence of the CAMPP team helped her last stages of life become extended beyond the two weeks she initially expected. Harriet outlined how the approach CAMPP took with their clients worked well for her and that the demonstration of care

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for her life were important pieces in ensuring that the inevitable *end* that she knew she would still face at some point would be a better one, absent the “filth” that she believed she would have experienced had she not connected with the CAMPP team.

Harriet: [CAMPP] really cares about people, ya know. That group, they just all care about human beings, ya know, about their lives, their dignity. They try to make sure you are comfortable. Like myself until, ya know, until I am done here... You will still die, ya know, but listen, it can be better. It doesn't have to be dirty and filthy, and you, you know, being, lying on the street.

Harriet no longer described herself as “dying” or even “nearing death,” but she knew that she was not completely relieved of the burden of her illness. She acknowledged that her life was still going to end, but that she now had the peace of mind to know that she could expect to die in a more dignified way than what seemed likely to her before, when her only option was to rely on the mainstream health system.

Chapa's Account: “If I didn't Listen to My Wife, I Wouldn't Be Here Today”

I met with Chapa at the building where he lived in downtown Calgary. The staff of the building buzzed me in on arrival and led me upstairs to a shared area with large windows, two leather chairs, some bean bag chairs, a rug, a small table in the middle of the room, a few house plants, and a rectangular table at the back of the room. I arrived a few minutes early and the staff member who walked me up asked me if I was okay to wait in the room for Chapa. They informed me that they were not sure when he would be ready as he had not been out of his suite yet that day. I agreed and told them that I had reading material to keep myself busy until then. I

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waited for a while and then I heard some rustling down the hallway a few metres from the room I was in. Chapa shuffled toward me with short steps and carried his head in a way that situated his chin close to his chest. I tried to catch his gaze and I waved. He waved back, nodded, and smiled softly. I walked to meet him in the hallway so we could walk back to the room together. When we arrived back to the room I had been waiting in, I asked him where he would like me to sit, and he pointed to the bean bag chair and then walked over to the cabinet against the wall. I noticed that he was gathering a few items: sage, a lighter, and a small tray. He pulled up the other bean bag chair and knelt on it and placed the items on a small round table located between the two chairs where we are seated. We were sitting across from each other, and we began talking.

Chapa: This is sage, do you mind if I light it? It will help me talk a little bit better as this is very painful.

Chapa lit his sage and placed it on the tray. He pushed it around so that the smoke billowed from it more heavily. I knew from previous encounters with Chapa while attending the ride-alongs with the CAMPP team that he was a 55-year-old man who suffered from severe heart problems. I had not spoken to him about his health before the interview and so I started by asking him how he was feeling and if he wanted to talk a bit about why he was connected with the CAMPP team.

Chapa: My name is Chapa. Um, let's see, before here, I've been homeless since um, I was thinking about this yesterday and the day before that and the day before that, oh boy! [laughs] Let's see, I go back well about 4 or 5 years I have been homeless, you know, didn't have a home of my own. Usually, I couch surf with my wife here in Calgary.

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We began talking about Chapa's health and he gently placed his right hand over the left side of his chest and stated that he had a "troubled heart." He then explained that a health professional told him that he had heart failure and that it was a frightening experience to learn about his diagnosis. He continued, stating that what he feared most about the prospect of death was having to leave his wife. In the interview, Chapa brought up his wife frequently. When we spoke about how he came to be connected with the CAMPP team, he told me that his wife had a meaningful role in facilitating this connection.

Chapa: My wife said "give [Lee from CAMPP] a chance." She said, "He's a really nice guy and he knows what you're doing, and he cares about you." I said, ok, all right, all right, I'll trust him. You know, when I met him, we were laughing, talking, sharing and things and all that. He opened me right up. Like he did a surgery on me! And um, after meeting him, I really care about him. I care about him a lot.

Chapa's first meeting with Lee from the CAMPP team was at a local emergency shelter that he and his wife stayed at intermittently for many years. He stated that many people were telling him about Lee, but that it was not until his wife told him to give Lee a chance that he decided to meet him. He was very frightened to speak to anybody about his "troubled heart" because he did not want to learn that he was dying and how this might lead to a separation from his wife through death. After talking further about this with his wife, Chapa made the decision to "trust" Lee. Chapa then explained that the relationship with Lee blossomed and as he began working with Lee, he explained, part of what helped foster trust between them was that he did not feel judged by Lee because of being homeless.

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Chapa: I have a lot of respect for Lee. For caring and showing me that he does care.

Judgemental is a bad bad word.

...

Chapa: People deny it, but everybody doesn't want to rent to us. It is so so hard, but we won't give up.

...

Chapa: Here in Calgary, some family members and some professionals, they won't talk to us because we are homeless you know. They judge us. You know if you have a heart condition like I do it was really hard for me to live that way. Sleep in parkades against those big cement blocks that stop the car...you get comfortable and then you hear the guards yell, "you gotta leave!" Because stereotypes. Why should a person have to change themselves?

These acts toward him contrasted with how he viewed the work of Lee from the CAMPP team.

With Lee, he felt seen and heard for who he was.

Having trust in the CAMPP staff members also became very important when he was asked to attend a very important medical appointment that he did not want to go to.

Chapa: I can open up [with Lee] about anything I have. I trust him. [Long pause] I was just thinking about the time with [housing staff member] and Lee and they were talking to me about coming to my heart appointment. It's way down South, hey? All the way in the campus area and I didn't want to go. It was far and I didn't want to

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find out more bad news, I didn't want to find out why I am sick and if I can't get better. I do 99% of the job, the 1% it's that one that helped me all the way through. Do you know what I mean?

Courtney: I think so.

Chapa: Maybe if I didn't take that 1% chance with [Lee] to go to that appointment I wouldn't be here.

Chapa described his emotional experience as one of distress because of his heart condition and he also voiced that there were other barriers to him attending this important appointment that made him not want to go. However, Chapa's expression of doing "99% of the job" oriented us to his agency and how he was the main actor in working to manage his health and daily activities. He also recognized that he needed that extra "1%" to position him to achieve what he set out to achieve, attending his medical appointment, and ultimately staying alive longer.

Chapa spoke about how the appointment was located "way down South" which was far for him to travel. Having a very low income and being in very poor health, a long commute was particularly challenging for Chapa. In this case, Lee supported him with transportation to the appointment and accompanied him to help ease his anxiety about going. He described to me how the information that the clinic gave him to prepare for the appointment consisted of a piece of paper that had the name of the physician, the location, and the time of the appointment, with little other information on it. He explained that the piece of paper did not reassure him about his fears about the appointment. The paper did not help him understand the clinical process or the people that he would be meeting with. Of utmost concern to him was that he did not know the

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physician he would be meeting with to discuss such personal matters. He had little trust in professionals he did not know, based on his prior negative experiences with healthcare systems, and this was no exception. He worried that he would feel judged or mistreated, which was another barrier to him attending the appointment.

The medical office provided appointment information on a piece of paper to Chapa. This institutionally embedded process of informing patients is deemed sufficient because it provided him with the logistical information necessary to attend. This was a standard process that the office provided to all patients, and it was likely sufficient for many, but it was insufficient for Chapa. The information given to Chapa about the appointment did not account for many of his unique needs, including the long commute, his apprehensions about dying and leaving his wife, or being judged or mistreated. The document did not provide him with the information he needed to feel equipped to attend. Instead, the document focused on logistical information which was only part of what was required for him to feel prepared and comfortable attending the appointment.

The structure of the CAMPP team is built in such a way that fears such as Chapa's are acknowledged and accounted for. This approach created a foundation where Chapa could gain confidence in attending the appointment. Chapa stated that he ended up attending the appointment and that he would not be here today if he had not trusted the CAMPP team and the other staff member to talk to about his apprehensions to go. The CAMPP team orients themselves to their clients in a way that creates space for them to express fears about judgement and mistreatment. They also provided support with transportation that helped Chapa follow through with the appointment. The barriers that existed for Chapa do not exist for other patients

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who do not struggle with the same challenges, and the way the CAMPP team is organized accounts for these individual nuances. Part of the CAMPP's work is building trusting relationships with their clients; Chapa's relationship with Lee, and in this case, the housing staff member, was something that Chapa felt helped prolong his life.

Chapa: They gave me a chance and I took it, and now look at where I am.

Chapa once again emphasized his agency in working with the CAMPP team to sustain his health, emphasizing that, with a little support, the kind of support that is not offered through the typical avenues of the mainstream health system, he was able to follow through with the appointment and achieve success in managing his heart condition.

Bringing it All Together

The interviews and observations with clients are foundational to understanding the work of the CAMPP team and how the need for this work comes to be necessary. In the interactions with clients during the interviews and ride-along visits, there were indications of how the health system has not only failed to work for these individuals but, at times, has actively worked against them. In this chapter, I framed the accounts through the analytic concepts of individual experiences and engagement in health-related "work". Using these concepts, we can start to see the interfaces between CAMPP clients, and the multiple institutional processes embedded within and adjacent to the mainstream health system that are significant to managing their health and daily lives. This approach makes visible why and how "hooking in" to the mainstream system is troubled, attenuated, and ruptured for this group.

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The interview with Rowan turned into an instance of crisis management and it became readily apparent how this was only a sample of his daily life and the challenges he experienced while trying to manage his health. The CAMPP team came to support him in various ways including helping him navigate the multiple intersecting institutional work processes that created a conflict for Rowan's access to oxygen. Steve helped him by speaking to the oxygen tank vendor to negotiate reserving the small oxygen tank to avoid his readmission to the hospital. Furthermore, transportation and accompaniment to his respirologist appointment was within the scope of the CAMPP's work of supporting him. The people representing the intersecting systems expected that Rowan carry out these activities before care could be provided. However, these expected activities were beyond Rowan's capability on his own. Rowan needed help to manage the competing demands and to make managing his health possible.

Harriet and Chapa both expressed negative experiences with the health system that made them apprehensive in accessing supports. At times, Harriet actively "pushed" support away by swearing at the CAMPP team or refusing to see them, but she recognized that she needed help from care providers who were persistent despite her occasional resistant efforts. Chapa also felt "turned off" by the health system. He had negative experiences with several professionals, but also felt fear about his own mortality and the possibility of leaving behind his beloved wife if he were to die. All these issues worked together to lead Chapa to avoid the appointment. The CAMPP team takes on these types of challenges as typical aspects of their work with clients as people with complex situations with nuanced needs.

An asset of IE is that, through this lens, by starting from the standpoint of CAMPP clients, we can make visible the areas of blocked access to healthcare. With this approach, we

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can make the areas of blocked access tangible and addressable as we take the experiences of clients and track how, when, and why these ruptures occur.

In the three client accounts, the system breakdowns are apparent in the areas of emotional work around health and related issues (i.e., demonstrating a non-judgemental reliability of “always being there”), logistical planning (i.e., medication management, supporting with managing appointment scheduling, as well as transportation issues) and speaking on behalf of clients (i.e., speaking to professionals to manage situations that the client may not be equipped to handle). This list is not meant to be understood as a comprehensive typological theming exercise but rather as a brief description of some of the work being done by the CAMPP team that will be further expanded upon in later chapters. These are specific areas of support that CAMPP fills in that are actively missed by the mainstream health system for this population. In the cases of CAMPP clients, the health system’s policies and procedures make it so that certain underlying assumptions about the condition and capacity of its patients are embedded in the work processes. These work processes then place unfair expectations upon certain patients that relieve the system of responsibility and place it upon the individual. The CAMPP team creates the “scaffolding” between the individual and the system that link them together in areas in which the connection would be otherwise broken.

For CAMPP clients, what matters, what works, and what does not work when it comes to provision of healthcare are different from what the mainstream health system currently offers. The problems for these clients originate within the health system but are expected to be managed outside of it. Therefore, the CAMPP team has come to exist to address this disparity in care for persons with life-threatening illnesses and who face extreme social marginality. The unique

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circumstances and needs that social marginality imposes upon people creates a disjuncture between the types of health services that are purported to be “universally” accessible to the public and the ways in which the health system is organized to functionally exclude groups of people.

In institutional ethnography, we are trained to be alert to disjunctures between the knowledge that arises for people in their everyday experience and the objectified knowledge that mediates institutional relations (McCoy, 2008). In each of these accounts, the clients speak to how they are challenged by the healthcare system and how the CAMPP team comes to be warranted in their need for care because of how the embedded processes work against people within the institutional relations of the health system.

These accounts describe typical situations that occur for clients of CAMPP and based on the literature, can be generalized to many people in similar circumstances experiencing unstable housing who have life-limiting illnesses. Rowan, Harriet, and Chapa's experiences help set up the foundation for this project as I delve deeper into the CAMPP's work processes in subsequent chapters. I will explore more about some of the other barriers that emerge for clients and the various ways that CAMPP staff do this work of supporting clients and keeping them hooked into the network of healthcare and other services.

Chapter Five: Describing the Daily Work Activities of the CAMPP Team

Introduction

In the last chapter, the focus was on how clients interfaced with the health system and how their experiences paved the way for the work of the CAMPP team to intervene in their lives. This chapter builds upon this by delving into a more in-depth description of how the CAMPP team goes to work in the interface between clients and the mainstream health system. This chapter focuses on the organization of the typical daily work activities for the CAMPP team. The previous chapter helped us see, from the standpoint of clients, the diverse situations that required attention for people with life-limiting illnesses who were homeless or vulnerably housed, which sometimes involved challenges associated with substance use and/or mental illness. Building from this, I discuss how the program members go to work each day managing the varied tasks and activities they are responsible for based on their unique program structure.

Arranging this section as if it were a typical day observing the work of the CAMPP team, I use a compilation of observational field notes, interview excerpts, and CAMPP documents to create a model of what a regular workday looks like for the CAMPP team. This is not a comprehensive account of all the work the team engages in nor am I alleging that each of these tasks happens in this order in their every working day. Rather, this chapter focuses on typical happenings using ethnographic descriptions from interviews, observations, and program documents to illustrate them.

To organize this chapter, I draw inspiration from the way that Michael Corman (2017) in *Paramedics on and off the Streets: Emergency Medical Services in the Age of Technological Governance* and Timothy Diamond (1992) in *Making Gray Gold: Narratives of Nursing Home*

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Care, organize their writing. These authors do something different from typical academic writings in that they offer composite accounts of their observations as if they were unfolding on a single occasion. Similarly, the current work aims to construct a narrative of typical instances of pieces of the CAMPP team's work to illustrate how a day might unfold for the CAMPP team. The current format is meant to provide an ethnographic account giving a sequential glimpse into the typical and expected happenings of CAMPP's work in a way that is intended to be easier to understand and more enjoyable for the reader, to help one imagine the CAMPP's work through a representation of it in a rendering of "real-time".

As we go through the arrangement of daily activities of the CAMPP team, some key aspects of their work arise that are important in understanding the organization of the team's operation. In many of these segments of work, the CAMPP team orients themselves around texts that help them arrange their activities with each other, their clients, and other service providers. Texts are an essential element in IE investigations because of their "capacity to co-ordinate social action" (Quinlan, 2009, p. 628) once they are activated by people. In this section, I show how the CAMPP team members activate texts in their daily practices which function to objectify the organization of their work (Smith, 2001) and how they use texts in comparison to what other institutional ethnographies have found in their study of textual organization in public service settings.

The way that this chapter is set up is that each section is meant to orient the reader to central aspects of CAMPP's work. First, I introduce the CAMPP team members. I then discuss how I arrived on scene as an observer and how my presence was negotiated; next I describe the CAMPP team's office and how they start their day. I then discuss how the CAMPP team

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engages in their work with clients, starting by “tracking clients down” and pivoting between client visits, followed by a description of the referral process into the CAMPP team and how people officially become “clients” through the “intake process”. The next section addresses how the team talks about assessing people as a “programmatic fit”. I then take the reader back to the office where the CAMPP team wraps up their day with administrative tasks like writing down notes about their work in their program software and making choices about what activities to log versus those that they exclude.

The CAMPP Program

The CAMPP team is a small three-person team that operates within a Calgary community organization called CUPS. Their primary client group are people who face social marginalization due to poverty and who are also experiencing a life-limiting illness. The CAMPP team is the only one of its kind in the Calgary area and they served 128 clients as of 2022. In an evaluation completed by Petruik & Colgan (2022), they found that of the 128 clients, 29 identified as female and 99 as male. They also noted that the average client was aged 58.9 years and the age range was between 22 and 86 years of age. The most common primary diagnosis for CAMPP clients was cancer. Most of the referrals to the CAMPP team came from community partners, acute care hospital units and the CAMPP team’s partner agency, CUPS Calgary Society (Petruik & Colgan, 2022). Common barriers for people who get referred to the CAMPP team include not having a primary care physician, unstable housing, low or no income, insufficient medication coverage for their needs, and lack of social supports (Petruik & Colgan, 2022). The CAMPP team often supports their clients with housing as a first priority of care, and so some of their clients become housed, but the CAMPP team continues to support them to sustain their housing.

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For this reason, CAMPP clients range from living on the streets, in emergency shelters, in transitional housing, couch-surfing, long-term stays in hospital, or in their own private dwellings.

The CAMPP Team. The CAMPP team was founded by a palliative physician, Charles, who is a tall, middle-aged man who usually wears a brown crossbody bag and dresses casually – often in khakis or jeans and a sweater. He speaks softly, but confidently, and greets people with a smile. Charles is the main palliative physician associated with the CAMPP and oversees much of the decision-making about the team including hiring and any structural or strategic decisions involved with the program. Charles also works as a palliative physician at the local cancer centre in the city. There are also three other palliative physicians that rotate in to support the CAMPP team monthly. In my research, I met one other palliative physician, James, a tall, thin man with dark reddish brown hair and a square jaw line who carried a black leather padfolio near his chest. He spoke confidently and authoritatively about the care for his patients, and I often saw him leaning over a counter writing notes in his padfolio.

The nurse coordinator, Lee, is a man in his late twenties or early thirties. He is soft spoken and smiles often. Lee organizes most of the daily activities and keeps the program running. He also provides care for clients and oversees much of the planning and administration of the program. The health navigator, Stephen, is a man who is also likely in his twenties. He is a jovial person who cracks jokes and often laughs and tells stories. He is often heard coming down the hall because his keys are jingling in his pockets as he walks. Stephen's role as a health navigator is to care for clients, a key component of that care being to help navigate the health and social service systems. He spends most of his days out of the office visiting clients.

“Are We Good to Go?” Negotiating the Presence of an Observer

A typical observation day starts with a text message that I routinely send to the team at 8:00 AM. The text usually says something to the effect of, “Hello all, are we still on for today?” I usually meet with the team at their office downtown at 9:00AM if the observation is still on. Sometimes I get a response back within seconds, other times there is a delay before the reply. The morning text message check-in is something that we do to ensure the day is set up to welcome an external party (me) to ride along. Soon after starting my observations, I learned that the team chooses to do this to be sensitive and respectful to their clients. While they are open and welcoming to “outsiders” learning about their work, they pay close attention and consideration to the appropriateness of timing to welcome people into the lives of clients.

Occasionally, there are days where it is inappropriate for the team to invite me to join. For example, if they expect to meet a highly sensitive client who is averse to new people, they let me know that having a third-party present could compromise the comfort of the client so they will invite me to reschedule the observation. There are also other occasions where the team asks me to reschedule my observation because other people are scheduled to ride along with them and having yet another person may be burdensome to the client. Out of respect for the clients and to help with ease of transportation (we travel in their personal vehicles which sometimes does not have adequate space for another body), too many observers present is one reason to reschedule for a different day.

Since 2016, there has been rising public interest in the CAMPP team’s work. The CAMPP team accepts requests from the public, healthcare, social services, media professionals, and students to ride with them to learn more about their daily practice. However, the team’s lead

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nurse coordinator, Lee, learned that he needed to set boundaries on the number of ride-alongs allowed to ensure the best care for their clients. He usually made the decision about permitting visitors based on the day's expected events and the team's best judgement of how appropriate and respectful it would be to have a person that the client was unfamiliar with observing the work. There were even times when the negotiation happened throughout the day. For example, the team was working with a client who was close to the end of his life and requested to see a pastor. I had met this man earlier in the day and he requested the pastor while I was present. Lee agreed to set this up for him and return later with the pastor. Later in the afternoon, Lee secured an appointment time with the pastor and was slated to return to the client late that afternoon. Gently, Lee asked me what time I planned to stay for the ride-along, and catching onto what he was asking me, I replied by asking him if he would prefer that I not attend the visit with the pastor. Lee nodded, showing that "it might be best". He then explained that the visit was going to be a very emotional one and having an observer there felt inappropriate. This sensitivity to the situation and the client continued to be critical in the ongoing negotiation with the CAMPP team during the data collection process, both in the outset of the ride-alongs as well as throughout the day.

The Main Office and "The Huddle"

When we agreed to go ahead with the ride-along, I usually arrived at the office at 9:00 AM. The office was in downtown Calgary in a large building that housed several programs for people who have been impacted by poverty who require social and health supports. These programs included health services, developmental services, economic supports, and social/emotional supports. When I walked in the door, I saw a sign that guided me up the stairs to a desk where I recorded my name to show that I was there and waiting to be seen by the

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CAMPP team. After I signed in, a receptionist behind a large desk alerted the CAMPP staff to my arrival by phone. I sat in the waiting area until a receptionist called my name to come to the back offices that were located behind a locked door next to the desk.

The waiting room was filled with plastic chairs like the ones at a doctor's office that were facing the large desk at the far end where three administrative staff members sat and greeted the people who came in. Behind the desk was a large white board listing the names of medical professionals next to the day of the week. The agency that the CAMPP team worked from was called CUPS and it housed various health programs including family physicians, women's health practitioners, mental health services, a liver clinic, an opioid agonist therapy program, and various medical specialists. The board was updated daily and gave people who came in an idea of who was in the office that week.

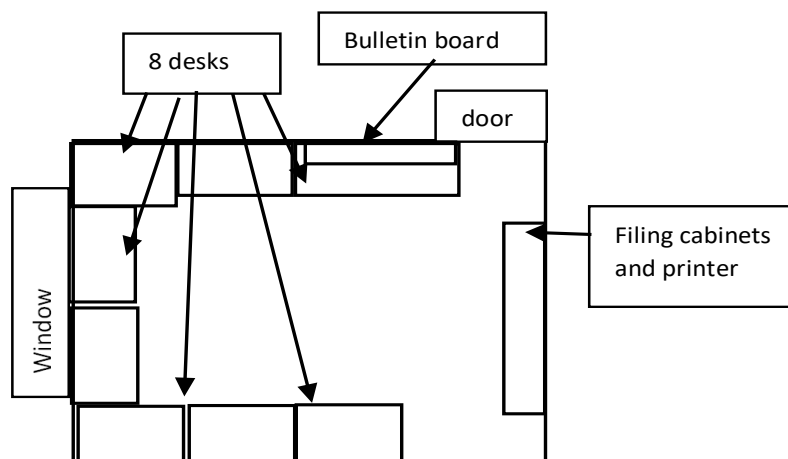
The CAMPP team as well as their partner program, the Healthcare Outreach Team (HCOT) comprised the outreach portion of the organization. Both teams worked in the community, literally "reaching out" to people instead of expecting them to meet with them in the office as other health professionals might expect. Later in the chapter, I will add more to the discussion about the administrative relationship between the two teams.

After I waited for a few minutes in the waiting room, a CAMPP team member opened the locked door and led me back to the CAMPP office. The CAMPP office was located at the end of a long hallway. As I walked down the hall, I could see other offices that had various things in them signifying medical specialties operated out of them. For instance, in one room I saw a dentist's chair, and, in another room, I saw a place where nurses drew blood as indicated by

special chairs with arm rests that I recognized from getting my own blood drawn at labs or donor clinics in the past.

The CAMPP team's office was straight down the hallway and looked like a typical office, like ones I had worked in in the past lit with fluorescent lights, walls lined with desks, computers, filing cabinets, a printer, a coat hanger, and some bulletin boards. The CAMPP team shared an office with the Healthcare Outreach Team (HCOT). The CAMPP team worked closely alongside HCOT; both programs worked with individuals who were low-income, homeless, vulnerably housed, who were suffering from multiple co-morbidities (the presence of more than one health problem in addition to a primary medical diagnosis) and were dealing with social issues that resulted in barriers accessing healthcare. There were eight desks surrounding the periphery of the small office. The desks faced the wall and there was a small window near the top of the far wall as in the basement of a house.

Figure 2 - Diagram of the CAMPP Office



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The lights were bright when I walked in. I found that there was much to look at, with bulletin boards on the wall covered in thumb-tacked-on pamphlets, brochures, posters, and sticky notes. When I looked closer, I noticed that some of the bulletin's posts were memorial cards like those you receive at a funeral or memorial service. The memorial cards were posted next to coloured paper cut-outs shaped like birds, hearts, and butterflies. Some of the cut-outs had names on them and I learned later that they were names of clients who had died. I was not surprised to see the memorial cards because of the nature of the CAMPP's work and all that I had learned about the high mortality of the population these teams work with. However, these posts were all around the office, not just near where the CAMPP team was stationed, and I learned that everyone in the office who worked with CAMPP or HCOT was familiar with their clients dying and that death was not a foreign issue to any of the outreach workers given the high mortality rate of people who are homeless or vulnerably housed.

It was busy in the mornings when I arrived. By the time I got to the office, there were several people already in the office, while others were trickling in. Some people were seated at their desks enjoying coffees, while others sipped from water bottles or munched on the last of their breakfasts. There was a consistent buzz of chatter while people greeted one another and chit-chatted about their evenings prior or the day's anticipated events. It was often a struggle to find a chair to sit in as there were too few chairs to accommodate everyone in the room, especially when I was there, as I was an extra body in an already crowded place. About twenty minutes to 30 minutes after my arrival, I noticed that the buzzing started to settle down as everyone found a seat and turned on their computers. The typical day of the week that I attended was on Tuesdays because this was the day that a palliative physician joined up with the team.

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The CAMPP team and I decided that Tuesday would be good days to attend since the whole team would be present.

After everyone was settled into the office, we arranged ourselves in a semi-circle at the far end of the office where the desks of Lee, the nurse coordinator, and Stephen, the health navigator were located. It was usually a tight squeeze as we tried not to bother the HCOT members who were working in close proximity. On the colder days, our winter jackets made for even less space, and we were often trying to avoid being distracted by the sounds of rigid winter coat fabric rubbing against itself as we shifted in our seats. I found myself trying to stay very still to prevent interrupting the conversations and other work going on in the room.

After the morning “buzz”, the CAMPP team would typically get right into discussing the day’s work. They called this the “huddle,” and it was when they came together in the office and “ran the client list”. This started with Lee printing off a piece of paper that was a print-out of a list of clients and their corresponding information (Alberta Healthcare Number, Name, Age, Sex, Date of Birth). It was created on what looked like an Excel spreadsheet. When I asked the team what the use of this text was, Lee said it was his way to track their day-to-day activities as they pertained to the people they worked with. He chuckled a bit when I probed about the information in each of the columns, as he said it was “thrown together” and that they “really needed to come up with a better system”. The printed piece of paper was a program text that listed all the “active clients” (usually about 25 in total). On the days I was present, the team went through the list one by one in the “huddle,” discussing any updates about the person, including information about where they last saw them, their health status, any requests they had, any problems or challenges, and any work that needed to be done with the person. They also

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discussed the urgency of the need and who on the CAMPP team would take on what work that day, how it would be carried out, and any other related updates.

The nurse coordinator usually took the lead running the team “huddle”. The team discussed each client individually and depending on who worked closest with the client, that person would take the lead describing the recent happenings associated with them. The team collectively made decisions around who would take on which pieces of work. Factors that were involved in planning the day often took a pragmatic approach including conserving fuel costs, attending to who had the best relationship with the client, as well as who had experience doing the type of work that was required. For example, if the client required blood drawn, the nurse coordinator would attend to that client since, as a registered nurse, he had the training to collect blood whereas the health navigator at the time did not have this medical training. The team typically planned on seeing 3-4 clients in one day.

After deciding on the day’s itinerary, the team set out in their respective cars to start the day’s work. The palliative physician would usually ride along with either the nurse coordinator or the health navigator depending on the needs of the clients and who they were seeing. Other times, the team would all go together if they determined that the client would benefit from having the entire team’s set of skills present or if it made sense pragmatically to have all parties in attendance (e.g., one CAMPP member had an existing relationship to the client, but if they required the skills of the other party or a second opinion on a particular issue, then they would have more than one person go).

“Tracking People Down” and Pivoting from a “Planned” Visit

While the “huddle” helped the team set a strategy for the day, often the plans did not go exactly as they intended. Locating clients was a distinctive feature of the team’s work: it was not

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just that the CAMPP members went out to see clients, the team went to clients who in many cases did not have a fixed address and did not always have the means to let them know where they were on a given day. For instance, the team kept a directory of a few places that they knew to find a client, but often, when the team arrived, the client would not be there, so they would move to the next location. In some cases, they ran into other clients that were not on their list for the day, but they were clients that the CAMPP team was working with and so the team would use this time to check in with them and ask questions about their health, housing, or other related needs. The team often used these situations as opportunities to “remain visible” to clients and stay connected with them. Steve mentioned to me that being present sometimes reminded clients that they were still “around” and could trigger a phone call or text message shortly thereafter.

Other times, the team received conflicting information from clients or care providers about the client’s whereabouts, or the client was found to have left before the CAMPP team’s arrival. These are examples of times where their attempts to carry out their initial plans changed and so CAMPP members adjusted their plan based on the new information.

Lee: Okay, so, Courtney would you want to go with Steve today? You two could start with a visit to Pete and Mel if they are around and if not, then Jazz is usually just around the corner so, two birds with one stone!

Courtney: What do you mean “around”?

Lee: Oh, nobody is ever where we expect them to be, that would be too easy! (laughs)

Courtney: (Laughs) I see! Yes, happy to hang out with Steve today.

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Steve: All right! Let's go!

The team structured their daily work around the idea that they may not know where their clients were, and this was within their scope of responsibility to sort out.

Courtney: Do you make appointments with your clients?

Steve: As far as we can, but for many of our clients, we respect that their lives aren't always predictable, and they may be on the move for one reason or another. A lot of our work is in the inner city, so we usually track people down, we try to see them when it works for them.

Figuring out locations of their clients was something that the CAMPP team did regularly but that was uncommon within the mainstream health system. "Tracking people down" involved tasks like making phone calls to the client directly if they had a phone number on file or to other social service providers in the community that worked with the client. It also entailed emailing service providers from other organizations to ask if the people who worked there had seen the individual and, if so, when. In some cases, staff from other organizations called CAMPP team members to alert them to the presence of a person who attended their organization that day. These collaborative inter-agency interactions helped the CAMPP team in their daily work to locate their clients.

Other times, the team's original strategy that came from "the huddle" would get sidetracked into another direction because something in the plan would shift and they would have to "pivot" from their initial plan for the day.

Lee grabbed some tubes and named the colours of the tubes as he grabbed them, “I will need a couple yellow, a purple...” I could see that these colours corresponded to the caps on the test tubes. Lee put all the supplies he needed to draw blood in his shoulder bag and walked out; I followed. We got into the car and started driving to the client’s mother’s place where the client was staying. We pulled over onto the side of the road so that Lee could send a text message to the client letting her know we were outside. We waited for a few minutes and in this time, Lee asked me to pass him his shoulder bag. I passed it over and he opened it up and went through the supplies once again to see if he brought everything he needed. I asked if it was all good and he said, “Yup, I think we have it covered!” A text message came through, and it was the client saying that she felt sick and did not feel up to getting bloodwork taken. Lee took a moment and explained to me that he respected her wishes, but that it was also especially important that he drew her blood because of it being a prerequisite for treatment next week for the client’s cancer so he felt he should persist a little. Lee called the client rather than texting her back and said, “Do you mind if I come up and say hello and just see how you are doing? If you are feeling ill, that is no good, so maybe I can just check in and we can have a short chat.” I asked about Lee’s choice to push a bit and he said that often, if he could manage to have an in-person conversation, the client may warm up to the idea of bloodwork and that sometimes the idea of the bloodwork was worse than it was in practice. However, she did not go for it and said she was sick on the toilet and so did not want any company. Lee looked a bit worried but affirmed the client’s decision and let her know that we would be in the area today if she changed her mind. Lee then told me that he would keep the supplies with him in case we needed to go back

there later today. Then, Lee made another phone call to a service provider and said, “Ooh good, [another client] is there, we will head there, it is just around the block.” –
Field Notes January 14, 2020

Here, Lee was doing the work of balancing his knowledge that his client needed the bloodwork with respecting her wishes. He did not force the situation but was flexible in that he allowed her the option of reaching out again later if she felt better, so he knowingly planned to see clients in the area so that he was available if she ended up changing her mind.

The CAMPP team members made it a priority to meet clients in the community on the clients’ time because they recognized that their clients often had unpredictable circumstances in their lives which made it difficult to access mainstream services. For this reason, the CAMPP team tried to accommodate their client’s schedules to connect them up to care. For example, when their clients were homeless and extremely ill, they would often have many things to keep track of such as medical appointments and medication regimens which were further complicated by where they might be staying that night, keeping their medications safe, and obtaining their next meal, for instance. Additionally, many of these individuals had fewer resources available to them to keep track of these tasks, such as secure places to store medications or ability to access calendars or computers, as much of the healthcare system now provides digital appointment notifications or if they are hardcopy, they may not have an address for the notice to be sent to.

As we saw with clients Harriet, Chapa, and Rowan, there were expectations that the mainstream healthcare system providers placed on patients as part of the systemic processes that uphold the patients’ responsibility that may not be achievable for all people, especially those in socially marginalized positions. These barriers have been discussed already in this work, but

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include, however are not limited to, strains on relationships with healthcare providers, fear of judgment and rejection by healthcare providers, inability to access transportation, no primary care physician, inability to keep track of complex medication regimens, among other challenges. However, the CAMPP team has built their work around the knowledge that these struggles exist for this population and so take it upon themselves as a program to be partly responsible for these types of tasks. In addition to taking on a part of the responsibility for their clients to ensure they are seeing them regularly; the team has also intentionally embedded the knowledge that individuals have trouble connecting to the mainstream health system into the way people come to be recognized as “CAMPP clients”.

How People Become CAMPP Clients: The Referral Form and Intake Process

Usually at around 10:00 AM, the CAMPP team and I would be getting ready to leave the office. On one occasion, as we were packing up, Lee’s phone rang, and he answered it.

Lee: Hello, Lee speaking. Good, thanks, and you? A couple minutes, yes, who is it?
Sure, are they willing to meet with someone? Do they know about you contacting us?
Okay, one of us will give you a shout later today if that works and we can set something up. Just on my way to another visit at the moment. No problem. Talk to you soon.

Hangs up

Lee: Hey Steve, that was Mags from the hospital, there is a person there that may need some support. Do you have time to give her a call and maybe drop in this week to meet her?

Steve: Yep, sure. I will give her a call this afternoon.

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A “referral” is the point of contact from the world “outside of CAMPP” to the world “inside of CAMPP”. There are a few ways that a person becomes visible to the CAMPP team via a referral. Referrals are initiated through fax, phone, text message, face-to-face conversation, and/or email from a service provider external to the CAMPP team. A common referral method into the program, as depicted in the above excerpt, is through a phone conversation with the person referring the potential client; this person was called the “referral source”. In cases where the referral form was not filled out by the referral source, the CAMPP member would take notes either on their phone or in a physical notebook and then transfer the notes into their electronic records later. Their electronic record was called “Bear” (pseudonym). All the programs at the main office where the CAMPP was located used “Bear” software for managing client information.

The CAMPP team structured its program in a way that allowed them to decide who their clients were through a flexible referral process that was negotiated with the referrer and the client. Another access point into the program was through the program referral form. The referral form applied to the CAMPP services and their “sister” program, the HCOT, who worked closely with them. The eligibility criteria for each program were listed on the organization’s referral form which is used by both HCOT and CAMPP. The CAMPP referral criteria were built from the HCOT form as there were many similarities in the clients they served. The main difference was the criterion of having a life-limiting illness or requiring end-of-life care. The CAMPP criteria also did not include the six emergency department presentations. This form was usually faxed into the office where a Medical Office Assistant or one of the CAMPP or HCOT staff members retrieved it. The receiving individual reviewed the form and passed it along to the proper team, either a HCOT coordinator or the CAMPP coordinator. The teams identified the


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appropriate program by reviewing the form and locating which team has been “checked off” under the section, “Reason for Referral” (see Referral Form below). If the last box denoting “palliative/end-of-life care” was checked off, then the form was meant for the CAMPP team.

Figure 3 - CAMPP and HCOT Referral Form



REFERRAL FORM

Health Care Outreach Team (HCOT) is a partnership between , Calgary [Shelter], and Calgary Allied Mobile Palliative Program (CAMPP). It is an intensive case management team that will provide transitional support from acute care to the community for low-income and socially vulnerable patients. The team will work to provide navigational support to individuals to improve access to health, addictions, housing, social, financial and mental health supports in the community, as well as palliative and end of life care.

Eligibility:

- Patient is homeless/vulnerably housed AND
- Patient is low-income AND
- Patient has at least 6 ED/Urgent care and/or 2 inpatient presentations in the last 12 months [Not required for CAMPP (palliative/end-of-life care) referrals]

Name: _____

Date of Birth: _____ Gender: _____ PHN (if known): _____

Has patient verbally consented to this referral? ☐ Yes

Reason for referral:


<input type="checkbox"/> Connection to primary care	<input type="checkbox"/> Mental health supports
<input type="checkbox"/> Frequent acute care use	<input type="checkbox"/> Discharge planning/care coordination
<input type="checkbox"/> Addiction/detox/treatment support	<input type="checkbox"/> Palliative/end of life care (provided in partnership with CAMPP)
<input type="checkbox"/> Housing support	
<input type="checkbox"/> Other _____	

Address/shelter where patient stays: _____

Best way to contact patient: _____

Referring source: _____ Date/time of referral: _____

Additional comments: _____

PLEASE FAX REFERRAL FORM TO 

HCOT PHONE: 555-555-5555
CAMPP PHONE: 555-555-5555

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The referral form was a text-based tool that facilitated and organized the first formal interaction between potential clients, service providers, and CAMPP and HCOT. It acted as a “ticket” into potentially becoming an “active” client of the CAMPP or HCOT. The information provided on the referral form directed the user of the text’s attention to the type of information that was relevant for the team receiving the completed form. In each instance, both the person filling out the form and the person receiving the form were activating the text (the referral form) into a social relation that generated the collective understanding that there was an intention that a working relationship was possible. The text coordinated the activities between separate groups of people across time and place (Smith & Turner, 2014) into a coherent, understandable relation.

The referral form included limited information, so frequently, members of the initial receiving program would transfer the documents pertaining to the individual to the other program and vice versa if, after gathering more information, the other program seemed more appropriate. There were also instances upon “intake”, receiving the referral form and accepting a client, when it was not clear which program would be most appropriate given the details provided. It was not always clear whether the prospective client was best suited for CAMPP services. Whether they needed “palliative/end-of-life care”, was, according to the referral form, how one would request CAMPP services. However, an aim of the CAMPP team is to get involved in client’s lives as early as possible if they are able. Therefore, if the CAMPP and HCOT teams could see that the person was on a trajectory where their health was deteriorating, but they did not necessarily have a medical condition that would deem them medically “palliative”, the CAMPP team could still take them on as a client. In these cases, the teams conversed in their shared office and often decided that a representative from one of the teams

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would attend the next step of the referral, a visit with the client, and it would be determined after the initial visit which team would lead the care.

However, the CAMPP team members did not rely too heavily on the referral form text to direct the course of their work. Instead, the team referred to the form as a “tool” that allowed people in the community to start a discussion with the CAMPP or HCOT teams to gain support for an individual. The referral form could be accessed by calling into one of the programs and it would be faxed to the caller to fill out and fax back unless they already had a copy of it from previous clients. In these instances, referrers could fax the form in at any time. Often the referral forms were used as a method to start the connecting-up process after hours because many adjacent service providers worked hours outside of the CAMPP and HCOT office hours which were Monday to Friday 9:00 AM to 3:00 PM. However, once a referral was made and a relationship between service providers was established, the referrers would often call into the CAMPP team by telephone if it was during office hours; otherwise, they would text or leave a message at the phone number for a CAMPP team member to reach them when they were able.

The referral form was not always filled out. The CAMPP team kept records of conversations but did not always require a referral form to be filled out if they were able to take the information via other mediums. The necessary file documents were the notes from the intake interview with the client and then any continuing case notes and medical records as they came up.

All referrals came to the CAMPP team from people who worked in the areas of social service or healthcare, on behalf of their patients or clients. Referrals to the CAMPP team tended not to come directly from individuals who needed support themselves. However, the CAMPP team would not refuse a referral based on who it came from.

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The CAMPP referrals are limited to those already connected to care. It is very rare that they get referrals from people who are not identified by a service provider as living with a life limiting condition or in need of palliative care. Recently, CAMPP had a referral form from a person who was concerned about her dad who was living with a life-limiting condition, isolated, and refusing to see a doctor; he died a few days later. This referral highlighted the reality that there are many people who are structurally vulnerable in need of palliative care who are not even accessing basic health service and who CAMPP may be missing. – Program Review Document (2018)

The tendency of referrals to come solely from other care providers is a by-product of the work processes occurring within the wider network of health and social services. There are systemic gaps in identifying isolated and vulnerable people who might want or benefit from care and the CAMPP team has started to recognize these gaps. However, because the CAMPP team is still mainly only known by service providers, who do the bulk of the referrals, clients' first route to the team is still partly shaped by the broader health and social care delivery system that itself generates overlooked care needs for this population.

To bridge this gap, the CAMPP team also made attempts to directly find or invite contact from people who might need their help. They attempt to make other channels available for people to connect with them by seeking out those who are homeless or by having conversations with people and inviting people to call them if they know of a person who needs support. The CAMPP team often did this alongside other programs that reached out to people in the community.

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An example of this is when I attended a ride along with Steve from CAMPP on a chilly winter day and we joined up with another agency that served people who were homeless in Calgary. We traveled to various encampments in the city to deliver bagged lunches to people and inquire as to supports they may need.

When we arrived, we pulled into a driveway up to a fence that was locked up with a chain. There was a driveway behind it, but it looked like there was a company who had put the lock up so that public could not drive in. There was a hole in the side of the fence, however, so the team decided to park the van next to it and we each grabbed 1-2 bagged lunches that were pre-packed by the team and stacked in the back of the van. We got out of the van and crawled through the hole in the fence and walked towards what looked like a ravine of trees. We were walking in a wide-open field space off the highway separated by a large ditch. The ground was covered in snow with many animal tracks across our path, but with only a few human footprints and some sparse tire tracks. It was clear that few people came in and out of this area. Along the distance and up a hill I noticed what looked to be expensive houses lining the field space.

All four of us (Steve from CAMPP and two other community service providers) walked together side by side in a 2X2 fashion. I had no idea where we were going. It appeared that nobody was around until we reached about 1 km into the field, and behind the first set of trees, I could see signs of people present. I noticed some food wrappers, heavily worn clothing, and other items like bike tires and metal scraps that were scattered about. In the distance, I started seeing more clearly that people had been living outside there. In the distance, there was a purple tarp draped across some tree branches that seemed intended to make a shelter. I was shocked by how large the living area was and how

many separate living spaces or enclosures were nested within it. The team called this a 'camp' which was short for 'encampment'. There were items like pieces of metal, single shoes, blankets, and other things lying around that appeared to be garbage because the items were left outside without order and were seemingly displaced. As we walked further into the encampment, about four more of these enclosures became visible and some were much larger than others. There was one that was just a tent with some rods sticking out as if it was improperly assembled, but the other enclosures looked much more robust and well-constructed. There were some that were propped up with makeshift walls created out of mattresses draped with tarps and blankets around them. It was noticeably very cold at this point, as I could feel my toes starting to go numb. I wondered how warm it was in the enclosures. I asked the team if they had ever been inside an enclosure and if they were warm enough or not and one of the team members told me that occasionally the people have propane tanks and other warming devices, but not always.

I followed the team closer to the surrounding area of one of the enclosures. They knew exactly who they were looking for and walked straight into the area where one of the larger tent type structures was located. They knocked on the side of the tarp and called out the person's name and identified themselves. There was no answer at first until we heard a soft-spoken woman's voice answer back, "The man you're looking for is here, but he is sleeping. Can you come back later?" One of the team members responded to her that they were there to remind him of a housing meeting that he had at 1pm that day. She asked if they could come back and pick him up for that meeting and the team member and his partner agreed and left two lunches for them. Steve [from CAMPP] remained quiet, but I noticed him looking around observing. He told me that he was taking a "backseat"

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to the other team members since Steve, and I were the guests on this trip and that they had the more formed relationships with the individuals at this point. I asked Steve about his role on these trips, and he said, “I like to be here in case someone needs us (CAMPP) and to be truthful, even if they don’t now, I am making myself visible if they need us in the future.” Steve is doing the work of inviting contact with possible clients and being present with the team that he scheduled to be with that day made it possible for direct referrals, self-referrals, or referrals from the encampment team. Steve is actively making CAMPP visible which is time consuming, but built into their day; for example, in this case, Steve clearly had arranged to go along with this other team – Field Notes January 17, 2020

The referral process was mediated by the eligibility requirements and assessment of appropriateness that took place after the first contact with the CAMPP team by an external party. The process was complex and involved many intricate details and decisions, but it was not a rigid process that one might expect in a larger health organization with many “well-oiled” systems and protocols in place. However, the process that they used was one highly recognized by typical health programs and services, the referral form. This document was similar to documents I have seen working in the non-profit and public sectors, yet the way that the CAMPP team used it did not adhere to a rigid expectation of institutional protocols that I was familiar with. Instead, while using a recognizable text that many healthcare service providers use, they could align with legitimate processes, but were able to use their autonomy to try to ensure this institutional process did not provide a barrier to clients accessing the service.

The CAMPP referral process takes a flexible approach and relies on the CAMPP team’s rapport and relationship with adjacent service providers in the community and professional

judgement of health and social factors. The referral form is part of the process, but the team does not rely on it as a replacement for gathering information from the client and the referring party. The form itself acts as a textual interface that helps organize the work amidst the wider agency and helps organize and distinguish the CAMPP work from the HCOT work.

The CAMPP team members accept referrals in several ways and seek out individuals who may not otherwise be able to access them. The next step in the process is deciding if the person will become a CAMPP client or not. If the person receiving the referral (either from HCOT or CAMPP) renders the individual an appropriate fit to the CAMPP team based on the form, the next step begins, the “intake” process. Transitioning from referral to “intake” occurs when a client is a “fit” for the program.

Determining “Programmatic Fit”

After a referral comes in, the team decides if the individual is a “programmatic fit” or not. This is a process that involves both the CAMPP team and the potential client in the decision to work together.

Courtney: How do you decide if a client fits your program?

Steve: It is usually a process or a conversation with their supports if they have them, and most importantly with the individual themselves. It may take a couple of chats or visits before we come to an agreement about if we will work together or not.

Courtney: Oh, interesting, so do you have criteria they have to meet?

Steve: Well, not really, I mean yes and no. Our job is to help with end-of-life care, but ideally, we see them as soon as they get a terminal diagnosis. That doesn’t always mean

they need or want support though. It's more of an assessment where we meet them and see. If they don't seem like a fit for our program, we don't leave them unsupported, they usually will still have HCOT, or other community supports. All our clients have multiple barriers to accessing care, social stuff like housing is a big one and even just not really understanding the health system or not wanting to engage with it is a barrier in lots of cases.

The CAMPP team labels their referral process and access to the program as “low barrier”. This means that they intentionally try to make entry into the program easier than if there were a set of stringent eligibility criteria to get into the program. They also make it so there are multiple routes into the program as described in the referral process above.

The CAMPP team does not use medical diagnostic tools at the point of referral. More than medical criteria, entry into the program is about the social factors that impact a person's ability to get care. Ideally, the CAMPP team wants people to be referred as soon as they can... [I]deally, the CAMPP team wants to identify people when treatment options are still available. – Program Review Document (2018)

Determining if a client is nearing end of life and is “palliative” can be tricky for referrers since not all referring service providers are equipped to identify whether someone has reached this stage of illness or not. This is when the referral comes in and the first visit by the CAMPP team becomes important to be able to determine “fit” for the program. The team also contends with what constitutes “palliative” or not. For instance, the circumstances in which people are without housing for extended periods of time often position people, especially those with serious illnesses, in situations where their health is much worse than if they had regular care and stable shelter.

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The CAMPP team has had major discussions that support the view that homelessness itself is a life-threatening condition. However, if they strictly adhered to lack of housing as an eligibility criterion, their team would not have the capacity to see all eligible clients since there are much larger numbers of people who are homeless than the small CAMPP team could realistically support.

The CAMPP team has offered training to many homeless sector serving organizations to help them understand palliative approaches to care and to try and extend the work that the CAMPP team does by educating others on the approach. For the CAMPP team, the criterion of “palliative” becomes essential as a case management tool such that the CAMPP team is responsible only for those who are in much poorer health and are much closer to end of life. It also distinguishes the team to funders as specialists in an area that other service providers are not. Individuals who are not deemed to be diagnosed with a life-limiting illness category then get referred “out” to other providers, in many cases to their partner program, HCOT.

CAMPP has never excluded people because the nurse coordinator’s case load was too high. There have been six people who were identified but were either not ready to engage or not a fit for CAMPP, or they “graduated” from the CAMPP program. Those who are not accepted into CAMPP have social determinant of health needs that can normally be met by HCOT, so not accepting the person into CAMPP does not mean they are rejected from support. In one case, the healthcare system was requiring a person to be housed and stable prior to initiating treatment for their life limiting condition. CAMPP stepped in to get this person housed, treatment was initiated, and they were no longer living with a life-limiting condition. – Program Review Document (2018)

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The CAMPP team approaches referrals and intakes in a flexible manner as they allow referrals to come in through the formal referral form or through more informal communications like text messages or in-person conversations. This intentionally flexible method is designed to minimize the “barriers” to their program as much as possible. Adjacent service providers echo this sentiment in how they describe the CAMPP team as “low barrier” programming. The language of “low barrier” programs was used several times by adjacent service providers about the CAMPP team and so I followed up with one service provider who described what this “low barrier” programming looks like and how it would be different from programs that are not considered “low barrier”.

Service Provider: CAMPP is just easy to access. They answer their phones and respond to texts quickly. Not just that, they don’t turn anyone away right off the bat because of what you fill out on a piece of paper [referral form]. They really explore who the person is and if they can help them given the extent of their capacity and resources. Even so, if they find that they aren’t appropriate for the person, they work with you to get the person situated. Not everyone gives you that kind of time or energy. They are truly just a phone call away.

“Low barrier” programming is a concept I heard repeatedly used by service providers in the community to describe the CAMPP team. This concept contrasted programs that they considered to be “high barrier” such as those with more stringent eligibility criteria or rigid referral processes such as the “income support” programs or applications for subsidized housing. The concept of being “low barrier” was a way of distinguishing the work of the CAMPP team from the more typical work of other programs that were “higher barrier”. However, interestingly, the language of “high barrier” was not used; it was only for those that were “low

barrier” that the barriers were pointed out, leading me to believe that most programs are inherently “high barrier”, and it is an advantage to have fewer barriers to care.

To be “low barrier” meant that they prioritized accessibility to the team through being available through multiple mediums including text message, phone call, email, and fax machine. They also built into their program that they would not turn people away if they were referred to the CAMPP team but would ensure they were connected to a program that would help them. Prioritization of accessibility, connecting people to support, and meeting with people to negotiate programmatic “fit” rather than adhering to stringent eligibility criteria through systemically imposed mandatory paper trails (e.g., mandatory completion of a referral form and making this the guiding practice of the initial referral) constitutes part of how their work functions as “low barrier” and how this is not common in programs serving the same population.

The determination of programmatic “fit” takes professional judgement and assessment skills and requires two sides of “fit” to be met. Two kinds of fit are apparent in the process of deciding if a person should become a client or not. There is the question whether the person’s health condition and social needs “fit” with the scope of services the CAMPP team offers and there is the question of whether, from the prospective client’s perspective, the CAMPP people and their service “fit” with what the client wants. The prospective client has a choice in deciding if the program is a fit for them as well. In deciding on the provision of services, both sides of “fit” must be affirmed before the CAMPP team takes on a new client. The CAMPP team’s work orients carefully to these two sides of fit. What is in question here is who decides “readiness” to come into a working relationship between client and service provider. In this instance, it is both the CAMPP team and the client, but it is within the CAMPP language to refer to the client as

“ready” or not. While it is possible that the client might say “I am not ready, maybe later”, it is more likely that they would decline by just refusing to meet with the CAMPP team or by not being accessible at all. It is CAMPP’s formulation that this person is not “ready” although not in the sense of not meeting a particular criterion such as sobriety or having a home. I will discuss this notion of “readiness” more in the next chapter when I speak about mainstream home-based palliative care and how this program decides on their clientele.

Additionally, part of the assessment of “fit” is how the CAMPP team decides if the prospective client needs palliative care. How the staff members determine if the client is “palliative” is carried out through their professional judgement and through the administration of a “palliative consultation” process which is typically led by the nurse coordinator and one of the team’s palliative physicians. Charles, the lead CAMPP physician, created a text which was a template to assess if a client had “palliative” needs.

The palliative assessment form (shown below) is a text that guides his professional assessment process and that then becomes part of the client’s file. The form is accessible to other care providers that have access to the file. These individuals can follow up with other palliative professionals using the contact information at the bottom of the sheet. There is also a boxed section at the bottom that refers to a program called the Palliative House Calls Program (PHCP). This is a program within the mainstream health system that provides palliative care to people in their homes in the community. I discuss this program more in the next chapter.

Figure 4 - CAMPP Physician Palliative Consultation Form

Palliative Care Community Consultation

Date:

Name:

Palliative Diagnoses:

Reason for Assessment:

Persons present:

Palliative Performance Scale³:

Goals:

History of Presenting Complaint:

Palliative Symptoms:

Pain:

Nausea:

Appetite/Constipation:

Fatigue:

Dyspnea:

Depression/Anxiety:

Cognition:

³ This is a standardized measurement scale validated for use in the mainstream health system which Charles transports for use within his CAMPP work. This textual information helps his work be made visible in hospital and mainstream health settings as it has relevance there but is put to use differently as part of the CAMPP work using the approach that CAMPP uses over time with their clients.

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Past Medical History:

Current Medications:

Allergies:

Social History:

Physical Exam:

Future Care Issues:

Prognosis:

Impression:

Plan:

Signed:

Palliative Consult service

CAMPP physician

www.campp.ca

Physician Pager: #####

Phone: #####

Fax: #####

To discuss this patient further please contact ##### and we will return the call.

To discuss OTHER patients for palliative support:

Regular weekday hours for urgent (<1 hour) phone advice: *Specialist Link:* #####

Urgent after-hours phone advice: #####

Non-urgent advice (<5 days): #####

To refer to Palliative House Calls Program (PHCP):

Contact PHCP Access ##### OR

The CAMPP physicians are employed by the mainstream health system and work with the CAMPP team one day per week. They have access to the mainstream health system electronic

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records of the clients, but the CAMPP staff do not have the same access. Because of the physicians' affiliation with the wider health organization, they use similar documents as the one above in their work with non-CAMPP clients.

The CAMPP physicians use this text as a guiding document to lead what they refer to as a “palliative consultation”. However, the team stated that using this template often does not work well with the people they are trying to reach. They are often unable to get through all the information in a single visit or even in the first several visits because many individuals they work with do not trust healthcare providers and it takes more than one or two visits to build trust. Normally, in Charles's day-to-day work with the mainstream system, he uses this form and gets through assessments in one sitting, but he finds that this method is not ideal for the CAMPP client population.

Charles: I often find that we/CAMPP never get through half of the issues in a first meeting with our CAMPP clients...we need lots of time to establish relationships. Lots of questions can appear to many folks to be overly intrusive. Therefore, it is very hard to do a “formal” well-structured consult that I would do, say, in my regular palliative practice.

Therefore, the actual consultation process with CAMPP clients looks different from what the palliative consultation document organizes for mainstream health patients. This means that the person doing the consultation with the CAMPP client is not always able to follow the topics of the form in the order they are listed or complete the consultation in one sitting. The text is formatted in a way that the consultant is expected to move from one item to the next; however, the consultant, in the case of working with CAMPP clients, does not insist on getting information

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in one category before moving on to another. Like the team's use of the referral form, the palliative consult is used as a guide, not stringently followed if it does not suit the need of the client. Instead, the physician would gather the information in a more conversational manner and if they did not obtain the information, they would allow the relationship with the client to grow and gain the information more "organically" rather than through a linear, time sensitive, "question/answer" format that could put the relationship at risk by rushing it and also shape the client in a way that suits the institutional need for order more than the client.

Learning about the palliative consultation process through interviews and through observations was striking because it is vastly different than how I recall my own experiences with palliative services in the hospital when I had loved ones there who were dying. In those cases, most often we did not have a palliative consult, but when we did, we felt pressured and rushed and we felt that we needed to disclose the information they requested regardless of how we felt about it. With CAMPP, they took their time with their clients, and they told me this was because if they did not do it this way, it was likely that the clients would not want to see them again at all, and so it was also a way of preserving the relationship to keep them connected to care. – Fieldnotes November 5, 2020.

The team prioritizes sensitivity in their conversations with clients and lets the clients disclose the information that they want when they want to. The CAMPP team lets the client have authority in the conversation rather than prioritizing the order of the program text. While the information in the consultation form is important and there for clinical reasons, the team is there to support the client and build a relationship of support and trust, so this is a key focus.

Scholars have done work in other similar settings such as shelters and hospitals where they look at how the person, transformed into a “client” in institutional settings, is constructed based on embedded institutional practices. For instance, Marvasti (2002) investigated how one American homeless shelter constructed “service-worthiness” through conversations between shelter applicants and service providers. Marvasti found that clients’ stories in and of themselves were not always enough to ensure they would be accepted to stay in the shelter, but they engaged in a practice of explaining themselves in ways that deemed them worthy of services. This institutional investigation helps us see how various practices between people come to elicit very real consequences in the lives of people who access social programs. Similarly, but in a different context, and using institutional ethnography specifically, in 2001, Campbell examined how a nurse used institutionally sanctioned forms to conduct an assessment with a patient applying to live in a government subsidized long-term care facility. She found that the assessment form directed the nurse’s work toward the topics listed on the form and detracted from what the applicant was telling her about his needs. The form oriented the nurse to specific details directing her to collect certain kinds of data from the applicant that “overrode the applicant’s attempt to communicate his experiences” (Campbell, 2001, p. 239). This was an important finding for Campbell because it depicted how a text mediated the interactional event enacting a particular relation between the nurse and the client that opposed the value that the nurse’s organization purported to operate under, “client-centred care”.

The above palliative consultation template is an adapted version of the standard palliative community consultation form that Charles used in his work within the mainstream healthcare organization. He adapted a version of it to use with CAMPP clients but found that he often could not complete it because the individuals did not always want to answer the many very

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personal questions without having a prior established relationship with him. In Campbell's study, she shows how an assessment form shaped the relationship between a nurse and an applicant which was structured by the organizational agenda that the form was constructed from. The CAMPP physician, and the wider CAMPP team who were charged with determining "fit" within their program, shifted the way they used this particular text that still adhered to and was recognizable as part of the wider organizational norms, but that was better adjusted to serve the clients using their forms as supplementary to their process rather than a determinant of their work. This is an instance of understanding texts as ways in which our interactions with one another can be coordinated and activated through our uses and interpretations of such texts.

If there were concerns outside the form that the client brought up, the CAMPP team members could address them because that was what was important for the client in that moment. The CAMPP physicians and the CAMPP team had the freedom to decide to stretch the assessment over multiple meetings, to gather information in an order other than that provided by the form and could justify this based on the clients' needs and preferences for giving information. In Campbell's work, the aforementioned nurse likely did not have that discretionary autonomy—she probably only got one visit with the client and her supervisor likely would not accept the client-led pacing justification for coming back with incomplete information. This is an example of the way the small size and independent management of the CAMPP program allowed staff to work in ways that accorded with their principles and the needs/preferences of clients.

However, noting their relatively independent operation is not to say that the CAMPP team exists outside of institutional ruling relations; rather, they have identified and worked into

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their processes an awareness of the way texts that are meant to support their work can guide their attention in a direction away from the needs of the client. For this reason, they actively work to produce a way of practicing a consultation that addresses this disjuncture. The form, however, still guides the information that Charles orients his attention to. Charles is still operating within the ruling knowledge of his medical practice as he is trained to look for specific details that are medically relevant to provide appropriate palliative care. However, the way he orients to this knowledge is driven by the client and not the content of the form. In this way, he and his approach to consultation straddle the recognized and legitimized way of working with an approach that, in his estimation, better suits the needs of his patients.

Further, defining “fit” for the CAMPP program is more than determining “eligibility” or filling out text spaces in a predetermined format. Rather, the CAMPP team enacts a type of practice that requires adaptability, discussion, flexibility, and ongoing monitoring. Their focus on determining “fit” tends toward the social factors that impact a person’s ability to sustain their health.

Lee: Most of our folks are homeless or vulnerably housed, that is pretty much first off. We need to make sure we can get them housing, or it is very difficult to help get them medically stable.

We meet with a young woman today who has end-stage renal failure. The team members state she is functioning well at the moment, but that they expect her health to rapidly decline. Today’s meeting is one of the initial meetings with the young woman and it is planned to take place on a sidewalk in a busy part of town. The CAMPP team

hears from another service provider in the community that she was seen there earlier in the day and so CAMPP slots this visit in their schedule. A major way of tracking clients is through communication between service providers at shelters and other social service agencies because these are the “eyes and ears” of the streets, and they are out there seeing clients so can tell each other if they see people that others are working with. We arrive at the planned spot, and we park the car nearby and walk over to where she is sitting. We meet with her on a sidewalk where she has a sign propped up next to a tree and it says, “handmade goods for sale”. I notice that the “goods” she is selling are bracelets and they are beautiful. We all sit down on the pavement, and she asks us to be cautious where we sit so that she could continue selling her items to the passersby and not block potential oncoming buyers. Charles agrees and states that he will just ask a few questions and perhaps they can continue chatting over lunch another time. She agrees.

As we walk back to the car, I overhear Charles and Lee talking about “next steps” in the care plan and they say, “first and foremost she needs stable housing, no way she is getting any better on the streets.” I notice that even this brief encounter with her helped build rapport through the agreement to a potential lunch meeting in the future which could be the start of their client-caregiver relationship. Perhaps between now and then, CAMPP can gain a lead on housing for her. – Field Notes October 22, 2019

While it was not clearly stated in the above encounter that the individual would be a client, the discussion between Charles and Lee assumed that the team would continue seeing her since she

did not have housing and had a serious and deteriorating health condition. They came to this decision without a formal palliative consultation form. However, the information they collected in the first encounter was enough to know that this would initiate a longer-term supportive relationship. The first visit did not appear to be medical in nature (i.e., taking vital signs, asking questions about health, etc.); however, it was a crucial encounter that established rapport with the client to get to the more personal medical information that they will require in the future to ensure a continued healthcare plan. This meeting allowed for a verbal agreement to take place for the next visit and served to ease the forming of rapport that would allow the care to continue.

In this encounter, the referral source informed the CAMPP team that the woman had a terminal diagnosis, but the team still needed to gather more health information to determine exactly how sick she was, the level of care that she would require, and if the client wanted support. The CAMPP team planned to do this over the next several visits, respecting the comfort level and space of the client.

The CAMPP team's process of determining if a person becomes a client involves the client's preference and timeline of being comfortable with disclosing personal information. The CAMPP team's attention to the client, using text-based processes recognizable by the institutional workings of social and public sector care services (e.g., the referral form or the palliative consultation form) that often take the place of the client-worker interaction and professional judgment, but adjusting them to suit their approach to care takes power away from the typical text-based process while still relying on the familiar text-based process. The structure of the palliative consultation form came from the way that the mainstream health system carries out assessments. While the CAMPP physician still used this assessment form as a

guide, he recognized that it did not fit the client population that they worked with and so adjusted the process to fit the clients' needs, removing them from the mainstream work process that bound him to the form for his "regular palliative practice". In this way, he is working within the confines of institutionally embedded practices but tweaking them to work for the client through the intended approach of their program.

"Graduation", Transferring Clients to HCOT, and referring to PHCP

I have discussed how the CAMPP team decides on who to work with as clients, and now I will turn to how clients "leave" the program. There are several ways to stop being a CAMPP client. First, given that the CAMPP team works with people who have a life-limiting illness and are nearing the ends of their lives, one exit from the program is death. Another exit is by "graduating from the program". With a "graduation", clients may get "transferred" to the CAMPP's sister program, HCOT, or they may get referred on to the more mainstream palliative community program called the PHCP.

In the following section, I discuss the processes of "graduation", "transfer" to the HCOT program and referral to the existing PHCP.

According to the CAMPP team referral form, the main eligibility criteria for a referral is that the person needs "palliative/end-of-life care". The section on the referral form is used by both the HCOT program and the CAMPP team. The form states that care is provided "in partnership with CAMPP" because the form is mainly used by the HCOT program. This "partnership" refers to the two programs (CAMPP and HCOT) that are intended to work "interdependently". This interdependent working relationship occurs primarily if the health and social status of the client changes drastically for better or worse. A "transfer of a client" occurs

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after the initial “intake” as stated above. This is a circumstance where “eligibility” could change after the initial referral and intake. The teams support each other in day-to-day work, but the “transfers” denote which team has primary responsibility to stay connected with clients and monitor their health and social situation. For instance, in cases where a client is supported by the CAMPP team but whose health improves to the point where they are supported by other service providers or no longer need “palliative/end of life care”, CAMPP can “graduate” a client from their program or they can be monitored primarily by HCOT.

Harriet: Life is good. I mean, I am not as well as I was you know, but you know I probably never will be, but um, I’m still living. I’m alive today. I’m trying. It’s wonderful you know...they [The CAMPP Team] actually said, “well we’d like to graduate you in the CAMPP program, you know, because you’re doing so well.” So, I thought that would be really wonderful, but we haven’t got there yet.

A “graduation” occurs if a CAMPP client no longer needs as much support from the CAMPP program as they did initially with the team. This typically happens if a client’s poor health is, in part, a result of social factors (e.g., vulnerable housing) and their inability to manage their illness. In Harriet’s case, she was working with the team for years when she was extremely ill with few supports in place to help her manage her illness. At the time of the interview, she was managing much better than when she met the CAMPP team, so they started discussing “graduating” from the program.

Graduation is not something that happens at once and is a “final” decision about the client. Instead, it means that the CAMPP team will “pull back” from supporting the client but

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can “revisit” their file if at any point the client needs their support. In practice, this means that they can continue to see the client, where the “file” acts as a stand-in proxy for the person.

Ellen Pence produced the concept of “institutional tweaking” which is relevant here as she spoke about slight changes in organizational work processes that had definite benefits such as creating a set of questions for police officers to ask when they attended a domestic violence call (McCoy, personal communication, May 5, 2023). This slight change was one that did not impact the functioning of the entire system, but that had definite benefits to the people, namely, the victims involved. Similarly, the CAMPP team models this institutional tweaking with how they use their referral forms, their palliative consults, and their use of the commonly recognized concept of “case files” in health care. They tweak these processes in ways that make visible the unique needs of their clients. The CAMPP team has the autonomy to use institutional texts in ways that help their clients and do not allow the texts to “rule” over their processes.

For instance, when a client graduates from CAMPP, but later post-graduation, the client requires help again, the CAMPP team’s practice is that this individual could bypass the referral process since they had a previous “case file”. The client could simply make a phone call or contact them in the way they preferred and the CAMPP team would support them once again. The CAMPP has created a zone of textual autonomy to use texts within the system differently than they may commonly be used in the mainstream system, but they are still recognized by other service providers in the same way so are credible in that way to ensure other service providers understand and “buy in” to their use.

Stated another way, “graduations” from the CAMPP team are instances where clients are in need of “palliative care” when they start working with the CAMPP team but become “stable” enough after a period of time that their health and social circumstances improve to the extent that

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they no longer need palliative/end of life care, but often only require ongoing social support through HCOT or other supports. Alternatively, the CAMPP team could deem them to be well-supported by other programs at their palliative stages and so the CAMPP team could step back and help those who have more urgent need. Lee describes how graduation is decided upon below,

Lee: Basically, our goal is to make sure that the client gets the same level of care as everyone else in the [healthcare] system. If we are able to remove the barriers that inhibit them from accessing the health system, which often can be difficult to do and will often re-surface after the fact, then we will step back. But because the barriers are really pervasive, more often than not, the wheels will come off and then we will be needed again. Basically, if we can get them connected to PHCP and housing and they're well-supported then we can back off because then the system is working. But the spiel that I would give a client when I was stepping back would just be to let them know that if things start going sideways and they feel like there are cracks or they are not getting the level of care they need, then they can just give us a call. There wouldn't be an intake process or referral or anything.

When there is a referral between CAMPP and HCOT, they do not use a referral form since they share an office space and a software system that houses client information. This process is called a "transfer of client" rather than a new referral. The transfer in the referral or intake processes between the programs is timely and effective because the teams update client information, case notes, and other relevant information in the same database and work in the same office. A "transfer" between the two programs is often a simple conversation over one's shoulder. For example, there may be a client who is working with HCOT for many months or

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years but begins to display deteriorating health. In these cases, the HCOT worker may invite the CAMPP nurse coordinator to attend a meeting with the client to determine if the client would be better supported by the CAMPP team based on the change in circumstances.

[Upon referral to CAMPP] the nurse coordinator will do the initial visit to obtain consent and begin building the relationship with the patient. In cases where the person is referred to HCOT initially, a health navigator may go out and do the initial visit and then determine if? or [sic] a referral to CAMPP is necessary. – Excerpt from Internal Program Review (2018)

In other cases, especially where a provider refers multiple people to the CAMPP team over time, the first contact is often by phone call, text, email, or in-person discussion because of their prior rapport. There is a difference between fitting with program criteria and being a “fit” with what a program offers. For the CAMPP team, the “fit” is determined in terms of what the person needs with their social context at the forefront and inextricable from their medical status. What the CAMPP team was not doing was determining “fit” in relation to set eligibility criteria.

We are driving along in the car and Steve pulls over because a text message comes in that will take longer than a quick glance to read. I notice the tires struggling a bit to gain traction in the snow. We laugh about snow and ice being hazards of the job when combined with the many phone interactions that the team must make throughout the day. We pull as close to the curb as possible, and Steve focuses on the text message. He starts typing a reply message and then stops and starts dialing. We share a laugh and a nod because of the shared experience of mild frustration with trying to capture a complex thought in a text message conversation. He puts the phone in speaker mode so he can drive and talk at the same time. He starts talking to another worker external to CAMPP

who may have a potential referral. I hear that the potential client is in the hospital and will not be discharged yet, but that they may be a “fit” for CAMPP. I listen closely to what a “fit” might be. The discussion is about where the client will go when they are discharged from the hospital and how they will manage in the community. The person on the phone explains that the potential client is “vulnerable” and “likely won’t do well” on their own. They continue explaining that the person had housing, but it fell through while in hospital and the person on the phone hopes that something else comes up before they are discharged from the hospital. They agree that Steve will meet with the individual to determine if they would be a good “fit” for the program. They hang up. I ask how they will know if they are a good fit and Steve states that he does not yet know who the person is and how connected to other workers in the community they are. Steve explains that some people have CAMPP’s phone number and so it is just easiest to call and if it is not immediately obvious then CAMPP will go meet with them and gather more information. I ask what will happen if the person is not a fit and Steve states that they will just make sure they are well supported through their own networks, HCOT, or other service providers— Field Notes January 14, 2020

In cases like these, a meeting comes before the completion of the referral form and in this case the CAMPP team fills out the form after they believe the client is a “fit”. The referral form is a widely used practice among social services and health care programs. It is an institutionally recognized way of formally requesting support between service providers and sometimes between the program and the public. In this case, I bring to light how the referral form is used slightly differently in the case of the CAMPP team; while maintaining the structure and appearance of an institutionally recognized form, they go to work adapting its use to better suit

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the needs of their client population. In the case of receiving a completed form, the team member then passes it off to the Medical Office Assistant to enter in the database as an “open file”.

Determining who did the initial meeting depended on who was initially contacted, who was available, and who was best suited to work with the client given the team’s experience and expertise.

The referral form is a text that represents the initial “connecting up” between the individual and the team but does not stand in for the client ongoing and does not “lock in” the client to either program.

As other institutional ethnographers have found in previous studies, texts can often serve to act in proxy of a human being and their lived experiences. For instance, Pence (2001) said, “in work processes, organized and limited by formalized texts, women’s experiences of violence and intimidation are erased, and issues of their safety disappear.” As we have seen with the referral and palliative consultation processes and will see more in the next section, the CAMPP team tries to keep the experiences of their clients “present” in their texts, from referral form to writing up case notes.

The CAMPP team also works closely with the PHCP team. As I have discussed, there are numerous ways “out” of the CAMPP program once someone has become a client, including graduating, transferring, and death. Another possibility is through a referral to the PHCP. As discussed earlier in the chapter, part of the work that the CAMPP team participates in is deciding who fits with their program, which is formulated through the language of “readiness”.

In a referral to CAMPP, the team and the clients decide “readiness” to engage in a working relationship through a mutual decision-making process. However, “readiness” is a term also used within the more mainstream palliative system, the PHCP, when they describe whether

people are to become their clients. Because the CAMPP is a program with limited resources and the mainstream palliative system is a much larger program with the ability to carry a larger roster of clients, the CAMPP team's work also involves referring clients to PHCP when and if they are "ready". The CAMPP team is not functioning as an entire alternative to the mainstream palliative care system or PHCP. Rather, the CAMPP team is intended to address the needs of people who are not, in the terms used by PHCP, "ready" for their program. So, for some people, the CAMPP care can be an *alternative* to PHCP, but others work with both teams to address their needs, and still others might transfer completely to PHCP once they are categorized by PHCP to be "ready. I discuss readiness more in the following chapter when I describe how the CAMPP team works adjacently to the mainstream palliative care system.

"Maybe we Can Finally Eat our Lunch": Office and Paperwork.

The team regularly ends their days with clients by 3:00 PM. At this time, the team wraps up their client visits and aims to head back to the office to complete administrative tasks like writing up their case notes, filling out time sheets, writing up program statistics, filing expense forms, returning emails, and whatever else might come up when they got back to the office.

As we walked into the office at the end of the day, Steve chuckled and said, "well maybe we can finally eat our lunch!" I laughed at this since we had picked up lunch at 12:30 PM that day and just when we started eating it at that time, Steve got a call that one of his clients was at the local shelter and he did not want to miss him, so we took one bite and quickly packed it up and drove over to see him. – Field notes November 19, 2020.

The team does not carry out each administrative task every day, but on most days the team update their client "case notes" in their shared online platform. The software program, "Bear", is

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a type of electronic medical record (EMR) used by the CAMPP team, the HCOT team, and all other teams that work out of the building. The team does not typically use hard copies of documents to keep client files. If the referral form is faxed in, the team scans the hard copy to Bear or in other cases, they manually enter the information. By sharing the software among the wider agency, the teams can see if their clients are connected to the other service providers in the organization. For the CAMPP team, they use only part of the software program to log their case notes but can view other areas of the program to obtain updates on client visits to other service providers in the organization such as if they have seen a physician or a mental health therapist. There is also a scheduling system within the software program that allows the team to see if the client has appointments with other service providers. This function helps them support clients to keep track of their appointments. The following figure is a simplified representation of part of the daily scheduler in Bear that the CAMPP team members have access to.

Figure 5 - Representation of the Bear EMR Scheduler Interface (Shown from 9:00 AM to 12: 00 PM)

Time of Day	Steve	Lee	HCOT Staff	HCOT Staff2	Mental Health	Physician
8:00 AM						
8:30 AM					<i>Client name</i>	<i>Client name</i>
9:00 AM					<i>Client name</i>	
9:30 AM			<i>Client Name</i>			<i>Client name</i>
10:00 AM						<i>Client name</i>
10:30 AM	<i>Client name</i>			<i>Client Name</i>		
11:00 AM		<i>Client Name</i>				
11:30 AM	<i>Client Name</i>					
12:00 PM						

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The figure illustrates a pared down version of the actual scheduler but shows the significant aspects that the CAMPP team refers to daily. The names of the service providers are across the top and the time of day along the left side. In the figure are client names next to the times they are expected to meet which provider. CAMPP team members can log in and see if their clients have upcoming appointments with a service provider and if so, can help ensure they can support their attendance, if needed. Other times, the scheduler makes it easier for the CAMPP team to connect clients up to service providers they would not otherwise have access to because they can request an appointment with a specific provider since they deliver care “in house” and can see when other service providers are available. The ability to share a scheduler takes much of the “guess work” out of the referral process between service providers within the organization.

Additionally, if a CAMPP team member is unable to find a client, they can log in and check if the person has seen a service provider recently and inquire about their whereabouts and health status by checking with that service provider about the last appointment.

Another part of the Bear EMR is the section where the CAMPP team logs their notes from the work they do with clients. Lee explained to me that their focus in taking notes is to provide “continuity of care”. This means that it is a way to communicate to other care providers what is happening for the client in the most clear and concise way possible. Below is a basic version of the template area where they write their notes. The team follows the common note taking format used by medical professionals, called “SOAP”. “SOAP” stands for the note headings “Subjective”, “Objective”, “Assessment”, and “Plan”. This is located on what is called the “Medical Summary” page of the EMR. Lee explained that this note-taking format comes

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from the medical model of care and while the CAMPP uses the spaces provided, the team's focus is more on the "socio-economic side of things".

Lee: We still use the same [SOAP] format, but we tend to gravitate more towards the subjective piece. And part of it is just the layout, there is less room in the objective part, right? But usually, it's because we are not looking at objective things. To me, from a nursing standpoint, the objective things are like things you can see that are like hard science, that's this person's blood pressure, that's the width of their wound, they're clearly struggling for breath, umm but most of the time that's not what we are working on, we are working more on the socio-economic side of things.

The "Subjective" text space is for the CAMPP team's observations of what the client reports to the team such as complaints about their health or social conditions and is where the CAMPP team tends to focus their notetaking. This could include things like unstable or unsafe shelter, transportation needs, support with navigating applications for government benefits, tracking appointments, and much more. The "Objective" space is where the service provider's physical observations are noted. The "Assessment" section is used as a sort of "title page" because this is what people see when they are scrolling through the notes in Bear. Lee describes that they use the "Assessment" section for two reasons,

Lee: We use [the Assessment section] to a) count our visits or count our interactions because it is easily pullable [for reporting purposes] and b) to use as a brief descriptor, like a two-word descriptor of what happened so that it is easier to refer to when we are looking back. Like you can search "CAMPP RN" and the note next to it would say something like "Home Visit: wound dressing change".

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The CAMPP team is focused more on the social aspects of the client's health situation and logged these under the other three headings. The "Plan" section is meant to be written at the end of the day and denote the tasks ahead for the writer or client to carry out.

Steve wrote in the "Medical Summary" page what he thought would be relevant to other service providers such as status of the client's social environment, who the client had been in contact with or had not been in contact with recently, current health needs, health status or change in health status, requests, and the work that Steve did for that person.

Steve stated that if he did not have time to update the entire client file, there was a "note" function that he could quickly jot down a note that would remind him of what he did in a day. The notes were attached to the client file and could be written in the "scheduling" component of the EMR so all it took was a click of a button to give the reminder and then when Steve had more time later to complete the "official SOAP note", he could update it. The "note" box was a blank text box without prompts about what was "supposed" to go in there and other service providers did not typically review this area, and this was not the "official" client case note that would remain on the client's file. – Fieldnotes December 23, 2020

Steve's attention to where he places his note, whether it is in the "official" section, is important because he is orienting to who will read the note and he wants to be sure when he logs the note that it is well thought out rather than a quick "jotted" reminder. I ask him about this:

I watched Steve as he updated his notes and I ask if he ever ran behind in his notetaking and he stated that currently he was still updating last Thursday's notes (today is

Monday). I asked if this has ever caused miscommunication between service providers and he stated that he kept people updated face to face, over text, or on the phone, and he preferred this because more informal contextual things could be shared in this way and not be permanently written in the case notes. – Field notes December 23, 2020.

Steve's orientation to how the client is construed via case notes is an example of how he is aware of the power that the text has in standing in for a client (Pence, 2001). He verbally shares information with the other service providers that is not written in the case notes and only records certain details. The prior valuable information is shared "informally" and "off the record" and by recording information, he is aware that there is a potential transformation that occurs that makes information "official" and "permanent". Steve wants to make sure that he only writes what he knows would not have negative consequences to the client if it were written in the permanent file, because without being able to fully explain the client's circumstances to the reader, and without knowing who is reading the note, based on his client's experiences and his own experiences in the health field knowing that not everyone takes the approach of understanding and withholds judgement, he may be worried it could get misconstrued and leave the client vulnerable to criticism or negative perceptions.

Steve alludes to the idea that once something is written down in the "permanent case file" that stands in proxy for the client as well as the providers' experiences with the client, there are many ways it could be interpreted because written notes are devoid of inflection, tone, and affect that come with communication in person. For instance, the notes are to be written quite succinctly and meant to focus on what is observed, with minimal individual interpretation. This style of writing notes is common in the medical field and the team adheres to this in the

“official” note-taking sense. That is, the CAMPP staff write the notes in ways where little can be left to interpretation. Steve might write succinctly in the notes, but then elaborate to Lee later about more details of the visit and how it “felt” or his interpretation of the visit, something that there is very little room for in the template provided in Bear. As Pence (2001, p. 203) described in her work studying domestic violence and the legal system, “organizational texts order and coordinate the practices of dispersed organizational settings. Hence, they will be read and interpreted differently on different organizational occasions (Smith, 1990).”

The prospective reader of the case notes may have separate organizational demands and interests leaving the notes to be interpreted differently depending on the role of the reader. It could also be the case that the way that the CAMPP team pays close attention to the “subjective” side of things is not rendered legitimate in the traditional medical model and so they keep that part outside of the “concrete” physical reporting system.

Lee explains to me that much of the notes that the CAMPP team take focus on the “subjective” aspects of the client’s situation and that the issue of misinterpretation is less a problem for the CAMPP team since Bear is only used internally to CUPS, so he would not feel entirely like he cannot include subjective pieces, but he has to make room for this in the template provided. However, Lee also mentioned that he has experienced negative reactions to subjective notes when he was a nurse in the mainstream system charting issues in other clinical roles where the information is shared more widely. Using the EMR text in this way demonstrates how the CAMPP team orients themselves to the organizational demands that require notetaking, but also adjust their practice to suit their clients.

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Another issue that Lee mentions is not having “access” to editing other program notes that only the physicians on the team can update, which can be a barrier in communicating about what is happening with clients.

Lee: Clinicare is a provincial database that has information like records of medications, any lab work, any formal consultations that were provided by specialists, and discharge summaries of patients as long as they are properly signed. We can read stuff on Clinicare, but we can’t chart on it. We also don’t have access to SCM which is the provincial acute care EMR which has records of the daily stuff like flow sheets, check-ins, and more up to date stuff. The nurses and docs document in SCM and some end up in Clinicare if they are properly signed, but the rest, the majority will not.

Courtney: What do you mean by “properly signed”?

Lee: Oh, okay well Clinicare has a lot of useful information on it, but there is often stuff we know happened with a patient that does not show up on Clinicare because it wasn’t properly signed off on yet by a doctor. We rely a lot on the [CAMPP] doctors because they are able to chart in Clinicare and access “SCM” and so we stay in touch with them throughout the week if we need something pulled up.

Note-taking to keep track of the CAMPP staff’s activities with clients is more than simply writing down the day’s happenings. There are several interfacing software programs that work together to generate a larger narrative of what is happening with a person that they are working with at any given time. Because the CAMPP team is not a formal program embedded within the mainstream health system, there are benefits and challenges associated with the varied access to

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chart notes located across various programs and this can comprise benefits and challenges when it comes to client care. They rely heavily on the physician whose work overlaps both systems. The physician role acts as a conduit between the CAMPP team and the mainstream health system so that the CAMPP team can stay informed and care for their clients with the most up to date information.

Disjointed communication can result in missing important medically related client events or appointments that can cause problems for the client. For instance, if medications have been updated by a physician for a client and this note is in a database that the CAMPP team does not have access to or if the note has not yet been logged when a CAMPP staff member is able to view it, and they are helping a client with managing their medications, the CAMPP staff may miss important relevant information. Navigating client charts across mediums of communication within their home program, their wider organization, and the mainstream health system is a key part of the work that the CAMPP team navigates through regularly to keep up to date on the happenings of their clients.

Conclusion

This chapter describes how the CAMPP team regularly organizes a typical day of work. I discuss how the CAMPP team works with texts in a way that recognizes that the texts hold the power to change the narrative of the client's experience and stand in for them. The CAMPP team also views the texts as supplementary to their processes rather than concrete unchangeable regimens they must follow. Because of the socially marginalized position of the clients that the CAMPP team works with, they adapt their work to suit client needs where possible. The CAMPP team has "tweaked" the use of common institutional texts without changing the overall

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rulings of the “system”. That is, they have adapted their work within the system to suit their client’s needs. These examples of texts that the CAMPP team uses, the referral form, the palliative consultation template, alternative use of case files, and the Bear EMR, are institutionally recognized by wider relations of healthcare, but the team goes to work tweaking their use of them to fit the needs of their clients.

The CAMPP team uses typical mainstream methods of charting to operate within relations recognizable and repeatable within the wider health system. However, they can operate within these confines to shift the way these programs and processes are mobilized to accommodate their work priorities. In later, research, it may also be interesting to do more of an in-depth exploration of the texts, especially the scheduling and EMR systems and how there may be disjunctures in the way these systems are meant to function and the way in which CAMPP must shift to accommodate them.

The team must also navigate several complex interfacing software programs that house various aspects of a client’s “story” all crafted in different ways, and in different formats, intended for different audiences. Their relatively independent status from the mainstream health system positions them in a way that keeps them reliant upon the CAMPP physicians to access and update certain pieces of client information. With the physicians attending only weekly, this can create challenges for the team in keeping updated on clients’ situations.

The daily tasks of the CAMPP team include planning and organizing the day, face-to-face client work, pivoting from previously held plans, and administrative duties. These tasks take skilled judgement which is guided by a purposeful way of working set up intentionally by the CAMPP team. The decisions that the team make throughout their day are shaped by their

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experiences working with a population with specific needs: those who are extremely ill and experience vulnerable housing.

In the following chapter, I discuss how the size of the CAMPP team and their relative autonomy in relation to the mainstream health system allows them to work in a way that is flexible and enables the team more discretionary range with respect to their service decisions. That is, the team has explicit principles/working experience that they draw on to make use of that discretion. I discuss how the team constructs their work in a way that reshapes the discourse of “palliative care” using well-recognized institutionally embedded healthcare concepts like “harm reduction” which allows them to permit themselves certain flexibilities and admissions in their work that mainstream health services such as the PHCP often do not recognize as part of their responsibility to patients.

Chapter Six: Constructing Palliative Care: How CAMPP Organizes Their Work While Operating in the Interstices of the Mainstream Health System

“It is not just about controlling symptoms, end-of-life is about much more than that, it is about your life, your legacy, your soul, the things that are important to you that make you the person you are, the human you are.” – Charles, CAMPP Physician

Introduction

Moving from a description of CAMPP’s typical daily work activities in the previous chapter, the current chapter discusses how the CAMPP team puts into practice what they describe as a particular model of harm reduction to inform their palliative care delivery. This chapter also describes how the team members go to work with and alongside the existing mainstream community palliative healthcare system, the PHCP. Drawing from the literature on the concept of the “good death”, this chapter also highlights how the construction of the “good death” that is pervasive in our society undergirds our societal idea of what it means to care for people at the end of life. This concept highlights that the needs for socially marginalized populations may not fit with what typical medical models of care offer. Because there are practices that are not recognized as typical, they may be excluded or delegitimized by mainstream service providers and decision makers. This chapter focuses on how the CAMPP team constructs their work in a way that, while within the boundaries of health and social care ruling relations, extends the discourse of palliative care to include practices and work activities that typically are outside of medical models of care.

As mentioned in the Literature Review and Background chapter, the traditional definition of palliative care refers to an approach that aims to “reduce suffering and improve the quality of life for people who are living with life-limiting illness through the provision of: pain and

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symptom management; psychological, social, emotional, spiritual, and practical support; and support for caregivers during the illness and after the death of the person they are caring for” (Framework on Palliative Care in Canada, 2018, p.4). In this definition, palliative care is an approach that can be provided at any stage of an illness. End-of-life care, by contrast, focuses specifically on the care provided to an individual when they are in the last few weeks or months of life. The PHCP is a program that is delivered by the publicly funded health care system. This team has a wider capacity to see clients and is the main service available for Albertans requiring support nearing end-of-life. While the CAMPP team is not a part of the mainstream public health care system, frequently, these two teams work closely to deliver care; however, the scope of practices for the respective teams is different.

As mentioned previously, the PHCP is the main public health care program that delivers palliative care in the community, that is, cares for people in their homes. This program is widely used in Calgary, Alberta, and the PHCP and CAMPP teams refer to each other based on the needs of the clients. The PHCP draws on several different disciplines within their program including but not limited to social work, occupational therapy, nurses, physiotherapy, respiratory therapy, and/or spiritual care. The eligibility criteria as listed on the PHCP website state that the patient must have a progressive advanced life-threatening or end-stage disease or illness with anticipated prognosis of less than 12 months, that disease-based interventions are primarily intended for symptom management and/or to improve quality of life, that the patient or family are aware of diagnosis and prognosis and in agreement with a palliative approach to care, that the patient requires ongoing expertise of a specialized palliative care interprofessional team, that an advance care planning or serious illness conversation has been initiated with the patient/family, that the client is 18 years or older, and that the client is a resident of Alberta or is in the process

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of setting up residency in Alberta. If a prospective client does not meet these criteria, then they are unable to access the PHCP services.

This chapter outlines some of the differences in the way that the teams frame their work as palliative care, with the PHCP aligning with the more traditional definition and the CAMPP team taking up and shaping an extended version of the discourse. While both teams routinely care for people who are nearing end of life, there are contrasts between how they approach the delivery of their work.

Beginning with how the CAMPP team, as a new program, negotiated its position within the terrain of the existing palliative care system, I discuss how some members of the PHCP reacted to the CAMPP team and the challenges that arose. The relationship between the two programs evolved through a negotiation between the teams about their relative placements in the palliative care community. This chapter uses interview and observational data to outline how each team uses specific language to position their work in a way that justifies their respective approaches and care priorities. Below, I show how both teams operate within discourses that rationalize their respective work processes and practices, which results in different modes of care delivery.

While both teams describe their work as “palliative care”, and most people have a general understanding of the meaning of “palliative care”, nuances come up when I examine the way the term is used within the context of the programmatic activities. The way that the programs use the term differ within the context of their respective service delivery models.

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This chapter explores how the teams run within a discourse of “palliative care” and how both teams use the concepts of “harm reduction” in diverse ways to differently organize their work. By exploring these differences, we see how the teams’ respective ways of organizing allow them to engage in specific types of work and not others. I will also discuss how the CAMPP and PHCP teams formulated what their programs did, in relation to each other, looking at the rhetorical work of their terms and concepts, as they practice in a high-stakes and somewhat contested terrain of “palliative care” delivery.

Defining Discourse. First, I will start by explaining how I use the term “discourse” in this chapter. Discourse, as described by Mykhalovskiy (2002) as cited in Bisailon (2012) is a “systematic way of knowing something that is grounded in expert knowledge and that circulates widely in society through language, including most importantly language vested in texts” (Mykhalovskiy, 2002, p. 39). Discourses are socially organized activities that circulate among people and through institutions. Dorothy Smith describes discourse in institutional ethnography as referring to “translocal relations coordinating the practices of definite individuals talking, writing, reading, watching, and so forth, in particular local places at particular times” (Smith & Griffith, 2022, p. 34). It is in this way that I will take up discourse in this chapter. I will look at “palliative care” as a discourse that shapes and is shaped by the language and activities of people in real time, but specifically in the context of the CAMPP team and their work compared to how members of the wider community of palliative health care professionals take up the concept of “palliative care”. This study has been conducted using institutional ethnography as a mode of inquiry and an important tenet of institutional ethnography is to stay grounded in the actualities of people’s everyday and every night activities. This grounded approach allows us to say something about the larger power dynamics that go to work shaping the experiences of people

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that lead to oppression or subjugation. By attending closely to language and everyday practices, we can learn about how social relations are constructed in day-to-day life to position some people in powerful roles and others in less powerful roles. In this chapter, by noting the conceptual language, how it is used, and the corresponding activities of the CAMPP and PHCP teams, larger discourses become visible. Like the study conducted by Rankin and Campbell (2006), who looked at nursing work and scrutinized the common use of the concept “client-centred care” within a nursing discourse, here I am interested in: what taken for granted concepts are used in the discourse of ‘palliative care,’ in what social relations do they exist, and how do these social relations go to work?

I begin with an instance of the CAMPP team’s work which will bring into view the team’s positioning in relation to the mainstream program. The following account comes from my fieldnotes in December 2019. I rode along with the CAMPP team on a chilly winter day and in the early afternoon, we planned to stop at a client’s house to check in with her. This young woman of 26 years was recently diagnosed with end-stage liver failure. The CAMPP team planned to check in on her to see how she was doing. This client, Mary, had undergone much change in her life since the diagnosis as it required her to move in with her aunt after living on her own and on the streets for many years. I found this visit striking because of Mary’s youth and the severity of her illness, but also because of how care was being coordinated for her.

When we arrived at Mary’s aunt’s home, it was not just the CAMPP team who attended the visit. Upon our arrival, there was also another care provider present who was part of the PHCP, the community palliative care team affiliated with the larger mainstream health system. The account below exemplifies one way in which the CAMPP team organizes their work with

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clients in relation to these existing palliative care service providers. It also sets up a later discussion of how the CAMPP team navigates “coming onto the scene” as a new palliative care program outside of the mainstream program, how the CAMPP team’s work is organized differently from the existing mainstream palliative community program, and how their work takes shape through their daily practices.

Mary is a CAMPP client. She is one of their younger clients at 26 years old. The average age of the CAMPP clients is fifty-nine. Mary is staying at her aunt’s house because she is expected to need more help with daily needs like showering, bathing, eating, drinking, and emotional support since her recent diagnosis of end-stage liver failure. I am riding with Steve today. Lee and Charles are in another car meeting us at the client visit. We arrive and park outside on the street about five houses away. We all get out of the cars and the four of us walk up to the house. Charles comments that it may seem intimidating to the family having all four of us approach. We approach anyways and Steve knocks on the door. Mary’s aunt answers and we all step inside. The house has a narrow doorway with the kitchen to the right and the living room straight ahead. I cannot see anything aside from half of the kitchen and part of the living room from where I am standing in the doorway. Mary and her aunt are sitting in the kitchen at the table. I also notice another woman standing in the corner wearing a blue dress. She has a name tag clipped to her dress and it has the logo of the mainstream health system on it. She is smiling at us. Mary and her aunt are not smiling. Mary is looking down at the table. On the table, there is an open kit with what looks like medical equipment such as bandages and gauze.

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After a few minutes inside with all of us new visitors in the doorway, Mary's aunt, who has already met Steve several times, says that she wished he would have told her that there were so many people coming over. Steve apologizes and says it is up to her and Mary who they have there. I take this and Charles' comment from when we were approaching the house as signs that I should step out and so I do. Lee nods at me and tells the group that he will be outside if they need anything. Lee, who had set down his heavy shoulder bag on the floor beside him (filled with equipment to draw blood, take vital signs, complete paperwork, etc.), picks it up and we both walk out the door and down the walkway onto the driveway and across the street to where the cars are parked. The snow crunches beneath our feet as we talk about our decision to leave the house. Lee reiterates what Charles mentioned earlier about there being too many people entering the house and says, "Yeah, there was definitely too many people today, especially with [PHCP] being there at the same time; I wish they would have told us they were going to be there." I clarify that the woman in the blue dress was from PHCP and Lee agrees. Lee and I stand outside the cars and start talking about PHCP. I ask Lee why there are so many people here today beyond the CAMPP team members. He explains that Mary lives with her aunt and so that is expected, but that the woman in the blue dress was a surprise. I ask how closely the PHCP team is involved in this client's situation, and he explains that it is usually "the more support the better" but that sometimes they run into situations where the program does not meet all the needs of the person. In this case, Mary wanted to keep Steve (the CAMPP member that she has worked most closely with) because she said that she did not get along as well with the PHCP person and felt more comfortable with Steve. Lee tells me that the

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mainstream program has much more capacity to manage large numbers of clients and so it is preferable if they can take on people who fit well with that program, but unfortunately there are people that do not fit with the program and so the CAMPP team continues to work with them.

A few minutes later, Charles joins us outside. He states that he stayed in the house longer because he felt obligated to introduce himself and explain a bit about why he was there to Mary and her aunt. He said that he felt torn between leaving the family alone and giving more of an explanation of what he does as a physician and what support he can provide. He and Lee talk about the fact that this client is housed and that they may not need to provide as much care for this client since PHCP is involved. Lee mentions that at this point, of the twenty-five clients the CAMPP team is currently working with, all of them are housed, which is not always the case. The CAMPP team helped most of them with obtaining housing and some of them will require support in keeping that housing ongoing. Lee mentions that getting their clients housed is “good” but that it then puts the CAMPP team in a different situation where they prioritize different forms of care to their clients, like managing appointments, access to food, support with organizing bills, ensuring they have support for daily activities if they need it, and other things that will help them sustain their housing. The PHCP staff engage in some overlap of this work but seem to focus more on care that is more medical or focused on the physical body. This also positions their clients to receive PHCP support while those without stable housing do not have that access. A few minutes later, Lee receives a text from Steve who is inside with Mary asking for Lee to return inside to complete bloodwork for the client. Since Lee is a Registered Nurse, he has the

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qualifications to do so and has brought the proper supplies. The PHCP staff do not collect bloodwork as part of their scope of work. Steve is a Health Navigator and does not have the same credentials for medical procedures like drawing blood but is currently studying to become an LPN which would allow him to do so. The CAMPP team has access to a lab where their office is, and they are able to drop off the bloodwork when they return to the office making it a relatively seamless procedure for the client without requiring the client to travel to a lab themselves.

Shortly thereafter, Lee and Steve exit the house and walk back toward Charles and me who are still standing outside near the parked cars. We all discuss the meeting once again and Charles brings up the importance of role clarity between the CAMPP team and PHCP, stating that it is a bit confusing and that they need to have more conversations about this. We get into our respective cars and reconvene later at a coffee shop to discuss the happenings that will take place later in the afternoon.

This client visit illustrates how the CAMPP and PHCP teams go to work alongside one another and co-exist, delicately negotiating collaboration and boundary maintenance to meet the needs of their clients. While both teams routinely work with people who are nearing end of life and sit with people as they are dying, if that is their wish, the mainstream healthcare system decisionmakers only recognize one team, the PHCP team, as “legitimated” palliative care and the CAMPP team’s work runs outside of the mainstream system. By using this account as an entry point to show that the PHCP and CAMPP teams operate in the same field but in diverse ways, we can envision the way that the programs are organized in relation to each other and how they

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go to work for the people they intend to serve. In the next section, I discuss what happened when the CAMPP team first came to be part of the palliative care service delivery system.

Forming CAMPP Amid the Existing Palliative Care Delivery System

The PHCP is the authorized palliative program in Calgary that exists within the mainstream health system. The PHCP team is not the focus of analysis for this project, but because of the nature of the clientele of the CAMPP team, the PHCP team often came up in conversations with the CAMPP team members and clients. For this reason, I have included sections that involve the PHCP team, but a valuable line of future inquiry could explore the work of this team further.

The PHCP is mandated in Alberta by the mainstream health system to help people with progressive life-limiting illnesses in the community stay in their homes for as long as they can when they are nearing end of life. The staff members in the program include nurses and nursing assistants who provide in-home care, support, and comfort to people coming to the end of their life and their families, with a focus on managing symptoms associated with their illness and providing emotional and psychological support. At any given time, the PHCP program has between 600-700 clients that they work with in Calgary, Alberta. The PHCP receives referrals via two “streams”: referrals that go through a program within the hospital that refers directly to them, and referrals that go through a community stream accessible to anyone outside of the hospital system. The latter stream is intended to be what they refer to as a “single point for service access and delivery” for community members to reach the PHCP. The community stream advisors then assess the situation and decide if the individual is eligible for PHCP support.

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As exemplified in the opening account, there are instances where the PHCP and the CAMPP work together with the same clients in the community. Depending on the needs of the clients and how well-supported they feel, the CAMPP team may continue to work with clients after they have been connected with the PHCP.

When the CAMPP team first started, there were tensions between the programs because of uncertainty about the CAMPP's role and the space they would take up in the larger palliative care delivery space. For the CAMPP team, finding a position in relation to the existing palliative care system was challenging because the present system was institutionally embedded, with well-established professionals, protocols, policies, and procedures. When the CAMPP team was introduced to the palliative care community intending to address needs that the existing services missed, some people working in the existing services were skeptical of the program. While this project did not explore these opinions and perspectives as a main research direction, data from observations and interviews elicited the opinions of people who echoed this sentiment. The skepticism may have arisen in part because existing service providers viewed the new program as an imposition, or a critique of their work, or as a potential threat in terms of access to finite healthcare resources, or other reasons or a combination of reasons. A member of the existing PHCP expressed concerns about how CAMPP initially came to be.

Courtney: How did CAMPP come into, kind of, your work, and how did you become aware of them and that sort of thing?

Linda (PHCP): I think I just got invited to a meeting years back. I don't know at what point that was in CAMPP's development, but it was...I found it very, let's say, frustrating initially, because there clearly, however CAMPP evolved in its very

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beginning stages, there was no clear invite to [PHCP] to come to the table. And so, a bunch of assumptions were made without any discussion with [PHCP], and I think a complete misunderstanding in the community about palliative care and what we do.

A distinct perspective was communicated by the original CAMPP nurse about how she thought the process was coming “onto the scene” of palliative care at the beginning.

Lynne (Original CAMPP Nurse): I think what the biggest challenge was, was sort of convincing people that we [current palliative system] didn’t provide great access to palliative services for this particular population. Like really convincing people that, people that use drugs deserve excellent care also and that extends to end-of-life care. Um, and also convincing primary care providers that palliative care is something that’s unique and special and you know, while [they might] think [they’re] doing harm reduction and [they’re] certainly taking care of people who are very complex; [taking harm reduction with a] palliative philosophy of care, [we can] start that palliative journey a lot earlier than we do [and as a result] can really have some excellent outcomes. So, kind of convincing people that it was a specialty that maybe deserved a little bit of a second look and a lot of people just said, “Yeah I do palliative care, I do it.” You’re like, “Oh yeah ok, but have you considered this, this and this?” So, talking to people about that I think was a big challenge too.

The relationship between the PHCP and CAMPP started off with difficulties as the staff negotiated their relative positioning to one another. However, the strain of the CAMPP team’s arrival into the palliative care delivery setting in the community subsided as they established the organization of their work and distinguished their service activities from one another.

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For example, as a palliative care physician, Charles works closely with the PHCP in the hospital and in the community as a regular part of his job. One of the problems that he noticed in supporting people in the hospital who faced social barriers like homelessness and/or substance use was during the referral process. He felt that the current palliative care system was falling short in connecting palliative patients who were homeless or vulnerably housed and who used substances to appropriate supports in the community. Part of this was because the referral process was difficult to navigate for this group. Often, he found that people who were terribly ill, facing homelessness or unstable housing, and especially those who were active substance users did not have a stable location to receive care from the PHCP in the community. Even if they were staying in a shelter, it was difficult for them to receive care because, while PHCP occasionally attended shelters to see their clients, the individual would have to keep track of the schedule of PHCP visits to the shelter and be present when the PHCP staff member was, and if they were not, they would miss out on the care until the next time, if they could catch them then. It was difficult for individuals to know when the PHCP would be at the shelter because the individuals often did not have access to a telephone or other means of contacting them and their day to day lives were often unpredictable, leaving little ability for planning ahead or tracking schedules.

Additionally, while having a presence at the shelter can support a portion of people, even if minimally, it still misses those who are not accessing shelters at all.

Linda: Now what [the PHCP] can't do and has never done is provide care to people that live under a bridge. If you don't have an address, we can't provide care to you...[PHCP] has always gone into the [shelter system]. What we don't do is see the

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folks that don't have somewhere to see them. So, on a park bench or under a bridge, those are people we don't see.

The living circumstances of people who are vulnerably housed or homeless make it likely that they are missed by the PHCP since part of the eligibility to become a client of the PHCP is to have a stable physical location to receive care. The emergence of the CAMPP team was intended by Chales address this missed population, but it took time and effort to build a relationship between the two programs.

The relationship between the CAMPP team and the PHCP has evolved into working more closely together. The PHCP has shown recognition and appreciation for the CAMPP's work and how it complements their own work. In a discussion I had with a PHCP care provider during a ride-along observation, she disclosed how confident she was in the delivery of the CAMPP's services and how grateful she was that they were able to do what they do, referring to their work in the community on the streets and in shelters. Because of the evolved working relationship, the challenges with the referral process are often reduced as the CAMPP team has privilege with the PHCP to bypass the formal referral process to the program.

Linda: Sometimes to bypass some of the black hole at [community stream] you know, we'll just have [CAMPP] write, "already discussed with [PHCP] and approved". Just to get them through the system without a lot of hiccups.

The representative from the PHCP recognizes the difficulties with referrals by suggesting that the process is a "black hole" and there are opportunities for a lot of "hiccups" within the system.

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While Linda mentions that there are now ways to speed up the referral process, tensions about roles and responsibilities of the respective teams still exist.

Linda: I think [CAMPP has] been really helpful in, one thing, I'd say I've really appreciated with CAMPP is a better understanding of harm reduction. And I would say that their support for these folks to become "[PHCP]-ready" where, you know, we can now work together with this individual, as opposed to some of the challenges with addictions and use and things like that that have been issues in the past. So, it's a bit of that collaborative relationship. What I found very challenging in the initial stages of CAMPP was that I think there was a real lack of clarity in terms of what this was and what the roles were. They seemed to have a focus on palliative care and it's like, well that's kind of what *we* do, that is what *our* expertise is. We need *you* [CAMPP] to sort of manage these other issues that we have, you know, the navigation, harm reduction, and "[PHCP]-readiness". I think where we have developed a relationship now with CAMPP is they're clear that they don't know palliative care. That's not their gig. Their gig is to arrange those components I just mentioned. What we bring to the table is the palliative care expertise and support for clients. So, you know, that readiness to engage, number one, with the [PHCP] regarding their health. So we appreciate that they don't have a home so you know maybe it's finding a place, negotiating whether it's a mat on the floor at a shelter or they come to the hospital or somewhere else... That way we can sit down and do our comprehensive [palliative] assessment and support that client, so then our role would be you know, connecting with that client regularly to see you know, how they are doing symptom wise, trying to prevent, you know, those crises as they move more towards end of life.

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The approach that the CAMPP team takes is to meet the existing system where it is as well as the client where they are and try to bring these two sides together. Linda refers to their palliative care program as if the model is taken for granted as being the proper way to “do palliative care”. They have set criteria that they expect the client to meet and the CAMPP team’s role is to help clients become “ready” for PHCP. This comment illustrates the belief that the system is not the entity responsible for changing to meet the needs of the client. This PHCP team member identifies that the CAMPP team has been useful in supporting the existing “real” palliative work because it helps them to access a group of people they would not have been able to access before.

Linda also highlights that the CAMPP team has expanded the PHCP’s scope of practice to include an understanding of a philosophy of care called “harm reduction” which was not something they had embedded in their program prior. Noting this specific approach of the CAMPP team’s work is a strategy that Linda used to distinguish the PHCP’s work from the CAMPP teams’ work.

Linda describes the CAMPP team’s work as helping with their understanding of “harm reduction” but says the CAMPP team’s work is not truly “palliative care”. Rather, the participant views the CAMPP’s work as helping clients to develop to a point where they are “ready to engage” with the existing palliative care system, the PHCP, not to provide “palliative care” in isolation from the existing system. In this person’s estimation, in the state that the individuals are in prior to engaging with either program, they would be not “ready”, or in different institutional language, they would be “ineligible” for the PHCP services due to their lack of stable housing and/or substance use practices. The way that the PHCP is currently

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organized does not allow the existing system of palliative care providers to take on the pieces of work that are necessary to ensure that this client population receives the care they need. That is where this representative sees the CAMPP fitting in to the larger system of care delivery. The CAMPP team has also expressed that the PHCP is an essential service and agrees that part of their job is to support “PHCP readiness” given that the PHCP team has much wider capacity due to their access to more resources. I asked Lee to reflect on this.

Courtney: I have heard the term “PHCP readiness” a lot. What does this mean? Can you shed some light on this term?

Lee: Oh yeah, that is definitely a thing and is getting easier because PHCP is a lot more on board. There is a lot that PHCP can do that we can’t do, like they have 24/7 supports and ability to visit people up to four times a day and we can’t do any of that. Compared to us it seems like they have infinite resources. That’s why we say that PHCP are the ‘big guns’ and we just want to be able to get them [clients] into the right place so PHCP can do their work.

Lee is referring to how the PHCP program has more capacity than the current CAMPP team to work with clients because of the depth of resources available to the PHCP. However, even with the seemingly “infinite” resources, the existing care system is structured in a way that creates a boundary between their work and the ability of some individuals to access their care. The CAMPP team does not have access to these same resources but is able to help clients become “PHCP ready”, a chunk of work located “outside” the bounds of what the current system is responsible for.

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Linda: I think there was a complete misunderstanding in the community about palliative care. There was initially the, you'd continue to hear at the planning tables at the very beginning, "well no one is providing palliative care", and I had to stop them and just say, "I would like to remind you that we have actually been doing this work for the last 20 years."

While Linda's statement accurately describes the existence of the PHCP in the community for decades, in the founder of the CAMPP team's view, the current system was not enough. It was the difference in the way the respective programs were defining palliative care which was creating the disagreement. The founders of the CAMPP team believed that there was a need to change the operation of what was commonly understood as "palliative care" to include work that focused on people who lived in circumstances involving homelessness and often substance use. This is where the PHCP distinguished a boundary, saying that the work is not palliative care. The CAMPP team, with the aim to reshape how we see palliative care, instead, is positioned by this PHCP representative as not the "true" palliative care delivery team but rather as a sort of "preparation crew" that helps people to meet the eligibility of the true palliative care team, the PHCP.

The shift that CAMPP makes in explaining how their work is palliative care is through their use of the term "harm reduction". They shape their work in different terms than the PHCP does, but while Linda recognizes the CAMPP team as being knowledgeable in the "philosophy of harm reduction" and acknowledges how this complements the work of the PHCP, the way harm reduction is implemented in the PHCP is different from how the CAMPP team implements

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it. Lynne, the original CAMPP nurse, explains below how harm reduction and palliative care are often seen as distinct from one another but are parallel in their philosophies.

Lynne: I mean, I think that the whole philosophy of harm reduction and a palliative approach to care are the exact same thing. Trying to convince people that they're different is silliness. Trying to convince them they're the same, I think, is where we might have those breakthroughs. I think that in the end that that's kind of where we got to. It was like, "look at this", like we think of harm reduction as it applies to substance use and people who use substances only and that's just not true. Like we do radiation to reduce the size of tumors too you know. Like you know we're reducing harm associated with that tumor. It's like why? These aren't different concepts, they're totally the same.

Lynne is explaining that there is a need to shift our understanding of what palliative care is and that it is not distinct from a "harm reduction" approach and that the current system stops short of providing a full menu of services at the end-of-life. In the next section, I delve deeper into discussion about the CAMPP team's positioning of their work within the wider discourse of "palliative care".

Positioning CAMPP's Work Within the Discourse of "Palliative Care"

The CAMPP and PHCP teams both operate within a discourse of "palliative care". The two programs delivering palliative care in the community have had tensions in figuring out their roles and responsibilities relative to one another. Charles, the CAMPP founding physician, established the CAMPP team because he identified that there were no services that were mandated, paid, or authorized to provide the help that people who are homeless or vulnerably

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housed at end of life needed. The aim of the CAMPP team is to provide care not offered through existing systems.

The CAMPP team intentionally uses language that shapes the way they construct their approach to “palliative care”. While the team members are trained in medically recognized fields, their involvement in mainstream care delivery has shown them that some people are not getting the care they need because of how the current system is shaped. From the referral process to the care until death, there are challenges that people who experience poverty and homelessness face that others do not. The CAMPP team uses tools like texts such as common expert knowledge around harm reduction to position themselves in a legitimate position to carry out activities that they otherwise would not be able to.

Revisiting the “Good Death”

The CAMPP team’s construction of how to address the problem of this missing care sets up their work as providing something different than what existing structures of care deliver. One lens in which we can analyze this is through the assumptions that current typical models of care make which are based on the common notion of “a good death”. Research and clinical work have tried to define and categorize practices and factors belonging to a “good death” (Davies et al., 2009; Kellehear, 2007; Krikorkian et al., 2020); however, it is important to also scrutinize this concept.

Harris explains that some deaths can be worse than others based on social identities and contexts and that “good death” literature tends to exclude those in socially compromised positions. Corpora (2021) elaborates that there is privilege associated with the notion of a “good

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death” because people with marginalized identities often face differences in their experiences at the end of life. While the idea of achieving a “good death” is ambitious and a noble effort to ease existential stress, it is constructed based upon “preferences” of the patient and when we look at what the menu of services provided, the “legitimized” preferences associated with it are based on socially approved dying and death preferences that are based in normalized behaviours and choices (Hart et al., 1998).

The way that the CAMPP team constructs their work is through shaping palliative care through discourses of harm reduction. This approach demonstrates that they are attempting to bridge this gap between mainstream end-of-life services and the type of work they deliver based on their identification of the needs of those they serve. These individuals are those who are more likely to fall outside of the socially approved way of life and socially recognized preferences around dying and the CAMPP team attempts to provide an access point to start to better understand what a “good death” means for individuals in these socially marginalized circumstances and what can be done to achieve it.

Conclusion

This chapter focused on how the CAMPP team fits into the larger system of palliative care in Calgary, Alberta, Canada. I discussed how mainstream providers have spoken about palliative care and how the arrival of the CAMPP team on to the “scene” of palliative care in Calgary caused tensions with the existing community palliative care program with respect to clarity of intentions, roles, and responsibilities.

I examined how the CAMPP team’s approach intends to complement and expand on current palliative approaches and how, instead of fitting into the present framework of palliative

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care, they aim to offer a different approach. The CAMPP team's method serves to extend and reshape the collective understanding of a known issue, people who need care at end of life, in a way that recognizes a specific group of people: those who are made vulnerable through homelessness and who need palliative care and are missed or not recognized as eligible by the mainstream palliative care system. While current programs acknowledge that people in these dire situations may require palliative care, they organize their services in a way that does not address the needs that this group presents, but rather is shaped in a way that deems them ineligible or not "ready" for services. The CAMPP team shapes their work around meeting the needs of this population by recognizing that while current palliative services meet a tremendous need in the population, they require reinforcement in areas they do not design their program to work within.

The CAMPP team calls themselves a "navigation model" rather than a "takeover model" to describe how they work within and alongside existing systems through which vulnerable people fall. That is, the CAMPP team agrees to work with existing programs to enhance them. They do this through the expansion of their scope of palliative care which includes addressing harms not only caused by the life-limiting illness, but also the social conditions that come from being homeless or vulnerably housed. The way that the CAMPP team defines and structures their approach to work allows them to deliver care in ways not typically mandated by health professionals in mainstream systems.

Furthermore, the CAMPP team's work is not accidental or provided by happenstance. They structure their work intentionally based on a palliative doctor recognizing that the need for care went beyond the scope of traditional palliative services and then designing a program that

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fits the needs of the population. This allows the CAMPP team the time and space to carry out services that do not align with what existing structures of mainstream palliative care deem their responsibility. This approach to working also picks up on the literature that recognizes that much of our current palliative system is based on the notion of achieving a “good death”, but as Corpora (2021) explains, this concept or “goal” is reserved for those who have the privilege to reach it. With continued exploration of the intersections between concepts like the “good death” and the very real barriers that individuals face in being included in this construction, we can start to identify what can be achievable without excluding segments of the population that are indeed experiencing unnecessary suffering and, at risk of reifying a construction, “worse deaths” than anyone deserves.

A mainstay of the CAMPP team’s “harm reduction” approach is in building relationships with people which involves intentional work activities that other programs are not designed to accommodate. The following chapter describes some of these intentional relationship-building activities by breaking them down and illustrating how they come to be coordinated in client-facing situations. By shaping their program to involve relationship-building, the CAMPP team can include people who are often excluded by the current community palliative program.

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“I think the [CAMPP] change strategy involves navigation and 'relationship-building' through a harm reduction lens” – Charles, CAMPP Physician

Introduction

This chapter includes selected excerpts from the CAMPP team program documents, observational field notes, and interview data to illustrate how “relationship-building” work “comes to life” in application. The language of “relationship-building” often came up in the CAMPP team’s program documents and discussions. This concept involves work activities that the CAMPP team puts in place intentionally and differ from practices typically employed in medical environments. The focus on this chapter is on the construction of the “blob term” (Smith, 2005) “building relationships” as a key aspect of the CAMPP team’s approach to palliative care. To clarify, Smith speaks about how sociology can tend toward what she calls a “blob ontology” which is the “disappearance of people and activities” when we talk about them using taken for granted concepts that we assume others share our understandings of. Recognizing writers’ tendencies towards “blob ontology” helps to attend to the concepts they might be trying to refer to that “lack determinate referents” (p.56). This attention can help us instead, link them together in real time and in real places. We can then make visible these physical referents by tracking what happens in people’s everyday lives.

In this chapter, I take up the concept of “relationship-building” as a concept that is used so commonly in formal and informal social interactions that we risk what Smith refers to as “filling in for an absence of a specific referent or clearly defined meaning” (p.56). With the social as the focus of study in an institutional ethnographic sense, it grounds the concept of

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“relationship work” in the social practices that can be observed in people’s activities or practices and how they are coordinated (Smith, 2005).

Following the discussion in the previous chapter on different installations of the discourse of palliative care, this section extends that discussion, following one of many possible threads of their approach, to provide an analytic description of how the CAMPP team goes to work through a specific way of coordinating their care, through “building relationships”. In my field studies, I heard the language of “relationships” and “relationship-building” repeatedly, and so this was the thread of interest that I chose to pursue.

In this chapter, I take the broad idea of “relationships” and “relationship building” and unravel some of the key pieces of work that connect up to construct it. To see what is happening in real live events and how we live them, and to avoid resorting to “blob” terms, we can, instead, follow the associated activities in the real world and make visible what the concept entails and how people move together in space to make it happen.

I will note here that this section is not meant to provide a comprehensive list or analysis of the CAMPP team’s work. Rather, as I have mentioned, the IE approach allows for the close examination of *pieces* of a whole rather than the entirety of an institution’s activities or processes. In this way, I focus on a piece of their approach that undergirds the ability for them to reach individuals who may not otherwise have the opportunity to access end-of-life care, that is, building relationships with clients.

Establishing rapport and building relationships with people. Many of the CAMPP team’s activities are medically situated and align with traditional models of palliative care such

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as helping clients with pain and symptom management, sitting with people in their final days before death, during death, and even after death to ensure proper arrangements are carried out for their clients, or to support their client’s loved ones after their loss. However, in this section, I highlight “relationship-building” which is a significant aspect of the CAMPP team’s approach that is embedded within the discourse of the “harm reduction” philosophy of palliative care. A substantial part of the CAMPP team’s harm reduction approach to palliative care involves the work of building relationships with the people they care for. In their 2018 Program Review, they refer to building relationships with clients as central to both a “palliative” and “harm reduction” approach.

1. CAMPP Program Review (2018)

The Values of CAMPP *[selected]*:

Palliative care is a philosophy and not a designation: CAMPP accepts anyone with a life-limiting diagnosis and does not require people to have a defined prognosis. The team prefers to connect with patients upstream where they can build the relationships and find out what their wishes are before they become too ill to make informed choices. Death is a social not a medical experience.

Harm reduction is relationship-centred care: Harm reduction is about relationship building and trust-building, respect, non-judgement, and meeting a person “where they are at”. Once this relationship is established, a provider can find out what the person truly wants and give advice that the person can understand and hear. It is about finding out how people are currently addressing their emotional, mental, spiritual, and physical

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pain (or not), and eventually working with them to find other ways to address these things. Harm reduction is knowing when to deliver care and where (i.e., the right place at the right time) and focused on addressing harms.

This relationship-building part of the CAMPP team’s “harm reduction” work is foundational to what the team does and is listed many times throughout their program documents as central to their work. Additionally, within the broad work of building relationships with people, there are pieces of effort that take time and that involve strategies and activities that are intentional and specific. That is, relationships do not just happen spontaneously between care provider and client. They take intentional and specific action to build and maintain. Many of the people that the CAMPP team works with have had negative experiences with health professionals and care providers and so it takes a deliberate and sensitive approach to build trust before a meaningful working relationship is created.

We leave the office and pile into Lee’s car. There are three of us riding together this afternoon, Lee (the nurse coordinator), Charles (the founding palliative physician), and myself. The third CAMPP team member, Steve (the health navigator) is attending to clients that do not require being seen by a palliative physician today. Charles sits in the back allowing me to take the front seat. There isn’t much room as it is a small car, and we all have big winter jackets on and are carrying work bags. We arrive at the [shelter] and we park outside. We get out of the car and walk together to the entrance of a large brown building. Lee tells me that the building is an emergency shelter for persons who are homeless or vulnerably housed. We walk through the front doors, and I notice an odour in the air. It smells damp and stale. It is noticeably dark in the room,

but I realize that is because people are sleeping on mats on the cement floor. There are about twenty people lying on blue mats on the floor in the middle of a wide-open room. There are a few people who are sleeping and others who are awake but lying down or sitting on their mats. The walls are brick, and the ceiling feels low. There are caged pot lamps that hang from the ceiling. A window spans across the front of the building, but it is covered in frost so we cannot see outside. We walk along the periphery of the room to an opening in the wall and a member of the shelter staff walks out to greet us and walks us to a nearby corner where there is a man sitting on a chair by himself a couple of metres away. He is crouched over with his elbows on his knees and his legs are crossed, he is facing away from us. The shelter staff member points toward him and tells us that he is the individual that they want to introduce the CAMPP team to. The staff member gives CAMPP some information about the client telling them that he is homeless and has been for a very long time. She continues to say that he is in his sixties, and drinks alcohol quite heavily. They also let the team know that he may not be too receptive to us but that he does know we are coming.

The man appears very slender and in physical discomfort as he slouches in the chair. The shelter staff member leads us over to him. The shelter staff member addresses the man and asks if she can introduce him to a couple of people. The man jerks up and seems startled and says in an aggressive tone, “who?!” The shelter staff says, “Remember how I was going to ask someone to come take a look at you because you haven’t been feeling well?” The man replies, “No, I don’t wanna see no fuckin’ doctor! No, just get the hell away, I don’t want no fuckin’ doctor anywhere near me!” The shelter staff glances up to look at the CAMPP team; the palliative physician moves

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in a bit closer and crouches about a metre away from the man, looking up at him, and he says, “Hi there, my name is Charles, and I am here to talk to you. I am a doctor, but I hope that you will give me a chance to talk to you and learn a bit about why you are in pain. Would you be okay if we chatted for a few minutes? It is completely up to you; I am just here to make sure you are doing okay. At any point if you don’t like the conversation or feel at all uncomfortable you just tell me, and we can stop the visit. Is that okay with you?” The man glances up and around and quickly says, “Who are these people?” pointing to me and the nurse coordinator. The physician introduces us by name and role. I smile at the man and say, “Hello, let me know at any time if you would like me to step away.” The nurse coordinator also says hello and tells the man that his role is to support him in any way he needs. The man then nods. The CAMPP physician gestures to a nearby office and asks if he would be okay if we move in there for more privacy. The man agrees and we all walk inside. – Field Notes November 19, 2019.

In the above fieldnote excerpt, Charles and Lee approach the man at the shelter in a sensitive way. Recognizing that the man is resistant to seeing a doctor, the CAMPP physician respects it by leaving space between them and by crouching down to a level lower than the height of the chair that the man is sitting in to disarm him through non-threatening body language.

Additionally, Charles introduces himself by his first name rather than leading with his physician role as I have seen many times through my own healthcare experiences (e.g., “Hi, I am Dr. ‘so and so’, what can I help you with?”). Charles then explains why he is there and asks for permission to talk with the man. This approach gains enough of a rapport with the individual to move from the initial space in the shelter to a more private office to talk about his health

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condition. Starting the relationship-building process begins with orienting one’s language and body positioning in a way that the team would later frame as “building rapport” and then shifts into other intentional activities that are aimed to sustain the rapport and develop into a professional worker/client relationship.

Lee provides the distinction between relationship and rapport and states that “a lot can be done in a few minutes” – he also states that it is also entirely beneficial in the relationship and bonding part to come at people not so directly but more tactfully, meeting and reading people’s energy in a respectful way. – Field Notes December 10, 2019

Moving from building rapport to sustaining relationships takes intentionality, proficiency, and purpose in one’s approach. The team commonly mentioned the technique of “listening” as a key component to achieving trust and building a relationship with clients. Charles explains that they embedded “listening” as an intentional and necessary work activity in their care for clients.

Charles: There is still the understanding that vulnerably housed people should be able to work out how to use the medical system themselves and there is little understanding of structural vulnerability, structural racism, overwhelming social determinants of health that preclude people from accessing timely help. They often have nobody standing in their corner. Health systems have historically been built on a “listening to tell” structure rather than a “listening to understand” one. We allow people to think we are listening, but we still know what our answer will be...you must be admitted, you must come to this and that clinic, you must take this treatment, etc. etc.

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Charles tells me how he is starting to see CAMPP as different than other services provided. He states that from his perspective, he sees CAMPP as a “listening tool” that provides clients with supports who truly listen to their needs. He states that the CAMPP team provides a model of care that is curious, vulnerable, and open to the needs of clients. He states that he really likes a quotation that he read that states that people in healthcare should be willing to change as a result of conversations with clients and this is how he likes to model the CAMPP team.

Charles explains how important it is to listen to people, especially with the population they work with as they are often not listened to by care providers. Rather, they are “told” what to do and how they should do it without anyone listening to their needs. He mentions that, often, in the medical field people state that they don’t have time to listen to their patients, but he sees things differently. He explains that if healthcare providers give the time with their patients in the outset, it saves a lot of time long term, it’s just a different approach. He says that he thinks there is something else operating that makes people feel that they do not want to spend that time with their patients. Perhaps this is a perception that it relates to self-preservation, but when I ask Charles, he says that when providers do not connect with their patients it achieves the opposite of what they intend and can be harder on care professionals. Charles emphasizes that the CAMPP model asks “why” things are happening as they are and tries to help improve clients’ situations using deep listening as a tool. – Field Notes November 19, 2021.

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In Charles’ view, traditional health system delivery does not provide space for relationship building. While Charles offers “listening” as an important aspect of the work of the CAMPP team, this does not mean that all clients undoubtedly accept the help of the team. There are instances where clients refuse help or are resistant to the interventions of the CAMPP team. It is part of the CAMPP team’s work to continue to “pick up the phone” if these clients request support later despite the earlier refusal.

In describing their work, Lee notes, “a lot can be done in a few minutes,” showing that there are places for improvement if a shift in the approach was to be made in how healthcare professionals care for people, that is, “to come at people not so directly but more tactfully, meeting and reading people’s energy in a respectful way.” This approach is embedded in the way the CAMPP team organizes and structures their system of delivery which positions them to build relationships as a foundation for the rest of their work.

Making “relationship-building” visible work. Relationship-building is enabled through how the CAMPP team is structured using a “harm reduction” approach to “palliative care”. Rooted in this work are important activities, much like “listening”, that the CAMPP team takes up that work together to construct their larger aim of relationship-building work. These include: 1. Activities that help them “match the energy” of their clients, 2. Identifying how differing approaches to work are perceived by clients as “judgemental” or “non-judgemental” and arranging themselves to ensure they are not falling into these tropes of service care workers, 3. Creating a service that can meet clients where they need to be met, that is, being “mobile-delivered”, 4. Establishing trust through consistency and persistence in their activities, and 5. “Making things happen” by “following through”. Each of these key pieces of work came up in

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observations and interviews as key aspects of how the CAMPP team coordinated their work as relationship-building. In the next sections, I move through each of these activities, describing their roles and significance in supporting the CAMPP team’s work of building relationships with clients.

“Matching the energy” of clients. Lee’s earlier comment acknowledges the importance of being tactful with how one interacts with clients to build sustainable bonds with people. Similarly, Charles emphasizes how important it is to be aware of how one comes across to one’s patients.

This afternoon, Charles requests that the CAMPP team meets at a coffee shop to discuss an upcoming meeting they have with management at CUPS. The first item they discuss is “roles and responsibilities” of CAMPP. Charles begins by stating that the CAMPP team takes on the nuances of what the PHCP does not provide for patients but that he is unsure about how to communicate this to interested parties. He goes further to state that there are some health professionals that “do not match the energy of the clients they serve”. I ask him what this means, and he explains that it is important in this work to “read and match the energy of clients in a respectful way” or it could lead to escalation of the situation or refusal of services since many of their clients are very sensitive and resistant to authority figures like doctors. – Field Notes December 10, 2019.

Charles explains how CAMPP’s clients are sensitive to the “energy” of health professionals. We discussed in an earlier chapter how many clients have had negative experiences with health professionals. The approach Charles speaks of acknowledges clients’ negative experiences and

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addresses them by ensuring that how he and the team come across is attuned to how the client is feeling. That is, if the client is anxious or resistant to meeting, the CAMPP team may respond by asking questions and asking for permission to speak with them rather than imposing their presence or taking offense to the way the client reacts. How Charles approached the man in the shelter by kneeling and introducing himself by name and asking for his permission to speak with him is an example of this. These are intentional steps that involve a recognition of one’s own physical embodiment of space relative to the client’s that they incorporate into their work as a key step taken to build rapport and sustain relationships with people who might be otherwise averse to it. Related to intentionally matching the energy of clients is how the CAMPP team recognizes that clients have often had negative experiences of feeling judged by authority figures including health care professionals. The CAMPP team takes steps to account for these experiences of judgement and adapts their work to acknowledge this.

How differing approaches to work are perceived by clients as “judgemental” or non-judgemental”. Something that came up often in observations and interviews was the importance of how clients perceived the people they worked with as acting “non-judgementally” or “judgementally” toward them. As I mentioned in earlier chapters, clients spoke about feeling judged by health professionals and that this negatively impacted their care. Below, Chapa explains how his perception of the CAMPP team’s non-judgemental approach made him feel.

Chapa: They [CAMPP Team] are not judging you. Not even caring what you look like or what you’ve done or whatever. Ya know, what you've done in your life or what you're doing. They make you feel like you deserve care too.

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Being perceived as “non-judgemental” is an important aspect of the CAMPP team’s harm reduction approach to palliative care that helps them build relationships with clients. As Chapa helps us understand, he has felt undeserving of care by health providers based on the perceived judgements by health professionals and others about his appearance or his activities. How the CAMPP team approaches clients is they initiate the interaction with the person with the intention of building a relationship rather than inserting protocols in place of their professional judgement of the situation. They recognize that by doing the latter, the client may perceive this as the team judging the situation negatively. Other programs that do not place relationship-building at the forefront of how they coordinate their work are oriented to other things first and may miss the opportunity to build trust with the client and could lead to a person feeling negatively judged and can risk losing the patient’s willingness to participate in care.

When policies are in place without attention to context such as relationships, they may prevent workers from providing care, missing important intervention opportunities for the client. In an instance with a client that Lynne describes below, the implementation of a zero-tolerance for alcohol policy deemed a PHCP worker unable to care for a client because of the presumed risk associated with a person who used alcohol. In contrast, the CAMPP team’s relationship-forward approach allowed them to view the social context of the situation and use their professional judgement to determine if the person using alcohol was, in fact, “dangerous” to the worker.

Lynne: With some [mainstream community palliative programs] they have all the rules you know that you can’t go into a home [that has] an open beer. You know those are excuses that I’ve heard over the years. Why people won’t, won’t go see somebody in

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their home. “Oh, they use cocaine, they have an open beer.” “Well, have you ever been to a night club? Cuz that is happening all the time.”

Lynne, the founding CAMPP nurse, speaks here about the PHCP’s rules about visible substances at a client’s residence as an excuse not to work with people in their homes. The program she refers to looks at these practices as posing risks to their workers. Alternatively, the CAMPP team sees it as unnecessary to immediately assess the client’s substance use as risky to the worker, but to make a professional judgement depending on the context and their relationship with the client.

The construction of these differing approaches sends the program workers down two separate care paths, one that allows them to work with the person and one that does not, thus setting a boundary around who is able to access care, and in this case, people who use alcohol or drugs are excluded.

Lynne’s comment above using the language of “excuses” referring to other programs’ refusal to work with people, and relating substance use practices to the common leisure activity in mainstream society of going to clubs normalizes these activities suggesting that they are similar to other everyday situations we might all experience. That is, the way she frames her work allows her to accept these practices and work with clients despite their substance use.

It is important to note again that this study does not track the policies of the PHCP team that sees palliative patients in the community. However, it is in the scope of this study to discuss how the CAMPP team members describe the other program’s positioning of substance use as a

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risk to the worker which can result in a termination of services with their clients and how this differs from the CAMPP team’s relationship-building approach.

Linda (PHCP): Um, you know, respectfully, um, you can't just send a nurse who is often a female...into an environment where there's active drug use, lots of people, yadda yadda yadda...and say, "Good luck."

Linda describes how her program views active substance use as risky to a worker and that this risk is elevated if the worker is female. Notably, it is understandable that a large program serving hundreds of clients and employing numerous care providers organizes their work differently than the CAMPP, a small team with approximately 25 clients at a time and assesses risk differently. However, this is of key importance because irrespective of the reasoning for the way the approach to risk is set up, there are implications that affect specific individuals and whether they receive care.

When service providers assess clients as dangerous to them, this can cause a chasm in the relationship as clients may take this assessment as negative “judgement” about their lifestyles. While safety is important in health care settings, assessments of safety that are based on blanket policies rather than professional judgement can be detrimental to client care. As Chapa alluded to, feeling judged can translate into feeling undeserving of care. Refusing care to people based on perceptions of their substance use can inadvertently cause the client to feel that the individuals providing care, whether they mean to or not, are judging them and this affects their level of comfort with receiving care. The way that the CAMPP team organizes its work to withhold judgement about risks associated with substances allows the continuation of services despite clients’ substance use practices, and this helps clients like Chapa “feel like they deserve

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care too.” Working with people in a way that fosters relationship-building allows the CAMPP team to reserve judgement about client’s lives and serves to reposition what the CAMPP team views as “danger” to the worker. Additionally, as Lynne notes below, not everyone should be expected to work in situations where they may feel unsafe or uncomfortable.

Lynne: [Safety is] important like, [safety’s] important obviously. Um, obviously I value my own safety too and don’t wanna put myself in harm’s way. But I have because of the experiences that I’ve had in my career are maybe a different (laughs) different idea of what is dangerous and what is not. Again, leaning on relationships that I have with people I maybe would take more risks um, than, than, with somebody who I didn’t know right?

Courtney: Right.

Lynne: I think that that was the biggest difference, right? I would, I would go to people’s houses that maybe [a PHCP worker] wouldn’t. I certainly ah, put up with colorful language um, a little bit differently than some of the [PHCP] nurses. Like I really am a firm believer that you know, nobody is forcing me to work with pediatric patients because I do not want any part of that. Like I can’t, no. So, I choose to work with this population because I enjoy it and because I, I have experience with this. So, I don’t think that it’s something that just because you signed up for [PHCP] you should also be forced to work with a population that you find extremely challenging, or your values don’t line up with. Their belief systems of their practices or their choices or whatever you wanna call it, I, I think that we should intentionally work with the populations that we wanna work with because we’ll provide better care that way. So,

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when you have these big systems that are meant to serve the whole of the population and we create systems for the masses and not for the outliers, then it’s not gonna’ fit right? We have to be unique and creative with that small group of the population that is a little bit more challenging. Um, and unique and most of the people that want to work with that population love them.

This interview excerpt shows how the CAMPP team’s approach results in the cultivation of a non-judgemental orientation that prioritizes building relationships and how they can provide a protective component that increases the comfort level of the team to work in situations that others might interpret as “unsafe” or “risky”. The CAMPP team’s philosophy allows them to judge the same situation differently from how other care providers might judge it. As Lynne puts it, an approach that involves serving the “masses” precludes the ability to hire people with specific affinities toward particular groups of clients, which she explains is a focus of the CAMPP team, specializing in care for people who may have different challenges, such as using substances, than those people the mainstream health system is modeled for. Furthermore, the mainstream system, serving large masses of people, thus having a much larger employee base, operates in the bounds of policies and protocols, about things like substance use mentioned above, that are more restrictive than those with which the CAMPP team can operate as shown in the example where the representative from the PHCP stated they are unable to see people who “live under a bridge”.

The way that the respective programs are set up determines everything from hiring practices to the ways they function on a daily basis. The different structures of each program are based on the needs of their key clientele and therefore changes the priorities and risk assessments

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of the programs. Part of the CAMPP team’s work, with fewer constraints from large institutional bureaucratic mandates, involves prioritizing relationship-building and assessing risk differently which leads to clients perceiving their work as having a more non-judgemental orientation. This perception can bridge the divide between clients and care. This approach to care allows the CAMPP team to be in areas that mainstream “palliative programs” are not, but this also means that their “palliative” legitimacy then could, and does, get called into question by existing care providers and organizational representatives.

Using mobility to hook clients into services. Another part of CAMPP’s relationship-building work involves how they have chosen to physically set up and deliver their services. The nature of the work that the CAMPP team does with clients involves recognizing that the people they serve are not always in the same physical space. Especially at the start of the work with people, they often must track down clients to find where they might be and check in on them regularly. Other times, even if clients have become more securely housed, CAMPP still uses their physically mobile set up to visit them rather than have them come to a clinic or office as is typical with many healthcare programs.

The CAMPP team’s ability to move from location to location to meet people in the community beyond their private residences or in agencies is an important aspect to their work because it allows them to meet people who would otherwise be missed. It also allows people to be cared for where they are most at ease, removing the potential barriers of having to enter organizations or buildings in which they may be uncomfortable.

We are about to leave the office to visit a client. Lee needed to pack his black and grey shoulder bag with supplies to draw blood. He tells me that it is important that he get

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the client’s blood work submitted as soon as possible because she needs it to attend her cancer treatment next week. She wouldn’t be able to attend if they don’t receive her blood results ahead of time and this could throw off the treatment which is not good for her health outcomes. Lee tells me that she frequently misses her bloodwork appointments and so he brings the supplies and meets her whenever and wherever he can. – Field Notes January 14, 2020.

An essential aspect of CAMPP’s professional work is to assume part of the responsibility that is normally left to the patient or patient’s family in typical healthcare settings. We see authors speak to this in works about and critical of the notion of being a “responsible patient” or a “responsible healthcare consumer” (Mykhalovskiy & McCoy, 2002). This work explains how when one is a “responsible patient”, they are fulfilling a moral injunction and the expectation of healthcare providers for getting organized and taking control of their health. The CAMPP team takes on some of this responsibility through their willingness to be on location at various places depending on the needs of their clients. Being mobile also affords the team the ability to remain flexible and adaptive to the client’s situation and respond accordingly. The team members develop clear conceptions of and help manage the client’s needs including tracking their scheduled appointments, their need for medical assessments and tests, knowing how to draw blood and submit it to the lab, and knowing the importance of bloodwork in the client’s larger care plan. Being mobile delivered, the team can help clients manage these typical and critical pieces of their illness care.

Pre-emptively deciding to bring supplies to draw blood from the client was part of Lee’s strategy to care for his client. Sometimes the CAMPP team members anticipate client needs

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ahead of time like Lee did in the field note above as preparation for possible situations, in this case, the event that the client was open to giving blood. Lee kept track of this client’s treatment needs so he was able to prepare to take her blood if she was ready and willing when he saw her. In this case, she was not open to it, but he picked up and moved to the next client who was not far away and kept the possibility of seeing her later that day because of the flexibility of being mobile delivered.

The ability for the CAMPP team to go to clients as a built-in aspect of their care approach was constructed based on the founders’ everyday work experiences in hospital and as a palliative physician, recognizing that typical care structures did not fulfill the needs of this population. Coordinating the work in this way, by meeting clients in the community, is also important because it helps the clients know that the team are “around” and that they are willing to be there for them when issues arise. Relatedly, another aspect of connecting up to people and “building relationships” involved the language of being consistent and persistent in their relationships with clients as is discussed in the following section.

Establishing trust through consistency and persistence. For the CAMPP team, a crucial element of connecting up with clients and maintaining that connection is through what they label as “building relationships” with clients. Part of this process involves interactions that help establish trust with people. As we saw earlier with Harriet’s account of her experiences with the health care system and with the CAMPP team, clients often resist services by pushing providers away through use of negative language or avoidance. However, Harriet helped show that despite these behaviours, she did not want to be fully disconnected from services and appreciated the team coming back to her. This takes understanding on the part of the care provider to understand

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these behaviours and practices and continue to reach out by taking it on as their responsibility as a service provider to communicate with their clients.

PHCP has come up in conversation many times throughout the course of my ride alongs and interviews. The CAMPP team members have stated that what the CAMPP team does is very much “fill the gaps” of service that PHCP does not recognize as being part of what they can provide as service to this population. For instance, Steve has mentioned that one thing that they do differently is in their approach to contacting clients. Steve has stated that some programs like PHCP, for instance, often limit their efforts in contacting clients to one or two phone calls and if they do not get an answer, they leave it in the hands of the client to contact them back. Steve explained that this is problematic with the population they work with because the clients often miss phone calls or are hard to reach for various reasons. He states that they may also have mobility issues that prevent them from getting to the phone in time or fear about accessing care. Furthermore, not everyone they work with has access to a phone and so it takes other measures of tracking clients down where they know them to be in the community to find them. He further explained that sometimes clients avoid the help because of fear at first and so it is important to remain consistent and persistent with them to build trust. – Field Notes December 10, 2019.

The way that the CAMPP team shapes their approach to caring for people in the community allows them the time and space to reach out to clients in whatever ways they have available to them. As Lynne mentioned earlier, she has sometimes had to deal with “colourful language” or client behaviours that might seem challenging and unacceptable to some service

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providers. This is not an accidental way of working, but an intentional aspect of the CAMPP team’s approach to work that fits within the purpose and intention of the team and in their philosophy of care that is underpinned by the importance of what they label as “relationship-building”. It is not solely on the client to be available when the care provider is reaching out, but rather, the care providers take this on as *part* of the scope of their practice. Many clients, as we have seen in earlier chapters, have a distrust of the healthcare system and the care providers who work within it (Hoffman & Coffey, 2008; Javanparast et al., 2022; Saragosa et al., 2022). These “challenging” behaviours or “colourful language” as Lynne describes it, is explained by some scholars and practitioners as a valid emotional reaction to earlier negative experiences (Hoffman & Coffey, 2008). The CAMPP team members, as a function of their roles, expect that these “challenging” behaviours might come up and their intentional persistence and consistence despite them is to stay connected with their clients so that their clients can continue to receive care. Related to the language of “persistence” and “consistence” was an associated concept that was often tied to it: “follow-through”. The CAMPP team and their clients often speak about the significance of “following through” which is foundational to building and sustaining trust which is fundamental to establishing relationships.

“Making things happen” by “following through”. When I listened to the language of the CAMPP clients and the CAMPP team, the phrase “follow through” and “making things happen” came up often. I was interested to know what this meant and why it was important to them. This came from the notion that the opposite is sometimes true, that people do not “make things happen” or “follow through” and the CAMPP team incorporated this phrase into their everyday approach to work. I found that this phrase was fundamental in helping the clients see the CAMPP team differently than they have other service providers who may not have “followed

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through” or “made things happen” with and for them. Following this, the actions tied to this phrase, a generality that is associated with physical actions in their everyday lives, their showing up when they say they are going to, helped to build trust like bricks help build a wall. This trust then started constructing a relationship between the CAMPP team member(s) and their client(s).

Harriet: [The CAMPP Team] made things happen for me. Ya know, like it was, it was I would have literally died. I would’ve already been not living anymore today. Ya know, I have not been, and by the grace of God I asked myself, “Who put these people in place for people like me?” Do you know what I mean? I needed somebody to come to me and they just did.

Harriet speaks here about how being there for her and “making things happen” was pivotal in extending her life. As we have seen previously, the CAMPP clients often have problems trusting health professionals based on negative experiences they have had in the past. The CAMPP team addresses this by following through on tasks for clients to show commitment and responsibility and to build a solid foundation for the client-provider relationship. Lee speaks below about the importance of this piece of work.

Lee: Sometimes, often times, we have to get creative with things, but the important part is that we are there and that we follow through.

“Following through” is highlighted as a vital part of working with people. The CAMPP team prioritizes the importance of showing up when they say they are going to show up, and they take it upon themselves to carry this responsibility. The team views this as helping the client to trust positive results from the provider, something that their clients have stated that they have had past

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trouble with in other service providers. Typically, the bulk of the responsibility to “follow through” with services falls on individuals who need them, but often, we do not look at the responsibility of the service providers in following through and what that means or looks like. It is in this way that the CAMPP team takes existing structures and, while working within them, shifts them to adapt to the needs of their clients.

Coming back to the discussion about “harm reduction” as a philosophy to extend the discourse of “palliative care”, the CAMPP team prioritizes getting things done with and for clients. Sometimes this includes tasks that may seem unrelated to “palliative care” based on traditional medicalized conceptions of the discourse. However, the intentional organization of the CAMPP team’s work allows them to expand their scope of activities to include other tasks allowing them to ensure that clients are living in better conditions than when they first met up with the CAMPP team and also to serve to build and sustain a working relationship.

Steve and I will be meeting Louis [a client] at the hospital after the trip to another client’s place. We will take Louis, who is staying at the hospital, from the hospital to a warehouse where he will be able to get some furniture to start up his new place. To get access to the warehouse to get furniture or other items, Louis needs a referral from a “worker” in the system. Steve had set this up prior via a web portal on the warehouse organization’s site.

The social worker from the hospital got Louis connected to the housing and Steve helped with collecting needed information and filling out the rental application and coordinating the house inspection. Steve tells me that he is still helping with working out utility connections. It appears that the CAMPP team prioritizes the work of “following-

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through” with clients and doing everything to make sure commitments are honoured.

*There does not seem to be a list of things they will or will not do for clients, but rather they help them with whatever the challenge is that they need at the time. – Field Notes
December 02, 2020.*

Before starting this research, I never would have described helping someone get furniture for a new house as “palliative care”. However, after working with the CAMPP team and observing how they frame their work, I understand how this task fits in with the scope of care that they provide. Louis was a client who suffered from an illness that bound him to a wheelchair. Before meeting with the CAMPP team, he was “deteriorating” in a basement and thought he was going to die. He was admitted to the hospital and discharged to the community. He did not have any supports in place through family and friends and was at risk of becoming severely ill once again if he did not have adequate supports in place. He described his situation as knowing that he would die from his disease one day, but that until that happens, he will live “much better” than he would have before meeting with the CAMPP team because they craft their approach specifically to take on this “extra” work as part of their “palliative approach” to care which is constructed differently than typical “palliative care” programs.

I also learned about other “follow-through” work of the CAMPP team. Some of this work did not always result in what they set out to achieve, but the “follow-through” aspect of the work remained. For instance, over Christmas, a client needed food for the holidays. Most of the social service program offices were closed over Christmas and the client thought that he had requested a Christmas food hamper the week prior. In a discussion with the client, Steve learned that it was likely that the food hamper was not confirmed. Given that Steve learned about this

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only days before the offices were closing for the holidays, it was unlikely that he would be able to secure him a food hamper in time for Christmas Day. Steve followed up with the agency that provided hampers and confirmed that he would not be able to get one in time for Christmas but submitted a request for one as soon as the agency could provide it. The client, while disappointed about not receiving a hamper for Christmas, was relieved to know that one was coming at all. Steve then worked with him to find sources of food that he could obtain in the meantime. While not accomplishing what the client and Steve set out to in the beginning, “following through” with the client and helping the client navigate the system ensured that the client had a back-up plan to get through the holidays which also sustained the relationship between Steve and the client and secured a hamper for the future.

Conclusion

This chapter, as much of this project, has focused on language and tracked language between service providers and clients and connected language up with activities that occur in the physical world. One of the key phrases that I noticed while observing and interviewing the CAMPP team and their clients is that of “relationship-building”. By following this thread of interest, I noticed that this broad concept was put together by pieces of work that often get left invisible because they are swallowed by the overarching concept of “relationship-building”.

“Relationships” are a key ingredient to the approach that the CAMPP team takes to their care and is embedded in the discourse of “harm reduction”. They extend harm reduction to their palliative care practice and argue that this is a separate way of approaching the work than typical mainstream systems approach it. By examining how they use this concept and construct it through their activities, we can see what this means in practice and make visible what we might

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take at face value without really understanding what this work entails. The CAMPP team’s program documents and language all speak to using a “harm reduction” approach to “palliative care” and explain that rooted in this work are important activities, much like “listening”, that the CAMPP team takes up that work together to construct their larger aim of relationship-building work. As I have discussed in this chapter, some of these work pieces include: 1. Activities that help them “match the energy” of their clients, 2. Identifying how differing approaches to work are perceived by clients as “judgemental” or “non-judgemental” and arranging themselves to ensure they are not falling into these tropes of service care workers, 3. Creating a service that can meet clients where they need to be met, that is, being “mobile-delivered”, 4. Establishing trust through consistency and persistence in their activities, and 5. “Making things happen” by “following through”.

It is my hope that in taking the concept of “relationship-building” and unraveling what that means in practice through following threads of social interaction and language interfaces, we can better understand the effort and activities involved in a core aspect of the CAMPP team’s practice, building relationships.

In the next chapter, the discussion will change directions from focusing on the work of the CAMPP team with clients to discussing the funding and accountability structure that the CAMPP team operates within and the challenges of being a small, independent, philanthropically funded organization.

Chapter Eight: With Relative Autonomy Comes Operational Precarity: Persisting Amidst Non-Profit Funding and Accountability Structures

Introduction

In earlier chapters, I described the CAMPP team's work, starting with accounts from CAMPP clients, moving to a description of a working day of the CAMPP team, to the language and discourses that frame the way they work, and the integral aspect of the work of "relationship building" as part of the team's approach to palliative care. The current chapter focuses on how the CAMPP team is *able* to do the work that they do and how this enabling aspect also involves yet another element of work. Continuing with the IE framework, I attempt to materially show, by collecting and examining the specific documents and practices of the program, how their work is coordinated between their frontline team, their clients, and higher levels of administration. An IE lens helps us make visible these interconnections that call into question the structures of the larger funding network that trickle down to the CAMPP team and, most importantly, directly affect client care.

This chapter is about where the CAMPP team's program funding comes from, how the funding arrangements are organized, how the team obtains these funds, the challenges that come with these funding and accountability structures and how this can detract from the work they intend to do or have the potential to do with clients. I argue that these funding and accountability structures are partly influenced by neoliberal ideologies, new public management ideologies, and the long-term erosion of the Canadian healthcare system that adversely impact, and even exclude, the population that the CAMPP team serves.

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The CAMPP clients, as I have introduced in previous sections, do not make an appearance in this chapter as this section is focused on funding, but it is important to note that they are the reason why any of the analysis of funding is important. That is, the CAMPP clients are directly affected by the work being done at all levels and I track how this occurs by mapping the way that funding is coordinated for the CAMPP team.

In earlier chapters, I described the need for the work of the CAMPP team from the standpoint of their clients and followed with a discussion of the team's daily work. I then explained how the team framed their work through concepts commonly used in the field of social and healthcare. In this chapter, I use this information as the foundation to set up the discussion about how the team's work is positioned in the wider philanthropic funding environment that they are accountable to for operations.

Since its inception, the CAMPP team has been on a quest for stable operational funding. They currently exist within a philanthropic, grant-based funding system and aim to achieve a more stable position where they can sustain their work. However, a concern of the CAMPP team is how to keep their approach to palliative care amidst a larger discourse and culture of existing palliative care that, the team surmises, does not recognize much of their work as legitimately positioned in mainstream public palliative health care.

By outlining the way that the CAMPP team secures funding and the challenges that go along with this, institutional ethnography allows us to view the coordination of the work between various sites (frontline, administrative, systemic, etc.) and how this coordination causes challenges. This approach reveals a question that the program faces: How can the CAMPP team

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make visible what they do in ways that count to the larger mainstream healthcare organization while also holding on to their specific way of operating?

The growth into what we know as the CAMPP team today did not happen easily or quickly and it continues to take a vast amount of work to ensure the sustained operation of the program. For the CAMPP team to sustain its services, there is a burden of administrative work involving interactions between people from several interacting organizations that take place “behind the scenes”. This section focuses on a description of the web of governance, funding bodies, and accountability frameworks that the CAMPP team works within, a discussion of the duties and tasks involved that ensure that program funding is upheld, and how this all shapes the client-facing work of the CAMPP team.

The Shift from Publicly Delivered Healthcare to the Community

Various foundations and organizations contribute to funding the CAMPP team, allowing them to continue operating. One of the CAMPP team’s main challenges is to secure reliable and sustainable funding. The CAMPP team exists in an era where the government provides less in the way of social and health program support and relies on community programs to offer much of the care that is not recognized as “medical” or that falls under what the government is mandated to cover. Some authors argue that this is because governments have retrenched the social safety net because of an enactment of neoliberal philosophies of governments that have reduced funding for social programs and emphasized prioritizing market-like efficiencies and individual responsibility in public health care. Further, these neoliberal ideologies do not recognize social determinants of health and change how responsibility for one’s health is viewed. Some scholars exploring these notions with respect to health care contend that there has been an

“array of political forces aimed at restructuring, reinventing, or otherwise shrinking the public sector” (Shields and Evans, 1998 in Armstrong, Armstrong & Coburn, 2001, p.7) which have resulted in cutbacks on funding for healthcare services. However, still other scholars have pointed out that there is more nuance to the argument of change in the delivery of health care programs and that, if neoliberalism was as powerful as we suggest, then it is quite remarkable that programs like the CAMPP team are able to function at all.

Jacob Hacker (2004) argued that something else is influencing change alongside the neoliberal retrenchment of social and health programs. These arguments help us to avoid overstating politico-philosophical notions by saying that we should also attend to other impetuses of change when it comes to national health care policy, especially those which affect programs on the fringes. That is, system change may be less due to reform, but rather, could result from “drift”, “erosion”, or “conversion” (Hacker, 2004) over time. Hacker reports that “the dominant pattern of reform over the past two decades is not radical [social] retrenchment” (2004, p.721). He contends that containing costs rather than cutting benefits has been the major aim, and these changes have mostly restricted public programmes only at the margins (Hacker, 2004). This idea would fit with how the CAMPP team views their situation because they argue that they are under-recognized by the mainstream health system due to being a program that does not align with what our public healthcare system typically provides.

In his comparison of OECD countries including Canada, Hacker argues that while much talk of radical retrenchment has occurred over the years, what has changed is more with respect to the “climate” in which we are offering health care. That is, the needs and risks of patients have transformed and the gaps in services are less tolerated than they once were. He further

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states that the way that the Canadian health care system is structured makes it difficult to implement large scale reform without high-stakes consequences for the party in power. So, while neoliberalism is involved in the underlying ideas of cost-effectiveness and efficiency as well as market-oriented ideas of health care delivery, it may also be that over time, due to the way that the health care system is governed and financed, the system is resistant to reform but that change occurs through bureaucratic inertia; as Hacker (2004) put it, it is “reform without change and change without reform” (p. 721).

Furthermore, Martin et al. (2018) argue that if our health system is to keep up “with the times” and not risk becoming severely outdated, then the social contract between governments, health care providers, and the public needs to be revised to acknowledge the social determinants of health. The social determinants of health are something that Canadian leaders have recognized as crucial to health outcomes long ago in the Lalonde Report of 1974 and was prominent in Tommy Douglas’ vision for public health care, but that are still largely left out of mainstream healthcare. Martin et al. (2018) point out the example that the “large number of Canadians who do not have access to supplemental health insurance has led to concerns about equity, fuelling calls for public coverage of a wider range of services than are currently available” (p. 1721). As a peripheral team, one that works alongside the health system and who they, their clients, and colleagues (Petruik & Colgan, 2022) deem a necessary arm of care for people experiencing homelessness and life-limiting illnesses, the CAMPP team risks dissolving because of funding constraints because their work is not in the scope of care of the mainstream system.

Other authors also write about healthcare system delivery changes in a different way. For instance, institutional ethnographers Rankin and Campbell (2006) point out in their book that, “the consensus for improving both the quality and the efficiency of the healthcare system tends toward managerial reform – towards implementation of strategies to use available resources more effectively” (p.25). The authors explain that in this climate of “reform”, one outcome has been that people are often ushered from hospitals to their homes to recover. This includes patients who are terminally ill who are being sent home to be cared for there until they die, often without proper supports. While for many, home is a preferred location for dying over being cared for in the hospital, for others who do not have homes or access to adequate support in the community, these pushes can cause unnecessary suffering. They further state that, regardless, pushes from institutions to home care, both informal (i.e., family and friends doing the caregiving) and formal (i.e., public healthcare programs within the larger mainstream health services organization), are becoming the norm in Canada. That is, there have been “shifts in the locus of care outside of hospitals and physician’s offices” to the community which then push these services to the periphery of “the rules and universal entitlements that are the responsibility of Medicare⁴” (Armstrong et al., 2001, p.10).

The argument follows that the move from publicly delivered care in formal institutions like hospitals and doctor’s offices to the community (e.g., relying on non-profit and charitable organizations), access to care in the community, including many of the same services that

⁴ Medicare is Canada’s system of public health insurance. Between 1968 and 1972 all province and territories in Canada joined the program. Before Medicare, many Canadians could not afford health insurance. There is not one single health care plan in Canada; rather, all provinces and territories are responsible for management, organization, and delivery of their health care services for their residents. Each province receives federal transfer payments and must operate their provincial health systems in accordance with the Canada Health Act.

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hospitals provided in the past, is no longer an obvious or expected entitlement (Armstrong et al., 2001, Northcott & Wilson, 2022). That is, as services are being more frequently delivered outside the purview of the public sector, this results in more people “falling through the cracks” as services can be harder to locate and many of these peripheral organizations operate on extremely limited resources. In this study, we can see these arguments at work in the very inspiration of the CAMPP team forming in the first place. Clients who have difficulties being “ready” for the mainstream palliative system struggle to find a place to find help, and for those who are available to help them, their services are contingent on those who wish to fund them.

As I discussed in the Introductory chapter, the CAMPP team grew from a palliative physician recognizing that the mainstream palliative services were not meeting the needs of people who were socially and financially marginalized. The responsibility of the mainstream palliative care program does not include the care that people who were homeless or vulnerably housed needed. While the mainstream health system offers palliative care support in homes, this community-oriented program does not carry out certain pieces of social-oriented work, which the clients and service providers have identified as being critical to improving their health outcomes and quality of life and death. The lead palliative physician, Charles, who argues that this work is inextricable from the medical side of palliative care for this population, sought out funding for a program in the community to serve this population. Since 2016, he and his team and supportive peers have pieced together funds from various philanthropic organizations to sustain the programming of the Community Allied Mobile Palliative Partnership (previously called the Calgary Allied Mobile Palliative Program). The team has struggled to obtain regular funding and Charles surmises that the team would not fit within the mainstream health services organization, so he has been trying to “prove” the “value” of the program since 2016.

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In the coming sections, I describe how the CAMPP program is governed and funded, how they go about finding, applying for, securing, and sustaining funds, and the challenges with being accountable to funding bodies. I then discuss how the goal of becoming “operationalized” in the mainstream health system is appealing to the CAMPP team for funding and sustainability purposes; however, it would also come with challenges as the accountability frameworks of the mainstream health system may not translate to measurement of the distinct and critical work of the CAMPP team. Therefore, if the CAMPP team must produce its visibility and show accountability via the existing terms used in the mainstream system in order to get and keep funding, and we have seen that there is an existing palliative program within the mainstream system that does not view their work as “true palliative care”, they surmise that they will not fit in the system and if they became part of it, it could result in their having to make changes to the way they work that would dilute their meaningful and intentional approach to care. The way the CAMPP team is designed is intentionally constructed to address gaps in current services that they consider to be crucial for meeting the needs of their clients, but it is currently viewed by “insiders” of the mainstream system as a team that helps clients become “ready” for what is *really* palliative care.

“Piecing Together” CAMPP’s Program Governance and Funding Structure

In the pilot phase (October 2016 to October 2017), the CAMPP team founding physician contacted his network of health care provider colleagues and community professionals to set up an advisory group to oversee and consult in the practices and planning of the CAMPP. This group involved a member of leadership of Palliative and End of Life Care (PEOLC) within the mainstream healthcare system and was attended by PHCP, other PEOLC representatives, Consultative Services for Palliative Care,

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representatives from the Faculty of Medicine at the University of Calgary, a research representative from Mount Royal University, a small organization affiliated with the University of Calgary meant to help support grassroots programs providing healthcare in the community, and the Calgary Urban Project Society (now known as CUPS). This advisory group met every 2-3 months and discussed program updates, stories of residents, challenges, learnings, and was occasionally attended by guest speakers. This community-based collaborative advisory group supported by the University of Calgary continued to provide additional, yet informal [not paid by the CAMPP team to do this work] layer of advisory consulting made up of individuals who were seeking to improve access and quality of healthcare for Calgarians made vulnerable by homelessness. – CAMPP Internal Document (2018)

Charles, the founding CAMPP physician, and Lynne, the founding CAMPP nurse coordinator, worked with community service providers to construct the CAMPP advisory group. The purpose of the advisory group was to ensure that the CAMPP team took a collaborative and co-operative community-involving approach. To achieve this, the group had representation from relevant agencies, programs, and organizations that had an interest in the work and goals of the CAMPP team, primarily, improving the end-of-life care delivery for persons experiencing homelessness. The members were equipped with the expertise to devise a successfully delivered program which tailored end-of-life care service for persons experiencing homelessness or who were precariously housed. The advisory group approached the CAMPP project with a “learn as you go” style, using the expertise of professionals and the ongoing lessons acquired through the everyday happenings of the program. The team consulted people from the community including those with lived experience of homelessness in the design of their program. Over time, with

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these consultations, the team made decisions and changes as the lessons presented themselves through the delivery of services.

During its pilot phase, the CAMPP team was funded through three main sources: a United Way Grant (\$20,000) which went toward the nurse coordinator position, a Public Grant (\$25,000) which also went toward the nurse coordinator position salary, and the Calgary Palliative Physician Alternative Relationship Plan (ARP) which was an agreement with the mainstream health system that contributed to the release of a palliative physician for the CAMPP team one day per week. The team also accessed donations from the public and what they referred to as “in-kind” support from the CUPS Organization in the way of office space, supplies, and some administrative support.

After October 2017, the CAMPP team secured larger grants that funded the program. One of the grant providers was the Calgary Foundation, which contributed funds for a two-year extension (2017-2019) of the pilot. The Calgary Foundation funds also contributed to the addition of an office assistant, mileage coverage, funds for administrative and medical supplies, and support for community capacity building and training (\$165,000). The second major funder for the 2017 year was the Saint Elizabeth Health Foundation, which contributed to the extension and expansion of the program including program activities, research support, office and meeting space, human resources, administrative support, consulting/honoraria for the palliative physician, nurse training, travel, and community capacity-building (\$309,000). The Calgary Palliative Physician ARP also extended beyond the pilot into ongoing program services by contributing costs of a 0.2 FTE palliative physician, expanded to include the flexibility of allowing other palliative physicians to work monthly with the CAMPP team.

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After 2019, CAMPP's funding situation was structured similarly to past years, but as the funding periods ended, if the team wanted to continue, they had to "piece together" applications to try to ensure funds. The team was always on the look-out for potential funding sources.

Charles: We don't know if we will be operating past March 2020, so it is hard to look ahead. We always need to piece together funds for another year. I didn't think that three years in we would still be at this stage. I hoped that things would operationalize and that we might be a part of the operations in the larger health system by now. It is a lot of work and it is tiring... We need to get sustainable funding.

The "piecing together" speaks to the extra work involved in securing program funds year over year. The CAMPP team could not assume they would be continuously funded so they put in effort to locate, apply for, secure, and sustain funds since they were not "operationalized" within the larger mainstream health services organization.

Operating in this way also creates challenges for staff retention. Precarious funding leaves competent and committed staff considering other opportunities to ensure they have sustained employment. Over the last two years, two staff members left the CAMPP team for other opportunities. This uncertainty of employment stability puts the program at further risk, since, even if they could replace members, legacy knowledge and program experience is lost with the team members who left. This likelihood of staff turnover adds more labour for the team because of the work involved with recruiting, hiring, and training new members, not to mention building relationships with clients from scratch.

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Charles: I can't blame people if they need to leave because we can't provide job stability.

We have some amazing people on our team and involved, but the certainty just isn't there so people stay for as long as they can.

Staff retention is something that the CAMPP team is concerned about because with funding instability comes employment instability. Piecing together the opportunities for program funding involves challenges and risks to the program; however, the work of managing the funds when they come in is also a task that involves immense efforts. With this burden to the program, the CAMPP team worries about how this shapes the care efforts that they offer to clients and how this will affect them. Clients who rely on the CAMPP team and who have built relationships with people who have been part of the team experience loss when a CAMPP member moves on as well. With clients who have deep distrust of the social and health services system, and the important relationships built with the CAMPP team care providers, this could cause significant setbacks for clients in their health management.

The work of managing CAMPP funds. The work involved in ensuring the team is funded involves several individuals and many hours of labour. Over the years, the CAMPP team has accumulated supporters that help with this process. For instance, securing initial funds for the program involved the work of several actors with specialized skillsets, such as a researcher from Mount Royal University who supported the CAMPP team by finding grant opportunities and writing up the applications. This researcher also helped with reporting requirements as needed. This piece of work was only a part of the labour involved in keeping the program going. As the researcher below explained, keeping the CAMPP team “afloat” involved the coordination

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of a network of individuals and skillsets and was often done “off the corner of everyone’s desks.”

Researcher: You don’t want them [CAMPP] to just disappear. Like, this is a need and it’s really important and doesn’t cost that much money. Yet, it’s all this work for all these other peripheral players and it’s also, I mean, it’s like off the corner of everyone’s desks. There are the fund officers at Mount Royal and UofC and other places, everyone is writing stuff up where they can and advocating over here and over there. If you really count the labour of this, it’s quite unbelievable.

For a small team like CAMPP, it would be impossible to navigate and complete this work within their small three-person team. They enlisted people who *believe* in the idea behind their program who are willing to work “off the corner of their desks” which is another way of saying that this work is not their primary role, but that they are fitting this work into their separate and distinct full-time jobs in other places. This “fund-seeking” work (Nichols, 2008) is unpaid and takes away from the paid work that programs like the CAMPP team intend to do. In Nichols’ paper, she refers to the constant seeking of funding for non-profit organizations and the precariousness of the journey as “the funding game”. While it is referred to as a game, it does not provide much “fun” for those who rely on the funds to maintain their employment. The notion of a game also comes from the uncertainty and “chance” of the ability to attain funds as well as the competitiveness between community social serving organizations who are pitted against each other even though they are all working towards similar goals: helping people in the community.

An important piece of the “funding game” is the internal work for the CAMPP team. Included in this game is the labour of “holding” the funds. The applications for funds are

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submitted through the CAMPP team's affiliations with representatives from two local universities, The University of Calgary and Mount Royal University. This means that the CAMPP team itself does not "hold" the funds as a program. Securing funds is not as simple as being awarded a grant from a funding body with distributes a cheque that goes to the CAMPP team directly. This is because one aspect of the larger overall funding structure is that the granting bodies require that the applications be submitted through "charitable organizations." That is, they do not accept application submissions from any program existing in the public; they must be part of (or partnered with) a charitable organization. This means that the organizations must hold the funds that they then distribute to the CAMPP team via embedded administrative work processes.

The CAMPP team is not independently registered as a charity but is affiliated with the University of Calgary. Since the University of Calgary can collect donations through its charitable registration title, "The Governors of the University of Calgary," they can funnel funds to programs affiliated with faculties. The CAMPP team is a program affiliated with the Cumming School of Medicine and the affiliation between the CAMPP and the Cumming School of Medicine is through the connection of Charles being a palliative physician and having working relationships to other physicians at the University of Calgary. This group was able to connect with the office within the Cumming School of Medicine that focuses on strategic partnerships and community engagement and set up an account with their "Fundraising Office". This relationship to the Cumming School of Medicine helped to broker the initial funds for the CAMPP team and forged the way into securing support from the department whose role it was to manage the administrative work that went along with securing grant funding and tracking donations.

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The people assigned to work for the Cumming School of Medicine and the CAMPP team at the university Fundraising Office administered funds to the CAMPP team through a researcher employed at the University of Calgary. This office managed what they called “philanthropic funds” (i.e., funds that are not government-issued or grants intended solely for research). Below is an excerpt from an interview with a Fundraising Office Director who oversaw the administration of part of the CAMPP’s funding at the time of the interview.

Fundraising Director: We distinguish when we say philanthropic from grants. That's why when I ask the question about if you refer to grants, because there's research grants, which we do not get involved with if those come from more of a granting agency, like a scientific agency or something like that, we don't get involved in that um, although it's helpful for [the Development] office to know those things but only involve ourselves only with funds, mostly that come from like, a foundation like the St. Elizabeth, you know, the Calgary Foundation and various foundations in existence and there's like a research grant and then there's a foundation grant. And the foundation grant would probably be, if you thought about it differently, would be more charitable, I think, than research oriented. Even though they [both] use the term 'grant'. We are involved in [the foundation] ones.

The management of funds involves becoming familiar with and ensuring restrictions associated with any contracts associated with the funding are met. The fundraising officers keep track of the paperwork associated with grants and ensure that any stipulations or regulations that the receiving party needs to be aware of to satisfy the conditions of the funds are adhered to. This

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department looks after all the paperwork associated with the grant and lets the assigned “principal investigator” of the project know what is happening, as necessary.

The principal investigator is someone working at a large institute affiliated with the University of Calgary whose responsibility it is to be aware of the activities and “sign off” (use their signature as a way of approving the motion) on invoices associated with the project. However, the project account itself is managed by the officers in the fundraising department. The PI is not involved in the day-to-day management of the CAMPP team, but as a supporter of the program and a knowledgeable researcher in the area that the CAMPP team specializes in, they take on the responsibility of signing off on the paperwork. The fundraising department officers ensure that the grant is distributed to the correct place and are also there to answer questions from the applicants, the receiving organizations, and the funders to help ensure “seamless” transfer of funds and to broker any issues that come up. The past fundraising director that worked on behalf of the CAMPP team speaks to this process in the interview excerpt below.

Past Fundraising Director: We look after all the paperwork etc. Uh, we of course let the PI know what’s happening. But really, we do all the paperwork, we look after getting the funds in, and then once the money comes in, the money goes into the project account that is set up, that is set up with the PI and our department as well.

The fundraising department officers also help to mitigate any challenges that occur while invoicing the work. Since there are several funders, with different requirements, the officers ensure that the way that the CAMPP team reports the work to them matches with what the funders recognize as valid according to their requirements. The invoices from the CAMPP team are expected to outline the correct reason for billing and show that it is going to the correct

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funder. For instance, if a funder agrees to fund “operations” but the invoice states that it is for a “capacity-building activity”, it is rejected once it gets to the funder.

The University of Calgary holds the money; CUPS handles the day-to-day financial administration of the CAMPP team by paying the salaries and bills. CUPS then invoices the university to get money released from the special CAMPP account. Officially the person “approving” this is a university researcher which is necessary because the money is housed at the university. However, this person is not actually the person in charge of the CAMPP team. The researcher is the “approver” and there is a more informal process which is not officially recorded in the financial documents by which the “real” person in charge, in this case, Charles, reviews and approves for the proxy approver (university researcher), the expenses submitted by CUPS. Each pot of money from different funders can be spent on certain categories of the CAMPP team activities and not others based on the restrictions put in place by the funders. With several funders involved in supporting the CAMPP’s work, the team must report to each of them based on the criteria that the funders deem necessary, often resulting in extra work for people associated with the CAMPP team.

There is also the provision of “in-kind” support that is garnered from CUPS and “in-kind” resources from community professionals who supply their time, expertise, office space, office supplies, and materials “free of charge”. There is also work involved in tracking this in-kind support that demonstrates to funders the efforts involved in running the program and how they are contributing to the community. One internal program report from a previous year, speculated that:

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The support from CUPS annually amounts to approximately \$10,000.00, the in-kind support from the universities comes to approximately \$20,000.00, and the support from across agencies and sectors would sum to \$20,800.00 if all hours and supplies were accounted for.

The CAMPP team also accepts donations which are set up through the Cumming School of Medicine's platform called "NetCommunity," which is at arm's length from the University's Fundraising Office, but both report up to a main institutional office called the "Office of Advancement". The Fundraising Office is tasked with much of the administrative work associated with managing the funds for the CAMPP team as part of their larger portfolio of fund management. This work involves tracking the donations, running the web page that takes the donations, sending out tax receipts to donors, determining which donors get a more detailed letter regarding the impact of their donation, and framing the information to the donors in "language" that, as representative explains, helps donors "understand impact" of their donation. All this peripheral work is put in place "ad hoc" to support the CAMPP team. Each of their pieces of labour interface with one another and make it possible for the CAMPP team to exist.

While there is extensive labour occurring "behind the scenes" to support the team, the CAMPP members are also responsible for funding work in addition to their frontline care provision. Initially, Charles and the original CAMPP nurse coordinator, Lynne, did much of the organizing work to gather interested parties and develop a group of people committed to supporting the project. However, having many people supporting the program in different ways also creates challenges.

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With several people offer substantial amounts of time and effort, this unintentionally serves to generate confusion around which responsibilities belong to whom, creating an unintended disconnection in communication and consistency in reporting and confusion around expectations. This added layer of work, sorting through confusion, and clarifying communication, is often counterproductive by producing redundancy in tasks. The small capacity of the team for administrative duties includes the lack of capacity for broad coordination and administrative leadership.

In an earlier quotation, the university researcher described how the CAMPP team's management of funding operated in a way that was "off the corner of everyone's desks" rather than as an official part of any one person's job. This respondent went on to explain that a more streamlined coordination of this work was needed because of some of the unintentional inefficiencies this fragmentation can cause.

University Researcher: That whole advisory group that we established at the start was like "Wow there's a lot of people around this table. People want this to succeed." But there is no coordination. And that was it, we really discussed that sort of end with the Calgary Foundation funders where I'm...like I'm trying to really lay it out here. I'm not managing this project, I'm coordinating this meeting, but I'm not coordinating this whole project you know. I can't and it's not my role. So, can we fund a coordinator for this work? Can that be the thing that gets funded, or you know something has gotta give here. And then there is the admin for the program and client services. That kind of unique piece and especially a new program that's evolving and has all these different people involved and we are wading through mud with good intentions all around. But with

nobody with any real authority or anything... There is money that's piecemeal pulled together and runs out and somebody's got to report on it. And who gets that work, who has the responsibility of reporting when money is being held at these universities? It can get really confusing and so unintentionally balls get dropped. Which I mean, like on one level you wanna just go "Okay" for the organization that's running the program, please hold the money you know. [Laughs.]

The unintended consequence of many well-intended participants working to make the operation of the CAMPP team possible is that there is not one person or program area that leads the process of ensuring the funds for the CAMPP team are sustained. When the funding deadlines approach, it creates a chaotic surge of people "jumping on board" to manage the ongoing crisis of the risk of losing funding for the program.

Managing the current funding for the CAMPP team has proven difficult for the team and its supporters. Adding to this burden is a second challenge: how can the team show the value of their work amidst the current modes of accountability that exist in the sector?

"Not Measuring up": the Meaning and Implications of Being "Philanthropically Funded"

A main aim of the CAMPP team and their advisory group is for the program to be recognized as a *regular* program within the larger mainstream health system. Charles describes this as the goal of "operationalization" within the health system. Charles surmises that achieving this goal would have the benefit of removing much of the current work associated with locating, securing, and sustaining funds.

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To be an “operationalized” program would mean that the CAMPP team would be embedded within the larger mainstream health system and would not have to repeatedly search for and apply for funding. The CAMPP team’s current funding arrangement involves several philanthropic organizations and donors that offer funds for the program to operate, which in the context of what I have argued as a neoliberal political climate and an eroded social and healthcare system, is in itself a feat that they were able to leverage the system to develop the program as it is. However, while that is the case, it is still part of the story that individuals are not receiving care that they need within the system that aims to provide care for people at the end of life. This funding structure limits what CAMPP can do and thus limits the care provided for patients who are most in need.

The CAMPP team has done well in leveraging the existing system, but not without challenges. The work that is created based on this “against the grain” approach comes from processes such as having to report to different funding bodies with different expectations in order to receive money.

Trying to obtain sustainable funding within the mainstream health system has been a challenge. The CAMPP team and the CUPS management are still uncertain as to why the mainstream system will not fund the CAMPP team and they speculate that it may have to do with how the mainstream system measures “success”. In my research, I have not located any documents or full explanations about whether the CAMPP team has gone through any “formal” application to become part of the mainstream system. It is unclear if such an application like this exists, but this section delves into how the CAMPP team makes their work visible and some of the issues that arise in their aims to operationalize the program within the mainstream system.

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The team suspects that the mainstream system, as it currently operates, does not seem to recognize their work as meaningful. In future studies, it would be interesting to explore the concept of meaningful and recognized work on the fringes of the health system. The current study only begins to reveal this puzzle. An excerpt from my field notes describes the goal and challenge put forward by Charles in discussions around funding sustainability and maintaining autonomy.

[He hoped to] operate for the first year with grant funding and then move into a funded operationalized program within the mainstream system after that. Charles said, however, that the caveat is that if this were to happen, he preferred that the program maintain their operational autonomy that the program requires to function differently than the status quo since the status quo was what inspired the creation of the program to begin with. -

Field Notes, December 03, 2019

When I spoke with a member of management at CUPS, she expressed her opinion around sustaining funding for CAMPP.

CUPS Manager: I honestly just think that between the healthcare system and [the funding bodies] if they could ongoing fund both of these programs [CAMPP and HCOT] together, we'd be laughing, you know, if it just became basically, operational dollar funding instead of just bridge funding or grant funding for like a year. Like if they just said, "Yeah we're gonna commit to three years" and we didn't have to worry about it, we would be able to really build the capacity of this team. Cuz we've got a lot of newbies, but they are passionate, and they are growing, and they are eager and hungry to grow. Outreach work is hard, we know we're gonna mostly get newer,

younger staff and we're ok with that, but at least if we had the capacity to for sure keep Lee as the CAMPP lead, the HCOT lead, maybe some more seasoned nurses or educators around that then you know, at least there would be enough consistency in the leadership realm that they, even if there's turn over on the front line it wouldn't be the end of the world...I know it has often been our Executive Director trying to wheel and deal with the bigwigs at [funding body] and the healthcare system saying "Look you're all saying you're obsessed with HCOT and CAMPP, where is the money for this?" They all just kinda say "Ah, we're short." You know the mainstream system really does not like funding non-mainstream programs even though we take a huge burden off of them and we're way cheaper. We're so much cheaper, we pay our people less and we also have more flexibility in how we can support our clients. We drive people around um, in our own vehicles and our you know, barfing all over the place and we're still showing up. But it, it just sort of seems like it's a supply and demand issue. I'm not too sure but dealing with funders it's just always kind of like this you sort feel like it's you, you have to date or court a number of different people and just hope that they'll show you the money.

The CUPS manager expresses how difficult it is to try and track down funding year after year and how having a longer-term contract would relieve a lot of the pressure that comes from not having ongoing funding. This manager also points out that part of the confusion for them is how they cannot seem to secure stable funding even though they are "cheaper" which, they surmise, would be an attractive selling point for a system so preoccupied with cost-savings.

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Charles and the CUPS manager both engage in analytical work speculating why the program has not yet been funded by the mainstream system. They tell how the CAMPP team's ability to run "cheaper" and with more flexibility provides benefits to both the clients and the mainstream system because they take on work that is otherwise missed by the mainstream system. Further dissecting the issue of how the CAMPP's work does not fit with what the CAMPP team expects an "operationalized" version of the work to look like, Charles surmises that much of the CAMPP team's work would not match the metrics used by the larger health organization that measure program outputs and impact. He states that the larger system focuses primarily on quantified measurements such as "numbers of patients seen within a given timeframe" and this is not where their program excels. Charles and the CUPS manager disclose that conversations have been held at the higher management levels where they have "wheeled and dealt" to try to obtain operational funding, but to no avail.

In a study conducted in 2008, Nichols recognizes a similar phenomenon to what Charles hypothesizes above. In her report she states that "an emphasis on measurable outcomes and tangible performance indicators directs people towards activities that can be undertaken in these terms and marginalizes work that does not fit this standardized model of accountability" (p.62). In the current accountability model that the CAMPP team operates within, they share their work in different ways depending on the reporting structure of the funder in question. The CAMPP team is held accountable by submitting a series of reports depending on the requirements from each of their funders. For instance, the team submits reports at set intervals (differing depending on the funder) which all ask for different information about CAMPP team operations that stand in as "proxies" for the work the team does with clients.

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In the current funding structure, most funders require reports that count things like “number of client contacts”, financial breakdowns, and/or examples of “measured impact” in the community. A review of several of the CAMPP team’s funding documents shows that the larger the amount of financial contribution to the program, the higher the expectation is on how the money is accounted for by the program.

A challenge arises for the CAMPP team in managing the reporting for various funders. Depending on reporting timelines put in place by the funding bodies, the CAMPP team and their associated supporters who work on their behalf (i.e., researchers, the university fundraising office, etc.) are expected to submit reports/textual representations of their work that show evidence of accountability and effective programming (Nichols, 2008, p.64). The main problems that arise for the CAMPP team in its current funding structure are the added labour of reporting to various bodies with different expectations and, secondly, how the precarity of funding makes it difficult to retain staff and build the program from year to year. The team hopes to receive sustained funding and sees this as a possibility within the mainstream health organization; however, they have not been offered a position within the system. The team speculates that this could be due to the way that the system measures “success” in their programs and how their current work does not fit well within that accountability structure.

McCoy (1998) states that, “of increasing currency are representational strategies that measure and quantify ..., converting local particularities into standardized, calculable units that enable quantifiable comparisons among different sites and activities” (p.396). However, given the anticipatory problem of not fitting in with the larger mainstream system that Charles and the CUPS Manager bring up, what happens when the representational strategies that are in place do

not fit with the program activities? Additionally, what happens when unrepresented work activities are highly valued by the people receiving the services yet not accounted for in reporting? Furthermore, as the CUPS Manager claimed, the representatives from the mainstream system all say they are “obsessed with HCOT and CAMPP”, but do not back that up with funding or specific reasoning for not funding them.

CAMPP members have said that their work is under-recognized through the way in which impact is measured in healthcare, through “health-utilization statistics”. Charles pointed out that healthcare often uses metrics like “utilization,” which captures things like the “number of clients seen,” or the efficiency of work measured in being able to “discharge” or “graduate” clients. Charles expressed, however, that this type of measurement did not highlight what the CAMPP team excels in. Rather, CAMPP’s work highlights *how* the work is done and, as described in earlier chapters, in things like relationships, listening work, and responding to the needs of the client even if they are not typically associated with “health services” (e.g., organizing and planning medications, advocating for use of third party oxygen tanks, helping with locating food hampers, finding housing, and moving furniture into a new residence, etc.). Indeed, the CAMPP team aims to improve the lives and deaths of their clients, but their “utilization” numbers tend to be lower because of their small team and the in-depth type of work they engage in, which they find is a drawback when they pitch their work to the larger health system.

Charles: I think we need to pivot how we measure things with CAMPP. We don’t necessarily fit in with how things are measured in the health system. It’s very quantity-focused and for us I think it is more about the story, people may respond more to

narratives that get at what we do.

Charles, working within the mainstream system, is knowledgeable in how they regularly capture metrics for their internal programs. With this insider knowledge, he expects that since the mainstream system focuses on measuring quantifiable activities, the work of the CAMPP team would not fit. He surmises that the CAMPP team's work is better captured through other ways of measurement like client stories or narratives.

What Charles is describing in his frustration with the misalignment between what the CAMPP team does and what he senses as “recognizable” in the mainstream system reflects the argument that Rankin and Campbell make in their book that examined nursing work in hospitals. Rankin and Campbell's (2006) research project took place in a Canadian hospital and they found that the restructuring of the health system toward a focus on “efficiency” led to ways of managing nursing work that involve the “standardization” of activities. The authors referred to this model of working as a “new public management”. They describe that “the new public management brings a specific set of knowledge practices to bear on health care, making its content visible in new and standardized ways” (Rankin & Campbell, 2006, p.8). The authors argue that the system aims to standardize activities to make the work “objectively” quantifiable, rendering any work tasks that fall outside of these classifications as “subjective” and thus devalued. This is similar to what the CAMPP team struggles with as we have seen in previous chapters with respect to operating within the medical model of reporting “case notes”.

Comparable topics to Rankin and Campbell's (2006) analysis also come through in the language that the CAMPP team and others use when they speak about “duplication” or “overlapping” services with other palliative healthcare providers. Charles frequently mentions

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how he is compelled to distinguish role clarity between the CAMPP team and the PHCP team to prevent this “duplication” or “overlapping” of services. An example of the team avoiding the “duplication” of services is illustrated in the excerpt below where a client is not seen by the PHCP because they are “already connected” to a community service.

Lee tells me that we will be seeing a client today for a palliative care consult. He states that originally this client was with a [community healthcare program] and they were not managing the case in a way that the client agreed with or to his satisfaction, and so they tried to refer him to PHCP. Then PHCP said they would not take him because he was “connected” already – referring to the previous healthcare program. – Field Notes December 23, 2020.

Resources are finite in healthcare. This is a key justification for not duplicating or overlapping services. However, not all services fit all people in the same way. For the client above, he did not feel the service was fitting for him, but, likely, that same program has served needs of other individuals sufficiently and has done so many times. Not fitting the needs of all people does not mean that the services are not useful; it means that the client, in this case, does not feel the program worked well for him. However, this client is not just stating a preference or being picky with services. As I have shown in previous chapters, the system has embedded barriers that make access not feasible for many socially marginalized individuals. These challenges are embedded in how the system is constructed, the expectations of leaders on staff to do more with less, and our ideas, with a capital I, of who “deserves” care. Because these things are weaved into the tapestry of our healthcare system, the PHCP, as part of the system, cannot take a client who is already connected, thus denying the person services, and more importantly, care they

need. Alternatively, the CAMPP team has constructed itself to exist in the interstices of the mainstream health system, for the people who do not “fit” within it. With this way of working, the team has the “freedom” to take the client, but the freedom is limited because the problem becomes that the team could face criticisms about “duplication of services”. The notion of “duplication” omits the needs that fall outside of what the mainstream system deems eligible as a recognized and legitimated type of service.

The CAMPP team mandates itself to satisfy the client’s needs by offering an alternative program. However, they do this within the restraints of the structures that exist, namely, the funding system and by using recognizable language that other service providers and professionals understand and “buy in” to. The CAMPP team recognizes that to show their usefulness in the larger culture of funding and healthcare, they must “prove” themselves as “distinct” from other services to ensure they are upholding the system’s priorities of efficiency and fulfilling a “need”. They must not “duplicate” existing services. Revisiting a passage from an earlier chapter, we see how Charles does the work of trying to make visible distinct aspects of the CAMPP team’s practice during his discussion with me. Extending this passage, we also see how Charles recognizes how the larger system runs and how they avoid “duplication of services” and how he tries to strategize a way for the CAMPP team to appear unique to what is already provided.

Charles begins telling me of how he is starting to see CAMPP as different than other services provided. It appears he is concerned with “duplication of services” – he states that from his perspective, he sees CAMPP as having distinctions from other services that he feels are important to identify. For instance, he states that CAMPP is

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very much a “listening tool” that provides clients with supports that truly listen to their needs. He states that the CAMPP team provides a model of care that is curious, vulnerable, and open to the needs of clients. He states that he really likes a quotation that he read that states that “as healthcare providers we should be willing to change as a result of conversations with clients”. This comes back to the issue of the possibility of “duplication of services” that has been flagged as a problem in the community and for funders. However, clients do not always know which worker does what and who is responsible for what needs they have so they end up just gravitating to the worker that they have the best relationship with. Charles mentions that it is not easy or feasible to silo services so distinctly because clients do not work well like that. It is an open-door policy with the CAMPP team, and they have a revolving door in the sense that if they are needed, they tend to the client. Charles states that they should create a checklist of needs and whether or not they are met by other programs in the community and perhaps this will help them tally what they do. - Field Notes November 19, 2020

In this excerpt, Charles orients to a plan that he expects could be consequential to getting funding. That is, he queries how the success of the CAMPP team will be made visible. He posits an idea of creating a textual representation, a checklist, of what the team does so that they can hook into the mainstream system, be validated by it, but also not be *so* hooked into it that they would be doing the same work as the current system is doing, thereby “duplicating” it.

In this excerpt, Charles is doing the work of making a case for the CAMPP team, which would not only show that the CAMPP team’s work is “good work”, but also addresses the

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concerns that mainstream health system gatekeepers have around “duplication”, in an easily visible, recognizable, familiar, and authoritative way. He is working within the ruling relations of the legitimized healthcare system, but constructing a way of working that also satisfies what he knows to be a widescale problem for the patients he serves who are socially vulnerable. Just saying “the CAMPP team is different” is not enough for them to gain sustainable funding.

Charles perceives these challenges as the reality that holds the CAMPP team itself in a marginalized and precarious position with respect to funding and recognition and tries to actively work within the system to frame their work in a way that can be legitimized even though he has seen and heard that his team’s work is effective in improving the care, lives, and deaths of patients through responses from the clients and through what he has seen in carrying out this work. However, Charles suspects that the embedded systems of measurement do not recognize this as adequate evidence. Summarizing the feelings about this state of precarity, Lee, the nurse navigator with the CAMPP team, explains,

Lee: Well, honestly, when you serve marginalized folks, the work itself is marginalized by the system...

Lee’s comment is about the lack of recognition that he sees that the people he serves receive in the mainstream health system. Therefore, by proxy, he sees a connection to a lack of recognition (in the way of funding) for the CAMPP team’s work. This is where a tension exists for the CAMPP team; maintaining their work with and for clients requires nimbleness and flexibility through being unaffiliated with a system that constrains their work. However, without affiliation to the mainstream health system (i.e., having an ongoing sustained funding source), the program faces precarity and continues to struggle for their place in the palliative health system. This

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demonstrates how, while resisting the mainstream health system's approach to care, and avoiding "duplication" of services, they are providing a program of care for patients that does not already exist. However, by doing so, they state that they are not legitimized or recognized by the system as "true palliative care" and thus not provided with sustainable funding. On the other hand, if they were conducting services that "fit" within the mainstream palliative care model, they would either be "duplicating" services, or they could risk getting "sucked up" into the mainstream service system and abandon their model that makes them different and offers socially marginalized patients a different service that is more suited to their needs. In this way, the CAMPP team does not want to become "operationalized" if it means that they will lose their relative autonomy that allows them to do the work that they do, but they also must find the balance in operating in a way that does not deem their program unnecessary given the institutionally recognized classifications of work that are legitimized through access to sustainable funding.

Conclusion

The CAMPP team operates in the interstices between the client and the mainstream health system. A significant challenge the team has is to try and meet the unique needs of their clients while also working to stay "afloat" outside a system that does not fully recognize their work as valuable through provision of sustained resources. A main funding-related challenge that the CAMPP team faces is to meet ongoing reporting requirements for various funding bodies. This is a sizable portion of paid and unpaid work that the team and others do above and beyond their client-facing work that is crucial for locating and maintaining the CAMPP team within the relations of philanthropic funding and accountability.

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In this chapter, I focused on a significant challenge that the CAMPP team has to demonstrate that their work differs from much of the mainstream work being done in end-of-life care. The team, recognizing the institutional language used about the avoidance of “duplication of services” due to the finite fiscal resources of the health system, goes to work constructing ways in which they can justify their team that makes them unique but also “recognizable” as “legitimate”. Charles speculated that the program’s work does not fit neatly into the institutionally recognized categories of measurement that are currently in place and so they must get creative to shape their work as meaningful, but also distinct from already funded services. The CAMPP team works in a way that accepts the priorities of the system including the finiteness of resources, and so tries to avoid “duplicating” already existing services. However, without a system that accounts for their work, and having to take on the extraneous work of searching for and maintaining grant funds year over year, they are endlessly concerned that they will be unable to sustain ongoing funding in the future.

In recent decades, there have been moves toward necessitating “more explicit and measurable (or at least checkable) standards of performance for public sector organizations, in terms of the range, level, and content of services to be provided” and these work against “trust in professional standards and expertise across the public sector” (Hood, 1995, p. 97 in Griffith & Smith, 2014, p.7). The expectation of measuring work activities of one organization over another is a phenomenon that has the consequence of undermining professional judgement and overlooks work being done that is deemed valuable by the people who receive it but is not deemed valuable by existing systems.

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The CAMPP team recognizes the need for their work, and this is confirmed by their clients and other service providers, but they must also maintain the work of proving their value to a system that does not recognize it officially. They have a vast amount of responsibility to clients and adjacent service providers, that many people even outside of the CAMPP team are committed to upholding, but with little certainty or validation for their own work.

I argued in this chapter that the team has worked to supply care to socially marginalized patients despite rampant neoliberal ideologies, new public management approaches, and erosions of the mainstream health care working against them. The team has leveraged a system that was not designed for them or for the clients they serve. However, it is also important to acknowledge that while neoliberal and new public management ideologies are undoubtedly in place in Canadian society, there is more to the story than just an overarching ideological force that causes reform in health systems. In Hacker's (2004) comparison of five OECD countries that were all exposed to neoliberal ideologies, he notes that all changed and shifted differently depending on their governance and financial structures. In Canada, while much of the change aligns with neoliberal ideologies of market-oriented ideals that involve cost-saving, Hacker argues that the change has less to do with widescale reform than it does a result of erosion of an existing system. He states that the change has been less about harsh "retrenchment" of social and health care programs and cutting services and more about cutting costs associated with existing services. That said, it is still timely to re-evaluate the structure of our health care system as needs evolve and divides between the rich and the poor widen. As Martin et al. (2018) have proclaimed, without bold political vision and courage to strengthen and expand the country's health system to include services that better acknowledge the social determinants of health, the Canadian version

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of universal health coverage, including the scope of services delivered within it, is at risk of being outdated.

The current funding climate and structure of the health care system as it stands leaves the CAMPP team in a position where they need to source funds for themselves through the philanthropic funding system in place for non-profit and grassroots organizations. The nature of the funding and accountability system of the non-profit sector unintentionally causes extra work for programs applying for funding and this is worsened for this very small program. The existing system makes the CAMPP team susceptible to extra work that inadvertently takes away from the work they are trying to deliver in the community to clients.

If client-serving work is not upheld to the standards of their funders, then the program's operation becomes even more perilous, and they risk losing the program altogether. Fortunately, much of the funding management work is completed by committed people external to the CAMPP team who are monetarily compensated by the institutions they work for, which relieves the CAMPP team from doing these administrative tasks themselves, which would otherwise take time away from delivering direct care to clients. However, coordinating many individuals who are accountable to different organizations and who have distinct roles, responsibilities, and skillsets also has its challenges which create extra labour that can cause confusion and disorganization for the CAMPP team, and all involved.

Charles and the CAMPP team have been engaging in thought work about how to make visible, in ways that would work to the larger mainstream system, how the CAMPP team's way of working is sustainable. Given the CAMPP team's two desires, securing sustainable operating funds and the ability to continue doing the work as they do, the key element involves how their

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project, and their ongoing work can be made visible/countable/knowable in a way that both satisfies the mainstream system and does not (overly) reshape their frontline work. The CAMPP team is left in the precarious position where the team would certainly enjoy the benefits of the stability of being part of the mainstream health system; however, they also recognize that there are consequences to being “sucked up” into a system with problems that their whole program is premised on solving. So, for the program to do their work, they need to have sustainable resources that provide the security of being part of the larger health system. However, to continue their work, that same system would need to recognize their unique service delivery model and allow them to continue providing care in ways they have been doing. This would afford the CAMPP team the relative freedom to continue to operate in the nimble way that they have been able to do so far without the extra work and worry of tracking down competitive philanthropic grant funding. As of July 2023, the CAMPP team has still not yet obtained operational funding within the mainstream health system. They are currently still funded by grants and donations.

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Introduction

This project focuses on the CAMPP team and how they produce a service for people that they perceive to be underserved by the mainstream health system, namely those who are homeless. This study uses the Canadian Observatory of Homelessness (2017) definition of homelessness that recognizes the complexity of the term and how it comprises not just the person, but the community, systemic and social barriers, and the spectrum by which homelessness can present. In this project, we see that all the clients interviewed were technically housed at the time, but CAMPP still offered support because the team determined their position on that spectrum to still be vulnerable enough for requiring their care. This study emphasizes the need for supports at all positions on the homelessness spectrum and how one's health and social status complicates their ability to access commonly available supports.

While this research explores the activities of service providers, it is grounded in the standpoint of clients, meaning that this is the starting place for the project. As Smith describes, “standpoint” is “the place from which the research can begin to look for how people's experience of their everyday world is to be opened up and explicated as it intersects with social relations that reach beyond the immediacy of their experience” (2022, p. 77). It is because the CAMPP clients value and appreciate the CAMPP team's work and their experiences are institutionally embedded that I focus on understanding how this work is put together. Often, an IE study explores an area of interest, and the issue or problem is not yet formulated in the outset of the investigation. The starting place for this project is slightly different.

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In 2016, the CAMPP team started to take steps to remedy the problem that they identified, that certain socially marginalized people were not getting the care they needed from the mainstream health system at the end of life. Their approach has been recognized by their clients and social service provider colleagues as useful (Petruik & Colgan, 2022). However, their approach has not been recognized by the mainstream system as useful in the same way. When I learned of this issue, it became the focal point of my research. My investigation was in the space where the CAMPP team was working to address the problem, in the interstices between the mainstream system and the acknowledgement of need from people who become their clients. My problematic, then, rooted in the standpoint of clients, became *how* is the CAMPP team's solution to this problem (their work) put together, delivered, supported, and resisted within and alongside the larger system of palliative healthcare provision?

This project also speaks to current ideas and debates about how our healthcare system is delivered in a way that is embedded in neoliberal ideologies and values and how these and more passive erosions of our health care system over time have contributed to significant changes in the way that healthcare is delivered in Canada. These changes have shifted the priorities of the Canadian health system from patients to cost savings. This can also be partly likened to a market-based managerial approach that leaders have implemented in health care which is often criticized as undermining a founding principle of the existing health system, “universality”. In this way, the responsibilities of care and access become those of the patients rather than of the paid service provider. As a result of these shifts, discussions about “health equity” and, for the interests of this study, “palliative equity,” have re-emerged as areas of importance in healthcare operation today.

The emphasis on “equity” over “equality” ensures that we understand that people in need of care who come from differing backgrounds and have differing requirements for support need to be recognized in service delivery if we are to claim that our system is truly “universally” delivered and accessible. Naomi Richards (2022) calls these discussions the “equity turn” in healthcare, highlighting how visions for healthcare have started to bring forth “equity-driven agendas”. This study continues this trajectory by explicating how lives of people socially marginalized by poverty and their connections with healthcare are troubled by structures in place and the organization of palliative care work. This study helps to make visible the scaffolding in the system that bends and supports only those who suit its structure, expectations, and policy boundaries. This study makes the argument that it is people experiencing homelessness and who are nearing the ends of their lives who need support but are not getting it in the way that they need, the way that works for them, to allow them to die on their own terms. In order to develop better and more attuned services, we need more studies that get at the nuances of how gaps in the system are created. These studies need to be grounded in the voices of people with lived experience of those gaps.

Researchers have taken up “equity” language as a way of recognizing discrimination in healthcare delivery based on what they name as “social determinants of health”. Martin (2018) explains that if our Canadian health system does not start incorporating the social determinants of health in the delivery of care, it risks becoming outdated and is not aligned with the original vision of Douglas, the “father of universal health care” in Canada. The current research recognizes the strengths of this work and acknowledges the importance of this turn while contributing a thread of research that embeds scholarship in real world language, practices, and activities. Using the scaffolding of the materialist institutional ethnographic approach, the

current project brings this literature into the worlds of real people, that is, by “start[ing] in the same world as the one we live in, among real individuals, their activities, and the material conditions of their activities” (Smith, 1987, p. 123).

Recapping the Research

This research was guided by the overarching research question, “How is the work of the CAMPP team socially organized in the context of the wider palliative and end-of-life care system in Calgary, Alberta, Canada?” Using an institutional ethnographic approach, I started with a broad question and collected data through observations, interviews, and program document reviews to help identify institutionally relevant “threads” to follow that examined the work of the CAMPP team. While I found all the work that the team did interesting, the scope of the project had to be limited to a manageable amount. I decided, after a period collecting “general” data on the team, on specific “threads” of interest to follow that I would focus on more intently.

A typical IE study often follows a similar trajectory of tracking and identifying important threads of interest to reach a “disjuncture” in the work of the people they are interested in. IE investigators often call this an “emergent design”. An emergent design means that the specific structure of an IE study is rarely fully planned. Rather, the process of inquiry is like “grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult in advance to specify exactly what the research will consist of...only step by step does the researcher know who they need to interview, or what texts and discourses they need to examine (DeVault & McCoy, 2006). In the current research, the thread of interest focused on how the CAMPP team’s

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work puts their work together, delivers care, interfaces with other institutions, and is supported or resisted within and alongside the larger system of palliative healthcare provision.

There is a wide body of IE literature that focuses on healthcare. However, while typical IE healthcare-focused studies locate a disjuncture within the work of the people they are investigating, in this research, I followed a slightly different path. As I mentioned above, I found that the CAMPP team had identified a problem in the world and that was the impetus for the creation of their program. I then started following how they worked within ruling relations of the wider healthcare system to put together their work in a way that serves the clients they deem as missed by the mainstream system. The expectation of the health care system is that it provides care to all individuals through universal insurance coverage, but the CAMPP team identified that those individuals who faced social marginalization through poverty did not experience the same care as those not adversely affected by such circumstances. The founding palliative physician faced tensions in his palliative work before he established the CAMPP team as what he felt he needed to do to care for these patients was not part of his recognized work activities as a physician in the mainstream system.

For this project, my focus became how the CAMPP team constructed the work addressing the problem that they identified. Their entire work project focused on addressing this problem and my role as the institutional ethnographer shifted from trying to locate the disjuncture within their work, to investigating how they went about addressing the wider problem they identified, how they worked within the ruling relations of healthcare, and how they adapted and shifted to find a legitimate place within the wider palliative care landscape.

This thread positioned me to construct a descriptive account of the CAMPP team's work while also trying to understand how their work reflected what they saw to be a tension between the work that they do and how they understand their work to be visible or (in)visible given the accountability structures and validated modes of care embedded within the mainstream palliative care delivery system.

My analysis of the data began at the outset of the observation stage of the research. It involved locating topics that came up in conversations, program documents, or in observations to identify where they connected up. The aim of the ongoing analysis was to examine the work of the CAMPP team in a descriptive way using the collected data pieces to warrant new understanding of who and how their work is shaped institutionally.

Starting from the standpoint of CAMPP clients. The "Findings" section of this dissertation begins with three accounts of CAMPP clients that help us see the kind of daily work that they engage in as people who are ill who have been previously homeless or who are precariously housed. These accounts show how they become reluctantly pulled into relying on a health system that is not built for them and how they navigate and are helped to navigate the system by pulling in supports external to the health system. The three clients, Rowan, Chapa, and Harriet, all have overlapping but unique circumstances that lead them to require support that the mainstream system does not offer. This is where they find the work of the CAMPP team useful in helping them navigate the requirements imposed on them by systems external to them (i.e., doctor's offices, government social programs, etc.). The intent of this chapter is to ground the rest of the study in the experiences of the clients which helps us understand how the work of the CAMPP team is warranted. From here, we start to see the way that our existing mainstream

palliative care system falls short in providing this group with the support they need. This sets us up to dive into the CAMPP team and their work through exploring tasks, routines, and activities they take on in a typical workday.

Describing the daily work. Following the client accounts, I gave a descriptive illustration of the central aspects of the CAMPP team's work that I drew from observations, interviews, and program documentation. The daily tasks of the CAMPP team included planning and organizing the day, the face-to-face client work, pivoting from previously held plans, and administrative duties. These tasks took skilled judgement which were guided by a purposeful way of working set up intentionally by the CAMPP team. The decisions that the team made throughout their day were shaped by their experiences working with a population with specific needs: those who are very ill and experience vulnerable housing.

I started with how the CAMPP team negotiated their presence in the “palliative care” environment in Calgary, Alberta, which initially caused tensions with existing community palliative care programs. One leader from an existing palliative care program explained that the CAMPP team was not truly delivering palliative care, but rather they focused on getting clients who did not “fit” the mainstream program “ready” for the program. Stajduhar and colleagues (2023) attribute may attribute this shift in attitudes of mainstream palliative home care service providers as due to the prioritization of acute care management thrust upon individuals in the public sector in Canada. Negotiating their position relative to the mainstream system, the CAMPP team described their work as extending beyond the mainstream service profile to offer care that is not recognized as “care” in existing approaches. From negotiating my presence as an observer, to investigating the daily work activities like “tracking clients down”, “pivoting”

between clients, how individuals come to be recognized as “clients” through an “intake process” and assessing “programmatic fit”, I found that the work of the CAMPP team extends the mainstream health provision to connect up with clients who often “fall through the cracks”.

Reshaping “palliative care”. After I described what the CAMPP team does daily, I looked at their work and the language they used to describe it. The CAMPP team constructs a way of working that repurposes the commonly understood mainstream discourse of “palliative care”. They repurpose it in a way to fit a specific population that is underserved by existing mainstream care programs. This section helps us understand how the institutional organization of palliative programs directly shapes the work activities involved in the program and either justifies or denies workers from engaging in specific activities and how this has direct implications on clients.

Using the widely recognized, but not always agreed upon, concept of “harm reduction,” the team curates a way of working that envisions palliative care in a different way to explicitly involve activities and responsibilities that are not expected of people working in the mainstream system. The way that the team does this is by installing specific language such as “harm reduction” which is becoming more widely recognized by the medical community; however, it is not implemented in the same way across all services. This concept acts as their “ticket of admission” to help persuade others of their legitimacy. They use this language to enter into legitimacy and to allow them to engage in the work that has shown to be useful for those they have identified to be underserved by mainstream systems. This intentional use of recognized concepts is not a manipulation tactic; rather, it is a way of making visible their unique approach, thereby avoiding “duplication of services” which the fiscally restrained healthcare system

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promotes as a standard. This intentional placement works to both align them with the already legitimized and powerful, mainstream system, but to also operate outside of it to address the needs of their focus population and remain unique enough not to be “overlapping” the care that other teams are already providing.

This findings section highlights the debate that Boucher et al. (2017) speak to when they discuss the controversy in developing a conceptualization of harm reduction in the literature and in practice and how this distinction can cause a rift in understandings of harm reduction. This study points to how it is not only within the practice of academic conceptualizing, but also in program service delivery, that definitions and understandings diverge. The CAMPP team organizes their work using a conceptualization of it that differs from that use in the mainstream delivery of palliative care. This study guides us to question these modes of delivery and the structures that lead them to operate in the way that they do and the real-world consequences of such differences. This project begins to highlight these differences in practice and how this work is carried out; and most importantly, how this impacts people that need care.

Understanding how the CAMPP team’s work is socially constructed is important because it allows us to see how it positions people who are meant to be served by the programs. On the one hand, the CAMPP team has an interest in people who they recognize as being “missed” by the mainstream palliative care system and the way they construct their work targets this population specifically. The CAMPP team asserts that the mainstream palliative care program is “missing this population”, but on the other hand, the mainstream programs do not view their work as “missing” this group; rather, they shape their work differently and the patients are not “ready” to be seen by them. That is, the latter programs position their work as “ready and

willing” to help this group but see this group as not “ready” for their services. The space between these two logics is in the “responsibilization” of the work. For the CAMPP team, their approach positions them as having responsibilities to reach out and build relationships with clients as part of their care work, but in the mainstream system, the responsibility is placed primarily on the patient to reach out to them. While this explanation risks simplifying the mainstream care work, it undoubtedly undergirds a major difference between how the CAMPP team approaches care and how the mainstream system palliative care system approaches it. These differences are made visible in tracking their work activities and understanding their use of intentional language that makes up their communications about the work.

Once the CAMPP team established roots in the community and fostered relationships with mainstream care providers, it became apparent that their work was useful. The mainstream providers in this study acknowledged the CAMPP team’s work but did not view it as “palliative care”. Rather, they described the CAMPP team’s work as helping with making clients “ready” to access what they viewed to be “true” palliative care. The differences in approaches and use of language permits both programs to operate within the space of care provision for this group, but there remains a tension in how this work is carried out and those who are seen as “legitimate” care providers and those who are not. A major aspect of the CAMPP team’s approach is the importance they put on “building relationships” with their clients and what work goes into this intentional work activity that undergirds their care approach.

The work of “building relationships”. Following observations of the CAMPP team, review of program documents, and interviews with the team and their clients, much of the focus of their care approach used the language of “relationship building”. Because of the prevalence of

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this concept in the team's everyday activities, it was important to me to follow this as a thread of interest in my investigation.

Tracking the everyday language that the CAMPP team used to formulate and construct their work activities, I tracked what it meant to them to “build relationships” with clients. The importance of this is to avoid what Smith (2005) calls using “blob” terms in sociology where we risk mentally “filling in” for an absence of a specific referent in physical space without a clearly defined meaning of what we are referring to. By tracking what is involved in “relationship building” for the CAMPP team, we can see that the CAMPP team coordinates their care through these activities and makes the compelling argument that the “medical” aspect of palliative care is not removed from the social, in particular, “building relationships”.

By taking the concept of relationship building and unraveling what it means in real physical everyday space of the CAMPP team's work, as we follow the threads of social interaction and shared language, we can better understand the effort and labour involved in a core aspect of the CAMPP team's practice and what it means for this work to be meaningful for their clients. However, as with most work, building relationships takes time and energy which leads us to the logistical side of the delivery of services in the social sector: the precarity of the CAMPP team's work and their sustainability as a program as they operate in the liminal space of philanthropic accountability structures in the non-profit sector.

The precarity paradox. The CAMPP team is valued and appreciated by their clients. They have also come to be valued by their partners delivering palliative care. However, their current position in the wider network of palliative care is precarious as they run outside of

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mainstream healthcare and thus are not included in the provincially funded system. Instead, they must locate funding for themselves through multiple funding sources.

The CAMPP team accesses funds through grants, agreements with provincial health authorities that reallocate funds for physician time, and third-party donations. With their team consisting of two main members, having to consistently secure funding creates workload and coordination issues for the team that detracts from the client-facing work. Additionally, it could potentially contribute to increased staff turnover as team members become nervous about job security as funding cycles reach their expiry dates.

The CAMPP team mentioned that being recognized by the mainstream health system as a needed service would be a possible solution to the precarity that the team experiences. Being recognized and taken into the mainstream system could end their financial instability woes because they would be sustainably funded. It may open up opportunities for expansion, staff retention, and resources for client-facing work. However, there is another side to this option that is not as appealing. If the CAMPP team were to become a part of the mainstream system, their worry is that this would also lead them to be limited in the work that they provide. That is, the mainstream health system would have to recognize and embrace their work as it is delivered now, not change it after taking it into the system. Being taken up by the current system would put the program at risk of being shaped by the policies, accountabilities, and practices that govern existing palliative programs. Becoming recognized and funded by the mainstream system could leave the CAMPP team without the program they designed, but not being recognized by the system continues their precarious position. This is the paradox that the team and their clients face.

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The CAMPP team as it is constructed at the time of the study has the freedom to work the way they know is necessary, but the way they are funded keeps them small and takes up time. Their quest is to be more part of the mainstream system, part of the officially funded public healthcare system, but the challenge is how they get there and how they continue to do the work that they do in the way that they do it, the way that clients value. Further, is there some other way in between these two poles that the team could sustainably function? The current research helps us understand how accountability structures influence practices and ultimately care for patients.

As the CAMPP team stands, they are not an alternative to the mainstream system, but a complement to it. They hook people into the mainstream system and pick up tasks that are not currently “covered” by existing programs. The question becomes, “why not?” If clients report that this type of work is helping them die better, and in some cases, live well longer, then how is this not part of the publicly funded system? It becomes a conversation between arbitrary, and, arguably, unnecessary, distinctions between the “medical” and the “social” and what “fits” in each category. It also points to the way that we responsabilize patients equally but those who are in quite different social categories and have vastly different challenges are disproportionately negatively impacted. This study also helps us see how funding models can limit and distort the work of palliative care providers, and as a result, negatively impact the care for clients, providing us the opportunity to think about how this might change. These are the questions that this study makes visible and that we, as researchers, caregivers, empathetic citizens, and people who will die ourselves, should be asking and exploring.

Limitations, Implications, and Possibilities for Future Work

To date there are no studies that qualitatively investigate the social organization of small non-profit community-based palliative care teams and their intersections with the mainstream health system from the standpoint of clients. This study focused specifically on the organization and production of the work of a small team involved in caring for clients in precarious social positions who have a life-limiting illness. While this study contributes to the wider body of knowledge about palliative care, there are limitations to the project that are important to acknowledge.

This study could have been strengthened by further investigation into the mainstream palliative care system and how this work is socially organized. The current findings are limited in that they cannot speak to the wider scope of practice that existing mainstream care providers work within. This study could have also been strengthened by having more client interviews incorporated, but with the onset of the global pandemic, the availability of clients was limited. Furthermore, while this study focuses on palliative and end-of-life care, there is limited data that collected the work being done while people were actively dying. However, with these limitations, the findings point to directions for important future research.

Health equity is a broad topic with many avenues of exploration. While this study looked at social marginalization by way of things like substance use, mental health problems, low income, and housing primarily, this topic is inextricably linked to other social marginalized statuses. Populations of Black and Indigenous peoples as well as people of colour are overrepresented in low-income and homeless populations. The CAMPP team serves people who identify with these groups; however, the team has traditionally not observed the same

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disproportions in their client base. That is, the CAMPP team has a lower representation of racialized and Indigenous people in their client base than we would expect given the high proportion of Indigenous and racialized people in the homeless population. The team is striving to address why this is and how they can ensure they do not miss key demographic groups in their work, through program reviews, exploration of research opportunities, and consulting with colleagues and services whose focus is primarily on Indigenous populations.

It is critical that future research into palliative work extends into the intersecting inequitable circumstances in which our healthcare system positions people of colour as well as Indigenous and Black citizens. While in my research I witnessed the CAMPP team work to ensure the safety of their program for people of all backgrounds by addressing concerns of clients, connecting people to cultural resources, and building strong trusting relationships, since my work with the CAMPP team, I have learned that they have continued to build relationships with Indigenous leaders in the health and social care systems to improve their work and ensure they are reflecting on the safety of their program for people of all backgrounds. This is evident in their mission statement that was developed in 2022 which reads, “To improve the palliative & end-of-life experience of persons with a life-limiting/ threatening illness and who are homeless (or at-risk of) by inspiring collaborations and advancing an adaptive, interfacing and outreach-based service that focuses on building capacity to uphold the delivery of quality palliative & end of life care, that is compassionate, evidenced, equity orientated, culturally safer; and grounded in an approach that is trauma informed and relationship based” (CAMPP Strategic Sightline, 2022).

A limitation of this research is that it did not report on the demographics of patients or staff which limits the depth of analysis speaking to race and gender in the work. It is crucial that

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scholarship builds on this and gathers this evidence to continue to address intersectional inequities in care.

Furthermore, this project has taken up an institutional ethnographic approach to explore a health system “adjacent” program and while healthcare is well-researched in institutional ethnographic circles, exploring the nuances of small peripheral healthcare teams who have identified, and work to address, disjunctures expands the scope of interest for IE. This work helps move this literature forward, opening new avenues of interest for IE investigators. Rather than primarily looking at institutions and finding disjunctures, this research looks at a team who is creatively coordinating their work within the larger ruling relations of healthcare, but in a way that shifts common “taken for granted” approaches to benefit their clients. These professionals are not working outside of ruling relations, but have done work to acknowledge constraints, and do their best to work within them.

This work positions the institutional ethnographer as not an external investigator of relations that may not be “seen” by the people who are doing the work that is being examined, but grounds the researcher beside the participants walking next to them, documenting what coordinates their work. It may be that some “purist” institutional ethnographers look at this work and see it not as “true” IE, but as McCoy (2022) argues, “from an institutional ethnographic perspective, any ontologically consistent study that contributes to our collective understanding of everyday experience and extended social relations is useful” (p. 43).

Additionally, the extended institutional ethnographic work contributes to the palliative care and palliative equity literature by helping us understand, more specifically, how these forms

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of palliative care are socially coordinated, constructed, and organized. This vantage point can aid in future program design, healthcare decision-making and policy implications.

Future studies might continue the findings of this project and explore more about the client's role in producing the work necessary for the CAMPP team to be successful in their care provision. This study touched on this briefly, and with any study, it must limit its scope for practical purposes, but clients have much to say and take up much labour in their daily practices as healthcare and CAMPP care recipients. This is a critical area and should be investigated closely and respectfully. Future research might also explore a more in-depth exploration of the electronic medical systems that the CAMPP team uses that interface with the mainstream system and how these systems are meant to function yet are used differently to adapt to the needs of the CAMPP team and their clients. Also, a more in-depth look is needed into why the mainstream system does not have a team like the CAMPP, if there is truly a resistance to this work and if so, where that resistance comes from and what the institutional processes are that create this resistance.

The current project also has implications for future policy decisions, program development, and for programs' relationships to mainstream health systems. Policymakers in the future might take from this work an opportunity to shift the expectations and format of funding applications and accountability structures to recognize the constraints of small teams. Similarly, this study can help inform program development through recognizing barriers and challenges that people accessing services experience and possibilities for ways forward. It is possible that through this research, the relationships between community palliative care programs and mainstream health services can be strengthened by better understanding the terrains in which

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each other navigate. Extending beyond palliative programs, other community programs also likely experience similar constraints that the CAMPP team does and so this work is relevant beyond just palliative community care.

There are many “trails to blaze” when it comes to the implications for this research and opening up more research directions from this project. While this study does not offer a clearcut pathway forward in terms of what “should” be done to address the wider structural issues that position people who are very ill and homeless to have difficulty accessing mainstream healthcare, it does offer insight into the tensions that arise around the critical issue of caring for people at the most vulnerable time of their lives, the end. This need becomes magnified when people’s social positioning leaves them to suffer needlessly while there is a health system that claims to be available for this purpose. It is my hope that while this work may bring forth more questions than answers, the questions will lead us to decisions that make lives and the ends of them more comfortable, equitable, and humane, regardless of social positioning.

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