Exploring the Nature and Impact of a Compassionate Community Initiative in an Inner-City Community: A Case Study and Participatory Journey

by

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ABSTRACT

This participatory thesis began as an exploration into the nature and impact of compassionate community approaches to health promoting palliative care using the Creating Caring Communities (CCC) initiative in St. James Town, Toronto as a case study. In the early phases of focusing my thesis, I wasn’t only interested in exploring how the field of health promotion could contribute to improving the experiences of death, dying, loss, and care. I was also motivated to engage in a research process that could facilitate change and saw this thesis as a unique opportunity to explore the nature and impact of engaging in a participatory research process. With this foundation, my thesis was structured into three cycles of action and reflection.

In Cycle 1: Grounding, I used first-person inquiry to critically reflect on my experience initiating and building a participatory research relationship with Hospice Toronto. It was this research relationship that formed the foundation for doing research together in Cycle 2 with Hospice Toronto staff and members of the CCC initiative.

Drawing on naturalistic case study and participatory health research approaches, the purpose of Cycle 2: The Photovoice Project was to: (i) understand how a compassionate community approach to health promoting palliative care in an inner-city setting could build community capacity to support isolated community members living with a life-limiting illness and/or their primary carer; (ii) articulate the impact of a compassionate community approach to health promoting palliative care from the perspective of those involved in the CCC initiative; and (iii) identify the facilitators and challenges of engaging in a compassionate community approach to health promoting palliative care in the context of an inner-city setting. The findings from this research underscore the significance of ‘scaffolding supports’ (e.g., organizational backbone support, focusing on the social determinants of health, and creating spaces for co-learning and connection to occur) in order to meaningfully support a compassionate community initiative.

From an impact perspective, the findings from this research also draw attention to the potential for compassionate community initiatives in inner-city contexts to promote opportunities for equity in palliative care.

Finally, Cycle 3: Ripple Impacts was the final action-reflection cycle in my thesis journey. Cycle 3 afforded an opportunity to stop and reflect on the impact of engaging in a participatory health research process during Cycles 1 and 2 from the perspective of those involved. Using a combination of first- and second-person inquiry approaches, we documented a number of ripple impacts across various ecological levels including: new professional and educational opportunities; interpersonal empowerment; new organizational linkages; and positive changes in neighbourhood perceptions of health promoting approaches to palliative care.

By exploring my thesis experience ‘as a whole’, I was able to draw attention to parts of the participatory journey that are often underreported (i.e., relationship building) and provide a more transparent account of the messiness, but also the value, of participatory health research processes.

PREFACE

This thesis is an original work by Krystyna Kongats. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Exploring Creating Caring Communities with Community Members", Pro00061633, February 2, 2016.

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I would also like to thank my supervisor, Dr. Jane Springett. In January 2012, you first introduced me to participatory health research, inviting me to join you to participate in the International Collaboration for Participatory Health Research annual working meeting, and I have not looked back since. I am forever grateful for your mentorship, generosity, and endless encouragement to be brave in taking the path less travelled. I would also like to thank my other committee members. Dr. Candace Nykiforuk, thank you for instilling your confidence in me over the years, and for supporting me as a writer and community engaged scholar along the way. Dr. Belinda Parke thank you for always being generous with your time and supporting my development as a participatory qualitative researcher. I will fondly remember our virtual early morning coffee chats and your encouragement.

Finally, I am thankful for the support of my family and friends through this doctoral journey. Thank you to my parents, sister, and Bapchia for all your love, your endless support of my educational pursuits, and for all the hot meals during the last phases of writing. Last but not least, thank you to my friends in Toronto and Edmonton for accompanying me on this journey and reminding me to have fun along the way. A special thank you to my Mum, Theresa, and Alessandra, Anisa, and Samra for your invaluable support in helping me make it across the finish line, I am very grateful!

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CCC	Creating Caring Communities
ICPHR	International Collaboration for Participatory Health Research
PHR	participatory health research

CHAPTER 1: INTRODUCTION TO THE CREATING CARING COMMUNITIES PARTICIPATORY CASE STUDY

OVERVIEW

In this introduction to my thesis, I provide an overview of how the Creating Caring Communities (CCC) participatory case study was conceptualized. My thesis is organized into three action-reflection cycles that formed the backbone of this research. Action-reflection cycles (i.e., cycles of planning, acting, observing, and reflecting) are a common model used to represent the participatory health research (PHR) process (Kemmis & Wilkinson, 2002).

In Cycle 1: Grounding, I present my first-person inquiry into my experience initiating and building an emergent participatory research relationship as a doctoral student with Hospice Toronto. It was this initial relationship building process with Hospice Toronto organization staff and CCC members that was critical for setting the groundwork to begin to do research together in Cycle 2.

In Cycle 2: I describe The Photovoice Project which drew on participatory and case study approaches to explore the CCC initiative, a compassionate community approach to health promoting palliative care in St. James Town, Toronto. Using the CCC initiative as a case study, Cycle 2: The Photovoice Project aimed to: (i) understand how a compassionate community approach to health promoting palliative care in an inner-city setting could build community capacity to support isolated community members living with a life-limiting illness and/or their primary carer; (ii) articulate the impact of a compassionate community approach to health promoting palliative care from the perspective of those involved in the CCC initiative; and (iii) identify the facilitators and challenges of engaging in a compassionate community approach to health promoting palliative care in the context of an inner-city setting.

Finally, Cycle 3: Ripple Impacts was the final cycle of action-reflection in my thesis. Cycle 3: was an opportunity to reflect back on the participatory nature of Cycle 1: Grounding and Cycle 2: The Photovoice Project. In Cycle 3 I documented and articulated the scope of impacts that emerged as a result of doing research together.

MY ROOTS

My thesis journey began with an interest in exploring how the field of health promotion could positively contribute to improving the experience of palliative care. My interest in palliative care was first ignited over 10 years ago during my undergraduate degree studies. During the second year of my undergraduate degree in nutrition and nutraceutical sciences, our student union facilitated a local volunteer matching service connecting students based on their interests. I completed the survey and received a list of different community organizations that I might want to volunteer with. At the top of the list was the local hospice organization—a term I hadn't heard before. I googled the organization, called their number, and found out that volunteer training was beginning that evening. I decided to try out the training—the hospice was only a short bicycle ride from where I was living—and after 30 or so hours of training sessions, I received a hospice volunteer certificate.

Over the next three years volunteering with hospice I had many different roles: fundraising support, bereavement support (which at 20-years-old I really questioned what experience I could offer a 70-year-old woman who just lost her partner), and later on when the residential hospice was built, kitchen support. In my kitchen support role, I felt most comfortable. Despite having taken intensive training as a hospice volunteer, I found myself still unsure of what to say to people who were in palliative care or experiencing grief or bereavement. However, I found that in my role as kitchen support, having a practical task to do (i.e., asking residents what I could bring them for lunch), provided an entry into getting to know someone and made the experience of providing palliative care support less intimidating. Being in the residential hospice every week, I was privileged to bear witness to many different palliative care experiences. Some residents had many family members visiting, even bringing overnight bags to stay in the guest room, while other residents had few visitors. Some residents I would see week after week, while others I only met once. Some dying experiences were quiet and calm, while for others you could hear and feel the distress and discomfort. While these experiences varied, my involvement as a hospice volunteer helped me to appreciate the importance of acknowledging and creating safe spaces to foster wellbeing across all stages of life, including death and dying.

When I began my studies in health promotion, my interest in learning more about palliative care continued. I was excited to learn about the 'life course' perspective, a theory that seeks to understand how different factors influence people's lives from birth to death (Braveman

& Barclay, 2009). However, I soon realized that the focus of the 'life course' perspective was more on how to prevent illness—and postpone death. While my own experience as a hospice volunteer normalized death and dying, I felt the opposite was true for the field of health promotion, resulting in a missed opportunity for health promotion to make a contribution to the experience of palliative care.

During my studies in health promotion I also started to appreciate key principles of this field including the importance of exploring health and wellbeing through an equity lens and using participatory/community engagement approaches (South, 2014; Springett, 2001). Reflecting back on my observations as a hospice volunteer, I thought about how those who had the opportunity to die at a residential hospice tended to be those who had good connections and supports already—observations echoed in the scholarly literature (Canadian Institute for Health Information, 2018; Sleeman, Davies, Verne, Gao, & Higginson, 2016). I started to reflect on what this meant for wellbeing for individuals in need of palliative care support who did not have family or friends to support them, who may be quite isolated, and who may have limited resources to realize their choice. As I learned more about current approaches to palliative care, I gained insight into some of the key challenges of this approach. As I will further articulate in *Chapter 2: Critique of Current Approaches to Palliative Care—Reimaging Palliative Care through a Health Promotion Lens*, I learned that current approaches to palliative care were:

- heavily focused on supporting individuals with a terminal cancer diagnosis (J. Abel & Kellehear, 2016; Kellehear, 2005; Sawatzky et al., 2016; Stajduhar, 2011);
- rooted in a medicalized, professionalized, and institutionalized framework (Kellehear, 2005; Rosenberg, 2011; A. M. Williams et al., 2010); and
- contributing to increasing inequities in palliative care opportunities for socially vulnerable populations (Stajduhar, 2019)

It was during my Master's degree that I learned about an emerging field called health promoting palliative care that first originated in Australia and sought to address the challenges of current approaches to palliative care through a social model of care (Kellehear, 1999b). Health promoting palliative care is:

> *"…a model of care that goes beyond simply providing care in the final stages of life and draws on critical and participatory principles from both palliative care and health promotion. Emphasising early intervention and a social approach to the problems and*

> *experiences of dying, it encourages service providers, family members, and the dying themselves to seek ways to promote emotional, social, and spiritual well-being, as well as physical health" Kellehear (1999a, jacket).*

I was drawn to this social approach to palliative care that sought "to enhance a sense of control and support for those living with a serious life-threatening illness" by incorporating health promotion strategies and principles into the field of palliative care (Kellehear, 1999a, p. 77). In Chapter 2, I provide a more detailed overview of health promoting palliative care including the different approaches within this model (i.e., education-based, community setting focused, and policy focused). In my early investigation of health promoting palliative care in Canada, I found that there was little exploration linking health promotion principles and strategies with palliative care practice. I saw this as an opportunity to explore health promoting palliative care from a Canadian perspective.

In beginning the process of focusing my research, I wasn't only interested in exploring how the principles and strategies of health promotion could contribute to improving the experiences of death and dying, I was also motivated to facilitate a research process that could foster change and lead to improvements in the palliative care experience. During my Master's studies, I was also introduced to PHR by my supervisor. PHR is an approach to research that is conducted together with people or communities whose life or work is at the centre of the research, across all phases of the research (Wright, Springett, & Kongats, 2018). I was drawn to this approach to research, as it bridged research with action for change in what Kemmis and Wilkinson (2002) describe as the action-reflection cycles. Action-reflection cycles follow four key phases: (1) planning for a change; (2) acting and observing the process and effects of the changes; (3) reflecting back on the process and effects, and finally (4) circling back to the re-planning stage, and so on [see Figure 1.1: The action-reflection spiral in PHR (Kemmis & Wilkinson, 2002)]. I was keen to engage in an action-reflection research process that had potential to bridge research with action for change.

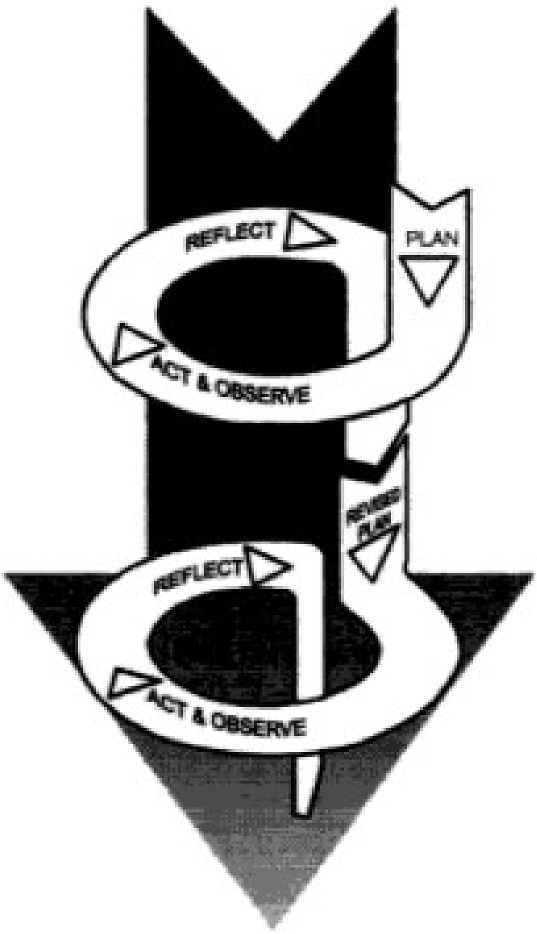

Figure 1.1: The self-reflective spiral in participatory health research (Kemmis & Wilkinson, 2002, p. 22).

In addition to the focus on action, the social justice roots of PHR resonated with my worldview, and my supervisor supported my enthusiasm and development in this approach to research by connecting me with members of the International Collaboration for Participatory Health Research (ICPHR). Through my engagement in this international collaboration, I learned first-hand how researchers from all over the world, and from different health related disciplines, were engaging in PHR practice. While I felt I had a good theoretical foundation in PHR approaches, I was keen to know what it was like to engage in PHR in a practical sense. It was with these roots—an interest in health promotion approaches to palliative care and PHR, that I started my emergent participatory doctoral journey.

THE CREATING CARING COMMUNITIES PARTICIPATORY CASE STUDY: AN EMERGENT JOURNEY

I came to this research with an interest in exploring how health promotion could contribute to the field of palliative care. However, a key aspect of PHR is engaging with those whose life or work is the focus of the inquiry in the research process, including determining the focus. I began the next stage of focusing my research interest by initiating and building a participatory research relationship with Hospice Toronto, one of the few organizations in Canada that appeared to have adopted a health promoting palliative care approach. In *Chapter 4: Cycle 1—Grounding*, I share how this research relationship was initiated and evolved over time to form the Creating Caring Communities (CCC) participatory case study research project. In getting to know Hospice Toronto and their work, I learned that since 2009, Hospice Toronto had been facilitating the CCC initiative in St. James Town, Toronto—an inner-city community (Hospice Toronto, 2014a). The CCC initiative shared many similarities with a compassionate community (i.e., a neighbours helping neighbours) approach to health promoting palliative care. This neighbourhood-based approach aimed to build community capacity to support isolated and socially vulnerable community members living with a life-limiting illness, by creating meaningful neighbour and community connections through culturally relevant social support.

In initiating this participatory research relationship, I learned that Hospice Toronto staff were eager to research their CCC initiative, as they saw this as an opportunity to: (i) learn how this initiative had evolved since it was first implemented; and (ii) better articulate the impact of their unique approach to palliative care. As Chapter 6 will further explain, the initial focus of this research had three aims. Using Hospice Toronto's CCC initiative as a case study, we aimed to:

1. Understand how a compassionate community approach to health promoting palliative care in an inner-city setting could build community capacity to support isolated community members living with a life-limiting illness and/or their primary carer;
2. Articulate the impact of a compassionate community approach to health promoting palliative care from the perspective of those involved in the CCC initiative; and
3. Identify the facilitators and challenges of engaging in a compassionate community approach to health promoting palliative care in the context of an inner-city setting.

Rooted in the naturalistic paradigm, and drawing on both case study and PHR approaches, we aimed to address these research aims using photovoice, a participatory method that blends photograph and storytelling (Wang & Burris, 1997). A comprehensive methodological overview of the research will follow this introduction in *Chapter 3: Critical Methodological Approach.* Both Hospice Toronto staff members, and myself, were keen to explore this research with community members using creative and engaging research methods, which made photovoice a good fit for this research.

This photovoice project with community members was an opportunity to shine a light on, and make visible, the vital care work neighbours in St. James Town were doing to support vulnerable community members living with a serious life limiting illness. It was also an opportunity to explore the impact of this approach to palliative care. However, as a novice participatory researcher, I also saw this research as opportunity to shine a light on what I felt was a more concealed aspect of PHR in the scholarly literature: initiating and building a participatory research relationship. Reflecting on my own experience, initiating and building a participatory research relationship with Hospice Toronto laid an important foundation from which the photovoice project was then possible. During the relationship initiation and building phase that preceded the photovoice project, I sought guidance from the literature. However, I soon realized there was a paucity of literature on this important relationship building phase of the research process. I saw my own experience as a doctoral student initiating and building a participatory research relationship as an opportunity to contribute to this gap in the literature and support other novice participatory researchers. It was with this intention, that I conducted a first-person inquiry into my experience initiating and building a participatory research relationship as a doctoral student. I called this first-person inquiry, Cycle 1: Grounding (Chapter 4). This cycle formed the first action-reflection cycle in my participatory research journey, laying the foundation for Cycle 2: The Photovoice Project which followed (Chapters 5-9).

Drawing on this same PHR lens, I also saw Cycle 2: The Photovoice Project as a unique opportunity to explore the impacts of PHR. As a member of the ICPHR, I had become aware of the challenges participatory health researchers experienced in trying to document and articulate the unique impact of this approach to research. Cycle 2: The Photovoice Project was a strategic case study opportunity to begin to unravel some of these challenges experienced by participatory health researchers in documenting and articulating the impact of this approach to research. Using the participatory photovoice project in Cycle 2 as a case study, Cycle 3: Ripple Impacts (Chapter 10) formed the final action-reflection cycle in my thesis. The purpose of Cycle 3: Ripple Impact was to: (i) explore strategies to document impacts in PHR; and (ii) describe the scope of impacts that can emerge from engagement in PHR processes.

It was these three action-reflection cycles (see Figure 1.2) that created an opportunity to explore my thesis as a whole. This research was an opportunity to combine my interest in exploring the contribution of health promotion to palliative care with my interest in contributing to the development of the field of PHR. It is these three action-reflection cycles that formed the helix backbone structure of my thesis: the CCC participatory case study.

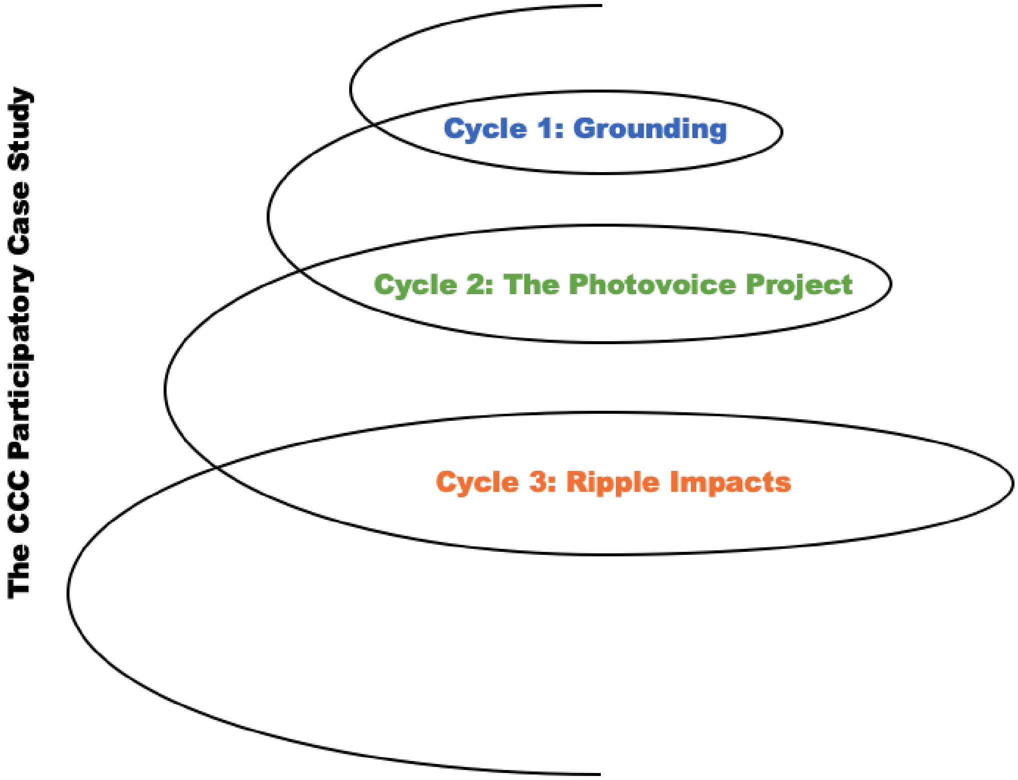

Figure 1.2: The three cycles of action-reflection in the CCC participatory case study.

ORGANIZATION OF THESIS

The remaining chapters of this thesis are organized as follows: in Chapter 2, I outline my critique of current approaches to palliative care and introduce an emerging field called health promoting palliative care. In this chapter, I conclude by highlighting current gaps in the literature on health promoting palliative care to contextualize the purpose of this thesis within the broader scholarly literature. In Chapter 3, I outline the critical methodological approach that informed the three action-reflection cycles of the CCC participatory case study. I also discuss the ethical and quality principles that guided this research. Cycle 4: Cycle 1—Grounding, is my first-person inquiry into my experience initiating and building an emergent participatory research relationship as a doctoral student.

Chapters 5 to 9 are focused on Cycle 2: The Photovoice Project. In Chapter 5: I provide a case description of the CCC initiative, the focus of Cycle 2: The Photovoice Project. Chapter 6 outlines the methods of Cycle 2 which drew on case study and PHR research approaches with a focus on photovoice methods. In Chapter 7, I outline the findings from The Photovoice Project according to the three aims of Cycle 2. Chapter 8 is a detailed discussion on the significance of the findings in Cycle 2. Specifically, I focus on three key takeaways from this phase of the research including the significance of context, scaffolding support, and capital generation in inner-city compassionate community initiatives. Chapter 9 concludes Cycle 2: The Photovoice Project and outlines my recommendations for practice, policy, and research to support compassionate community approaches to health promoting palliative care.

Chapter 10 is the final cycle in the CCC participatory case study: Cycle 3—Ripple Impacts. In this chapter, I describe the impact of doing research together across Cycle 1 and 2 and outline my approach to documenting participatory ripple impacts. Chapter 11 concludes my thesis. In this final chapter I reflect on the strengths and limitations of the CCC participatory case study as a whole.

CHAPTER 2: CRITIQUE OF CURRENT APPROACHES TO PALLIATIVE CARE—REIMAGING PALLIATIVE CARE THROUGH A HEALTH PROMOTION LENS

OVERVIEW

The purpose of this chapter is to present a critique of current approaches to palliative care that impact the experiences of death, dying, loss, and care. I focus on three key limitations of current approaches including: a primary focus on dying persons with a cancer diagnosis; the medicalization of death, dying, loss, and care; and increasing inequities in palliative care for socially vulnerable populations. To situate this critique of current approaches to palliative care, I begin this chapter by providing a brief summary highlighting how experiences of death, dying, loss, and care have shifted over the past century.

Next, to address the limitations of current approaches to palliative care, I introduce the emergence of a new approach rooted in health promotion strategies and principles called health promoting palliative care. This new approach seeks to address limitations with current approaches to palliative care. It is this reimagined approach to palliative care rooted in health promotion that is the primary focus of this thesis. I conclude this chapter by noting current gaps in the limited evidence base on health promoting palliative care, which sets the stage for the contribution of this thesis to practice, policy, and research.

HISTORICAL OVERVIEW: HOW EXPERIENCES OF DEATH, DYING, LOSS, AND CARE HAVE CHANGED OVER TIME

The experiences of death, dying, loss, and care have drastically shifted in Canada over the last century (Arnup, 2018; V. Marshall, 2015; Northcott & Wilson, 2016). During the early 20th century, death and dying were characterized as highly visible experiences in the public domain (Arnup, 2018). The fatalities from World War I, epidemics such as the Spanish Influenza, infections caused by rapid urban growth and poor living conditions, and childbirth were the major causes of death in Canada at this time (Arnup, 2018). During this period most individuals died at home and were primarily cared for by family, friends, and community (Arnup, 2018). The period after death was typically marked by different community rituals, all of which contributed to an increased community familiarity with dying and death (Aries, 1974; Kellehear, 2005). Arnup (2018) cautions however against romanticizing this period, noting that death was frequently sudden and painful.

During the latter half of the 20th century, a number of health system improvements meant that many Canadians were living longer, and circumstances around dying and death were changing (Arnup, 2018; Northcott & Wilson, 2016). These improvements included: the infant welfare and public health movements pre-World War II, and health care system advancements post-World War II (i.e., the Hospital Insurance and Diagnostic Services Act passed in 1957 and the Medical Care Act passed in 1966) (Arnup, 2018; Northcott & Wilson, 2016). By the 1950's the location of birth and death had shifted from the home to the hospital, with over half of all deaths taking place in the hospital setting (Arnup, 2018; V. Marshall, 2015; Northcott & Wilson, 2016). However, experiences of dying and death were poor as "Modern health care in the affluent post-war years was invested in saving lives, not in improving end-of-life care" (Smith & Nickel, 2003, p. 333). The shift in location of death from the home to the hospital setting marked a turning point in the decline of community capacity to support palliative care (Ariès, 2013). As Northcott and Wilson (2016, p. 4) explain, "Knowledge of and skills in end-of-life care, once common among family members, became the responsibility of health care professionals."

In response to the perceived neglect of the dying by the medical community, the hospice palliative care movement emerged in the late 1960s (Rosenberg & Yates, 2010). The aim of the palliative care movement was to restore "an holistic approach to patient care, the family as the focus of care, and the importance of multidisciplinary collaboration on a day to day basis" (Hockley, 1997, p. 84). J. Abel and Kellehear (2016, p. 21) suggest that the early hospice palliative care movement was influential in "[setting] the standard" for our current approaches to caring for people who are dying. They argue that three core features of the palliative care movement have defined our current approach to dying and loss: (1) the development of clinical specialties such as palliative medicine and nursing that focus on evidence-based management of physical symptoms; (2) the addition of multidisciplinary teams to palliative medicine and nursing specialities (e.g., psychological, spiritual, and other allied health workers); (3) a strong, yet increasing professionalized, volunteer movement (J. Abel & Kellehear, 2016; Guirguis-Younger, Kelley, & Mckee, 2005).

While the development of the hospice palliative care movement has made important contributions to improving quality of life, "the social roots of organized care for the dying" are largely absent from this approach (Kellehear, 2005, p. 1). Further, Kellehear (2005) has argued that the hospice palliative care movement is largely a professionally-driven and cancer focused response to supporting people in their final months and days of life, as opposed to a more upstream focus. In the following section I outline three critiques of current approaches to palliative care that have impacted the experiences of death, dying, loss, and care.

CRITIQUE OF CURRENT APPROACHES TO PALLIATIVE CARE

There are three main critiques of current approaches to palliative care. These critiques include: a primary focus on dying persons with a terminal cancer diagnosis; the medicalization, professionalization, and institutionalization of death, dying, loss, and care; and increasing inequities in opportunities for palliative care among socially vulnerable populations.

First, hospice palliative care has historically focused on supporting cancer patients, a legacy of the pioneering work of Cicely Saunders in leading the hospice palliative care movement (J. Abel & Kellehear, 2016; Kellehear, 2005; Sawatzky et al., 2016; Stajduhar, 2011). The emphasis on palliative care support for terminal cancer diagnoses has had many positive impacts on care for patients and their families (Greer et al., 2012; Higginson & Evans, 2010; Hui et al., 2014). For instance, a recent study found that cancer was not a major factor in hospitalized death, despite cancer being the most common cause of death in Canada (Arnup, 2018; Wilson, Shen, Errasti-Ibarrondo, & Birch, 2018). This may mean that people living with a terminal cancer diagnosis have had more of an opportunity to choose where they receive palliative care (e.g., at home or a at residential hospice) as a result of early palliative care support.

However, while palliative care has played a valuable role in supporting people with terminal cancer and their families, palliative care supports have not had the same impact on people dying from chronic health conditions. In Canada, more people are living longer and dying from serious chronic health conditions as opposed to acute illnesses (Lozano et al., 2012). With this shift, Kristjanson, Toye, and Dawson (2003) and Sawatzky et al. (2016) have advocated for palliative care to be a central part of non-cancer illness, including advanced chronic health conditions. One of the challenges however is that primary and secondary health care providers find it difficult to recognize people who may be at the last phase of their life. As a result, there tends to be limited engagement with advance care planning with this population (J. Abel & Kellehear, 2016). However, cancer and chronic illnesses are not the only causes of death. Every day people die “in road traumas, suicides, and homicides, and disasters” Kellehear (2005, p. 16). In Canada for example, unintentional injuries were the fourth leading cause of death, suicide the ninth leading cause of death, and homicide the 25th leading cause of death in 2018 (Statistics Canada, 2020). Given the diversity in death, dying, loss, and care experiences, there is a need for palliative care supports to be more inclusive of these different experiences, expanding beyond terminal cancer care.

The second critique of current approaches to death, dying, loss, and care is that the medicalization, professionalization, and institutionalization (hereinafter referred to as ‘the medicalization’) of these experiences is problematic for a number of reasons (Kellehear, 2005; Rosenberg, 2011; A. M. Williams et al., 2010). First, the medicalization of death and dying is argued to have contributed to a decrease in viewing death and suffering as important aspects of life (Clark, 2002; Illich, 1976). Clark (2002) argues that over the past four decades attitudes toward death have changed from viewing death as a natural part of life to something that should be avoided, resisted, and postponed. Second, the medicalization of death and dying has not only contributed to a decrease in the role of family care at the end-of-life, but also a decrease in community capacity to support death, dying, loss, and care (Clark, 2002; Horsfall, Noonan, & Leonard, 2012a; Illich, 1976). This medicalized shift has been criticized for separating the dying person from their social context (Rosenberg, 2011). Horsfall et al. (2012a, p. 373) explain that “Dying is now firmly located within the domain of medical science and its perceived experts. As a consequence, community knowledge about [end-of-life] care has declined, thus further increasing reliance on healthcare and medical systems for [end-of-life] care.” Third, the dominance of a medicalized approach neglects to consider that the longer part of dying occurs outside of medical care. Kellehear (2005, p. 15) explains that “if dying is about living, loving and working with a life-threatening illness until one can no longer do so”, then the longer part of dying occurs outside of medical institutions, and professional treatment and care. However, when needs of the dying person and their family are identified, it is typically solved by identifying the appropriate professional best suited to support this need (Kellehear, 2005).

The rise of the “caring professions” such as medicine, nursing, social work, and psychology (Kellehear, 2005) have also contributed to the increased professionalization of death, dying, loss, and care experiences. The increasing professionalization however is in part a response to the “geographical fracturing of family ties and social support networks” (Gibson, 2011, p. 20) and the significant change in family values and structure (Broom & Kirby, 2013). Such changes have led to a "rise of a technical and impersonal rationality that produces impersonal, contractual relations" (Gibson, 2011, p. 20). These three critiques of the medicalization, professionalization, and institutionalization of death and dying raise additional questions of whether continuing to increase professional supports is the best way to support people who would benefit from palliative care support and their families—in addition to questions on the economic feasibility of this high cost approach (J. Abel & Kellehear, 2016).

Last, the third critique of current palliative care approaches is the privileging of certain groups of people "while rendering 'others' invisible" (Stajduhar, 2019, p. 90). In Canada, current research suggests that 89% of deaths in Canada could benefit from palliative care support, however only 15% of adults who died in 2016-2017 received palliative care home services, and only 6% of adults who died in a long-term care homes received palliative care in the last year of life (Canadian Institute for Health Information, 2018). In Canada, honouring an individual's palliative care choices is the cornerstone of providing high-quality care (Fraser, 2016; Health Canada, 2018, 2019) and an important indicator of a 'good death' (Kinghorn & Coast, 2018). However, Grindrod (2020) argues that while choice is a key component of palliative and end-of-life care rhetoric, seldom are the structural factors that enable or constrain choice recognized in this context. Current research demonstrates that certain groups of people were found to be less likely to receive palliative care at home or in hospital settings including: people with a non-cancer diagnosis; older seniors; and those living in an urban area[1] (Canadian Institute for Health Information, 2018). While the Canadian Institute for Health Information (2018) report found there were no substantial sex- or income-based differences in access to palliative care, research in the United Kingdom had found that people living in more deprived neighbourhoods were less likely to experience an inpatient hospice death (Sleeman et al., 2016).

Furthermore, research on access to palliative care has also found that people with a serious life-limiting illness that have strong family (biological) and community connections were also more likely to have received quality palliative care (Stajduhar, 2019). Findings from the Canadian Institute for Health Information (2018) echo this finding in their recent report which

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[1] The difference in access to palliative care between urban and rural and remote settings may be a reflection of the higher percentage of deaths that occurred in rural and remote areas of people with a cancer diagnosis in the year 2016-2017 compared to urban areas (Canadian Institute for Health Information, 2018).

found that 99% of people in Canada who received at home palliative care had family or friend caregiver support (Canadian Institute for Health Information, 2018). This suggests that family or friend caregiver support is one of the most important factors in influencing access to palliative care, particularly ‘at home’. This has significant consequences for many isolated and vulnerable individuals who would like to remain at home in their community for as long as possible, but who do not have strong family or community connections. While ‘home’ as a place for palliative care is a contentious issue (Pollock, 2015), it is where many Canadians wish to be cared for (Canadian Hospice Palliative Care Association, 2013). ‘Home’ is significant for a number of reasons. Home has been described as “a place of comfort and belonging; places of social connection and collaborative caring; places of connection to nature and the non-human; [and] places of achievement and triumph” (Horsfall, Leonard, Rosenberg, & Noonan, 2017, p. 58).

In addition to the importance of family and friend supports, the needs of individuals with a serious life-limiting illness who also experience homelessness/unstable housing, mental illness, substance use, and/or poverty are largely neglected by the health care system and unable to access quality palliative care (Stajduhar et al., 2019). While there are a few examples of initiatives in Canada addressing the inequities in access to palliative care for individuals who are homeless or vulnerably housed [see the Palliative Education and Care for the Homeless (PEACH) program (Inner City Health Associates, n.d.), and the Calgary Allied Mobile Palliative Program (CAMPP) (Calgary Allied Mobile Palliative Program, n.d.)] the system of palliative care as it is currently organized has continued to neglect vulnerable populations from access to quality palliative support.

While the 1960s hospice palliative care movement was a welcome response to the perceived neglect of the dying, this critique highlights the limitations of our current approaches to palliative care. To address these limitations, I present an emerging approach to palliative care rooted in the principles of health promotion.

HEALTH PROMOTING PALLIATIVE CARE: RE-IMAGING PALLIATIVE CARE THROUGH A HEALTH PROMOTION LENS

Health promoting palliative care was first theorized and applied in practice in Australia by Prof. Allan Kellehear in the 1990s as a new social model of practice, “to enhance a sense of control and support for those living with a serious life-threatening illness” by integrating the principles and strategies of health promotion into palliative care (Kellehear, 1999a, p. 77). While the field of health promotion has historically avoided researching and practicing in the field of palliative care (Kellehear, 1999b), Antonovsky (1996) has challenged the field of health promotion to expand beyond a pathogenic orientation that categorizes individuals as healthy or sick, to a salutogenic orientation rooted in an assets-based approach. Antonovsky's (1996) salutogenic approach to health promotion creates an opportunity for the principles, values, and strategies of health promotion to positively impact wellbeing anywhere along the "healthy/dis-ease continuum" (Antonovsky, 1996, p. 14). In Appendix A, I present a more detailed discussion on: the tension between health promotion and experiences of death, dying, loss, and care; and the value of a salutogenic orientation.

Internationally, there is a growing movement of researchers and practitioners applying the principles of a health promoting palliative care approach to improve experiences of death, dying, loss, and care (Noonan, Sallnow, & Richardson, 2020). Despite the increasing use of this new approach, definitions of, and approaches to, health promoting palliative care are quite varied. In Table 2.1 I outline select examples of commonly cited definitions of health promoting palliative care.

Table 2.1: Commonly cited definitions of health promoting palliative care within the literature.

Author(s)	Definition
Kellehear (1999a, jacket)	"…a model of care that goes beyond simply providing care in the final stages of life and draws on critical and participatory principles from both palliative care and health promotion. Emphasising early intervention and a social approach to the problems and experiences of dying, it encourages service providers, family members, and the dying themselves to seek ways to promote emotional, social, and spiritual well-being, as well as physical health."
Rosenberg and Yates (2010, p. 206)	"… a social model of care based upon a conceptual perspective that promotes optimal health even in the presence of incurable disease, utilising palliative care philosophy to inform the

	development of organisational mission, values and strategic directions, and the *Ottawa Charter* to supply parameters for determining the scope of goals and objectives.”
Karapliagkou and Kellehear (2015, p. 5)	“The public health approach to end-of-life care is concerned with social efforts led by a coalition of initiatives from governments, their state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, caregiving and bereavement.”
Public Health and Palliative Care International (n.d.-b)	“Death, dying, loss and care is everyone’s responsibility. A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life.”

While these different definitions share many common elements (e.g., a common focus on the social nature of death, dying, loss, and care, and the emphasis on these experiences being ‘everyone’s responsibility’, etc.), they also highlight some confusion in the conflation of different concepts. For instance, Whitelaw and Clark (2019, p. 8) have highlighted a few “confusing *non sequiturs*” in the literature including, “a public health approach to palliative care is a health promotion approach to end of life care” (Public Health and Palliative Care International, n.d.-a) and “a public health approach to palliative care necessarily adopts the tenants of both palliative care and health promotion” (Stjernswärd, Foley, & Ferris, 2007). While this concept was first coined as ‘health promoting palliative care’ in the early 1990s (Kellehear, 1999a, 1999b) it is now more commonly referred to as ‘public health palliative care’ (Public Health and Palliative Care International, n.d.-a). This is part of a broader shift in ‘public health’ terminologies replacing the use of ‘health promotion’ concepts (Scott-Samuel & Springett, 2007).

In addition to the variety of definitions used, a recent review exploring public health approaches to palliative care, identified three different paradigms of a public health approach to palliative care being operationalized within current empirical research (Dempers & Gott, 2017). The three different paradigms identified in the review included:

1. The health promotion approach that is rooted in the principles and strategies of the Ottawa Charter for Health Promotion with an explicit emphasis on community driven and asset-based approaches (Dempers & Gott, 2017);
2. The World Health Organization (WHO) approach that is rooted in the WHO Public Health Strategy for Palliative Care with a core focus on national policy, drug availability, education, and service provision (Dempers & Gott, 2017); and
3. The population-based approach that included studies that did not explicitly make a connection to health promotion or the WHO approach, but focused on strategies at the population level traditionally relying on epidemiological research for evidence (Dempers & Gott, 2017).

In this thesis, I use the term ‘health promoting palliative care’ to indicate an approach that is rooted in the principles, values, and strategies of health promotion practice. I also use the term palliative care rather than end-of-life care to indicate care for an individual with a serious illness in which a cure or complete reversal of disease is not possible, as opposed to care in the last months or year of life (Krau, 2016).

While there is a need for better clarity on the use of different terminologies describing health promoting palliative care, there are some common themes central to this approach. First, the field of health promoting palliative care is united in a shared understanding that the problems and experiences of death, dying, loss, and care are everybody’s responsibility (i.e., individuals, communities, schools, health professionals, allied health workers, religious institutions, workplaces, and all levels of government) (Kellehear, 2005; Public Health and Palliative Care International, n.d.-a). Rooted in this understanding is a belief that a professionalized and medicalized approach to death and dying is ill-equipped to dealing with many common social experiences associated with death, dying, loss, and care (e.g., loneliness, isolation, and stigma) (Sallnow, Richardson, Murray, & Kellehear, 2016). Rather, these common social experiences associated with death, dying, loss, and care are best tackled by friends, community members, and other social networks by creating supportive environments in the places we live, work, play, and love (Horsfall, Noonan, & Leonard, 2012b; Sallnow et al., 2016).

Health promoting palliative care is typically described as being associated with a core set of action areas and a core set of values. The underlying action areas for health promoting palliative care are rooted in the World Health Organization’s (1986) Ottawa Charter for Health

Promotion including: build healthy public policy, create supportive environments, strengthen community action, develop personal skills, reorient health services. Examples of the application of these action areas are outlined in the following section exploring common approaches to health promoting palliative care.

Health promoting palliative care is also characterized by a core set of values that guide the application of this approach. For example, the Public Health and Palliative Care International association (n.d.-a) have outlined six core values:

- *Participatory relations*: working together with people we care for and valuing the knowledge and experience of people with lived experience, not only professional knowledge;
- *Community development*: building off participatory relations to use a community development approach to work with communities to map out assets, priorities and needs in death, dying, loss, and care and develop community capacity;
- *Partnerships*: taking a broad partnership approach that sees death, dying, loss, and care as 'everybody's' responsibility including schools, workplaces, churches and temples, art galleries, the media, businesses, etc;
- *Education*: that focuses on increasing support and reducing anxiety and misconceptions about dying, loss and end-of-life care for families and communities;
- *Population health approaches*: expanding beyond one-on-one clinical encounters to include broader community education and engagement; and
- *An emphasis on ecological/settings perspectives*: by focusing on how physical and social environments promote or degrade health (Public Health and Palliative Care International, n.d.-a).

Common Approaches to Health Promoting Palliative Care

There are three common approaches to health promoting palliative care described in the literature. These include: education and awareness initiatives; settings-based initiatives; and policy-level initiatives. While these types of approaches are presented as separate entities, in practice these approaches often overlap and build off each other.

Education and awareness initiatives

Education and awareness initiatives that start to change the public's knowledge, attitudes, and beliefs are one approach to health promoting palliative care. This approach aligns with the 'developing personal skills' and 'creating supportive environments' action areas of the Ottawa Charter for Health Promotion. These types of approaches help to reduce stigma surrounding death, dying, loss, and care by advocating for the universality of these experiences (Kellehear, 2016). Examples of education and awareness raising initiatives include:

- "Good Death Week" in Scotland that aims to provide "individuals and organisations with an opportunity to promote the positives of living in a society where people can be open about dying, death and bereavement" (Good Life Good Death Good Grief, n.d., para. 3).
- "End Well Symposium" in the United States that "brings together a multidisciplinary community that unites design, technology, health, policy and activist initiative to create a cultural shift to transform our thinking around the end of life" (End Well, 2020, para. 1).
- "Beer mat chats" in Scotland where 15,000 beer mats were distributed to pubs across the country as a strategy to introduce storytelling and reflection on loss, grief, and mortality (Hazelwood & Patterson, 2015).

Setting specific initiatives

Setting specific initiatives are another common approach to health promoting palliative care, which aligns with the 'create supportive environments' action area in the Ottawa Charter for Health Promotion. For example, schools have been identified as important settings in a health promoting palliative care approach (Kellehear, 2005; Paul, 2016). In Canada, the Canadian Hospice Palliative Care Association (2016) has also focused on workplaces as important settings for health promoting palliative care through their 'Canadian Compassionate Companies' initiative. For example, Canadian companies can receive a 'Canadian Compassionate Company' designation for adopting policies to support the increasing number of employees who are caregivers, grieving, or experiencing a life-limiting illness themselves (Canadian Hospice Palliative Care Association, 2016).

One of the most commonly adopted approaches to health promoting palliative care, and the focus of my thesis, is through community setting focused initiatives (J. Abel, Bowra, Walter,

& Howarth, 2011; Kellehear, 2013; Kellehear, Heimerl, & Wegleitner, 2015). Sallnow et al. (2016) explain that these initiatives, called compassionate communities, tend to focus on the mobilization of community resources through naturally occurring or externally facilitated social connections among members (J. Abel et al., 2011; Horsfall et al., 2012a; Kumar, 2007; Rosenberg, Horsfall, Leonard, & Noonan, 2014). Compassionate communities are often facilitated by local organizations, such as the local hospice (Public Health Palliative Care International, n.d.-b). However the neighbourhood helpers involved are typically not necessarily formal volunteers of the facilitating organization, rather they tend to be “ordinary neighborhood citizens” working together with other organizations to support members of their community in experiences of death, dying, loss, and care (Public Health Palliative Care International, n.d.-b). The ‘Neighbourhood Network in Palliative Care’ in Kerala India is one of the largest examples of a compassionate community approach (Kumar, 2007, 2012). In the last five years, Canada has also seen a growth in compassionate community initiatives across the country. A recent review by Tompkins (2018) identified twenty different compassionate communities initiatives in Canada [British Columbia (2), Alberta (1), Ontario (16), Nova Scotia (1)].

Policy initiatives

Policy focused initiatives are another major pillar of health promoting palliative care. This approach aligns with the ‘reorient health care services’ and ‘build healthy public policy’ action areas of the Ottawa Charter for Health Promotion. One of the most commonly cited policy level initiatives is called the Compassionate Cities approach first articulated by Prof. Kellehear in 2005 in his book *Compassionate Cities – Public Health and End of Life Care* (Kellehear, 2005). This approach is rooted in the World Health Organization’s Healthy Cities model. Key to a Compassionate Cities approach is strong intersectoral collaboration between local governments, workplaces, schools and universities, recreational sites, care homes, hospitals, churches, voluntary organizations, community groups, hospitals, and primary care institutions (Kellehear, 2005). The Public Health Palliative Care International association has documented eight examples of Compassionate Cities initiatives across the globe including: Kozhikode, India; Inverclyde, Scotland; Plymouth, England; Cologne, Germany; Jiujia Village, Taiwan; Vic, Spain; New Westminster, Canada; and Ottawa, Canada Public Health Palliative Care International (n.d.-b).

The Impact of Health Promoting Palliative Care

As the field of health promoting palliative care is relatively new, there is a limited evidence base beginning to document and assess the impact of a health promotion approach to palliative care. Indeed, a systematic review by Sallnow et al. (2016) exploring the impact of a new public health (i.e., health promotion) approach to end-of-life care is the most comprehensive synthesis of impact in this field to date. In their findings from only eight included articles, they documented impact across three core themes:

- "making a practical difference" (e.g., addressing basic needs, decreasing social isolation, etc.);
- "individual learning and personal growth" (e.g., increase confidence and new knowledge/skills in palliative care, etc.); and
- "developing community capacity" (e.g., increasing social capital, changes to professional practice, etc.) (Sallnow et al., 2016, p. 205).

While the findings from this systematic review demonstrate some promising impacts of a health promotion approach to palliative care, there is a need for more research to better understand the impact of this approach, particularly across a range of different contexts.

KEY CONSIDERATIONS MOVING FORWARD: DEVELOPING THE HEALTH PROMOTING PALLIATIVE CARE EVIDENCE BASE

There is a need to continue to better understand what a health promotion approach to palliative care is, what the impacts of such an approach are, and how this approach is applied in different contexts. Continuing to build the health promoting palliative care evidence base is vital for understanding how we can improve death, dying, loss, and care experiences. As the field of health promoting palliative care continue to evolve, here I note two issues that require a deeper consideration in the evidence base: the need for a more critical engagement of both the benefits and limitations of bottom-up community driven approaches to palliative care; and the need for a stronger health equity emphasis by focusing action on vulnerable populations.

As one of the key aspects of health promoting palliative care is a focus on re-engaging 'community' in experiences of death, dying, loss, and care (Horsfall et al., 2012a; Kellehear, 2005), it is important to critically assess both the benefits and limitations of bottom-up community driven approaches to palliative care. This critical engagement is important to minimize the possibility of romanticizing the role of community in experiences of death, dying, loss and care. Indeed, sociologists including Lois Bryson and Martin Mowbray are critical of embracing a community empowerment discourse, and refer to the romanticization of community as a "spray-on solution" to complex social issues (Bryson & Mowbray, 2005). Similarly, Horsfall et al. (2012a) in their study illuminating the impacts of informal caring networks, emphasize the need to carefully analyze the function and impact of what a community care network is really able to provide. These authors explain that it is important to not over simplify the concept of community and see community as a universal panacea (Horsfall et al., 2012a). This critical lens is important to remember as communities are "contradictory and contested [concepts], not simply an inherently good thing" (DeFilippis, 2010, p. 12). For example, the actions of communities can play a role in both reinforcing and rejecting the status quo (R. Williams, 1983). Further, Mowbray (2005) cautions that embracing a community empowerment discourse can justify cynical attempts to decrease the role of the welfare state in providing health and social services. Over the past 30 years, the impact of neoliberal roll-backs on basic services by the state has led to the creation of new public-private partnerships, and new roles for not-for-profits to essentially fill the gaps left as services continue to be protracted (DeFilippis, 2010). While community efforts can play a role in challenging contemporary neoliberalism, DeFilippis (2010, p. 12) warns against "[romanticizing] the power and potential of community efforts" and assuming that community efforts are always contributing to positive social change. It is important to consider health promoting palliative care approaches within this broader neo-liberal context. As Patterson and Hazelwood (2014) remind us, the supports we also receive from government bodies, workplaces, the education system and wider society also have a major impact on how we live, decline, and die.

The second issue that requires greater attention as the field of health promoting palliative care continues to emerge is the need for a stronger health equity focus by focusing strategies on vulnerable populations. While one of the essential elements of a health promoting palliative care approach is described as "equal access for all" (Becker et al., 2014, p. 404), this approach appears to be rooted in Geoffrey Rose's (2001) 'population-level' public health approach that aims to increase overall population health. For example, Public Health and Palliative Care International (n.d.-a) identifies 'population-level' approaches to health promoting palliative care as a core principle of this approach. In addition, while issues of health equality are referred to in health promotion palliative care literature, it has primarily been in relation to equal access in low- and middle-income countries (Sallnow, Kumar, & Kellehear, 2013). While a population-level approach to health promoting palliative care is important for improving the overall health and wellbeing of populations, it does not necessarily reduce avoidable health differences between groups (Frohlich & Potvin, 2008). It is important to consider that population approaches can inadvertently increase health inequities as "those with the most resources at hand to adapt to new situations will be the first to derive maximum benefits from population-approach interventions" (Frohlich & Potvin, 2008, p. 219). This is known as the inverse care law (Hart, 1971). To address the limitations of a population-level approach, Frohlich and Potvin (2008) have recommended complementing population-health approaches with a vulnerable population approach. A vulnerable population approach is specifically focused on making changes in social and environmental conditions (i.e., reducing barriers) that put socially vulnerable groups "at higher risk of risks" (Frohlich & Potvin, 2008, p. 219). Notwithstanding the valuable contributions of Grindrod (2020) and Stajduhar (2019) among others, health promoting palliative care has had limited engagement with a vulnerable populations approach, and as a result has not lived up to its full potential to address inequities in death, dying, loss, and care experiences. A stronger engagement with a vulnerable populations approach, by focusing on ways to reduce social and environmental barriers to palliative care will strengthen health promoting palliative cares' equity principle.

THE CCC PARTICIPATORY CASE STUDY: ADDRESSING GAPS IN THE CURRENT EVIDENCE BASE

This thesis, the CCC participatory case study, aims to contribute to the emerging health promoting palliative care evidence base by addressing these two key considerations. It is these two considerations (i.e., the need for a more critical engagement of both the benefits and limitations of bottom-up community driven approaches to palliative care and the need for a stronger health equity focus) that informed the development of the CCC participatory case study.

To the best of my knowledge, there are no empirical examples in the scholarly literature exploring the nature and impacts of a compassionate community approach to health promoting palliative care in the Canadian context. To address this gap, my thesis explores the nature, impacts, and facilitators/challenges of Hospice Toronto's CCC initiative, a compassionate community approach to health promoting palliative care, in an inner-city setting. As the case description in Chapter 5 will further outline, the CCC participatory case study, situated in St. James Town (an inner-city community) creates an opportunity to explore how a compassionate community approach can facilitate opportunities, and reduce barriers to, palliative care in socially vulnerable communities. The findings from my thesis will contribute to developing a more nuanced understanding of the benefits of compassionate community initiatives in inner-city settings, as well as the challenges and limitations of such an approach.

SUMMARY

In this chapter I outlined my critique of current approaches to palliative care and outlined an emerging model rooted in the principles of health promotion. While the principles and strategies of health promoting palliative care show promise, there are limited empirical studies exploring the nature and impact of this approach to palliative care (particularly in a Canadian context). In addition, I argue that future research on health promoting palliative care needs to include a more critical assessment of the benefits and limitations of bottom-up community driven approaches to palliative care and a stronger health equity focus. It is with these two considerations that I began the CCC participatory case study. In the following chapter, I outline my critical methodological approach that guided the CCC participatory case study.

CHAPTER 3: CRITICAL METHODOLOGICAL APPROACH

OVERVIEW

> *"It is better, we believe, to find new seas on which to sail than older ports at which to dock." (Barone & Eisner, 2011, p. 4)*

The purpose of this chapter is to provide an overview of the critical methodological approach I used to explore the CCC participatory case study. A critical methodology involves "a de-emphasis on method per se, the need for methodological innovation and the continual critical examination of the assumptions that undergird methods and other research resources" (Yanchar, Gantt, & Clay, 2005, p. 35). I was drawn to a critical methodological approach as this approach provided the space to best explore the emergent nature of the CCC participatory case study, and resonated with my own personal values as a researcher. I begin this chapter by describing how the naturalistic paradigm rooted my inquiry into the CCC participatory case study. Next, I introduce the two research approaches that informed my emergent research process: case study and PHR. I also present the three action-reflection cycles of the CCC participatory case study that provided the structure for my thesis. These include: Cycle 1 – Grounding; Cycle 2 – The Photovoice Project; and Cycle 3 – Ripple Impacts. Finally, I conclude with a discussion on the ethical and quality considerations that influenced the inquiry into the CCC participatory case study.

NATURALISTIC PARADIGM

I rooted the CCC participatory case study in a naturalistic paradigm, the theoretical framework that outlines my belief system and worldview as a researcher. A paradigm holds together a particular worldview, set of assumptions, perceptual orientations, and appropriate research methods that as a whole, provide the scaffolding for a coherent research frame (Davis, 2012; Donmoyer, 2012). The naturalistic paradigm arose out of a dissatisfaction with the natural sciences' (i.e., the positivist paradigm) ability to explore many of the questions in both the natural and social sciences (D. Wicks, 2010). Lincoln and Guba took issue with the positivist approach to research, arguing this paradigm: limits the conceptualization of science by focusing primarily on theory testing versus theory generating; over depends on operationalism (i.e., measurement); tends to disregard ‘humanness’ or emic perspective; and follows ‘flawed’ assumptions such as value freedom and linear causality (D. Wicks, 2010). To address the challenges and limitations of the positivist paradigm, Lincoln and Guba (1985) outlined an alternative—the naturalistic paradigm. In this section I outline the key axioms and characteristics of the naturalistic paradigm that formed the foundational building blocks from which the CCC participatory case study was developed.

The naturalistic paradigm is characterized by five axioms. Axioms are a group of indemonstrable basic assumptions that are accepted by convention as the building blocks of a conceptual or theoretical structure (Lincoln & Guba, 1985). First, as a naturalist, I accept the ontological assumption that there are multiple constructed realities that can only be explored holistically (rather than as fragments) (Lincoln & Guba, 1985). Second, I accept the epistemological assumption that the ‘knower’ and the ‘known’ interact to influence one another (although I re-frame this axiom from a PHR lens in a later section) (Lincoln & Guba, 1985). Third, I view the possibility for generalizations as ‘working hypotheses’ (Lincoln & Guba, 1985). Fourth, I also believe that all entities impact one another and therefore it is not possible to separate out causes from effects (Lincoln & Guba, 1985). Last, I accept that research explorations are value-bound in at least five ways: (i) the research is influenced by my own personal values, and impacts how I frame the research questions; (ii) the research is influenced by the specific paradigm, or ‘worldview’ that I subscribe to; (iii) the research is also influenced by the research approach, or substantive theory, that is selected which influences data collection, analysis, and interpretation of findings; (iv) the research is influenced by the values inherent to the specific context; and (v); in order for research to produce meaningful results, there has to be ‘value resonance’ with respect to these four previously outlined values (Lincoln & Guba, 1985).

In addition to these five key axioms, eleven characteristics of the naturalistic paradigm influenced how I conducted the CCC participatory case study. These eleven operational characteristics include:

- **Natural setting:** the research was conducted within the everyday setting of the CCC initiative (i.e., the St. James Town neighbourhood). This is because the naturalistic ontology assumes that realities can only be understood as a whole, in context.
- **Human instrument:** CCC members and staff who took part in the CCC participatory case study, including myself, were the primary knowledge generating ‘tools’, as any

other type of tool (e.g., technical instruments, pen and paper) would not be able to adapt and adjust to the many different perspectives that we expected to encounter.

- **Use of tacit knowledge:** intuitive and felt knowledge (tacit knowledge) was important to incorporate as part of the inquiry in addition to propositional knowledge (spoken) in order to understand the phenomena as a whole. As such, observation played a key role in the CCC participatory case study.
- **Qualitative methods:** Hospice Toronto staff members and myself opted for qualitative methods as this approach provided more flexibility for understanding multiple perspectives rather than aggregated quantitative perspectives.
- **Purposive sampling:** Hospice Toronto staff members and myself purposefully identified CCC members who were knowledgeable about the CCC initiative while also trying to engage a range of perspectives (different roles in the initiative, gender, age, etc.) to increase the chances that multiple realities can be included.
- **Inductive data analysis and grounded theory:** I used a hybrid approach to data analysis primarily relying on analyzing the data from the ground up (i.e., not using a priori codes) as this process was more likely to consider the multiple realities that were generated from the data.
- **Emergent design and focus-determined boundaries:** The CCC participatory case study was rooted in an emergent process that allowed the research design to be adapted as I began to learn more about the CCC initiative and the various stakeholders. This emergent process was important as it was difficult to know ahead of time the multiple realities that emerged, and because the interactions between research members were unpredictable. The focus of the inquiry became clearer as I spent more time in the local context. This emergent process also created space to research other important aspects that emerged from the CCC participatory case study including the relationship building phase and exploring the impact of participatory processes.
- **Negotiated outcomes:** all CCC project members played a role in interpreting the findings (albeit to varying degrees) as CCC members and Hospice Toronto staff were well situated to interpret and confirm the multiple complex interactions of the CCC initiative in the local context.

- **Case study reporting mode:** I adopted a case study approach to reporting as this allowed for more of a descriptive reconstruction that was better able to incorporate the various influences of context.
- **Idiographic interpretation and tentative application:** I used rich descriptive re-telling which allowed for naturalistic generalizations (time- and context-bound) to emerge.
- **Special criteria for trustworthiness:** finally, I used a set of quality criteria that aligned with the core axioms of the naturalistic paradigm—credibility, transferability, dependability, and confirmability which will be further presented under the 'Quality' section later on in this chapter.

These eleven operational characteristics of the naturalistic paradigm rooted my research and informed the specific research approaches used to explore the CCC initiative: case study and PHR. These research approaches will be described in the following section.

RESEARCH APPROACHES

Building off the foundation set by the naturalistic paradigm, I drew from both case study and PHR approaches to explore the CCC initiative as opposed to strictly following one particular method. The case study approach provided an overarching framework for bringing together the different aspects of my thesis research into a 'whole'. The PHR approach was selected to address the limitations of the naturalistic paradigm in order to better reflect my positionality as a researcher by layering on the principle of 'participation.' In this thesis, I opted to use the term approaches (e.g., case study approach and PHR approach) rather than methods. I embraced Yanchar et al.'s (2005) call for a critical methodology that encourages researchers to de-emphasize their focus on method use "in favor of a focus on the creative processes of theory formation and problem solving, which [are] aided by various methodological procedures" Yanchar et al. (2005, p. 154). This practice-based orientation recognizes the need for research strategies that are flexible to contextual circumstance. In addition, this approach can be adapted as the research progresses and new questions emerge that may require a different set of strategies (Yanchar et al., 2005). Barone and Eisner (2011, p. 1) echo this sentiment writing that "matters of meaning are shaped–that is, enhance and constrained–by the tools we use." Last, a critical methodology encourages researchers to question the core axioms and strategies of the underlying philosophical framework or paradigm and the limitations that are imposed by these assumptions

(Yanchar et al., 2005). Using a critical methodological approach, I was able to critically reflect on the underlying naturalistic paradigm that informed the inquiry into the CCC initiative. Second, I was able to incorporate new assumptions that better suited my thesis research.

While I adopted a critical methodology for my thesis work, a certain degree of methodological coherence between research approaches on core values and assumptions was required to develop sound and meaningful research findings (Chamberlain, Cain, Sheridan, & Dupuis, 2011). Tensions in methodological coherence are less of a concern for research that makes the case for multiple qualitative methods or approaches, as there tends to be more overlap in core values [as opposed to combining positivist and naturalist approaches (Chamberlain et al., 2011)]. In the following sections, I outline how drawing upon case study and PHR approaches created a multifaceted tool to explore the CCC initiative and my thesis experience as a whole in a methodologically coherent manner.

Case Study

A case study approach was used to help frame the overarching structure of the investigation into the CCC initiative as a whole—from building the participatory research relationship with Hospice Toronto and CCC members, to facilitating the CCC photovoice project, and finally to reflecting on the impact of doing research together. A naturalistic approach to case study was selected as this approach aligns with the naturalistic paradigm. A naturalistic approach to case study is “a way to unravel the complexity of one demarcated entity” (Abma & Stake, 2014, p. 1150). Another popular approach to case study research is that developed by Yin (2014), however this approach to case study is rooted in a post-positivist tradition, uses a predetermined theoretical framework to understand the complexity of the case, and tends towards universalism and explanation (Abma & Stake, 2014; Boblin, Ireland, Kirkpatrick, & Robertson, 2013). Rather, a naturalistic approach to case study better aligned with my ontological, epistemological, axiological lens. From here on in, when I use the term case study, I am referring to a naturalistic orientation. The case study approach is characterized by five key features: (i) emic issues that emerge from the case; (ii) the influence of context (meaning that the case does not exist in isolation and context is important in understanding a social phenomenon); (iii) meaning and interpretation facilitated through research processes that foster dialogue in order to co-construct a meaningful understanding; (iv) arriving at a holistic understanding of the case by including multiple perspectives; and (v) learning from the case by providing a vicarious experience for those reading about the case, commonly through thick description revealed through people's stories (Abma & Stake, 2014; Simons, 2009; Stake, 1995).

The defined entity, for my thesis research was first proposed as Hospice Toronto's CCC initiative in St. James Town. Aligned with the naturalistic paradigm, studying the CCC initiative within it's 'natural setting' (i.e., the St. James Town neighbourhood) allowed for the initiative to be explored and understood within this specific context. Cases from a naturalistic orientation to case study are selected by what can be learned from the case, rather than focusing on how representative the case is (Abma & Stake, 2014). The CCC initiative was selected as a case study as it had a long operating history in Canada (i.e., since 2009) allowing for a more in-depth and nuanced study opportunity to examine the nature and impact of compassionate community approaches to health promoting palliative care within an inner-city setting. While there has been a rapid increase in the number of compassionate community approaches in Canada since 2015 (Hospice Palliative Care Ontario, 2018a; Tompkins, 2018), many initiatives are only in the planning or pilot phases. Hence, these pilot initiatives do not provide the same richness of learning that a longer running initiative, like the CCC initiative, would. Second, the CCC initiative was facilitated in St. James Town, Toronto, one of Canada's most socio-demographically diverse neighbourhoods (St. James Town, 2020), which added another learning opportunity in terms of exploring a compassionate communities initiative within this unique inner-city context.

However, while my thesis started with an initial focus on the CCC initiative as a case example to better understanding the nature and impact of compassionate community approaches to health promoting palliative care; I also saw an opportunity to use the CCC participatory case study as a unique opportunity to contribute to the field of PHR. Thus, the CCC participatory case study became a case within itself to reflect on the experience of relationship building in PHR and the impacts of such an approach.

In terms of data generating strategies, case study research draws on three approaches: observation, interviews, and document analysis (Simons, 2009). In the CCC participatory case study, I drew on these core data generating strategies throughout the project. The specifics of how these data generating approaches were used is outlined within the different phases of the research. In terms of analysis and reporting approaches in case study research, there are a variety of different methods that can be used making it a flexible approach (Simons, 2009). As the later chapters will highlight, I drew on a variety of different analysis strategies including interpretive analysis and hybrid thematic analysis. Similarly, there are many different reporting styles in case study research that can be drawn up according to the purpose and the audience involved. These examples can range from the traditional report (e.g., portrayal or interpretive) to more creative reporting approaches (e.g., storytelling, documentary film, or other artistic forms) (Simons, 2009). In the CCC participatory case study, we (myself and project members) used a variety of different forms to share what we learned in the case (e.g., reports to the Hospice Toronto Board of Directors, a community photo and story exhibition, etc.). The case study approach was valuable in bringing context to the forefront of the research and not merely an isolated section of the backdrop (South et al., 2020). Using the case study approach, we were able to present a complexity informed understanding of the CCC initiative.

Participatory Health Research

The PHR approach was also incorporated as another essential lens to explore the CCC participatory case study. The International Collaboration for Participatory Health Research (ICPHR) defines PHR as research done with people whose life or work is the focus of the research, in an active and meaningful way, across all phases of the research process (Wright et al., 2018). There is a certain degree of coherence between PHR and the naturalistic paradigm. Similar to the naturalistic paradigm, the PHR approach also values the use of multiple forms of knowledge (including tacit knowledge), an emergent design, the people as the primary knowledge generating 'tools', and negotiating outcomes with those involved in the research (Heron & Reason, 1997; Wright et al., 2018). However, the PHR approach highlights major blind spots of the naturalistic paradigm: the influence of 'participation' on research processes and impacts; and the role of power in research. Within a participatory ontology and epistemology, the principle of participation influences what counts as knowledge and also how knowledge is generated. PHR also draws attention to power imbalances that exist in knowledge generation and aims to challenge these power imbalances by working to better equalize the power distribution with the research process (Muhammad et al., 2015). Unlike in a naturalistic paradigm, PHR does not separate 'researcher' and 'researched', rather all 'participants' in a PHR project can be considered researchers and contribute to the knowledge generation process.

However, in order to meaningfully support this democratic process of knowledge generation, power dynamics must be considered. Muhammad et al. (2015) offer different suggestions for how to consider power in research from their own learnings including reflecting on researcher positionality, building diverse research teams, and engaging in reflexivity among others. It is through the consideration of participation and power that a PHR approach adds value to the naturalistic paradigm.

Under the PHR umbrella, there are a variety of different ways PHR is practiced. These differences may vary by region [e.g., Southern (Borda, 2001; Freire, 2000) vs. Northern (Lewin, 1946) PHR traditions] and by discipline. However, the ICPHR has identified eleven principles as being common to many approaches. These shared principles include, PHR:

- is participatory;
- is locally situated;
- is a collective research process;
- processes are collectively owned;
- aims for transformation through human agency and empowerment;
- promotes critical reflexivity;
- produces knowledge which is local, collective, co-created, dialogical, and diverse based on an extended epistemology of multiple ways of knowing (e.g., tacit, presentational, propositional, and practical);
- strives for broad impact;
- produces local evidence based on a broad understanding of generalizability;
- follows specific validity criteria; and
- is a dialectical process characterized by messiness (Wright et al., 2018).

In addition to these eleven principles, Trickett and Beehler (2017) have also included interdependence, drawing on principles from ecology, as another defining feature of PHR. While a full discussion of these principles of PHR has been previously outlined elsewhere [see: Trickett and Beehler (2017); Wright et al. (2018)], here I highlight some of the key influencing principles of PHR in the CCC participatory case study. These defining principles include participation, the role of dialogue, interdependence, and having a broad impact.

The principle of participation is the core defining principle of PHR and was at the forefront of shaping the CCC participatory case study. The aim of this principle is to maximize the participation of those whose life or work is the focus of the research across all phases of the research (Wright et al., 2018). The participation principle breaks down the divide between researcher and participant as all involved play an active role in shaping the research. As a result, all ‘participants’ can also be considered ‘researchers.’ In the CCC participatory case study, non-academic researchers (i.e., CCC members and Hospice Toronto staff) were not considered as research participants, but as CCC project members. This principle of participation challenges the epistemological assumption of naturalistic inquiry by reframing the idea that there is a ‘knower’ and ‘known’, to the idea that there are multiple knowers beyond the traditional academic researcher or expert. However, PHR is similar to the epistemological assumption in the naturalistic paradigm in that the relationship between those involved in the research inquiry is one of mutual influence, and that this relationship cannot be separated from one another (Lincoln & Guba, 1985; Wright et al., 2018). Further, within a PHR approach, the mutual influence that occurs between different people involved in the research is also seen as a strength of the approach in terms of influencing the nature of reality (Cook, 2009).

Promoting meaningful dialogue was also at the forefront of the CCC participatory case study research design. Mutual influence is fostered through dialogical processes in PHR and enhances the quality of the research (Cook, 2009; Springett, Wright, & Roche, 2011). Within PHR, the aim is to create spaces for people to come together on a common issue to share their own experiences and learn from other’s experiences. Through these dialogical exchanges, people can walk away from these processes with a new or different understanding of the issue. In this way, PHR not only assumes that realities are multiple and constructed (the naturalistic ontological assumption), but also that realities are not static and can be changed through interaction. In an ideal form, dialogue is not just a conversation but a way of learning together, where both individual and group perspectives can be disrupted creating opportunities for new ways of seeing an issue (Cook, 2009; Ledwith & Springett, 2010). Both Kemmis, McTaggart, and Nixon (2014) and P. G. Wicks and Reason (2009) believe that creating opportunities for people to get together and talk about their work and lives is one of the most important tasks for the participatory researcher and is a core aspect of PHR practice.

In the CCC participatory case study, we aimed to create as many spaces for CCC project members to come together as a group (small or large) to talk about their experience being part of the CCC initiative in St. James Town and the impact they thought it was making, and to learn from one another. In the CCC participatory case study, we facilitated a group-based introductory training workshop on the research. We also facilitated large group opportunities for project members to come together to share their photos and stories (a description of the specific participatory data generation strategies will follow). However, due to the unique nature of who was involved with the CCC initiative, not all photovoice project members were able to attend these group-based sessions due to health/mobility challenges. This challenge pushed our CCC participatory case study team to think creatively in terms of how we could create meaningful spaces for dialogue for project members who were homebound. As such, we experimented with creating mini-groups in project members' homes with other CCC initiative members they were comfortable with (e.g., a CCC neighbourhood helper), keeping the principle of participation at the forefront.

Another core principle of PHR, that informed the CCC participatory case study was the concept of 'interdependence', which is also central to an ecological perspective (Trickett & Beehler, 2017). This principle is also shared by both the naturalistic paradigm and case study. Interdependence is about viewing "the world as an integrated whole rather than a dissociated collection of parts" (Capra, 1996, p. 6). The principle of interdependence informed the structure and presentation of my thesis (presented below). In developing the overall structure, I felt it was important to present the different elements that made up my thesis as a whole, and built upon one another (e.g., how the initial relationship building phase created new opportunities for doing research together). The principle of interdependence also informed my data analysis process (e.g., drawing on an ecological lens, exploring connections between structure and agency, etc).

Last, contributing to broader impact beyond the academic setting was another PHR principle that informed the CCC participatory case study. As a novice participatory health researcher, the potential of the PHR approach to have a broader impact was one of the factors that drew me to this type of research and contributed to a meaningful doctoral experience. The seeds for broader impact to emerge are planted when research questions explore issues that are meaningful and relevant to people's lives (Ledwith & Springett, 2010). One of the characteristics of the naturalistic paradigm is for academic researchers to spend time in the context of focus to get a sense of the issues that are resonant. Similarly in a PHR approach, getting a sense of the issues that are resonant happens by: (1) building a relationship with those whose life or work is affected by the issues; and (2) identifying appropriate inquiry approaches together to explore the topic of mutual interest. These dimensions of the PHR help to foster ownership of the process which is central to later taking action on findings (i.e., to contribute to making a broader impact) (Kongats, Springett, Wright, & Cook, 2018; Wright et al., 2018). Given how important this initial relationship building is in a PHR project for generating broader impact, I thought it was important to describe and critique the relationship building process that occurred in the CCC participatory case study (Chapter 4) as it laid the groundwork for the projects to follow.

THESIS STRUCTURE: THREE CYCLES OF ACTION AND REFLECTION

The structure of my thesis followed three action-reflection cycles that formed a helix structure. The action-reflection cycles are thought to follow four key phases: (1) planning for a change; (2) acting and observing the process and effects of the changes; (3) reflecting back on the process and effects, and finally (4) circling back to the re-planning stage, and so on (see Figure 1.2: The action-reflection spiral in PHR in Chapter 1) (Kemmis & Wilkinson, 2002). The three action-reflection cycles in the CCC participatory case study included: Cycle 1 – Grounding; Cycle 2 – The Photovoice Project; and Cycle 3 – Ripple Impacts. In addition, each of action-reflection cycles presented in this thesis was informed by one of the streams of participatory practice. These streams include: first-person inquiry (i.e., personal self-reflective practice), second-person inquiry (inquiry together with others), and third-person inquiry (inquiry among broader communities of practice) (P. G. Wicks & Reason, 2009).

In Cycle 1 (Grounding), I drew on first-person inquiry to explore the initiation and building of the CCC participatory case study research relationship. In Cycle 2 (The Photovoice Project), as more members of the CCC initiative were engaged, I drew on second-person inquiry practices. In Cycle 3 (Ripple Impacts) I drew on first- and second-person inquiry to explore the impacts of doing research together and discuss how the CCC participatory case study began to move into third-person inquiry. Adams (2014) suggests that first-person inquiry is required to engage in second person inquiry which is subsequently required to engage in third-person inquiry. Further, Reason and McArdle (2004) suggest that ‘good’ participatory research should aim for inquiry within each of these streams and create connections between them. Figure 3.1 presents a visual overview of the action-reflection cycles of my thesis and the streams of inquiry that informed the different cycles. While these phases are presented as three big action-reflection cycles, in reality, there were multiple mini-cycles of action-reflection within each phase.

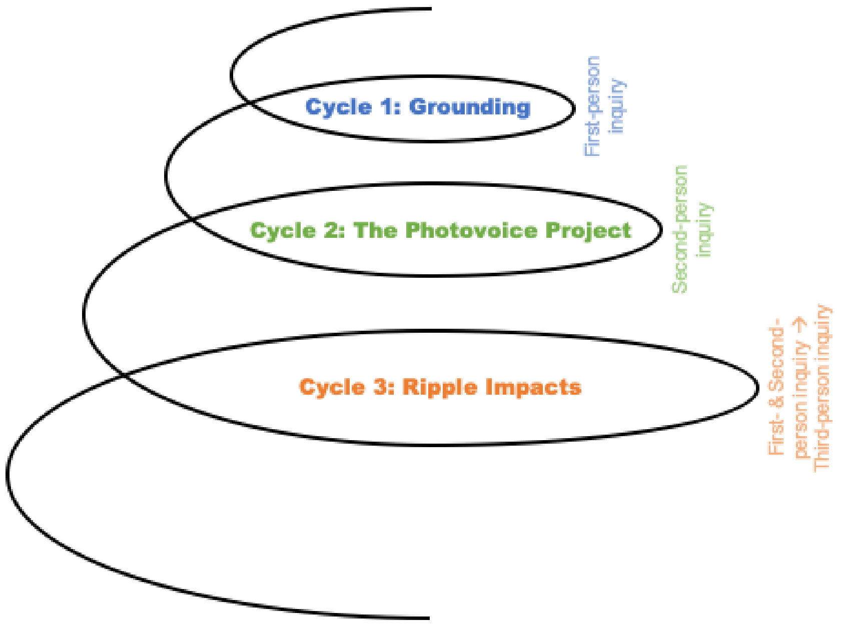


Figure 3.1: The three cycles of action-reflection in the CCC participatory case study and associated participatory streams of inquiry.

Cycle 1: Grounding

The aim of Cycle 1: Grounding (Chapter 4) was to conduct a first-person inquiry into my experience initiating and building a participatory research relationship as a doctoral student. I chose the relationship building phase of the PHR project as the focus for an in-depth first-person inquiry, as it is the relationships with those whose work or life is the focus of the research that creates the foundation for the PHR process. While the research relationship played a central role across all phases of the CCC participatory case study, I chose to go into detail on the initiation phase as there are limited in-depth published examples on this phase in particular. First-person inquiry is a stream of PHR that refers to “research undertaken by researchers as an inquiry into their own actions, giving conscious attention to their intentions, strategies and behaviour and the effects of their action on themselves and their situation” (Adams, 2014, p. 350). I used writing as my primary first-person inquiry strategy to reflect on, and make sense of, my experience initiating and building a participatory relationship with Hospice Toronto as a doctoral student. Drawing on my own fieldnotes, audio recordings, and email records with Hospice Toronto, I used writing to explore the relationship building process as a way of "seeing what comes, as part of the reflection phase in cycles of action and reflection" (J. Marshall, 2016, p. 99). By opening a window into my own experience, I hoped to encourage other doctoral students who may be unsure of the compatibility between PHR approaches and doctoral programs to feel hopeful about the potential for a meaningful PHR experience.

Cycle 2: The CCC Photovoice Project

The aim of Cycle 2: The Photovoice Project (Chapters 5-9) was to explore the Creating Caring Communities (CCC) initiative in St. James town to:

1. Understand how a compassionate community approach to health promoting palliative care in an inner-city setting could build community capacity to support isolated community members living with a life-limiting illness and/or their primary carer;
2. Articulate the impact of a compassionate community approach to health promoting palliative care from the perspective of those involved in the CCC initiative; and
3. Identify the facilitators and challenges of engaging in a compassionate community approach to health promoting palliative care in the context of an inner-city setting.

In Cycle 2: The Photovoice Project, as more members of the CCC initiative were engaged, I drew on second-person inquiry to explore the CCC participatory case study. Second-person inquiry is one of the most common streams of a PHR approach and often involves at least two or more people coming together to explore an issue of mutual relevance (Coleman, 2014). To facilitate this exploration, we drew on a variety of participatory and case study methods including document analysis and observation, however photovoice played a central role in the knowledge generating process. The process of how we collectively decided on these knowledge generating strategies will be further described in Cycle 1: Grounding.

Photovoice

Photovoice is a participatory arts-based approach to research that blends photography and narratives, first coined by Wang and Burris in the early 1990s (Wang & Burris, 1997). The three primary goals of photovoice are: "(1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important community issues through large and small group discussions of photographs, and (3) to research policy makers" (Wang & Burris, 1997, p. 369). In conversation with Hospice Toronto, I proposed using the photovoice method to explore the CCC initiative because of the flexibility of this approach for meeting different community needs which was important for strengthening the relevance of the findings for broader impact (Nykiforuk, Vallianatos, & Nieuwendyk, 2011). Second, as Bagnoli (2009, pp. 565-566) emphasizes,

> *"The introduction of a simple visual task … may be very helpful for elicitation purposes. Focusing on the visual level allows people to go beyond a verbal mode of thinking, and this may help include wider dimensions of experience, which one would perhaps neglect otherwise. A creative task may encourage thinking in non-standard ways, avoiding the clichés and 'readymade' answers which could be easily replied."*

Last, the creative and collaborative processes of photovoice have been shown to enhance participant engagement and a sense of ownership in the issues being explored through elicitation of emic representations and narratives (Catalani & Minkler, 2010; Nykiforuk et al., 2011). Collier and Collier (1986) also report that the photovoice process helps to build rapport among participants and researchers by reducing initial awkwardness. The photographs can help offer something to focus on and can facilitate discussion. The photovoice method has been used in a wide range of disciplines including anthropology, sociology, and public health (Catalani & Minkler, 2010) The growing interest and use in photovoice may be a reflection of the different benefits of this method for different stakeholders involved including community members, researchers, the broader community, and policy-makers (Nykiforuk et al., 2011).

The underlying values of the photovoice method were consistent with key PHR principles including an emphasis on empowering strategies, identifying individual and community assets, co-learning, community capacity building, and finding a balance between research and action for change (Catalani & Minkler, 2010; Nykiforuk et al., 2011). For example, the photovoice method is thought to support individual empowerment by letting project members determine what is important to photograph and share around a particular issue from their perspective. In addition, the opportunity in photovoice to come together as a group and share experiences is thought to also support co-learning and community capacity building. A more detailed description of the photovoice method using in Cycle 2 will be presented in Chapter 6.

Cycle 3: Ripple Impacts

The aims of Cycle 3: Ripple Impacts (Chapter 10) were as follows. First, I aimed to describe the scope of participatory ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of the research. Second, I aimed to describe how participatory ripple impacts were documented across the CCC participatory case study. The purpose of Cycle 3 was to contribute to a better articulation of the value of PHR approaches. In this thesis, I define impact as any changes, effects, or benefits to society, culture, health, policy, or service (Research England, n.d.). I also adopt the term ripple impact (as opposed to only 'impact') to refer to the interdependent/relational nature of action in PHR, and expand the focus on research impacts beyond the individual level to impacts across multiple ecological levels (Trickett, 2019; Trickett & Beehler, 2017).

I drew on first- and second-person inquiry approaches to explore the impacts of the CCC participatory case study and highlighted how the project began to move into third-person inquiry. Drawing on first-person inquiry approaches I used a combination of observations, field notes, and journal entries collected across the entire lifespan of the CCC participatory case study (and beyond) to document impact. Observation, a key data generation method in a naturalistic case study, was one of the most important tools for documenting impact outside of the more formal research activities. I also used second-person inquiry approaches, such as activities to reflect on impact during the photovoice project as well as interactive mapping activities conducted at our celebratory reflection workshop at the soft close of the project. Finally, I was also able to demonstrate how the CCC participatory case study began to shift towards third-person inquiry as Hospice Toronto connected with a broader compassionate communities' community of practice. Third-person inquiry generally refers to activities that move beyond a single case to broader networks of people who generally do not have direct contact with one another (Bjørn Gustavsen, 2014; Hynes, 2012). This chapter contributes to a growing evidence base articulating the types of impacts that ripple out from a research project informed by PHR principles (Abma et al., 2017; Banks, Herrington, & Carter, 2017; Cook et al., 2017; Cook & Roche, 2017; Springett, 2017).

ETHICAL CONSIDERATIONS

The CCC participatory case study adhered to standard procedural ethics throughout the project. It abided by Canada's Tri-Council policy guidelines on ethics and was approved by the University of Alberta's Research Ethics Board 1 (ID# Pro00061633). At the first introductory session, we reviewed the information letter and the process of obtaining informed consent to participate including: study procedures, benefits, risks, and confidentiality. All interested CCC members were told that their participation was completely voluntary and would not impact their relationship with Hospice Toronto or the CCC initiative. A similar process was also completed in the individual sessions for project members who were unable to attend the group training. We had two project members who had a basic understanding of English but were primarily fluent in Bengali. The CCC community development coordinator, who was also fluent in Bengali, assisted with informal translation as we went over each section of the information letter and consent form. The majority of CCC members who expressed interest in the photovoice project provided consent to participate, with one CCC member deciding not to participate for privacy reasons.

In addition to procedural and institutional ethics, PHR and photovoice both required specific ethical considerations that took into account the nuances of these approaches. First, PHR approaches require specific ethical considerations that may not be considered in traditional institutional ethics frameworks as the distinction between 'researcher' and 'research subject' is blurred (International Collaboration for Participatory Health, 2013). To address some of the unique ethical sensitivities and challenges in this approach, we sought guidance from the International Collaboration for Participatory Health (2013) 'Guide to Ethical Principles and Practice'. We incorporated the following ethical principles into the CCC participatory case study (International Collaboration for Participatory Health, 2013, pp. 9-10):

- Equality and inclusion: it was important for anyone who wanted to be involved in the CCC participatory case study to have the opportunity regardless of potential research barriers. For example, there were project members who wanted to join the project, but who were not fluent in English. To facilitate inclusion, another project member was able to identify an informal translator (who was also part of the initiative) to assist with communication.
- Democratic participation: the aim was for all project members to have the opportunity to be involved in shaping the research. However, as will be discussed Cycle 1: Grounding, some research members had more influence in certain aspects than others.
- Active learning: I aimed to create spaces for project members to get together as a group to learn from one another during the research process.

- Collective action and making a difference: I aimed to encourage collective action through knowledge generation strategies (i.e., photovoice) that created opportunities for engagement in research on issues that were identified as important by project members
- Personal integrity: for me, this meant engaging in a research process that was aligned with my worldview.

Many of these ethical principles were already embedded into the way the CCC initiative was facilitated by Hospice Toronto (e.g., creating an mutually respectful environment, fostering active learning, etc.) and so it was important for the CCC participatory case study research design to mirror these ethical principles.

Similar to the unique ethical considerations required for PHR, visual methods such as photovoice require their own specific ethical considerations. To address these considerations, Wang and Redwood-Jones (2001) developed a minimum best practice for ethics in photovoice which we followed in the CCC participatory case study. For instance, these best practices include, but are not limited to: requiring project members to obtain an ‘acknowledgement and release’ written consent for people they photograph; facilitating a training workshop on safety, power, ethics, and responsibility that come with using a camera; and requiring permission to publish any of the photographs taken by project members (Wang & Redwood-Jones, 2001). In Cycle 2: The Photovoice Project we had two phases of consent: consent to participate at the start of the project, and consent to use the photographs at the end of the project (e.g., in a community exhibition, community reports, etc.). We found this two-phase consent process to be very helpful as it gave project members a clearer understanding once they had been part of the project to make a better-informed decision about giving permission to share their photographs and stories in the research, including the final photovoice exhibition. We also requested project members to seek permission from any subjects in the photographs at this stage to obtain consent to have their photo included. In the end, only photographs that received consent from project members, and subjects of any photographs were included in public exhibition and in this thesis report.

Finally, PHR and photovoice approaches challenge commonly held perspectives on maintaining confidentiality and anonymity in research. From a PHR lens, one of the key ethical principles is democratic and meaningful participation across all stages of the research. While it is common in qualitative research to use pseudonyms for participants, Gubrium and Harper (2013, p. 51) question the use of giving pseudonyms to participants, asking “what does this say about the ability of participants to reclaim an authorial role in knowledge production?" Further, from a photovoice lens, it may not be possible to provide confidentiality and anonymity to project members given the visual element. There is the possibility that participants may use visuals that are well-known to community members, or that may expose an experience about another person that they would rather keep hidden from the public (Gubrium & Harper, 2013). To work through these ethical dilemmas around confidentiality and anonymity while keeping the principles of PHR top of mind, we provided an opportunity for all project members to choose how they would like to be identified as they prepared for the community photovoice exhibition. Some project members wanted to use their real name, while other project members wanted to use a pseudonym. Unfortunately, when we asked members to choose how they wanted to be identified in the CCC photovoice project at the community exhibition, the consent did not extend to how they wanted to be acknowledged in the broader research project. Because of this, we needed to use pseudonyms in this final thesis research report and in any subsequent publications.

QUALITY

I had to consider a combination of different approaches to assess and demonstrate the quality of the CCC participatory case study given the use of different research approaches. There are many different types of quality criteria for naturalistic qualitative research (Mayan, 2009) and PHR (Springett et al., 2011) found in the literature. Indeed, Brink (1991, p. 164) agues, "We have so many terms to cover the same concept. Nobody is talking to anybody. Anybody who does anything at all on reliability makes up a new term to cover what has previously been discussed in another field". In exploring how I would assess and demonstrate quality in my thesis work, I opted to focus on the key concepts that were most salient across different criteria sets, recognizing that these core concepts may be labelled differently in different sets of criteria.

First, I started with Lincoln and Guba (1985) trustworthiness concept that is rooted in the naturalistic paradigm. While these criteria are over 30 years old, they provided an important foundation for re-thinking quality in research that was coherent with a qualitative perspective, while emphasizing certain aspects particularly important in case study research. The four original criteria that make up the concept of trustworthiness include: credibility, transferability, dependability, and confirmability. First, credibility (i.e., the truth value or plausibility) is about being able to demonstrate that the findings make sense. Here, it is not about establishing confidence in a single truth, but establishing that the reconstructions presented in the research accurately represent the multiple constructions of reality articulated by the different project members in the research (Lincoln & Guba, 1985). I used a variety of different strategies to promote credibility including prolonged engagement, triangulation of data, and checking back with CCC project members (albeit to varying degrees) on 'working' findings (Mayan, 2009). Second, transferability (i.e., applicability, generalizability) is about assessing the applicability of the findings to other contexts (Lincoln & Guba, 1985; Mayan, 2009). From a case study perspective, transferability, or generalizability is situated in a particular place- and time-bound context (Simons, 2009). The meaning that is developed from a case study inquiry is dependent on being connected with the particulars of the specific context (Simons, 2009). I used a number of strategies to promote transferability or generalizability including using open ended interview questions that gave space for CCC project members stories to be told, and spending time observing and getting to know the CCC initiative and the St. James Town neighbourhood. In addition, I used thick-description in the presentation of CCC project members perspectives to ensure that context and the particulars were captured, as context is not a static description but embedded and entangled in our everyday lives and actions. Third, dependability (i.e., consistency): is about the ability to review, post-hoc, the decisions that were made during the research process (Mayan, 2009). I promoted dependability by creating an audit-trail of how findings were constructed to promote transparency. Last, confirmability (i.e., neutrality) is about whether the findings are logical (Mayan, 2009). As the researcher taking the lead on analyzing the different knowledge generated by researching together, I used a reflexive process to consider how my biases might be influencing the analysis and worked to keep an open perspective. For example, having a critical friend to ask for their interpretations on some aspects of the research data was valuable in gaining other perspectives and seeing where interpretations were similar and different. In particular, sharing research analyses with Hospice Toronto staff members was also valuable in helping to deepen the interpretation of findings by providing additional context.

In addition to Lincoln and Guba's (1985) concept of trustworthiness, I also used particular criteria specific to PHR approaches as outlined by the International Collaboration for Participatory Health Research (Wright et al., 2018) as well as a range of other influential scholars in PHR (Dadds, 2008; Reason & Bradbury, 2001; Sohng, 1996; Springett et al., 2011). These criteria include participatory, intersubjective, catalytic, and empathic validity. First, participatory validity refers to the extent to which all project members are able to take an active part in the research process to the fullest extent possible (Reason & Bradbury, 2001). We used a variety of approaches to promote participation including facilitating sessions at a variety of different times, facilitating sessions in close walking distance, and ensuring there was informal translation support so that language was not a barrier. In addition, I also used a participation matrix (presented in each cycle of the research) to document, assess, and reflect on the levels of participation across the phases of the study, and explored how the nature of participation influenced the impacts that occurred. Second, intersubjective validity refers to the extent to which the research exploration is viewed as meaningful and credible to relevant stakeholders from a variety of different perspectives (Springett et al., 2011). In the CCC participatory case study I worked closely with Hospice Toronto and CCC members for over a year to determine a mutually relevant focus of the research inquiry. Third, catalytic validity refers to the extent to which the research can create new possibilities for social action. Catalytic validity builds off intersubjective validity in that the research has to be meaningful for those involved and to build ownership for action (Sohng, 1996; Springett et al., 2011). Further, using photovoice as a knowledge generation method presented many opportunities for bringing together community and raising awareness (e.g., community exhibitions) to help stimulate action. The catalytic validity of the CCC participatory case study will be more explicitly explored in Chapter 10: Ripple Impacts. Last, empathic validity refers to the extent to which the research has increased empathy among those who were engaged in the research together (Dadds, 2008). In our CCC participatory case study, creating spaces for dialogue was important to foster sharing of different experiences and perspectives.

Drawing on both naturalistic and PHR frameworks for assessing and demonstrating the quality of the CCC participatory case study allowed for a more robust analysis of case.

SUMMARY

This chapter presented an overview of the critical methodological approach of the CCC participatory case study. I began by presenting the key axioms of the naturalistic paradigm that rooted my thesis inquiry. Next, I demonstrated how case study and PHR approaches complemented and strengthened my methodological approach. Finally, I outlined the three action-reflection cycles of my thesis rooted in the different inquiry streams of PHR to strengthen the overall quality of the thesis investigation. Finally, quality and ethical considerations were presented.

Chapter 4 presents Cycle 1: Grounding, a first-person inquiry into my experience as a doctoral student initiating a PHR project and building a relationship with Hospice Toronto and CCC members to set the foundation for researching together.

CHAPTER 4: CYCLE 1—GROUNDING

OVERVIEW

> *"The participatory research process is invigorating, and likewise exhausting. But then that is the beauty of it. You will not be detached. You too, not merely the participants, will be rehumanised. Participatory research is not only about trying to transform social structures 'out there' and 'the people', it is about being open to transforming ourselves and our relationship to others. Just as I examined the dilemmas and contradictions in participatory research, I was challenged daily to consider the dilemmas and contradictions of my own life choices. I was forced to question my part in the social construction and maintenance of large social structures, systems and relationships. And, relentlessly, I found myself asking, How am I choosing to be in the world?"*
> *(Maguire, 1993, p. 174)*

Cycle 1: Grounding, is the first loop in the Creating Caring Communities (CCC) participatory case study (see Figure 4.1). This chapter presents my first-person inquiry into my experience initiating and building a participatory research relationship as a doctoral student. This chapter begins with a discussion on the central role of relationships in PHR. This is because it is the relationships with those whose work or life is the focus of the research that lay the foundation for the PHR process. Next, I make the case for why first-person inquiry is an invaluable learning tool for doctoral students and novice participatory researchers and outline my first-person inquiry approach. I then describe my experience initiating and developing a participatory research relationship and reflect on: the influence of my positionality, facilitators and challenges of the process, and the participatory nature of the relationship building process that influenced later cycles of inquiry within the CCC participatory case study. Like Maguire (1993, p. 174), this first-person inquiry was an opportunity to ask "How am I choosing to be in the world?" In presenting this first-person inquiry, I hope to encourage other doctoral students who are unsure of the compatibility between PHR approaches and doctoral programs to feel hopeful about the potential to engage in successful and rewarding PHR doctoral projects.

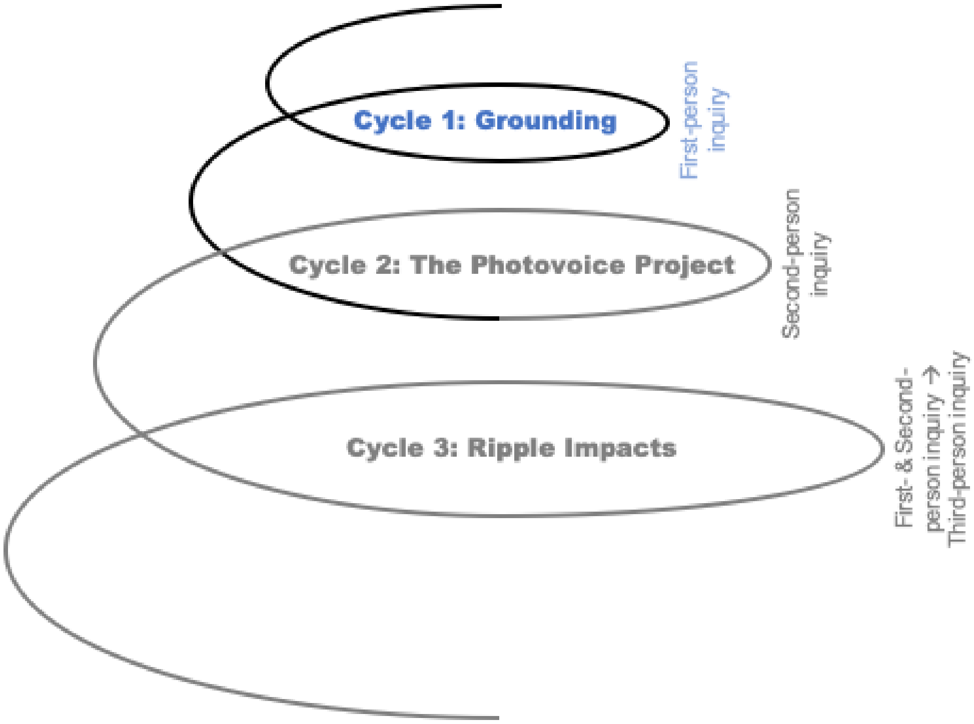


Figure 4.1: Cycle 1 – Grounding.

THE CENTRALITY OF RELATIONSHIP BUILDING IN PHR

Participatory health researchers "[see] research as a relational process through which new knowledge is produced collectively rather than by an individual on their own" (Abma et al., 2019b, p. 7); and aims to bring about some type of action or change (Kongats et al., 2018). As PHR is a relational research process, the first—and most important step—is to initiate and develop a relationship with those whose life or work is the focus of the research. It is this participatory relationship that lays the foundation for PHR and influences the later stages of the PHR process. It is in collaboration with those whose work of life is the focus of the research that decisions are made to determine: the focus area of the research; the research design; analysis processes; ways to share findings; and identify the next 'action' steps (Abma et al., 2019b). This is important as what we measure or assess shapes later practice and policy decisions, therefore it is important that we assess what counts rather than what can be easily counted (Deneulin & McGregor, 2010; Milat, Bauman, & Redman, 2015).

Given the influence of the participatory relationship on all stages of the PHR process, it is surprising there is a paucity of published resources for doctoral students and novice participatory health researchers to draw upon that focus specifically on the relationship initiating and building phase. For example, Abma et al. (2019a) provide a practical overview of key considerations of initiating a participatory research partnership. Abma et al. (2019a) outline strategies to build trust and develop research topics together, as well as practical recommendations such as how to develop a working agreement. These authors also pose a number of questions for reflection on ethical issues that can arise in the relationship process, and provide guidance for anticipating later stages of the research process Abma et al. (2019a). Duran et al. (2012) also outline strategies for university or other institutional-based researchers in their journey of initiating and sustaining community-based participatory research (CBPR) partnerships. Duran et al. (2012) recommend beginning the relationship building process by self-reflecting on your own capacities, resources, and liabilities including identifying the history of your institution's engagement with community organizations. These authors recommend that one way to identify potential community-based partners is through relevant networks, or associations, or leaders (Duran et al., 2012). Further, these authors recommend collaboratively negotiating a research agenda "based on a common framework on mechanisms for change" and building mentorship opportunities into the relationship (Duran et al., 2012, p. 50). In addition, Christopher, Watts, McCormick, and Young (2008) focus on the importance of building trust in CBPR projects with American Indian community members and provide different examples on how to build trust between university and community partners. Christopher et al. (2008, p. 1400) outline five recommendations for trust building that have emerged from their experience: "(1) acknowledge personal and institutional histories, (2) understand the historical context of the research, (3) be present in the community and listen to community members, (4) acknowledge the expertise of all partners, and (5) be upfront about expectations and intentions."

While these guiding principles are valuable for doctoral students and novice participatory health researchers, there are certain limits of propositional knowledge (i.e., knowledge 'about' something that is expressed through ideas and theories in the form of informative statements) in supporting PHR learning (Reason & Rowan, 1981). Similar to other doctoral students engaging with PHR for the first time, I also felt that the "full transparency of the process was not always apparent in published accounts of [participatory] research" (Grant, 2007, p. 268). For example, I wondered how to initiate a potential research relationship with an organization that I did not have a previous connection with. In keeping with the principles of PHR, I also wondered how to invite an organization to join an open project (i.e., not coming with a predetermined focus) or what Herr and Anderson (2005, p. 69) refer to as projects where you “[design] the plane while flying it.” My own experience of starting from the very beginning in the PHR process wasn’t reflected in the published literature, and I had to learn by doing (Grant, 2007). As my own research relationship began to develop (described later on in this chapter), I soon experienced how messy the process was. I was confronted with the different emotions that emerge from an uncertain and evolving process—from worry and anxiousness to excitement and joy. While the published literature on the relationship building dimension of PHR can better support students by more accurately reflecting the messiness of the process through rich description, I also realized the limitations of what I could learn from reading other’s accounts. This is because propositional knowing, the most common type of knowing in academic institutions, is only one way we come to understand ‘something’, in my case, the relationship initiation and building process in PHR. In addition to propositional knowing, there is:

- practical knowing (knowing how to do something, expressed in a skill),
- experiential knowing (knowing through encounters with another person, place or thing, felt through resonance and empathy), and
- presentational knowing (emerging from experiential knowing that is expressed through creative means) (Abma et al., 2019b; Reason & Rowan, 1981).

In reflecting back on my own experience, much of how I learned to initiate and build a participatory relationship, like Grant (2007, p. 265), was also through the experiential learning process of ‘being’ and ‘doing’. Additionally, I found depictions of other doctoral first-person inquiries on the experience of conducting a PHR project to most closely reflect my own experience on the highs and lows of engaging in PHR as a doctoral student, capturing a fuller range of the experience (Burgess, 2006; Gibbon, 2002; Gittins, 2019; Grant, 2007; Maguire, 1993; Southby, 2017). PHR doctoral students can support one another by sharing reflections through rich storytelling (i.e., a form of presentational knowing) on the experience of initiating and developing a participatory relationship as they are closest to the experience of ‘doing’ as a novice. In this chapter, I contribute to this limited but growing evidence base on the experience of PHR as a doctoral student, with a particular focus on the early relationship initiation and building phase. While relationship building in PHR is not limited to the early relationship initiation stage and is an ongoing process, I chose to specifically reflect in-depth on this early phase in the relationship as I found there were limited experiences documented in the literature. As Grant (2007, p. 267) notes, "Few scholars have…discussed at length complex and time consuming aspects of the research process such as finding, establishing and maintaining sound relationships with research participants." Next, I describe the value of, and my approach to, first-person inquiry in exploring my experience initiating and developing a participatory research relationship in the CCC participatory case study.

FIRST-PERSON INQUIRY

First-person inquiry is a stream of PHR that refers to "research undertaken by researchers as an inquiry into their own actions, giving conscious attention to their intentions, strategies and behaviour and the effects of their action on themselves and their situation" (Adams, 2014, p. 350). First-person inquiry is an invaluable tool in the development of participatory health researchers, and an important starting place in the PHR process before practicing second-person inquiry approaches (i.e., research facilitated between two or more people on an area of shared interest) (Reason & Torbert, 2001). First-person inquiry provides a space for researchers to articulate, critique, and reflect on "the knowledge inherent in their actions in order to understand their practice better or become more effective in the pursuit of worthwhile aims for themselves, their community or workplace or the wider world" (Adams, 2014, p. 350). First-person inquiry is also an opportunity to engage in reflexive validity [i.e., to reflect on bias as a researcher(Waterman, 1998)] and strengthen the quality of the research. In particular, the importance of first-person inquiry for doctoral students or novice participatory researchers cannot be undervalued. As doctoral students, it is easy to fall in the trap of continuously focusing on 'action' and 'doing' in our excitement to "get on with the task", without stopping to reflect and digest the nuances and complexities of our participatory research experience (Burgess, 2006; Grant, 2007, p. 266). Further, despite 'emergence' being a key principle of PHR, doctoral students might not be fully prepared for the disappointing feeling when projects do not necessarily bring about the impacts that were expected (Grant, 2007; Moore, 2004). As Klocker (2012) emphasizes, participatory processes are messy and project members "will surely not become empowered, liberated or transformed on our schedules" (Maguire, 1993, p. 176).

However, rather than seeing the project as a failure, first-person inquiry can provide space to, "Take a step back and 'look' at what we have achieved to date, and how it compares with where we want to be, now and in the future" (Grant, 2006, p. 301).

Despite the value of first-person inquiry in the development of doctoral students, there are few published examples in the scholarly literature for others to learn from (although many other examples may be buried in unpublished thesis work). Furthermore even fewer published examples of first-person inquiry outline their approach. For example, doctoral student first-person inquiries have been conducted in the fields of applied social science and learning disabilities (Southby, 2017), education and feminist studies (Maguire, 1993) education and sustainability studies (Moore, 2004), geography (Klocker, 2012), women's health (Gibbon, 2002), nursing (Burgess, 2006), management (Grant, 2007), and peace and conflict studies (Gittins, 2019). My first-person inquiry contributes to this small but growing evidence base from a health promotion and palliative care lens with a local hospice organization. In the following section I describe my approach to first-person inquiry.

First-person inquiry is still a developing field (Adams, 2014, p. 351)—and while Bartlett (1987) suggests that self-reflection is best learned informally through experience—Adams (2014) outlines six key features of the approach that may be useful to those experimenting with this style. First-person inquiry:

1. is a systematic and sustained exploration into one's own practice;
2. is a purpose driven approach (e.g., to inform and/or to transform);
3. is rooted in an extended epistemology that acknowledges multiple ways of knowing (i.e., proposition, experiential, presentational, and practical);
4. uses Gardner's (2006) multiple intelligences to explore the first-person experience (e.g., visual-spatial, linguistic-verbal, inter- and intra-personal, logical-mathematical, musical, bodily-kinesthetic, and naturalistic)
5. embraces a critical methodological approach, in that there is no agreed upon on fixed methodology; and
6. involves iterative cycles of action and reflection (Adams, 2014).

Heen (2015) also draws attention to the role of feelings in supporting first-person inquiry. Rather than understanding feelings and rationality as polar opposites, a Western perspective (Heen, 2015), feelings play a role in our ability to transfer learning from one particular context to another (Immordino-Yang & Damasio, 2007). For example, while we find it easier to learn from mistakes that generated unpleasant feelings, we find it more difficult to learn from situations that were successful and 'felt good' (Heen, 2015). Thus, in situations where things 'went well' it is important to be more purposeful in reflecting on why that was the case. Drawing attention to our feelings also supports the aim of first-person inquiry by becoming more aware of our actions in the world. For instance, in Figure 4.2, Heen (2015) explains that how we perceive a situation (i.e., how we think and feel about it) is impacted by our past experiences (i.e., our experiential base). Consequently, how we act in a situation is influenced by how we perceive the situation. One of the aims of first-person inquiry is to act more mindfully, and increase our alternatives for acting in the world (Heen, 2015). This is accomplished through our encounters with new experiences as well as an improved awareness of what is happening in the world around us (Heen, 2015).

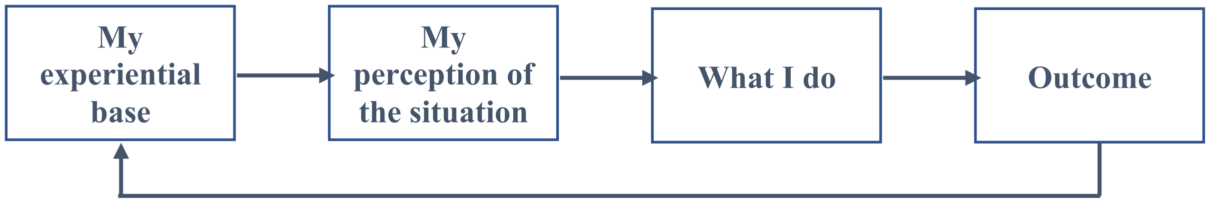


Figure 4.2: What is happening in a situation (Heen, 2015, p. 622).

I used writing as my primary first-person inquiry strategy to reflect on, and make sense of, my experience initiating and building a participatory relationship with Hospice Toronto as a doctoral student. Writing has been described as "a process of discovery" (J. Marshall, 2016, p. 97), a "compact account of sensemaking" (Wallas, 1926, p. 106), a way of knowing, and as a method of analysis (Richardson, 2000, p. 923). J. Marshall (2016) suggests that writing as inquiry is an important part of an interconnected participatory research process. For instance, writing as inquiry can help to explore a particular issue, image, or event (both past and future) by writing and "seeing what comes, as part of the reflection phase in cycles of action and reflection" (J. Marshall, 2016, p. 99). To inform my writing, I drew from my field notes, email trails, and audio-recorded/written journal reflections. I also shared and discussed sections of my first-person inquiry with my academic supervisor and with Hospice Toronto staff members which helped me to further process and make sense of my experience initiating and building a participatory research relationship in the early phases.

As part of my first-person inquiry I felt it was important to reflect on the nature of participation across the relationship building phase of the CCC participatory case study with Hospice Toronto and CCC community members. While I echo other graduate students frustrations that "Much of the [participatory action research] literature is dismissive of 'impure' or inauthentic' endeavours," I disagree that reflecting on the levels of participation in a PHR initiative implies that "unless a project is operating at the highest rungs—it has simply not got it 'right'" (Klocker, 2012, p. 157). Rather, like Cook et al. (2017, p. 476), I believe the aim of reflecting on levels of participation isn't to create a hierarchy between 'good' and 'bad' PHR, but to create an opportunity to reflect on "the variety of participatory engagements and the associated impacts that could be used by researchers". In Cycle 3: Ripple Impacts (Chapter 10), I built off these reflections and described the impacts that emerged from the previous cycles in the context of the participatory nature of this specific project. By reflecting on the participatory nature of the relationship building phase I hoped to present a more transparent snapshot of what was possible as a graduate student initiating a brand-new research relationship. I used a participation matrix (presented later on this chapter), adapted from Cook et al. (2017) to summarize the nature of participation across the initial relationship building phase of the PHR project. I used Cornwall (2008) levels of participation (see Table 4.1) as framework to reflect on the participatory nature of Cycle 1: Grounding.

Table 4.1 The six different levels of participation presented in the dimensions of participation framework (Cornwall, 2008).

Co-option	Token representatives are selected but have no significant input or power in the research process.
Compliance	Outsiders determine the research agenda and direct the process, but tasks are given to participants and incentives provided by the researchers.
Consultation	Local opinions are asked for, however the outside researcher conducts the work and determines the course of action.

Co-operation	Both local people and outsider researchers work together to determine the research priorities, with responsibility remaining with outsiders to guide the process.
Co-learning	Both local people and outsider researchers share their knowledge in order to create new understanding and work together to develop the research priorities and action plan, with outsider researchers providing facilitation.
Collective action	Local people determine their own agenda and self-mobilize to implement the research in the absence of outside researchers or facilitators.

I chose to present my experience in the form of a story through an interpretive lens that allowed me to dig deeper into understanding the facilitators and challenges of the participatory relationship initiating and building process. In doing so, I aimed to open a window into my experience using rich descriptions that allowed for naturalistic generalizations to emerge. As Stake (1980, p. 69) explains,

> "Naturalistic generalizations develop within a person as a result of experience. They form from the tacit knowledge of how things are, why they are, how people feel about them, and how these things are likely to be later or in other places with which this person is familiar. They seldom take the form of predictions but lead regularly to expectation …"

While Klocker (2012, p. 151) notes that the doctoral experience of students is "fractured along lines of gender and ethnicity—among other attributes", there is also a shared common experience across disciplinary fields and even methodologies. In providing a vicarious experience through a rich storytelling account that is, "personal, describing the things of [my] sensory experience, [and] not failing to attend to the matters that person curiosity dictates…", (Stake, 1995, pp. 86-87) my hope is that other doctoral students can decide which aspects of my experience they can generalize to their own context (Simons, 2009). The following is my story of initiating and building a participatory research relationship as a doctoral student.

A WINDOW INTO THE PARTICIPATORY RELATIONSHIP BUILDING EXPERIENCE

Taking A Leap: An Invitation to Explore

Previously in Chapter 1, I shared how my early experiences as a hospice volunteer and my interest in participatory research approaches formed the roots from which I started my participatory doctoral journey in health promoting palliative care and PHR. With the support and guidance of my supervisor, an experienced participatory and health promotion researcher, I started to map out the start of my participatory research journey. While there is an assumption that ideal forms of participatory research "should ideally be initiated by members of marginalized groups" (Klocker, 2012, p. 152), there are many different ways PHR initiatives can begin. As Abma et al. (2019a) describe, sometimes PHR projects begin with a small community-based organization or group who want to explore and improve a particular health or social well-being issue and invite service users or community partners to be a part of a research team. In other cases, a doctoral student or academic researcher may have a particular interest in a topic and invite community members and organizations to join a research team (Abma et al., 2019a). In my case, I was a doctoral student interesting in initiating a PHR project with a particular interest in health promotion approaches to palliative care.

As a first step, I began to scan the websites of different hospice organizations in my area that had some description of a community-development type of initiative [as community development is considered a cornerstone of health promotion practice (Wakefield & Poland, 2005)] that extended beyond the traditional home hospice one-on-one volunteer model. For example, if the hospice organization discussed community-capacity building, or community-awareness raising initiatives as part of their description, I included these organizations on my contact list. Going solely off of information published online, there were few hospice organizations in my area that I included on my contact list. As a result, I also included local community health centers engaged in community-development initiatives, as I thought they could be sites that may have an interest in health promoting approaches to palliative care. The process of identifying potential community partners from the ground up was messy, informal, and relied on my own judgements from information that was publicly posted.

From this scan, I developed an introductory expression of interest, and tailored it to the different organizations I had identified. The purpose of this introductory email was to learn more about their community-development orientated initiatives, introduce myself and my intentions as a doctoral student, and inquire if they would be interested in exploring a potential research collaboration together. Box 4.1 is an example of the expression of interest I sent to initiate the participatory relationship building process.

> Dear [name],
>
> My name is Krystyna and I am a doctoral student in health promotion hoping to study the impact of community engagement in health and wellness settings. I have a special connection with the Hospice Community in Ontario, having spent many years volunteering with Hospice during my undergraduate degree in [location].
>
> I am writing to you to inquire about your interest in collaborating in a potential research project on connections between community development approaches and experiences of death, dying, loss, and care. I am interested in learning more about the role of volunteers within your organization. I am particularly interested in participatory research approaches, that are community-driven from the ground up.
>
> From your website I see that there may be a few opportunities within [organization name] to explore connections between community development approaches and experiences of death, dying, loss, and care such as your [initiative name].
>
> Thank you for your time in reading my expression of interest. If this is something you would be interested in exploring further, it would be great to have a telephone conversation!
>
> I look forward to hearing back from you regarding your thoughts,
>
> Krystyna Kongats

Box 4.1: Initial email expression of interest.

I sent the invitation emails and waited. As time went on and no responses came in, I felt anxious about the possibility of doing a PHR project from the ground up, while also recognizing that I had to start somewhere. Of the five or so organizations I reached out to, I eventually heard back from two. Reflecting back on my initial introductory email, I saw how it may have been intimidating to respond to an open (and vague) research invitation. However, in keeping with the principals of PHR, I wanted to keep the focus of the research as open as possible, while recognizing that I also brought certain interests to the table. The two organizational responses I eventually received back were different in their suggestion of next steps (see Box 4.2). The response from Organization A requested a research proposal that would be reviewed by the organization. However, at this stage of my PHR journey I didn't have a full proposal—while I had a broad area of interest and a set of intentions, I was looking for an organization that would be interested in developing a research purpose together. In contrast to Organization A, the reply from Hospice Toronto had a different response. My initial reflection was that Hospice Toronto was more comfortable with the openness of my expression of interest to explore the possibility of working together.

Organization A	**Hospice Toronto**
Hi Krystyna Thanks so much for your email and for your interest in doing research at [organization name]. We have a process set in place in order to accept research projects. Would you have a proposal that you would be able to send to me, so that I could pass along to our director [name]? Thanks again, and looking forward to hearing back from you. Kindly, [Program Coordinator]	Email #1: Hi Krystyna, Thank you so much for your email and your interest in the [name] Program. I'm so glad you've heard about us and have such an interest in raising awareness through research for [program name], and through a hospice model at that. I have included my Executive Director, Dena, in this email, as she will be able to give you more information in terms of connecting your research with us. Dena if you don't mind following up with Krystyna, and then we can go from there. Thanks again, [Program Lead]
	Email #2: Hi Krystyna What a generous offer ...we would all love to explore this further with you! My daughter is getting married this week but following that I am open to a conversation and some brainstorming... [Program Lead] are you able to set something up for us? Thanks! Dena

Box 4.2: Organizational responses to my invitation email.

After the lack of replies to my initial invitation, it was exciting to have the opportunity to move on to the next phase of getting to know one another. I was particularly enthusiastic to meet with this organization as I had noted they were facilitating a few different innovative initiatives that seemed to align with a health promoting approach to palliative care. As a next step, we set up a time to meet in person. I also followed up with Organization A, providing further context to the possibility of identifying a topic together, however the contact between us slowly fizzled out.

Getting to Know One Another

During the first meeting with Hospice Toronto, I met with the Executive Director, Dena, and one of the program staff, and we spent time getting to know more about one another at their office. Abma et al. (2019a) emphasize that during the 'getting to know one another' phase, it is important to consider: the values and motivations of the different individuals and organizations coming to the table, concerns and possibilities for the future, and to explore compatibility. In our first meeting together, I learned about the history and current work of Hospice Toronto. We discussed two innovative projects: their Young Carers Program (YCP), an initiative supporting young carers (an invisible population among carers) (Young Carers Program, n.d.), and their Creating Caring Communities (CCC) initiative in St. James Town, a neighbours helping neighbours approach to care (Hospice Toronto, 2014a). In this initial meeting, I also shared a bit about my own history and experience as a volunteer with hospice, my field of study as a doctoral student, and my interest in an emerging area of study: health promoting approaches to palliative care. At the end of this first meeting together, we both felt that there was potential to explore a research collaboration around one of Hospice Toronto's initiatives and started to brainstorm some initial topics (e.g., assessing impact). We made plans to meet again and I left the first meeting feeling optimistic about the possibility of being able to engage in a PHR project as part of my doctoral work.

After the first meeting with Hospice Toronto, I reflected on what I had learned about the history of the organization and their current initiatives. In particular I was drawn to learning more about the CCC initiative in St. James Town because of the community-development approach taken. I followed up with Hospice Toronto and suggested some next steps to guide the exploration of a potential research collaboration (see Box 4.3).

Hello Dena and [Program Lead],

It was wonderful to chat further last week. Here is the book I was mentioning: Compassionate Cities by Allan Kellehear.

Next steps: I'm aiming to get something written down on paper about the potential directions we were brainstorming last Tuesday—e.g., exploring the impact of caring communities (broadly) through a health promotion/public health lens in the next week.

Dena, if you have any additional information about the Creating Caring Communities initiative that you could send, that would be great. [Program Lead], I hope the leadership weekend was a success!

Talk to you soon,

Krystyna

This is wonderful!

Krystyna I'll send you anything I have...also will take a look at the book link!

Take care
Dena

Box: 4.3: Brainstorming next steps.

Over our next few telephone meetings together, I learned from the Executive Director that she was also particularly interested in doing research together on the CCC initiative for a number of reasons. First, she expressed that she saw this opportunity to research together as a way to raise the profile of the CCC community capacity building approach, an approach that had received less provincial support compared to the traditional one-on-one volunteer support model of hospice care. Second, she also felt that by doing research together, it would be an opportunity to stop and reflect on how the CCC model had evolved over 10 years since it was first initiated. Last, she was also keen to learn more about the overlap between the CCC community-capacity building model and the international health promoting approach to palliative care approach, and to identify opportunities to learn together with this broader international community.

Building a Project Together: An Emergent Process

There wasn't a formal moment where Hospice Toronto and I decided to do research together; as our conversations back and forth continued to positively flow, the research relationship continued to naturally evolve. Over the next few months while I was completing my graduate coursework, I kept in communication with the Executive Director about the CCC initiative through telephone meetings. These meetings were focused around learning more about the CCC model by mapping out a rough logic model of the initiative, something the organization did not have at the time. My positionality as a participatory researcher was as an outsider in the research relationship with Hospice Toronto. While it is not uncommon for outsider participatory researchers to have some level of familiarity, or first-hand knowledge of the setting as I had (e.g., I had extensive experience as a hospice volunteer), I was neither a member of the Hospice Toronto Staff, nor a member of the CCC initiative. Herr and Anderson (2005) describe that there is also a continuum of outsider positionalities in participatory research including: reciprocal insider-outsider collaborative teams (i.e., equitable power relations) and outsiders in collaboration with insiders (i.e., where insiders and outsiders work together, but with responsibility remaining with outsiders to guide the process). In my experience in the relationship building phase, my positionality didn't fit neatly in one category and shifted throughout the relationship initiation and building phase. For example, while the research focus stage was a reciprocal back-and-forth of ideas and discussions, I played more of a central role in suggesting different research methods and writing up our methodology. As Herr and Anderson (2005, p. 29) emphasize, "Much action research is centrally concerned with these issues of the relationship between outsiders and insiders, since clarity about them is necessary for thinking through issues of research validity as well as research ethics." In a later section of this chapter, I reflect on the shifting participatory nature of my role in the early relationship initiation and building phase and the implications for the research.

The research planning really began to move forward when the Executive Director suggested integrating the research on the CCC initiative into a grant she was applying for (see Box 4.4). This opportunity to move the project forward was a turning point in our research relationship. While I was optimistic about the direction of our collaborative research, I also started to feel a tension bubble up between the emergent (and uncertain) participatory process and the timelines of my doctoral program. In debriefs with my supervisor, she kept reminding me to 'trust the process'. This is a phrase I would hear again many times over the course of my PHR project but wouldn't truly appreciate until the end of the project looking back.

Hi Krystyna

I am going to be submitting a proposal for this grant stream and writing over the next week...Is it possible to connect Monday to explore the potential to integrate your work?

Look forward to hearing your thoughts!
Dena

Box 4.4: Focusing the research planning.

Having this tangible project was an important means to continue to facilitate our collaborative research relationship. Contributing to the grant writing process provided an important opportunity to clarify each of our understandings of research, and to identify the broad aims and objectives of the research. For example, I proposed participatory evaluation as an overarching framework to guide our research together, which the Executive Director was open to exploring (see Box 4.5).

Hi Dena,

I came across this policy brief that gives an overview of "Participatory Evaluation". This approach to documenting and evaluating impact seems to really fit with the Partnership Grant's objectives to:

(1) Develop the capacity to demonstrate/articulate the results of programs in the [not-for-profit] sector
(2) Increase the capacity for program evaluation

I thought I would share it in advance.

Krystyna

I'm very open to this if staff have the time and desire ...

I think we tried a hybrid narrative approach in the past and there were pros and cons..[Clinical Director] could speak to this

Dena

Box 4.5: Suggesting a participatory lens.

It was at this grant planning stage of the relationship that I was introduced to more members of Hospice Toronto including the CCC Community Development Coordinator, the Clinical Services Director, and different administrators. Working on the research aspect of the grant together helped to facilitate discussions on focusing in the research question and on the methods we would use to collect data together. I was particularly interested in arts-based methods such as photovoice and so I contributed that approach to the discussion. Hospice Toronto was familiar with photo storytelling methods (they had used a similar approach in a previous intergenerational carer's initiative), and they were curious to explore this approach as a research method. Within the organization, there were competing ideas emerging on what the focus of an impact evaluation should be. For example, one member from Hospice Toronto wanted to focus on indicators that were tracked by the provincial government (i.e., reducing visits to the emergency department), while another staff member saw this as opportunity to make the case for a broader discussion on what is meaningful in health promoting approaches to palliative care. Through conversations back and forth, we settled on the later.

For doctoral students working with community partners that are juggling multiple competing priorities, the grant writing stage helped to prioritize the research planning phase and provided a focused opportunity to work together and learn from one another. For myself as a graduate student, this tangible project also helped ease my internal tension of not wanting to rush the planning stage of the process, with concerns about making progress on my doctoral program. Unfortunately, we were unsuccessful in this larger provincial grant, however the process of working together was intrinsically valuable to the participatory relationship building process and getting to learn about the CCC initiative.

While I continued to finish graduate course work requirements for my doctoral degree and prepare for my candidacy exam, I remained in contact with members from Hospice Toronto. For example, I would share updates on how I was thinking of writing up my candidacy research proposal, using the grant we worked on together as a guide. Similarly, Hospice Toronto would share activities and events that were happening with CCC initiatives as well as new potential funding opportunities to support this research on the CCC initiative. We later identified another smaller municipal grant that seemed to be a really strong fit to explore the impacts of the CCC initiative called 'The Vital Ideas' grant from the Toronto Foundation and decided to apply. The aim of this grant was to "increase the effectiveness of high-impact initiatives in Toronto" on core issues identified in Toronto's Vital Signs report (e.g., leadership, civic engagement, and belonging, or health and wellness, etc.). The second time around applying for a grant was a lot easier and by this point we had a better understanding of what our proposed project would involve – the previous grant and my proposal for my candidacy exam helped to support this process. We had submitted the grant proposal together on the same day I passed my candidacy exams—I celebrated on both fronts!

Table 4.2 presents the participatory matrix for the CCC participatory case study, with a focus on Cycle 1 – Grounding. I adapted this table from (Cook et al., 2017) to reflect on the participatory nature of the relationship building phase among members of the Hospice Toronto organization and among CCC community members (the later will be discussed in the next section). In reflecting on the participatory nature of the relationship building phase with Hospice Toronto (the organization), the process of determining the focus of the research and designing the research methods was a combination of *co-operation* and *co-learning* participatory processes (previously defined in Table 4.1). As an outside researcher, I brought my own research interests, and research experience to the table, and Hospice Toronto brought their own interests and experiences working in the community to our conversations together. It was through our process of going back and forth that the research focus and methods were shaped. At times, I supported the process as a facilitator, and other times I took the lead in writing up what we had discussed to share back with the group.

Table 4.2: Participation Matrix for the CCC participatory case study: Cycle 1 - Grounding [adapted from (Cook et al., 2017)].

Type	**Deciding on Research focus**		**Designing research methodology**		**Data Generation**		**Data analysis**		**Report writing**		**Dissemination**		**Action**	
	O	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**
Co-option														
Compliance		✓		✓										
Consultation				✓										
Co-operation	✓		✓											
Co-learning	✓		✓											

Collective Action	
Notes: O = Organization (i.e., Hospice Toronto) | C = Community (i.e., CCC members)	

After my candidacy exams, I started to apply for institutional ethics from my university. While I had been warned that university research ethics boards struggle to understand essential dimensions of PHR (e.g., the emergent process and primacy of participation) (Flicker, Travers, Guta, McDonald, & Meagher, 2007; Khanlou & Peter, 2005), my experience was very supportive. Indeed, Guta et al. (2010) have found that research ethics boards in Canada are making slow but promising shifts in supporting participatory research. First, I found the process of applying for ethics helpful in thinking through important issues on privacy and confidentiality in visual and participatory methods. Similar to Klocker (2012), I also found it was possible to build uncertainty into the ethics application. Second, while I led the research ethics application process, decisions as to the ethical processes were a result of discussions between Hospice Toronto and myself. This was a helpful process as we hadn't created a 'working together agreement' as recommended by Abma et al. (2019a) that outlines how the research partners would work together. These working agreements can be helpful in thinking through potential challenges together and increase the transparency of the PHR process. However, I found that working on the ethics application with Hospice Toronto prompted us to have many of these conversations. Third, in reflecting back on the participatory relationship building phase, it became clear how many of the everyday ethical dilemmas in participatory research fall outside the scope of institutional ethics review boards (Banks et al., 2013; Flicker, Guta, & Travers, 2017). For instance, I found relational boundaries difficult to manage at points, authentically balancing the relationship between friendship and as an outside researcher. While I was warmly welcomed into CCC project members homes, which strengthened our relationship, there were still power imbalances at play. For instance, I was not reciprocating the invitation and welcoming CCC project members into my home. The imbalances and confusion at points in the relationship proved to be problematic in one instance, an example I will reflect on later in the discussion. In addition, everyday ethical decisions around who is involved in determining the research focus and process are not common components of institutional ethics reviews. However, these questions of whose voices are heard and who has influence in these planning stages of the research have serious ethical consequences from an epistemic justice perspective (i.e., who contributes to the generation of knowledge).

Meeting CCC Members

While we waited for the outcome of different funding submissions and the ethics review board, we decided to proceed with the next phase of the relationship initiation and building process which was getting to know CCC community members. Neither Hospice Toronto nor I saw the funding as a major barrier. As a doctoral student, I was able to commit to facilitating the participatory photovoice project regardless of external project funding. Similarly, Hospice Toronto was committed to identifying ways to creatively facilitate the project on a shoestring budget. As we didn't have ethics approval, we weren't able to formally begin engagement in the CCC photovoice project, however I was invited to informally participate in CCC. For example, the CCC Community Development Coordinator invited me to visit the 'The Community Corner' where the initiative was housed and took me on a tour of the neighbourhood. I was also invited to join in on the CCC Friday Group (where members discussed different topics) and participate in different community events and festivals. Other PHR researchers have also reflected on the importance of 'showing up' and participating in community events as part of relationship and trust building process (Springett, Atkey, Kongats, Zulla, & Wilkins, 2016). Similarly, participatory researchers have shared the importance of spending their first year 'drinking tea' to slowly build trust to even get to a point of considering any formal research (Castleden, Morgan, & Lamb, 2012). As PHR is a relational process, it was important to show up and be present in an informal way to slowly get to know different CCC members.

By spending time in St. James Town, other dimensions of my positionality as an outside researcher became more apparent. I was a white, middle-class, doctoral student co-initiating a research project with Hospice Toronto in one of Toronto's most ethnoculturally diverse and lower-income neighbourhoods. Not only did my insider/outsider position influence the participatory research process, but so too could other dimensions of my positionality including: my hierarchical position/informal power within an organization or community, my position "vis-à-vis dominant groups in society" (e.g., race, ethnicity, gender, class, sexual orientation, ability, religion, age, etc.), as well as my position "within colonial relations within and between nation states" (Herr & Anderson, 2005, p. 44). Muhammad et al. (2015) have argued that the core principles of participatory research (e.g., collaborative relationships) cannot be meaningfully applied unless issues of uneven power dynamics are named and addressed. This is because positions of power and privilege can reproduce systemic inequities and further disadvantage community members that are being asked to be a member of participatory research project. As an academic researcher, I represented "centres of power, privilege, and status within [my] formal institutions, as well as within the production of scientific knowledge itself" Muhammad et al. (2015, p. 1046). Further, I also held power and privilege from my racial background, class, and education.

In reflecting on how issues of power were considered in the CCC participatory case study, certain elements of the research design helped to redistribute power, while other decisions made in the research compromised the principles of my participatory aims. For example, Muhammad et al. (2015) recommend including research team members whose identities (i.e., race/ethnicity, sexual orientation, gender, and class) intersect with those whose who's life or work is the focus of the research is one way to work towards redistributing power. In our research team at the organizational level, the CCC Community Development Coordinator who identified as a visible minority, played a critical role in the planning stages of the research, and also later on as the CCC photovoice project evolved in terms of co-facilitating both small and large-group discussion sessions. While the St. James Town community is diverse, building a research team whose "identities (i.e. gender, race/ethnicity, sexual orientation, and class) intersect" with those of the community was one way we considered issues of power (Muhammad et al., 2015, p. 1058). Another aspect of how power was considered in the CCC participatory case study related to how funding was distributed. In this research project, research funding to support the project was directly given to Hospice Toronto to manage (rather than to my academic research institution). As a result, Hospice Toronto was responsible for managing the distribution of research funds. Thus, they were able to use this funding to directly support the extra research responsibilities of the CCC community development coordinator.

However, I also made decisions in the relationship building phase that privileged my own academic goals which had consequences for the participatory nature of the CCC photovoice project and compromised the redistribution of power. For example, CCC members had not been part of the initial conversations in developing the research question (i.e., a *compliance* level of participation engagement, see Table 4.1 for definitions and Table 4.2 for the participation matrix). However, we did build flexibility into the research photovoice process to allow for members to decide how they would like to engage in the research. For example, some CCC project members wanted to facilitate small group photo sharing sessions with their neighbourhood helper, or another community member, while others decided to engage in 1:1 photo story telling sessions with myself. However, these were minor decisions within a structure that had already been determined, and so I categorized this level of engagement between *compliance* and *consultation* in the participation matrix (Table 4.2). While it would have been possible to continue to explore the focus of the research and methods at the community-level, I made a decision as a doctoral student to limit engagement at this phase in order to continue moving ahead in my doctoral program. Reflecting back, I don't know if CCC members would have identified the same research focus that was identified at the organizational level. As I learned by participating in the CCC Friday Group, members discussed a range of issues in the community from identifying ways to support their neighbours better to concerns on community safety. If the research relationship with Hospice Toronto, CCC members, and myself continued to evolve over time, engaging CCC members in the planning stages more directly would be easier in future projects as the relationship had been already developed from our CCC photovoice work together.

Once we had ethics approval, we then formally began to present the CCC photovoice project to CCC members. We first introduced the project at a community potluck, and members interested in learning more added their name to a sheet. The enthusiasm for the project was strong among members (as evidenced by the number of CCC members who signed up to learn more), some indicating they wanted to showcase this program, others were interested in the photography aspect. Similarly, another CCC member added that he thought that photovoice was a good way to 'blend two worlds we live in'. He described how we currently live in a visual culture but added that for many of the people in the room, they grew up in an oral culture. He thought photovoice was a good way to blend the two cultures we live in: an oral culture and a visual culture.

Around this same time, we also found out we had been awarded the Toronto Vital Ideas grant. Further, we had been selected by an external corporate sponsoring partner to be part of a special round of funding in which corporate teams would select initiatives that interested them and then entered a competition to try and get the final judges to select your program for funding.

While our corporate team was not successful in this special round, one of the members of that team was very keen on the work that hospice was doing and joined the Hospice Toronto board of directors and has been an important leader in supporting the mission of the organization (a small ripple effect of our grant application). Receiving the grant for the CCC photovoice project was an important step in moving the project forward for a number of reasons. First, it eased financial pressure on the project to allow it to run as we had ideally intended. Second, the deadlines set by the funder helped to set some milestones and goals for the project. While some participatory researchers have found the timelines of funders a barrier to the emergent and organic nature of the project (Cook et al., 2017), I felt it gave the project momentum and energy, in addition to easing my personal concerns regarding the completion of my doctoral program. In Chapter 5 to 9 (Cycle 2: The Photovoice Project), I present the next phase of the research, that was built off of the intensive relationship building phase.

DISCUSSION

Facilitators and Challenges of the Participatory Relationship Initiation and Building Phase

Facilitators

Reflecting back on my experience initiating and building a participatory research relationship, I identified a number of different facilitators of the process. These facilitators included: identifying potential partners who are 'participatory' research ready, having small concrete projects to work on together, capacity to engage in a PHR project, taking time to get to know the community slowly, and shifting roles and using strengths.

Identifying potential partners who are 'participatory' research ready

When I first sent an invitation to engage in a participatory research project to different community organizations, I followed my instincts about what 'felt right' based on the responses I received back. For graduate students who do not have previous experience with PHR, trusting your instincts can be a useful guide in the initiation process. However, it was by reflecting back on the experience that I was able to realize certain organizational characteristics that laid the foundation for a strong participatory research relationship. First, a core aspect of Hospice Toronto's mission was on "imaginative partnerships and a focus on research and innovation" (Hospice Toronto, 2014b). From my initial email, the Executive Director of Hospice Toronto was open to exploring a potential research collaboration opportunity. Second, Hospice Toronto had past experience in research collaboration opportunities that were mutually beneficial. As such, the organization was comfortable working with the iterative, organic, and messy nature required to shape the PHR process. Referring back to Figure 4.2 by Heen (2015) on how our actions are determined by past experiences, Hospice Toronto had different research experiences as part of their 'experiential base'. This experience impacted their perceptions of my open research invitation, and their subsequent actions to engage in this process. Because these key characteristics were in place, unbeknownst to me at the time, the process of initiating the relationship went fairly smoothly and we were able to move to a planning exploration phase quite quickly. This isn't to say that it is not feasible to initiate a potential participatory research relationship with an organization that doesn't have research as part of their mission or hasn't had past experience. In those cases, the initiation process may take more time as both partners learn more about each other, and in the case of the academic research, there may be a need to support research capacity building.

Having small concrete projects to work on together

The planning of the CCC photovoice project really started to progress when we had a small concrete project to work on together as it gave a tangible structure to our planning process. The process of applying for a grant together also helped to set a concrete deadline which helped to prioritize the research aspect among many other organizational priorities. It was during this grant writing phase that I was also able to learn more about the CCC initiative, and I was also able to share and contribute my own research knowledge and experience to the process.

Capacity to engage in a PHR project

Hospice Toronto was very engaged in the initial planning stages of the CCC photovoice project and was committed to working with a collaborative approach. The organization's capacity to engage in the CCC photovoice project was influenced by a number of factors. First, Hospice Toronto was committed to working together as they viewed the project as mutually beneficial. Second, the CCC Community Development Coordinator was enthusiastic to participate in the planning stages as she saw it as an opportunity to connect with others, locally and internationally, who were using a health promoting approach to palliative care. She thought this was a valuable opportunity as she expressed it could sometimes be isolating to facilitate an approach that isn't always well understood within the field. For CCC members, many didn't see the CCC photovoice project as a separate project outside of their involvement in CCC, they saw it as an embedded activity. While PHR projects can be time intensive in nature, embedding activities into the existing model helped to facilitate in engagement. Most importantly, we aimed to create flexible opportunities for different levels of engagement in the initial relationship building stages and beyond.

Taking time to get to know the community slowly

Another facilitator of the participatory research relationship building process was that all CCC research project members were able to get to know one another over a longer period of time. This slow relationship building process helped to lay a strong foundation of working together before the CCC photovoice project formally started. While the slow process of relationship building has been presented as a challenge of the PHR approach (Moore, 2004), the structure of graduate work can align with this process. For example, I was able to slowly build the research relationship while I completed required coursework and prepared for my candidacy exams. This isn't to say I didn't feel a tension with timelines in the moment, but it was reflecting back that I had a better understanding of congruence between participatory principles and institutional timelines. Similar reflections have been presented by Klocker (2012) who added that the early investment in the relationship building process can pay off in terms of time saved in later stages of the process. Similarly, other community-based participatory researchers using photovoice also reflected that "While the photovoice method necessitated a significant time investment to achieve the goals of both the community and research partners, it also created a strong foundation – and relationship – from which to continue collaborative work" (Nykiforuk et al., 2011, p. 115). Further, Moss (2009, p. 69) adds that while the four-year doctoral degree is "scarcely long enough to complete a participatory project" it is a uniquely focused opportunity in that there is rarely another moment in an academic career to bring this level of focus and dedication.

Shifting roles and using strengths

Shifting roles and using strengths was another facilitator of the participatory relationship building process. Project roles during the relationship building phase shifted in order to capitalize off different strengths. During the first level of relationship building with Hospice Toronto staff, I played a more active role in certain aspects of the planning, such as supporting the methodological plan. However, during the second level of relationship building with CCC community members, the CCC Community Development Coordinator was more of 'the face' of the project as she already had strong relationships with the different members and also had a strong understanding of what engagement approaches would be more likely to be successful. As there is overlap between community development approaches and PHR (i.e., a focus on community capability building, starting where people are at, etc.), the CCC Community Development Coordinator was a strong asset to the research team as she had many skills to co-facilitate the research process including interpersonal skills, facilitation skills, and community organizing. Capitalizing on the strengths of different research partners in the early stages of the research contributed to the success of the CCC photovoice project.

Challenges

Reflecting back on my experience initiating and building a participatory research relationship, I surprisingly identified few challenges in the process, an aspect I will reflect on at the end of this section. However, the two challenges that were most prominent in the relationship building phase included: navigating relationship expectations and boundaries, and my own internal tension of negotiating institutional timelines with participatory principles.

Navigating relationship expectations and boundaries

One of the relational challenges I experienced was navigating relationship expectations and boundaries, not only during the relationship initiating and building phase, but across the entire research process. In particular, because one the key underlying principles of PHR is the relational dimension of the approach, I found it difficult at times to authentically manage my role as 'researcher' and sometimes 'friend' especially when lines started to blur.

As an example, a few months after the CCC photovoice project concluded with a celebratory reflection workshop (a strategy I used to mark a soft close of the work we had done together), one of the members of the CCC photovoice project lost her husband. I had learned of this news from the CCC Community Development Coordinator, who I remained in frequent contact, and decided that the next time I was visiting the community I would give my condolences in person. As the photovoice project had come to a natural close, I was not in contact with other CCC project members, however I was invited on occasion to stop by community festivals or join in on CCC Friday Group sessions by the CCC Community Development Coordinator. The decision to give my condolences in person when I was in the community next, rather than a personal call, was my response to try to authentically balance my professional and personal relationship with CCC project members and to set up soft boundaries post-project. However, before I had a chance to visit the community, I received a text message from the project member whose husband had died with an image of a quote on 'hypocrisy'. I was taken back to receive the message and called the CCC Community Development Coordinator for advice on how to proceed. I ended up calling the CCC photovoice member, gave my condolences, explained that I had received her text message, and apologized that I had not seen her sooner to give my condolences. She explained that the text message on hypocrisy wasn't about her feelings about me, rather an image she liked that she sent to other people as well. I don't know if that was true and that my own discomfort in negotiating boundaries contributed to my assumptions of the context, or if my call and apology had diffused the situation. Regardless, this scenario highlighted some of the relational challenges in PHR.

This relational tension isn't unique to PHR. Many other qualitative, and feminist, scholars have written about the risks of a "friendly façade" and "disingenuous friendships" (Huisman, 2008; Kirsch & Kirsch, 1999; Wolf, 1996). As Huisman (2008) quotes in her own reflections on feminist ethnography, "the greater the intimacy, the apparent mutuality of the researcher/researched relationship, the greater is the danger" (Stacey, 1988, p. 24). However, in PHR, mutuality is a core principle of the process, and I believe that aspect helps to decrease some of the risks (Chapter 10 describes some of the impacts CCC members described as a result of their participation in the project). Regardless, it is the everyday ethics and values in the decisions we make in terms of what we do, and how we act, in the PHR process that can be the most challenging to work through (Banks et al., 2013).

Internal tension of negotiating institutional timelines with participatory principles

Another internal challenge I experienced related to negotiating the balance between doctoral timeframes and honouring the core principles of PHR. Relational approaches to research, as is the case with PHR, can be time intensive. As Maguire (1993) emphasizes, is it not possible to ‘short-circuit’ the relationship building process, and it is important for PHR projects to be seen through to avoid disappointing and breaking the trust of project members (Herr & Anderson, 2005). As a graduate student, I was not alone in negotiating this tension (Burgess, 2006; Grant, 2007; Klocker, 2012; Moore, 2004). There were decisions I had to make in the research process to continue to move things along (i.e., not adding an additional researcher planning phase with CCC community members). The implications of these discussions will continue in the discussion below on assessing the participatory nature of the relationship building phase.

Reflections on challenges overall

Despite many challenges of the participatory research process highlighted in the literature (Israel, Schulz, Parker, & Becker, 1998) and particularly for graduate students (Moore, 2004), I found that our participatory project didn’t experience many of these tensions and wondered why. In part, these challenges were mitigated by the facilitators previously described in the relationship building process, but I felt there was more to this conclusion. For example, participatory researchers have discussed challenges related to conflicts associated with different perspective and priorities, differences in underlying assumptions and values, conflict over funding, and tensions as a result of social and political dynamics within a community (Abma et al., 2019a; Israel et al., 1998). One of the reasons I didn’t experience these challenges in the relationship building process was because I was working with one smaller organization in the process. This isn’t to say that these tensions aren’t present within an organization or between academic researchers and community organizations. Rather, these issues are more likely to rise to the surface when you are working with a larger group made up of many diverse partnerships. While there were differences of opinions in the relationship building process, they were not seen as major challenges, rather a positive sign that organizational project members were comfortable expressing and negotiating these differences together. For example, one of these tensions related to different perspectives in determining the focus of the research. While some staff members were keen to explore impact of the CCC initiative from the perspective of CCC members, others felt that the focus should be more on determining the impact on the health care system. It was this latter research question that staff felt would be most meaningful to government funders. However, it was through discussions that Hospice Toronto staff members and myself that we settled on understanding the impact of the CCC initiatives from the perspective of CCC members as a starting point for determining key impact areas (such as health care service usage) for further exploration. As a graduate student doing a PHR project for the first time, it was helpful however, to negotiate these tensions in a smaller partnership as I 'learned by doing'.

The Value of First-Person Inquiry as a Doctoral Student

Engaging in first-person inquiry into my experience initiating and developing a participatory research relationship contributed to my development as novice participatory health researcher. This approach provided a space to reflect on what I had learned through 'learning by doing', (i.e., a practical and experiential type of knowing) to improve my future practice as a participatory researcher. Grant (2007, p. 270) suggests that a certain level of developmental and intellectual maturity in the PHR process—achieved through 'being' and 'doing'—is needed to better appreciate the nuances and complexities of PHR, but also to "channel any feelings of discomfort which arise from this self-awareness in a manner which may further both our development and knowledge". First-person inquiry was a valuable approach to more mindfully process my experience initiating and building a participatory research relationship before the experience was cemented in my 'experiential base' that would inform my future actions as a participatory researcher (Heen, 2015). It was only through reflection, after my 'experiential base' had been further developed, and that I could appreciate my supervisor's words of wisdom to 'trust the process' in participatory research. It was difficult to take comfort in this encouragement, as I didn't have a participatory 'experiential base' to draw from to feel this advice to be true.

Engaging in first-person inquiry also provided a space to shine a light on some of the tacit choices I made in the relationship building process, and to "step outside the everyday common sense of [my] presuppositions…to explore [my] behaviour for potential incongruity with [my] purpose leading to more effective action" (Reason, 2003b, p. 117). It was an opportunity to engage with and demonstrate reflexive validity. Reflecting on my positionality and the participatory nature of the relationship building phase, I identified ways in which 'power' in the

CCC participatory case study was redistributed (i.e., research team identities, funding) and ways that differences in power were reproduced (i.e., I would have liked the additional time to engage CCC members in more of the early relationship building planning phases such as determining the focus of the research). However, as Klocker (2012) found helpful in reconciling these tensions, it isn't helpful to be 'puritanical' in participatory research about the need to engage in participation "deeply or not at all" as "the road to 'doing research differently' has to begin somewhere" (Kesby, Kindon, & Pain, 2005, p. 145). Similarly, Dedding, Goedhart, Broerse, and Abma (2020) have also reconciled the tension of engaging in participatory research in less than ideal circumstances (e.g., serious constraints on time and budget), as to choose not to engage may only further exacerbate 'epistemic injustice' and lead to situations where top-down policies do not accurately reflect the experiences of people's daily lives. Reflecting on these tensions in participation has brought to the forefront the necessity of addressing power imbalanced in PHR and has challenged me to more purposefully consider strategies and process to address issues of power, particularly as a white, educated, middle-class researcher.

SUMMARY

This chapter presented my first-person inquiry into my experience initiating and building a participatory research relationship as a doctoral student. By opening a window into my own experience, I hope to encourage other doctoral students who are unsure of the compatibility between PHR approaches and doctoral programs to feel hopeful about the potential for a meaningful PHR experience. In this chapter I reflected on the facilitators and challenges of developing a participatory research relationship from the ground up and described the value of engaging in first-person inquiry for my own personal development as a novice participatory researcher. While I have used first-person inquiry to reflect on my experience across the relationship building phase, reflection played a key role across the entire CCC participatory case study.

Building off the early relationship initiation phase, in the following chapters (5 to 9) I present the next cycle of the CCC participatory case study, Cycle 2: The Photovoice Project a second-person inquiry into the CCC initiative in St. James Town, Toronto.

CHAPTER 5: DESCRIPTION OF THE CCC INITIATIVE

OVERVIEW

During the participatory relationship initiation and building phase of the CCC participatory case study (Cycle 1: Grounding), I started to learn more about Hospice Toronto as an organization and the CCC initiative in particular. In this chapter I present a description of the CCC participatory case study context. This description of the case study context was developed early on in the research planning to help set the boundaries of the case and it was continuously revised as the research progressed. A variety of data sources were used to develop the CCC case description including conversations with Hospice Toronto Staff, Hospice Toronto documents relevant to CCC provided by staff, my own visits to the initiative, City of Toronto reports on the St. James Town neighbourhood, and CCC photovoice data. Having a deeper understanding of the case study context was important in designing the research and in the interpretation of a findings from a more nuanced perspective.

BACKGROUND ON THE CCC INITIATIVE AND HOSPICE TORONTO

Creating Caring Communities (CCC) is a neighbourhood-based community capacity building initiative in St. James Town, Toronto, Canada (an inner-city neighbourhood). This initiative aims to create meaningful neighbour and community connections to support isolated and socially vulnerable community members living with a life-limiting illness, through culturally relevant social support (e.g., friendship, practical, emotional, informational). Through these new connections in the community, CCC aims to: (i) support isolated and vulnerable community members life with a life limiting illness and/or their carers in their choice to remain at home in their community; (ii) better connect individuals to social and health services in the community; (iii) increase well-being and self-efficacy for all involved, and (iv) contribute to making St. James Town a more caring and compassionate place to call home.

The CCC initiative is facilitated by Hospice Toronto (formally Trinity Home Hospice), "Toronto's first not-for-profit community and volunteer-based in-home hospice palliative care program" (Hospice Toronto, 2014b). Hospice Toronto has a long history of taking a grassroots approach to palliative care. The organization was first established in 1988 out of an informal care group of 60 friends, neighbours, and acquaintances who supported a woman named Margaret

Frazer in her wish to die at home after being diagnosed with cancer (Hospice Toronto, 2014b). This story is documented in the novel *Twelve Weeks in Spring* (Callwood, 1986). The CCC initiative is part of a group of innovative, and health equity focused, approaches to palliative care led by Hospice Toronto, including:

- the Young Carers Program that supports children and youth in Toronto who have a primary carer responsibility (Young Carers Program, n.d.); and
- Journey Home Hospice that provides palliative care for Toronto's homeless community (Journey Home Hospice, 2020).

The CCC initiative was first developed in response to reports in St. James Town of isolated seniors dying, and not being found for days and in some cases many weeks at a time (personal communication, D. Maule, September 2015). Hospice Toronto recognized that many isolated and socially vulnerable community members living with a life-limiting illness would not be supported in more traditional approaches to volunteer-based palliative care and that a different approach was needed. This was because these more traditional volunteer-based programs typically received referrals from individuals already connected to the broader social and health care system (personal communication, D. Maule, September 2015). The CCC initiative in St. James Town was rooted in the assumption that neighbours living in the community would be one of the most effective resources for identifying and engaging isolated and vulnerable community members life with a life-limiting illness.

ABOUT ST. JAMES TOWN

The CCC initiative is based in St. James Town, 1 of 140 neighbourhoods in the City of Toronto, Canada. Images 5.1-5.3 present different views of the St. James Town neighbourhood. This community in Toronto has been called 'a world within a block' and is Canada's most densely populated neighbourhood (St. James Town, 2020). The CCC initiative has a shared office space at The Corner (see Images 5.4 and 5.5), a neighbourhood hub dedicated to supporting local initiatives (St. James Town, 2020). According to 2016 Statistics Canada Census of Population data, St. James Town has an official population size of 18,615 and a population density of 44,321 people per square kilometre (compared to 4,334 people per square kilometre in Toronto as a whole) (City of Toronto, 2018). In St. James Town, 90% of residents are renters (compared to City of Toronto average of 47%) and 93% of neighbourhood residents live in apartment buildings with five or more storeys (City of Toronto average is 44%); nearly a quarter of which is subsidized housing (City of Toronto, 2018).

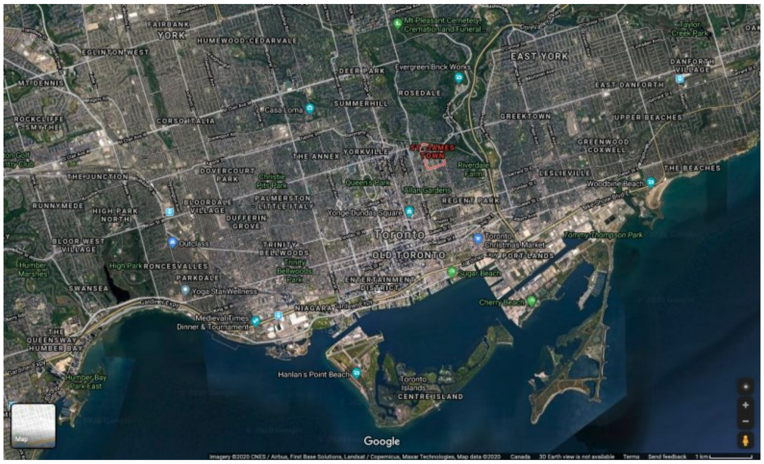


Image 5.1: Location of St. James Town in Toronto, Ontario, Canada highlighted with red borders.

Image 5.2: Zoomed-in view of St. James Town, Toronto, Ontario, Canada highlighted with red borders.

Image 5.3: Bleecker St. looking North in St. James Town, walk from the subway to The Corner.

Image 5.4: The Corner office at the bottom right of one of the subsidized apartment buildings in St. James Town.

Image 5.5: Entrance to the Corner with a welcome board outlining the different activities and groups present for the day.

St. James Town has a lower median household income than the City of Toronto ($41,016 CAD vs. $65,829 CAD) and a higher percentage of people in private households living below the poverty line (40.1% vs. 21.9% in Toronto overall). In addition, 45.9% of residents in St. James Town hold a Bachelor's degree or higher, comparable to the City of Toronto average (44.1%) (City of Toronto, 2018). Recent immigrants and non-permanent immigrants make up 13.8% and 8.0% of the population, respectively. More residents in St. James Town identify as a visible minority than in the city as whole (67% vs. 51%) with South Asian, Filipino, Black and Chinese as the top four visible minority populations. In addition, the top four non-English languages spoken at home in St. James town include: Tagalog, Tamil, Nepali, and Mandarin (City of Toronto, 2018).

Focusing on the senior population (age 65+) specifically, St. James Town has a lower percentage of seniors compared to the City of Toronto average (8.7% and 15.6%, respectively), however there are a higher percentage of seniors living alone (50.5% compared to 26.7% in the City of Toronto) and a higher percentage of seniors below the Low Income Measure – After Tax, (41% vs. 17%) (City of Toronto, 2018). Overall, St. James Town has a unique socio-demographic profile that influences how the CCC initiatives functions in the community. The interplay between these unique contextual factors, and the CCC initiative will be discussed further under the 'Findings' and 'Discussion' chapters of this thesis.

KEY MEMBERS OF THE CCC INITIATIVE

In 2016, the key members that made up the CCC initiative included a part time community development coordinator, 14 neighbourhood helpers, 30 isolated and vulnerable community members with a life-limiting illness, and 9 primary carers. More recently (2019), a part-time community outreach assistant had been added to the CCC initiative. In addition to these core members, the CCC initiative was reported to have collaborative relationships with many different social and health service organizations in the community and the wider Toronto area (e.g., legal aid, domestic violence, primary care and hospitals, cultural seniors' associations, housing and employment, mental health, etc.). The roles of different CCC members are summarized in Table 5.1.

Table 5.1: Description of the different roles of CCC members.

CCC member type	Description of 'role'
CCC community development coordinator	• The primary role of the community development coordinator is as a community connector. • For example, they receive notices of isolated and vulnerable community members life with a life-limiting illness and help connect these individuals with neighbourhood helpers and other relevant services as appropriate.
CCC community outreach assistant	• The primary role of the community outreach assistant is to support the community development coordinator in raising awareness about the CCC initiative in St. James Town with a focus on engaging new neighbourhood helpers.
CCC neighbourhood helpers	• The primary role of neighbourhood helpers (i.e., community members who live or work in the St. James Town neighbourhood) is to provide social support to isolated and vulnerable community members life with a life-limiting illness across a variety of dimensions: friendship, emotional support, practical support, and informational support.

	• In many cases, CCC neighbourhood helpers have recently immigrated to Canada (e.g., in the last 3 years) and joined the CCC initiative as a way to become more connected with their community.
CCC community members (living with a life-limiting illness)	• CCC community members are members living in St. James Town who are living with a life-limiting illness and characterized as isolated and socially vulnerable (e.g., low-income, recently immigrated, etc.). • Demographic characteristics vary from year to year however in 2016, there were at least 30 community members needing support: 52% were age 65 years or older and 48% were between 18 and 64 years. Roughly half of these community members had no informal care support (i.e., from a family member) and the majority were experiencing multiple co-morbidities including but not limited to heart disease, renal failure, cancer, diabetes, and depression.
CCC primary carers	• Primary carers are CCC members who are the primary support for a CCC community member living with a life-limiting illness and are also characterized as being socially vulnerable (e.g., low-income, recently immigrated, etc.) • There are fewer primary carers in the CCC initiative as this initiative is traditionally focused on support CCC community members who do not have any family or friend supports.

SUMMARY

To conclude this case description, the CCC initiative takes place in one of Toronto's most socio-economically diverse inner-city neighbourhoods. The CCC initiative involves many different key players to facilitate this community capacity building initiatives to support isolated and vulnerable community members living with a life-limiting illness. This initiative was one of Canada's first compassionate community approaches to health promoting palliative care and it is currently the longest running which made it a strong case example to better understand this approach to palliative care in the Canadian context. In the following chapter, I present the data generating methods used in Cycle 2: The Photovoice Project to explore the nature, impact, and facilitators/challenges of the CCC initiative, a compassionate community approach to health promoting palliative care.

CHAPTER 6: CYCLE 2—THE PHOTOVOICE PROJECT PROCESS

OVERVIEW

In this chapter, I outline the specific methods that guided the data generation process in Cycle 2: The Photovoice Project process (see Figure 6.1). In this chapter, I describe the different phases of Cycle 2: The Photovoice Project from engaging CCC members to the final community photovoice exhibition in St. James Town. The data generation strategies used in Cycle 2 are rooted in case study and PHR data generation strategies. Finally, I also reflect on the participatory nature of Cycle 2: The Photovoice Project, building off the participation first matrix presented in Cycle 1: Grounding.

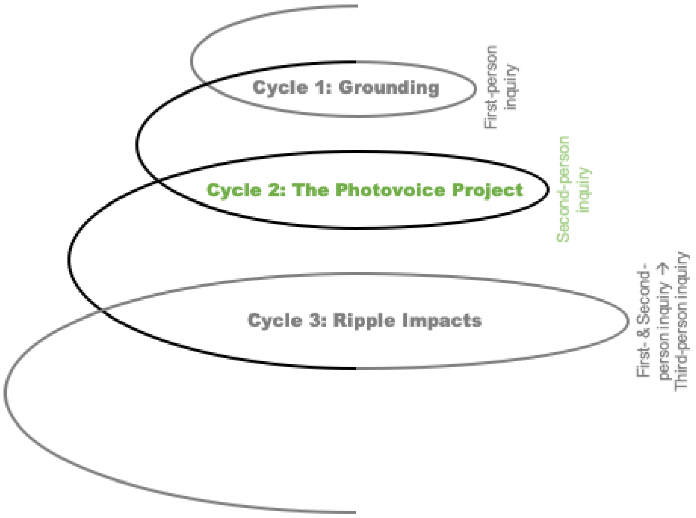


Figure 6.1: Cycle 2 – The Photovoice Project

PROCESS OF ENGAGING CCC PROJECT MEMBERS

The initial engagement with CCC project members was previously described in Cycle 1: Grounding (Chapter 4) that focused on the early informal relationship building phase of the CCC participatory case study. Once I had ethical approval (see Appendix B for ethics materials), the formal engagement approach was guided by a purposive stakeholder sampling strategy, consistent with the aim of our participatory case study approach to gain insight into this specific case (i.e., the CCC initiative) (Simons, 2009). Therefore, it was important to engage CCC members who were embedded in, and knowledgeable about, the CCC initiative. The inclusion criteria comprised the following:

1. CCC members (i.e., CCC community members living with a life-limiting illness, CCC primary carers, CCC neighbourhood helpers, and staff) who had been part of the CCC initiative for a minimum of 6 months;
2. CCC members who were 18 years of age or older; and
3. CCC members who had a basic working understanding of the English language (or who we were able to connect with an informal translation support from the CCC member network).

Most case study guidance on sampling has avoided discussions on identifying an appropriate number of project members (or participants) as this number is dependent on the size of the case and the resources available to conduct the research (Flyvbjerg, 2006; Simons, 2009; Stake, 1995; Yazan, 2015). CCC was a medium size case with varied membership (40-60 CCC members in a given year). As such, I aimed to engage between 15 and 20 project members from different perspectives (role in the CCC initiative, age, gender, race/ethnicity, etc.). The CCC community development coordinator played a key role in engaging a variety of different perspectives.

As a first step, we (myself and the CCC community development coordinator) formally introduced Cycle 2: The Photovoice Project of the wider CCC participatory case study at the CCC end-of-summer potluck. We created a short visual presentation to introduce the project. After the presentation, we collected the names of CCC members who were interested in learning more about the project. In addition, the CCC community development coordinator called or visited CCC members who were unable to partake in the potluck (e.g., due to scheduling conflicts or health/mobility limitations) to share the project and ask if they would be interested in learning more. All interested CCC members were subsequently invited to an introductory workshop to learn more about the photovoice project. The CCC community development coordinator played a key role in engaging CCC members as she had an existing relationship with the community. However, the CCC community development coordinator also emphasized that participation was completely voluntary and CCC members decisions on whether to participate would not impact their relationship with the CCC initiative or Hospice Toronto.

OBSERVATION

Observation was a key aspect of Cycle 2: The Photovoice Project. During Cycle 2, I used observations and field notes as a means to provide a richer description of the events that took place across the research including description of settings, interactions, and conversations with others. For example, during my initial visits to The Corner, I found observation helpful for gaining a deeper insight into the setting in which the CCC initiative was housed. Additionally, observation played a key role during group-based activities to note dynamics between different CCC members. These observations helped to gain a deeper insight into the relationships between members.

DOCUMENTS

In addition to observation, I also drew on CCC related documents to better understand the nature, impact, and facilitators/challenges of the CCC initiative. These documents were either publicly available or provided by Hospice Toronto staff. In particular, these documents were particularly useful in the early phases of developing a case description of the CCC initiative. To better understand the CCC case, I included the following documents in my analysis:

1. CCC communication and initiative material
    a. Hospice Toronto website
    b. Program member excel sheet with demographic details
    c. CCC recruitment flyer
    d. CCC neighbourhood helper description document
    e. CCC Friday Group yearly calendar of topics
    f. CCC grant proposal document
2. CCC case reports of community members living with a serious life-limiting illness
    a. Case report 01
    b. Case report 02
    c. Case report 03
    d. Case report 04
    e. Case report 05
3. Media coverage on CCC

a. Toronto Star article covering the CCC initiative

INTRODUCTORY WORKSHOP

We facilitated two types of introductory sessions: a group workshop for CCC members who were able to come to The Corner in St. James Town where the CCC initiative was based, as well as individual introductory training sessions for CCC members unable to attend in person. Training workshops have been identified as a common component of photovoice projects to build capacity around the photo and storytelling process (Catalani & Minkler, 2010). Different strategies of engagement were important for ensuring everyone who wanted to join the CCC photovoice project had the opportunity to do so. We emailed or delivered an invitation flyer (see Image 6.1), information letter, and consent form (see Appendix B) to all interested members prior to the introductory workshop. The week before, one CCC neighbourhood helper volunteered to call each of the interested CCC members to remind them of the workshop at the end of the week.

CCC
Creating Caring Communities
Hospice Toronto

Photography & Storytelling Project

Join us for the
1st Introductory Meeting
to help tell the caring community story together!

When: Friday!
Time: 5:30pm - 7:00pm
Where: Community Corners

- ✓ **Contribute** YOUR experience & stories of being part of a caring community
- ✓ **Practice** taking photos, discuss the project together & ask questions ☺
- ✓ **Bring a photo taking device** if you have one such as a camera, phone, tablet. *We will have extras!*

Questions? Contact:

Minara Begum
minara.begum@hospicetoronto.ca

Krystyna Kongats
sendyourstory@hospicetoronto.ca

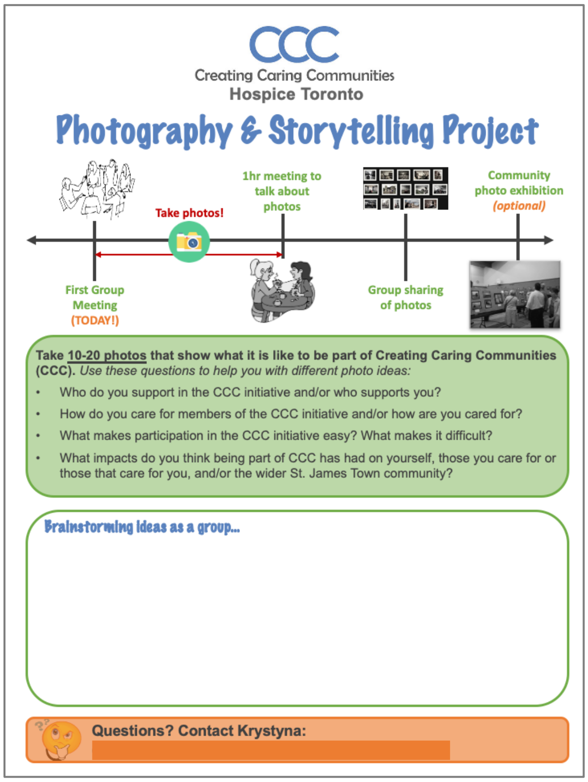
Image 6.1: CCC Photovoice Introductory Workshop Invitation

The purpose of our introductory workshop was to:

- share more details of the photovoice project (i.e., the goals, different phases, photo taking ethics);

- introduce different CCC members to one another who might not have met;
- review and discuss the information letter and consent form as a group;
- facilitate a creative warm-up activity to practice working with images, metaphors, and stories; and
- loan cameras to CCC members as requested.

While we had additional cameras to loan to CCC members who requested one, most CCC members already had their own, most commonly on their mobile phones. In total, 8 CCC members participated in the group introductory workshop, while 8 other individual/pair introductory sessions, mirroring the group process, were facilitated. The introductory training workshop was helpful in preparing CCC project members for the next photo mission phase, particularly for CCC members who felt unsure of how to begin taking photos, it also helped to build a group identity around the CCC photovoice project. CCC photovoice members were provided a 'photo mission' handout to help remind them of the broad goals of the project (see Image 6.2).



CCC
Creating Caring Communities
Hospice Toronto

Photography & Storytelling Project

Take 10-20 photos that show what it is like to be part of Creating Caring Communities (CCC). *Use these questions to help you with different photo ideas:*

- Who do you support in the CCC initiative and/or who supports you?
- How do you care for members of the CCC initiative and/or how are you cared for?
- What makes participation in the CCC initiative easy? What makes it difficult?
- What impacts do you think being part of CCC has had on yourself, those you care for or those that care for you, and/or the wider St. James Town community?

Brainstorming ideas as a group...

Questions? Contact Krystyna:
[redacted]

Image 6.2: Photovoice process handout at the introductory workshop

While CCC members were not directly involved in determining the focus of the research (as previously described in Cycle 1: Grounding), like Nykiforuk et al. (2011) we kept the photo mission broad to allow CCC project members (which included Hospice Toronto staff and community members) to express their own interpretations of the photo mission. In the participation matrix (see Table 6.1), I considered this to be a ‘co-operation’ level of engagement where both CCC community members and Hospice Toronto staff contributed to the interpretation and implementation of the photo mission, however as the outside researcher I was primarily responsible for guiding the process.

Table 6.1: Participation Matrix for the CCC participatory case study: Cycle 2 – The Photovoice Project [adapted from (Cook et al., 2017)]

Type	**Deciding on Research focus**		**Designing research methodology**		**Data Generation**		**Data analysis**		**Report writing**		**Dissemination**		**Action**	
	O	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**
Co-option														
Compliance		✓		✓						✓				
Consultation				✓			✓	✓	✓					
Co-operation	✓		✓		✓	✓								
Co-learning	✓		✓				✓	✓	✓	✓	✓	✓		
Collective Action														

Notes: O = Organization (Hospice Toronto) | C = Community (CCC members)

ABOUT CCC PHOTOVOICE MEMBERS

In total, 8 CCC neighbourhood helpers, 4, CCC community members living with a life-limiting illness (hereinafter referred to as CCC community members), 2 CCC primary carers, and 2 staff members participated in the CCC photovoice project. These 16 CCC project members who joined the CCC photovoice project are referred to as CCC project members in this thesis. Only one CCC member who participated in the introductory workshop decided to not join the project for privacy reasons. Before proceeding with next phase of Cycle 2: The Photovoice Project (i.e., the photo storytelling sessions), all CCC project members gave written informed consent and completed a demographic questionnaire (see Appendix B). For visual ease, I presented a summary of demographic information provided by CCC project members who participated in this research together (See Table 6.2). From this demographic questionnaire, I learned that CCC project members had a lot of experience with the CCC initiative, with project member indicating they had been involved for an average of 2.5 years (the shortest being 6 months and the longest being approximately 8.5 years). In addition, a wide span of age groups participated in Cycle 2: The Photovoice Project from 18-29 years of age to 90-99 years of age, with the majority being between 40 and 60 years old. Similarly, CCC project members identified as being from diverse racial and ethnic groups with South Asian being the most commonly reported, followed by Black-African and White-North American. Most CCC project members spoke English, with the second most common language spoken being Bengali. Half of CCC project members spoke two or more languages. In addition, the vast majority of CCC project members identified as women, and indicated they were born outside of Canada. As well, the majority of CCC project members denoted that their total family income before taxes in the last year was between $0 to $29,000 CAD (6 project members) or $30,000 to $59,000 CAD (4 project members). Overall, the demographic characteristics of CCC project members tended to reflect the diversity of the St. James Town community, as previously reported in the Chapter 5 case description.

Table 6.2: CCC project member demographic information.

Variable	n (%)
Role	
CCC Community Member	4 (25)
CCC Helper	8 (50)
CCC Carer	2 (12.5)
Hospice Toronto Staff	2 (12.5)
Gender	
Male	2 (12.5)

Female	14 (87.5)
Transgender	0 (0)
Age (years)	
18-29	2 (12.5)
30-39	3 (18.8)
40-49	3 (18.8)
50-59	3 (18.8)
60-69	2 (12.5)
70-79	0 (0)
80-89	0 (0)
90-99	2 (12.5)
Place of Birth	
Canada	4 (25)
Outside Canada	12 (75)
Race/Ethnicity	
Asian - South	6 (37.5)
Black – African	2 (12.5)
Black - Caribbean	1 (6.3)
Black – North American	1 (6.3)
Metis	1 (6.3)
White - European	1 (6.3)
White – North American	2 (12.5)
Afghan	1 (6.3)
Household Income ($ CAD)	
$0 to $29,999	6 (42.9)
$30,000-$59,000	4 (28.6)
$90,000 to $119,999	2 (14.3)
# of people in household income supports	
1	3 (21.4)
2	3 (21.4)

4	2(14.3)
5	3 (21.4)
Languages spoken (at least one of the following)	
Bengali	4 (25.0)
English	14 (87.5)
Hindi	3 (18.8)
Urdu	2 (12.5)
Other*	7 (43.8)
# of Languages Spoken	
1	8 (50.0)
2	4 (25.0)
3	2 (12.5)
4	2 (12.5)

**note: 'other' included one response each for Amharic, Arabic, Farsi, French, Portuguese, Marathi, and Nepali*

PHOTO MISSION ACTIVITY

Following the introductory workshop, project members were given approximately one month to take photos of their experience being a member of the CCC initiative. CCC project members were provided with guiding questions to help their photo mission process (See Figure 6.2). Consistent with our research purpose, the CCC photovoice guiding questions included:

- Who do you support in the CCC initiative and/or who supports you?
- How do you care for members of the CCC initiative and/or how are you cared for?
- What makes participation in the CCC initiative easy? What makes it difficult?
- What impacts do you think being part of CCC has had on yourself, those you care for or those that care for you, and/or the wider St. James Town community?

Further, we asked project members to take between 10 and 20 images as previous photovoice research had found that participants can take a large volume of photographs that can be a challenge to negotiate at the photo discussion stage (Nykiforuk et al., 2011). In some cases, the CCC community member needed assistance taking photos. In these cases, either the CCC community development coordinator or a CCC neighbourhood helper, assisted by taking photos at the direction of the CCC community member.

After one month, we followed up with CCC project members to collect their photos in preparation for the photo storytelling sessions to follow. Most photovoice project members emailed their photographs or we collected a USB or memory stick. Duplicates of all photographs were printed so that CCC project members could keep a copy of their pictures.

INDIVIDUAL/PAIR/MINI GROUP PHOTO STORYTELLING SESSIONS

Three different types of photo storytelling sessions were used, including 9 individual sessions, 2 pair sessions, and 1 mini-group session. CCC project members who were able to attend 'The Corner' for any of the group-based sessions (i.e., the initial potluck, the introductory workshop) including the proceeding group photo story telling session, participated in individual photo story sharing sessions at 'The Corner', approximately one-hour in length. The individual photo storytelling sessions also allowed for more in-depth sharing. For project members who were unable to participate in the group-based sessions, most commonly for mobility or health reasons, pair or mini-group storytelling sessions with other CCC project members were prioritized, in some cases this was with their neighbourhood helper. In keeping with the principle of participation, it was important to facilitate sessions where there was the possibility for co-learning and dialogue among group members. This flexible approach allowed us to create a participatory environment for project members who would not normally have the opportunity to participate in the group sessions due to limited mobility or health reasons. The pair or mini-group sessions were longer, lasting approximately 1.5 to 2 hours.

With consent, all interviews were audio recorded. We used an unstructured interview format to guide the photo storytelling process (Mayan, 2009; Nykiforuk et al., 2011). In some cases, I conducted the interview myself. In other cases, the CCC community development coordinator participated as well, for example when informal translation support was needed, or if the CCC community member was more comfortable with the CCC community development coordinator present. We followed Nykiforuk et al. (2011) process for the photo storytelling sessions. We started by asking CCC project members to select a photo that was meaningful to their experience being part of the CCC initiative. We then asked follow-up questions including, why was this photo important and what does it share about the CCC initiative. When there was nothing left to share about the photo, we moved on to selecting another one. We also supplemented the photo focused questions with the initial photo mission guiding questions to cover a wider range of their experience if it wasn't explored in the photo stories. All interviews were conducted over a two-and-a-half-month period.

GROUP PHOTO STORYTELLING SESSION

The group photo storytelling session, which we called the CCC photovoice sharing circle, took place after all interviews were completed and transcribed. The purpose of the CCC photovoice sharing circle was to provide an opportunity for CCC project members to come together again and share their photos and stories and to learn from other stories. It was also an opportunity to provide project members with an interim project update of what we had accomplished together and explore where we wanted to go next. All CCC project members were sent an invitation to participate either by phone, or personally dropped off at their apartment (see Image 6.3).

You're invited to...

Hospice Toronto's

CCC Photovoice

Sharing Circle

Come join us for a fun afternoon of sharing your photos & stories from the photovoice project and hearing other's photo stories!

We will have copies of your photos for sharing!

Date Friday Feb 24th, 2017

Time 4:30-6:30 pm

Location Community Corner

200 Wellesley St E, Toronto, ON M4X 1G3

Light refreshments will be provided

Image 6.3: Sharing Circle Invitation Poster.

To prepare for the group photo storytelling session, I transcribed all individual/ pair/ mini-group interviews verbatim and prepared individual photo storytelling packages. Each CCC photovoice member was provided an individual folder that contained: (1) a transcript of their interview, (2) a copy of their photographs, (3) clips of their transcript directly related to their photographs originally shared during the individual or pair/mini-group sessions, and (4) a summary report of the progress made together on the CCC photovoice project. This package, explored over refreshments, was used as a strategy to help jog the memory of the photos and stories previously shared.

In total, 11 of the 16 CCC project members took part in the sharing circle. The sharing circle, with consent of the group, was audio-recorded. We arranged the set-up in a semi-circle of chairs around a white board (see Image 6.4 for a collection of photographs from the workshop). The photo sharing process had 3 phases: (1) share one of your photo stories with the group; (2) identify a short title for the photo that captures the main message behind it; and (3) add the stories to the white board for later grouping. One CCC project member volunteered to help with the whiteboard grouping (i.e., theming) process. We started the session by having one CCC project member volunteer to share their photo and explain why they selected it and what it tells about their CCC experience. It was then added to the whiteboard with a title, and the circle was open for another CCC project member to share their story. After one round of sharing was complete, we opened up for the circle for discussion among the group. For instance, we asked members to reflect on: what patterns were emerging, any thoughts that surprised them about others' stories; and to reflect on similarities and differences with their own experience. In total we had time for two rounds of storytelling. As more photos were added to the photo story board, we started to cluster similar photos and stories together (see Image 6.5). This group sharing and clustering process was akin to a basic participatory analysis process. These clusters would later help to inform the thematic data analysis process that I took on independently. For this reason, I labelled the data analysis phase in Table 6.1 as 'co-learning' as both CCC project members (both Hospice Toronto staff and community members) and myself as an outside researcher contributed to interpreting the stories, making new meanings together as a group, with myself providing facilitation support.

Image 6.4: Collage of photos from the sharing circle

Image 6.5: Clusters of photos and key messages from the sharing circle workshop

We concluded the session by asking CCC project members one thing they learned from the group and explored next steps for the CCC project. For example, we asked CCC project members if they would be interested in sharing their experiences supporting members of their community in a photovoice exhibition. We also asked CCC project members if they would like to be involved in further participatory data analysis of the stories and photos. CCC project members expressed enthusiasm for a community photovoice exhibition and were keen to support the process. However, we didn't have any project members indicate an interest in further rounds of participatory data analysis.

CCC PHOTOVOICE EXHIBITION PREPARATION

In preparation for the photovoice exhibition, all CCC project members were invited to partake in the planning and preparation process. We had proposed creating a participatory data analysis and exhibition planning group that would meet every two weeks for 1.5 hours. However, as CCC project members were juggling many different work and caring responsibilities, we were unable to form this group. Additional rounds of participatory data analysis did not happen.

However, we were able to meet with most photovoice project members in preparation for the exhibition to explore which photos they wanted to share, as well as work on the story that went with each photo. In total, CCC project members selected approximately 3 photos and stories to share in the exhibition. At this stage of the process, we went through a second phase of consent to decide which photos could be part of the CCC photovoice project, and which were not to be included. Additionally, all photos that had people in them required another layer of written consent from the person directly to be included in the CCC photovoice project. Sadly, one photovoice project member died before the final CCC photovoice exhibition. Her passing also created an ethical dilemma of whether to include her photos in the photovoice exhibition which we explored as a group. In speaking with her partner (who was also in the project), her neighborhood helper, and the community development coordinator, all felt strongly that she would want to contribute her stories as part of the project and to not do so would be a disservice to her contribution.

In preparation for the photovoice exhibition we printed the photos and text on 11x17 photo paper and mounted them on to foam core board. This was a cost effective and aesthetically pleasing way to prepare and present the photos and stories. We were also able to book space at ‘The Corner’ to host the exhibition launch. Next, we developed a poster for the exhibition (see Image 6.6) and shared the invitation widely, posting it around the community, and sharing it with CCC project members local health and social service organizations in the community, and the local newspaper. CCC project members played different roles in preparing for the exhibition. For example, one CCC project member with an interest in photography helped to photograph the event on the day of, while a group of other CCC project members helped with preparing refreshments (including over 200 homemade samosa and a few trays of biryani). CCC project members (Hospice Toronto staff and community members) and myself as the outside researcher all contributed to determining the content for the CCC photovoice exhibition (what I considered to be akin to ‘report writing’ in Table 6.1) and to supporting dissemination activities (i.e., preparing and implementing the CCC community photovoice exhibition). For these reasons I considered both the ‘report writing’ process and dissemination process to be a ‘co-learning’ level of engagement (see Table 6.1). However, I primarily took the lead on the formal report write-up for the CCC photovoice project for our funders in consultation with Hospice Toronto staff (i.e., a ‘consultation’ level of engagement for ‘report writing’), but with minimal input from community members at this stage (i.e., a ‘compliance’ level of engagement).


Come Join Us as We...

REIMAGINE OUR COMMUNITY ONE STORY AT A TIME

A photo & story exhibition

When: Wednesday May 17th, 2017
Where: The Corner, 200 Wellesley St. E
Time: 4:00 - 6:30pm *(opening remarks at 4:30pm)*
Light refreshments provided

Isolation is said to be the greatest health crisis of our time.

Come see, hear, and learn how **neighbours in St. James Town** are using local knowledge, skills, and networks to support each other through chronic illness and end of life care.

These photos and stories were created by residents of St. James Town and reflect their views on the value of creating a **compassionate community**.

CCC Creating Caring Communities in St. James Town
HOSPICE TORONTO
With support from:
TORONTO FOUNDATION

Image 6.6: Photovoice Exhibition Flyer

CCC PHOTOVOICE EXHIBITION LAUNCH

The photovoice exhibition was well attended by over 50 attendees from the St. James Town community, as well as representatives from different health and social service organizations (see Image 6.7 for photos from the exhibition). The exhibition had 3 components: welcome and speeches; exhibition viewing and refreshments; and an exit reflection survey (this survey will be later discussed in Cycle 3: Ripple Impacts). At the request of the Executive Director of Hospice Toronto, the community development coordinator and myself provided the opening welcome and a bit of background about the program. We then had opening remarks from the Interim Director of the Toronto Central Palliative Care Network, part of the Local Health Integration Network, our regional provincial health authority. We were also going to have opening remarks from the late Counsellor and Deputy Mayor Pam McConnell from Toronto-Central however she was caught up at another community event and wasn't able to attend until later on. Finally, we had closing remarks from two CCC project members on their experience as a CCC member supporting members of their community.

Image 6.7: Collection of photos from the photovoice exhibition. From top to bottom: exhibition attendees; speech by CCC neighbourhood helper; Hospice Toronto staff with the late Counsellor and Deputy Mayor, Pam McConnell (middle).

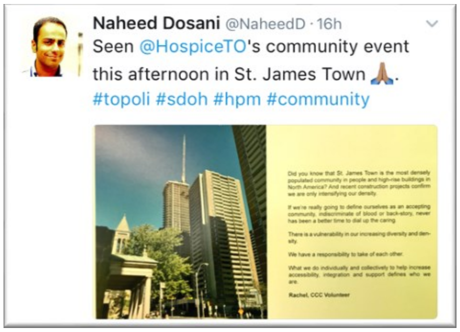
The exhibition was positively received by community members who worked or lived in St. James Town. Image 6.8 is a snapshot of some the feedback on social media and the local neighbourhood newspaper. The late deputy mayor had also indicated an interest in sharing the photos from the exhibition with her colleagues at City Hall.

Namarig Ahmed @Namarig_A · 17h

"She feels light" this photo exhibit is breathtaking! #creatingcaringcommunities @StJamesTownCC @HospiceTO

She feels light, she doesn't feel mental pressure. She said, at home she feels suffocated, but when she goes out she feels good. She said if someone is sick we call each other, talk to each other.

Mashuka, CCC Client (translated from Bengali)



Naheed Dosani @NaheedD · 16h

Seen @HospiceTO's community event this afternoon in St. James Town 🙏🏽. #topoli #sdoh #hpm #community

Did you know that St. James Town is the most densely populated community in people and high-rise buildings in North America? And recent construction projects confirm we are only intensifying our density.

If we're really going to define ourselves as an accepting community, indiscriminate of blood or back-story, never has been a better time to dial up the caring.

There is a vulnerability in our increasing diversity and density.

We have a responsibility to take of each other.

What we do individually and collectively to help increase accessibility, integration and support defines who we are.

Rachel, CCC Volunteer

snapd

CABBAGETOWN/VILLAGE

RYERSON · CHURCH

One Foundation

PG 13

July 2017 | cabbagetownvillage.snapd.com | Free Issue

Event volunteers & staff snapd at Reimage Our Community One Story at a Time

PG 14

REIMAGE OUR COMMUNITY ONE STORY AT A TIME

We stopped by a wonderful exhibit in the St. James Town community. Photos and stories included were created by residents of St. James Town and reflected their views on the value of creating a compassionate community. This exhibition shared how neighbours in SJT are using local knowledge, skills, and networks to support each other through chronic illness and end of life care. This event was hosted by Hospice Toronto and held at The Corner. For more information or to get involved, visit hospicetoronto.ca

Event by Britney Townsend
Website code: pew4b2q

Wonderful women

Image 6.8: Social media and local community newspaper feedback on the CCC Photovoice exhibition.

The CCC photovoice exhibition marked the end of Cycle 2: The Photovoice Project. CCC project members came together after the final community exhibition for a celebration reflection workshop (this final reflection phase of the CCC photovoice project will be described in Chapter 10: Cycle 3—Ripple Impacts). Overall, the CCC photovoice project took roughly 10 months to complete from the introductory potluck to the community photo exhibition. A summary of the different phases of the methods in Cycle 2: The Photovoice Project is found in Figure 6.2.

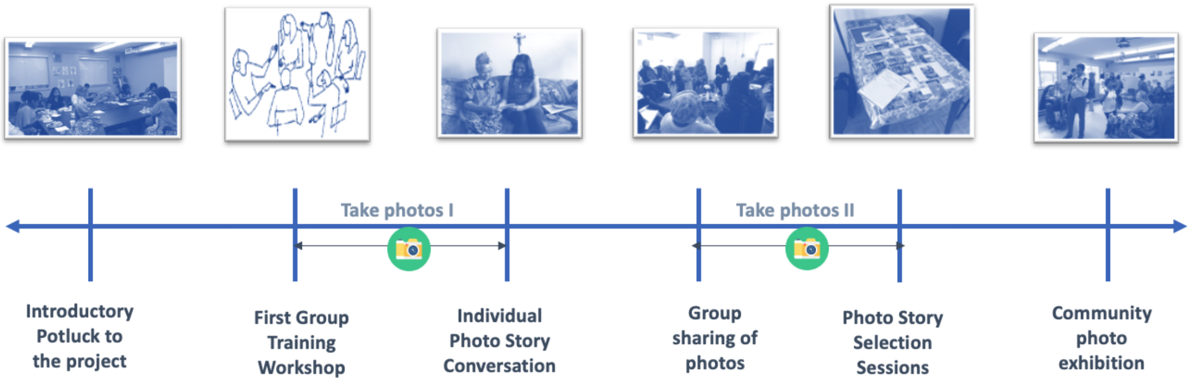


Figure 6.2: Summary of the CCC photovoice process

ANALYSIS PROCESS OF DATA GENERATED DURING THE CCC PHOTOVOICE PROJECT

Data analysis began during the ‘group sharing of photos’ stage, and in in the CCC community photo exhibition preparation stage. However, data analysis primarily took place after the various phases of the CCC photovoice project were complete. While CCC project members participated in a very initial and basic ‘participatory analysis process’ as part of the group sharing circle phase of the CCC photovoice process, the majority of analysis was individually conducted by myself. For this reason, the participatory nature of the data analysis phase (Table 6.1) was also labelled as ‘consultation’ for the Hospice Toronto Staff and community members as I primarily conducted the bulk of the analysis with Hospice Toronto staff providing feedback along the way.

Analysis and interpretation of the CCC Photovoice Project followed an emergent process deductive-INDUCTIVE thematic coding (Braun, Clarke, Hayfield, & Terry, 2019). All CCC photovoice data were added into NVivo 12 software for Mac including:

- Transcribed individual/pair/mini-group photo storytelling interviews;
- Summary notes from the group sharing circle workshop taken from the audio file and the visual story board of initial clusters of themes by CCC project members;
- CCC documents as previously outlined early in the chapter; and
- My own transcribed audio reflections of observations (or field notes) across the CCC photovoice research process.

Deductive-INDUCTIVE Coding

The first phase of analysis followed a deductive-INDUCTIVE coding process. Inductive coding is presented in all capitals to emphasize that while I used a hybrid coding approach, inductive coding predominantly informed this phase. As a first step, I developed a small codebook as a means to help organize the different sources of data in order to address the goals of the research. This codebook is outlined in Table 6.3 below.

Table 6.3: Codebook for the CCC Photovoice Project Analysis.

Code name	Description
Goals or Purpose	• Any description of how the goals or purpose of the CCC is understood by different project members, and documents • This can include any comments on the issue or problem this initiative aims to address, what the essence of the initiative is, and what the desired outcome of the CCC initiative is
Context or Conditions	• Any description of the St. James Town Community • About background information on CCC members (community member with a life-limiting illness, neighbourhood helpers, primary carers) • Facilitators and challenges of the CCC initiative
Inputs or Resources	• Any description of the resources or investments that are needed to support the CCC initiative
Activities	• Any description of the processes of the CCC initiative, for example, any examples that describe what the CCC community development coordinator does, or how CCC neighbourhood helpers support CCC community members, or any other examples of key aspects of the CCC initiative (i.e., training, support groups, etc.)
Impacts	• Any comments on how CCC members or documents describe the impact of the CCC initiative. This can include any

	description of impacts on themselves, on others they support, and on the wider community

The codebook was subsequently entered into NVivo 12 as nodes. The pre-determined codes used in this codebook were purposefully developed to be broad, as the main purpose of this codebook was as an initial organizing tool to bring together similar chunks of data for later inductive analysis.

With the pre-developed codebook providing a rough framework for data organization, what followed was an inductive approach to data analysis that drew from key principles of reflexive thematic analysis (Braun et al., 2019). From this reflexive stance, a theme was conceptualized as a "pattern of shared meaning" organized around a central idea or concept (Braun et al., 2019, p. 845). Braun and Clarke (2019) contrast this conceptualization to using a theme as a domain summary around a shared topic that aims to capture the diversity of meaning in relation to a concept. For example, from this stance of thematic analysis, theme titles are often connected to data collection questions (i.e., benefits and drawbacks). While my initial organizing codebook was akin to this later non-reflexive approach to thematic analysis, I needed to 'dig deeper' as to leave it at this step would result in "under-development themes" (Braun & Clarke, 2019, p. 593). Other characteristics of a reflexive approach to thematic analysis used in this analysis process included: centering researcher subjectivity; following an interactive process of coding; and emphasizing both deep reflection and engagement with the data (Braun & Clarke, 2019).

The hybrid deductive-INDUCTIVE coding approach to reflexive thematic analysis that I used had four stages. The first stage involved becoming more familiar with the interview transcripts, documents, and fieldnotes. This familiarization stage began with the process of transcribing all the interviews, and subsequently involved reading the different sources of data over again without engaging in coding at this stage. The purpose during the first stage was to begin to take note of any connections or patterns in the data (Braun et al., 2019). The second stage involved a deductive-inductive coding process. As I read through the transcript, I sorted the data according to the codebook. For example, if a neighbourhood helper was describing how they supported another CCC community member, I inductively coded the text using either semantic (i.e., explicit, high-level) and latent (i.e., implicit, deeper) coding and added the code under one of the broad categories, in this case under ‘activities’, as a sub-node. In the third stage, I went back to the initial codes (or sub-nodes) that were created under each of the broader nodes from the codebook and began to group together similar codes in a word document table, creating prototype themes in the process. The initial coding done as a grouping during the CCC photovoice sharing circle also helped to inform the development of these initial prototype themes. Re-exploring the codes also meant that certain groups of text were re-coded in new ways. As Braun et al. (2019, p. 854) emphasize, in a reflexive approach to thematic analysis, themes are generated, massaged, “and given meaning at the intersection of data, researcher experience and subjectivity, and research question(s).” During this same stage, I continued ‘memoing’ my own ideas and thoughts on the different themes in the margins of the organizing table. During stage four, as I began to write up my findings, I continued to refine the themes and subthemes to answer the different aims of the research. Writing and re-writing was another important phase of my analysis process to continue to refine the themes and subthemes presented in the next chapter.

SUMMARY

In this chapter I outlined the different phases of the research and analysis process in Cycle 2: The Photovoice Project. I drew on both case study and participatory approaches to inform the data generation process. Overall, Cycle 2 took roughly 10 months to complete. As presented in Table 6.1, the participatory nature of this Cycle varied from co-learning level of engagement (e.g., during the data collection phase) to compliance levels of engagement during the report writing phase. The implications of these levels of engagement will be further explored in Cycle 3: Ripple impacts.

In the following chapter, I present the findings of what we learned doing The Photovoice Project together.

CHAPTER 7: FINDINGS FROM CYCLE 2—THE PHOTOVOICE PROJECT

OVERVIEW

The findings from the thematic analysis of Cycle 2: The Photovoice Project are presented according to the three aims of this research. Pseudonyms are used for all CCC project members. Although CCC project members determined how they would like to be acknowledged in the CCC community photovoice exhibition (i.e., real names or pseudonyms), this consent did not extend beyond the exhibition. Quotes from CCC project members are used as appropriate to illustrate findings. Using the CCC initiative as a case example, I first describe how a compassionate community approach to health promoting palliative care in an inner-city setting can build community capacity to support isolated community members living with a life-limiting illness (*herein after referred to CCC community members*) and/or their primary carers. Second, I articulate the impact of a compassionate community approach to health promoting palliative care from the perspective of those involved in the CCC initiative. Last, I outline the specific facilitators and challenges of engaging in a compassionate community approach to health promoting palliative care in the context of an inner-city setting. These findings contribute to a better understanding of the nature and impact of compassionate community approaches to health promoting palliative in an inner-city Canadian community.

CORE COMPONENTS OF A COMPASSIONATE COMMUNITY APPROACH TO HEALTH PROMOTING PALLIATIVE CARE IN AN INNER-CITY SETTING

Together with CCC project members and organization staff, I identified a number of different themes that illuminated how a compassionate community approach to health promoting palliative care in an inner-city setting can build community capacity to CCC community members and/or their primary carers. Figure 7.1 provides a visual overview of the core aspects of the CCC initiative. At the foundation of this compassionate community approach to health promoting palliative care was the theme of organizational backbone support. Building up from organizational backbone support were three themes that described the specific types of organizational activities that were core to facilitating the CCC initiative. These themes included: the connecting role of the CCC community development coordinator, training and continuous learning opportunities, and outreach and engagement. In turn, these activities helped to build community capacity to support death, dying, loss, and care in the community through the social support role of CCC neighbourhood helpers in St. James Town (presented at the top of the diagram). These core themes of the CCC initiative will be presented in detail below.

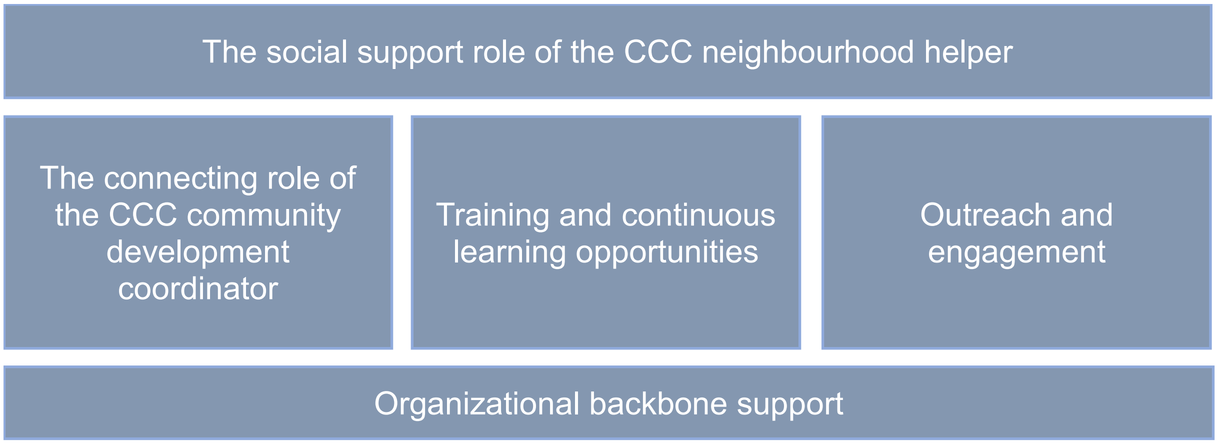


Figure 7.1: The core aspects of the Creating Caring Communities compassionate community initiative.

Organizational Backbone Support

Organizational backbone support, which in the case of the CCC initiative is currently provided by Hospice Toronto, was considered the foundation of building community capacity to support CCC community members and/or their primary carers in an inner-city setting. In early conversations with Hospice Toronto staff members, in addition to my own observations over the research period noted in my field notes, I learned about the different ways Hospice Toronto provided backbone support to the CCC initiative. For example, Hospice Toronto provided organizational backbone support by:

- Providing funding for the CCC community development coordinator position through local fundraising and short-term grants to initiate and sustain the CCC initiative;
- Using their status as a well-regarded organization to secure communal office space in St. James Town at ‘The Corner’, a community hub;
- Building off existing relationships with local organizations and institutes to support the development of the CCC initiative;

- Bringing experience in training hospice volunteers in death, dying, loss, and care from their traditional hospice volunteer program to help support a new training program for CCC neighbourhood helpers; and
- Providing in-kind administrative support from the head office to help support different tasks such as reporting to government, proposal writing, etc. (personal communication, D. Maule, 2015).

In particular, the financial investment in the form of the CCC community development coordinator position was found to be an essential backbone support in the initiation and continued facilitation of the CCC initiative.

The Connecting Role of The CCC Community Development Coordinator

The connecting role of the CCC community development coordinator was another core aspect that helped to understand how a compassionate community approach to health promoting palliative care can build community capacity to support CCC community members and/or their primary carers in an inner-city setting. I learned that the connecting aspect of the CCC community development served to facilitate different connections in the community. In turn, these community connections helped to build community capacity to support isolated community members in St. James Town living with a life-limiting illness and/or their primary carers. The CCC community development coordinator explained that this ‘connecting’ aspect of her role was at the core of the CCC initiative,

> *“So the purpose and goal is to keep the community alive and connected. And save from shame. Like people is dying in the community without knowing, next door neighbour doesn’t know that you are dying…It’s not the shame for the health service provider or something, this is the shame for the community that one of my community member is dying without having adequate support, or a person. This is a shame for the community actually. CCC is about keeping the community alive actually, not the person alive.”* (Alia, CCC community development coordinator, individual photo storytelling session)

From the perspective of the CCC community development coordinator, this quote illustrates the significance of making connections among community members as a way to keep the community ‘alive’ and build community capacity to support other community members.

Within this theme, I identified two aspects of the CCC community development coordinator connecting role: (i) connecting CCC community members and/or their primary carers with CCC neighbourhood helpers, and (ii) collaborating with local social and health service organizations to better connect CCC members with relevant supports.

Connecting CCC community members and/or their primary carers with CCC neighbourhood helpers

I learned that one of the key aspects of the CCC community development coordinator connecting role was to pair CCC community members and/or their primary carers with CCC neighbourhood helpers. In recognizing the persistent health inequities in inner-city settings like St. James Town, the CCC community development coordinator was primarily focused on connecting CCC neighbourhood helpers with community members who were considered socially vulnerable (i.e., isolated, homebound, living with a life-limiting illness, low socio-economic status, newcomer status, etc.) (field note, 2016). For example, a former senior Hospice Toronto staff member further explained the intention of the CCC initiative,

> *"…the intention is to first of all identify individuals who might be in need, because often people aren't identified, they might be very isolated, or they might have people around them but they don't really know what they are going through…"* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session)

Similarly, the CCC community development coordinator echoed this intention explaining that, *"[CCC community members] are not a regular person of The Corner (the local community hub), they never come to here…"* (Alia, CCC Community Development Coordinator, individual photo storytelling session). By focusing on supporting community members living with a life-limiting illness who are considered socially vulnerable, the CCC initiative demonstrated how compassionate community approaches to health promoting palliative care can take a health equity lens.

I also learned that the CCC community development coordinator was responsible for initiating the majority of CCC members connections among one another. As Margaret, a CCC community member explained, *"We got to know each other through the [previous CCC community development coordinator]"* (Margaret, CCC community member, pair photo storytelling session). Similarly, Leslie, another CCC community member described her positive experience being connected with a CCC neighbourhood helper. Leslie, describing the CCC community development coordinator as ‘a great lady’, explained, *“This great lady here, that introduced me to Kamya [CCC neighbourhood helper]..She brought us together and we hit it off”* (Leslie, CCC community member, individual photo storytelling session). The CCC community development coordinator connected pairs based on the mutual interests and needs of both parties (later discussed under facilitators of the CCC initiative).

Collaborating with local social and health service organizations to better connect CCC members with relevant supports

The second key aspect of the CCC community development coordinator connecting role was to collaborate with local social and health service organizations to better connect CCC members with relevant supports. While St. James Town is situated in Toronto’s urban core with many diverse health and social service organizations in close proximity, these services are not always accessible for isolated and socially vulnerable individuals. To address this challenge, one of the key aspects of the CCC initiative was to build relationships with other organizations in the community, and to connect CCC members to supports as appropriate. As one former senior Hospice Toronto staff member explained,

> *“Part of CCC is showing up and being part of you know, provider circles that are meeting various needs that are comparable. And building capacity because that’s where you get the referrals, and linkages and you’ll also advocate. You might not be the housing expert or the legal expert but you know someone that works at the community legal clinic, or you know someone that works in housing, or you know someone that has the connection to the food bank…”* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session)

I learned that the CCC community development coordinator proactively initiated relationships with other local organizations (i.e., by attending ‘provider circle’ meetings) to capitalize off the unique strengths of each organization (e.g., legal, housing, primary health care, settlement workers, etc.). In turn, this led to opportunities to better support the diverse needs of CCC members. For instance, collaborating with local organizations led to opportunities for translation support to communicate with CCC community members/primary carers who did not speak English. Multiple CCC case reports by the CCC community development coordinator documented collaborations with other community organizations to assist with translation. As one example,

> *"I have contacted one of the settlement workers in St. James Town Community Corner who speaks Mandarin for translation and interpretation. The following week, I and the settlement worker visited her at her home, did the first assessment with [the settlement workers] help."* (CCC case report 02)

Developing connections with other organizations created an opportunity to build off the local assets in St. James Town (i.e., the variety of languages spoken by local organization staff members) to better support community members. Translation support was particularly significant in St. James Town, were "On any given day, you can hear over 50 languages spoken in the area" (Canadian Public Health Association (CPHA), n.d., paragraph 1).

In addition to making connections to language supports, the CCC community development coordinator also collaborated with local social and health service organizations to better support CCC members housing concerns. For example, in one of my visits to The Corner, I noted how the CCC community development coordinator was speaking with a building superintendent, advocating for basic repairs to be completed in an apartment unit rented out to one CCC community member (field note, 2016). Similarly, in a CCC case report document, the CCC community development coordinator described how in collaboration with the local housing support worker, she was able to support one of the CCC neighbourhood helpers in securing affordable housing through the municipal subsidized housing program. This CCC neighbourhood helper was privately sponsored by her daughter to come to Canada and paying for two rent expenses was taking up over 80% of her daughters' income. As documented in a CCC case report,

> *"Yonge Street Mission [a Christian development agency] helped [one of our CCC neighbourhood helpers] to apply for Toronto Community Housing. Besides me, one of our CCC primary carers also helper her with interpretation. [The CCC neighbourhood helper] got the approval for a one-bedroom apartment in St. James Town from Toronto Community Housing within 4 months after launching the application. It was the result*

> *of strong coordination between Health Access [a health and social service collaborative in the community], CCC, and the housing worker from Young Street Mission. Now she has a place to stay here without being a burden to her [child]"* (*CCC case report 05*).

This example highlights how the CCC community development coordinator also addressed the social determinants of health concerns of CCC neighbourhood helpers as well. In another example, a CCC neighbourhood helper—an internationally trained nurse who recently immigrated to Canada—described how when she joined the CCC initiative, the CCC community development coordinator also helped to connect her with information on navigating her career as a newcomer. Sharing this photo and story below, the CCC neighbourhood helper described how she was connected to other supports in the community and how she genuinely felt cared for by the CCC community development coordinator,

> *"When I meet [the CCC community development coordinator], first time, she ask my personal information like, what you are doing, how many children, and what is your husband doing, and what is your plan? She asked me everything and I answer and then she gave me some information like you can talk to, someone to get help, to get some information and she told me, if you need I will give some information about your nursing how to register how to go to school, so this makes me, like oh I think she will care me. I decide myself I need to sit with her like closely because I was new [to Canada], still I'm new, if someone give, some information, then we feel like very happy."* (Kamya, CCC neighbourhood helper, individual photo storytelling session)

In addition to connecting CCC members to social service supports (i.e., language, housing, education supports, etc.), the CCC community development coordinator also helped to link CCC community members to various health care related supports (e.g., personal support workers, primary care, etc.). For example, it was described in a case report how the CCC community development coordinator helped one isolated CCC community member by connecting them with a family doctor,

> *"I was trying to connect with [CCC community member] for few weeks. She was not answering my calls even when I left messages. After trying for three months, she finally answered and said she is struggling with everything. She is very sick and she does not have a family doctor… I assured her that I will try my best to connect her to the resources she needs. As the first step, I met with the health access team to know about the status regarding [CCC community member] as she mentioned that she approached the Health Access team almost a year ago. Health Access team [a health and social service collaborative in the community] received her request but could not move forward for some reasons. I requested them to help her if possible. Team Lead of Health Access informed me that Sherburne Health Center might have space and she will coordinate…. [later] I was informed by Health Access that [CCC Community Member] has been accepted by Sherbourne Health [a community health centre]. After 2-3 hours, [CCC Community Member] called me. She was very happy. Now she has a settled relationship, better understanding with her new family practice."* (CCC case report 04)

In summary, the connecting role of the CCC community development coordinator was realized in two ways: (i) connecting CCC community members and/or their primary carers with CCC neighbourhood helpers; and (ii) collaborating with local social and health service organizations to better connect CCC members with relevant supports, acting as a bridge between community and local services. Further, the breadth of different connections made by the CCC community development coordinator underscored how there was no set formula for how to support CCC members. Rather, the CCC community development coordinator had to really understand the local context and be responsive to the needs of CCC members as they emerged. The result was that the CCC initiative supported community members in ways that expanded beyond the normal scope of hospice practice supports (e.g., friendly visits, respite support, etc.).

Training and Continuous Learning Opportunities

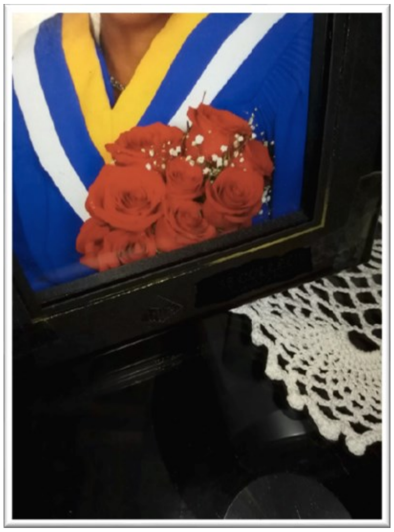
Training and continuous learning opportunities was another core theme to understand how a compassionate community approach to health promoting palliative care in an inner-city setting helped to build community capacity to support CCC community members and/or their primary carers. Two aspects of this theme—the initial training, and the continuous learning opportunities—are explored below.

Initial training

The initial training provided to CCC neighbourhood helpers was a key aspect in understanding how the CCC initiative built community capacity to support CCC community members and/or their primary carers. All CCC neighbourhood helpers participated in 14-hours of initial training that included topics on: confidentiality and privacy, learning about different health issues, interactions within the home, learning about resources within the community, and topics specific to palliative care including advance care planning (Hospice Toronto recruitment document). This training was facilitated by the CCC community development coordinator and other Hospice Toronto staff. During the training phase, all CCC neighbourhood helpers were required to pass a police reference check. Many CCC neighbourhood helpers provided additional insight into the nature of the CCC initial training. For instance, one CCC neighbourhood helper elaborated on the types of topics covered during the initial training,

> *"In this training, we completed what is the confidentiality, what is the ethics, working with clients, what is the policy, what are the dilemmas, and then, grieving, what is the grieving, like when if anything happens to client, then what is the process of grieving. Confidentiality, privacy, how to maintain the privacy, how to help the person."* (Kamya, CCC neighbourhood helper, individual photo storytelling session)

In addition to these topics, another CCC neighbourhood helper shared how the training created a space to meet others in the community and learn more about the Canadian context. She shared the following photo and story,



> *"I came to know more about Canada, even though, I've been in Canada for a few years. But if you don't do the things like [the CCC initiative], you will not really know… all the details. Even though I did some upgrade, some school in college, because, of course you have to go, forget about the education you have back home, you have to go to school in Canada, so I went to school. So [the CCC] training was good because we met friends from that training. We got to know the community very well, get connected with the seniors, and learn a lot about Canada."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

For Esi, she felt that learning more about the Canadian context and getting to know the community was a valuable aspect of the initial training as someone who had recently moved to Canada.

Last, with respect to the initial training, another CCC neighbourhood helper discussed how she was unsure how to support seniors in her community, but that the training helped facilitate her engagement with the CCC initiative,

> *"I had no clue what it would be so support a senior, but then they told us that if we are interested, they are going to give us a three-month training. And ah, certificate and all that thing and we can decide what to do. So I decided to stay and attend that training and I found it very interesting. And, as I was doing the training they gave us a lot of information about hospice, what hospice does, what CCC does."* (Amita, CCC neighbourhood helper, pair photo storytelling session)

In short, the initial training in the CCC initiative not only provided a platform to gain knowledge and develop skills related to palliative care, but it was also seen as an opportunity to meet new people in the community, learn about the Canadian context, and gain confidence in supporting isolated community members in St. James Town living with a life-limiting illness.

Continuous learning opportunities

Continuous learning opportunities were another important aspect of the CCC initiative. Continuous learning opportunities were primarily facilitated through the 'CCC Friday Group'. The CCC Friday Group drew on adult education principles. CCC members came together every two weeks to share their experiences of supporting members of their community. It was also an opportunity for CCC members to ask for support from the group with regard to any challenges or issues they may be facing. The CCC Friday Group was open to all CCC members (i.e., CCC neighbourhood helpers, CCC community members, and CCC primary carers). In addition to sharing experiences with the CCC initiative, the CCC Friday Group was also a space to learn about new topics. In my own observations participating in the CCC Friday Group over the course of the research, the CCC community development coordinator engaged CCC members in determining topics they would like to learn more about. At one of the CCC Friday Groups that I attended, the session was spent as a group planning activity for future topic discussions (field note, 2017). One CCC neighbourhood helper provided insight into the structure of the CCC Friday Group,

> *"We sit together and we share each other like, how we spend our week and what we are doing. And what we do for the [CCC community member] and what we have the plan. So that is very interesting. Two weeks ago we meet and we discuss about mental health. It is very helpful topics…[CCC community development coordinator] always provide to volunteer like information regarding how to do taxes, how to give the ticket to go to if we want go to Royal Ontario Museum"* (Kamya, CCC neighbourhood helper, individual photo storytelling session).

This quote from Kamya highlights the wide variety of topics CCC members wanted to explore (e.g., how to file taxes, how to visit cultural sites such as museums, etc.). It is possible that because CCC members were responsible for directing the focus of future topics, CCC members were more engaged and found the topics ‘very interesting’ as it was on something they wanted to learn more about.

Another CCC member, Omer, echoed Kamya that the CCC Friday Group was an opportunity to share and learn from one another,

> *“If I have a problem, I ask people what do you think about it. Can you suggest anything, or can you give advice. So that was my benefit thing from this project because I can learn from those people*.” (Omer, CCC neighbourhood helper, individual photo storytelling session)

Omer felt that the opportunity to learn from the group was a personal benefit. However, not all CCC members thought the structure of the CCC Friday Group was beneficial. For example, some CCC members who worked during the day were unable to take part in the CCC Friday group,

> *“…I've' never attended any of the meetings if it is on weekdays.... In the morning I am at work. I can't, leave until it's after 5 o'clock. I don't have to do it every month, or at least once every 3 months if we can get together that whatever we are doing at our building it would be great.”* (Subira, CCC neighbourhood helper, individual photo storytelling session)

In this quote, Subira offered a suggestion for how the structure of the CCC Friday Group could be more inclusive.

The initial training and continuous learning opportunities theme was a core aspect of the CCC initiative. This core aspect played an important role in building community capacity to support CCC community members and/or their primary carers by building connections among different members, fostering new knowledge and skill development.

Outreach and Engagement

Outreach and engagement was a core aspect in understanding how a compassionate community approach to health promoting care can build community capacity to support CCC community members and/or their primary carers in an inner-city setting. This theme included the different strategies used to raise community awareness of the CCC initiative in the community, and to engage CCC members. In early conversations with Hospice Toronto staff and the CCC community development coordinator, I learned how the CCC community development coordinator used a variety of outreach activities to identify isolated and socially vulnerable community members living with a life-limiting illness, as well as new CCC neighbourhood helpers. Examples of the different type of outreach activities included: meeting with superintendents in the different buildings in the community, engaging with community members in everyday spaces (i.e., grocery stores, the library and recreation centre, and apartment lobbies), participating in community festivals, and developing relationships with other organizations to raise awareness (field note, 2015). It was also through relationships with other local organizations that the CCC community development coordinator was notified of other isolated community members who may benefit from their participation in CCC program. Having more 'eyes in the community' helped to identify community members who were the most isolated and socially vulnerable. For example, the CCC community development coordinator documented in a case report the following quote,

> *"I have received a referral from client support worker at Health Access [a health and social service collaborative in the community], for a senior who is sick and lives alone. From her initial description… I have learned that [CCC community member] speaks a little English. His primary language is Farsi."* (CCC case report 01)

CCC members themselves also played a key role in raising awareness about the initiative with others too. For example,

> *"I have told about two friends, two ladies, who are struggling to take care of sick relatives. Just come to community corner and say you want to talk to [the CCC community development coordinator]."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

Outreach and engagement were core aspects of the CCC initiative. These exemplary quotes highlight the variety of ways different members of the CCC initiative helped to raise awareness about this approach to palliative care support in the community

The Social Support Role of CCC Neighbourhood Helpers

The social support role of CCC neighbourhood helpers was the final theme of the CCC participatory case study to understand how a compassionate community approach to health promoting palliative care in an inner-city setting can build community capacity to support isolated CCC community members and/or their primary carers. The social support role of the CCC neighbourhood helpers is presented at the top of the CCC initiative core functions overview, in Figure 7.1, as this aspect of the CCC initiative was only possible with the support of the previous core functions creating a foundation. While definitions of social support vary, a common conceptualization of social support includes four dimensions of supportive acts and behaviours including: practical everyday day practical support (i.e., tangible, instrumental support such as labour, money, time); emotional support (i.e., esteem, concern, affect); informational support (i.e., advice, recommendations, information sharing); and companionship (i.e., providing a sense of belonging, someone to engage in activities of mutual interest) (Sherbourne & Stewart, 1991). This theme captured the various ways social support was provided by CCC neighbourhood helpers to CCC community members/primary carers based on the dimensions previously outlined by Sherbourne and Stewart (1991).

Everyday practical support

CCC members described the various ways CCC neighbourhood helpers provided everyday practical support for CCC community members and/or their primary carers. For example, many CCC community members described needing support with grocery shopping. One CCC community member shared the following photo and story to describe how the CCC neighbourhood helper and herself mutually helped one another,

> *"When we go outside, we help each other to buy things, to carry things"* (Roxana, CCC community member, informal translation, pair photo storytelling session).

Similarly, two other CCC neighbourhood helpers also described how helping with basic tasks like grocery shopping was something they often supported: "*And you know we would go for walks sometimes to the grocery*" (Amita, CCC neighbourhood helper, pair photo storytelling session). Also, "*If he wants to go grocery and stuff, I'll be there*" (Omer, CCC neighbourhood helper, individual photo storytelling session).

Other CCC neighbourhood helpers described providing help with light cleaning, tidying, and laundry. As one CCC neighbourhood helper commented, "*... before Christmas, [CCC community member] needed someone to clean her pictures. I went and we did it together, we put it all back together and she was so happy*" (Esi, CCC neighbourhood helper, individual photo storytelling session). Another commonly cited example of practical help was cooking for (or together with) CCC community members and/or their primary carer. For example, one CCC neighbourhood helper commented, *"I cook for [CCC primary carer and spouse]. Whenever they need anything, they call me and for help, even I cook at their home"* (Nasrin, CCC neighbourhood helper, informal translation, pair photo storytelling session). In a similar example, another CCC neighbourhood helper also described how after she went grocery shopping together with the CCC community member she was supporting, she was invited back to her house for a potluck. She captured that dinner together in the photo and story presented below,

> *"So we got the fish from one of the Indian grocery stores and she said, you know what I'm going to make this fish today evening, why don't you come in the evening to taste*

> *the fish. So I said, OK. So what I did was, at home, I used to always tell her about the lentil I prepare. So I said I will prepare my lentil and that's my lentil!"* (Amita, CCC neighbourhood helper, pair photo storytelling session)

Other CCC community members needed help getting to their appointments, a type of everyday practical support that CCC neighbourhood helpers supported. For instance, the CCC community development coordinator explained how "*one of my neighbourhood helpers, Omer, takes [CCC community member] to the TTC (Toronto Transit Commission) wheelchair service for their interview*" (Alia, CCC community development coordinator, individual photo storytelling session). This transit service was important for this CCC community member to get around the city using his walking aid. Likewise, another CCC neighbourhood helper described why she accompanied Margaret, the CCC community member she was connected with to various medical appointments,

> *"But then Margaret (CCC community member) has her age. Which the doctor has told her to be careful. That is why we always ensure that even though she is still capable of going on her own, but it's always safer for her to be accompanied by somebody… We do appointments with the doctor, to the hospital…"* (Amita, CCC neighbourhood helper, pair photo storytelling session)

In addition to these everyday practical everyday supports, CCC neighbourhood helpers also provided practical help in times of emergency, for example,

> *"You know, [CCC community member], fallen down a few days ago, she immediately called [CCC neighbourhood helper] who took her to the hospital. CCC community members who doesn't have anybody, they can depend on this helper, they can depend on this network."* (Alia, CCC community development coordinator, individual photo storytelling session)

CCC neighbourhood helpers did not provide more personal types of care support however (e.g., bathing, etc.). The CCC coordinator would connect CCC community members requiring these types of supports with professional, government funded services (e.g., personal support workers). Similar to the connection support by the CCC community development coordinator, the types of practical everyday supports that CCC neighbourhood helpers offered varied according to personal circumstance. Helping with everyday tasks like groceries, light cleaning, getting to appointments were all important for supporting the independence of CCC community members living with a life-limiting illness, and created an opportunity to remain in their community.

Last, while I placed these examples above in the 'everyday practical support' category, in many cases they were also a form of companionship, or friendship, type of support. For example, in many cases going grocery shopping, taking walks, or cooking was done together as a pair, or small group. The social nature of these everyday tasks contributed to a mutual companionship type of support, rather than a purely transactional service.

Emotional support

Second, CCC project members described the variety of ways CCC neighbourhood helpers provided emotional support (e.g., empathic understanding, positive affects) to isolated CCC community members. In particular, a few CCC project members discussed the importance of CCC community members knowing that someone is there for them that they can talk to. One CCC community member commented, *"I have somebody I can talk to. You know sometimes we need to talk to somebody else [other than primary carer]. And, I know Leah [CCC neighbourhood helper], she's there"* (Helen, CCC community member, small group photo storytelling session). Similarly, another CCC neighbourhood helper shared the following photo and story to represent the significance of emotional support for isolated CCC community members,

> *"You need love. [CCC community members] need someone to talk to. Someone who can give them a hand, that Nancy (CCC community member) can at least feel confident, oh I have someone I can call and talk to…"* (Esi, CCC neighbourhood helper, individual photo storytelling session).

In a similar instance, another CCC neighbourhood helper also shared how she tried to offer emotional support to the CCC community member she was paired with who was worried about a war going on in the country she emigrated from,

> *"Sometimes it could be about back home. So it will be like, 'Oh I talked to my family, there is a lot going on, I'm worried about them.' so I'm like, 'everything it's going to be fine, just take it easy, pray'."* (Subira, CCC neighbourhood helper, individual photo storytelling session)

For many CCC project members, the emotional support provided was reciprocal. As the CCC community development coordinator explained, *"The best part of their relationship, they both are lonely, they accompany each other, they speak about their families, they speak about religion, they speak about afterlife, they speak about all those things together"* (Alia, CCC community development coordinator, individual photo storytelling session). This reciprocal element of the relationship was another key aspect of the CCC initiative differentiating this initiative from a more transactional service type of support.

Informational support

Many CCC neighbourhood helpers described how neighbourhood helpers used their knowledge of community resources from the initial CCC training and continuous learning opportunities (as well as their own experience), to provide informational support to CCC community members and/or their primary carers. For instance, one CCC neighbourhood helper described how she was able to share her knowledge of advanced care planning with the CCC community member she was supporting who wanted help with the process,

> *"… one day when we are going for our walk, Margaret (CCC community member) wanted help to know things for the will. So she had requested a meeting with Father John. He's a very nice person. He is well connected to the parishioners. So then I told Father John and we arranged for a lunch meeting over here, and then we had this note*

> *on Power of Attorney and all that. And I was very happy because what happens with CCC trainings and meetings they give you very good information, you know literature, material."* (Amita, CCC neighbourhood helper, pair photo storytelling session)

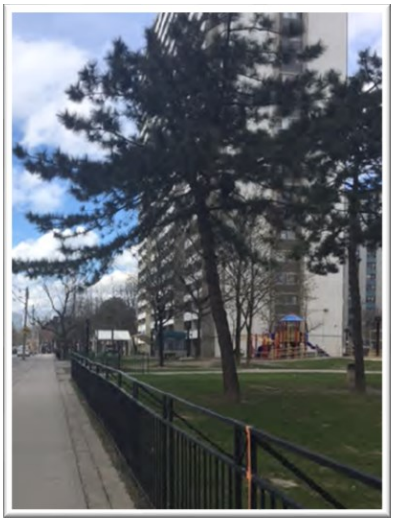
Similarly, at one of the CCC Friday Group sessions that I attended, another CCC neighbourhood helper asked if she could get copies of handouts from a presentation on diabetes management to share with her CCC community member (field note, 2017). These examples demonstrate how the knowledge gained during the initial training and CCC Friday Group sessions benefited a wider network of community members.

Interestingly however, the role between CCC members was not always clear cut (i.e., it wasn't only CCC neighbourhood helpers that acted in a 'helping' way). For example, a CCC primary carer who was receiving support in the CCC initiative for her husband who had a serious life-threatening illness, used her local knowledge to support the CCC neighbourhood helper she was paired with. In the example described below, the CCC primary carer helped to support the CCC neighbourhood helpers' spouse with his health condition, highlighting how informational support was also reciprocal among CCC members,

> *"I said don't worry, I will take, her husband was, he is a diabetic patient, it was very bad stage. I take him to 333 (Sherbourne Health, a community health care centre). [The nurse] said, oh my god, he need insulin right now. So, he doesn't have, they are immigrant, but they don't have, OHIP card [provincial health insurance] because the daughter [sponsored] them. So, they have to give money. So, I go find a family physician for them. It's at Sherbourne. It's a health centre. I've come to know that, from the nurse and the dietician, they are serving who doesn't have any health card insurance, anything, when you are in a very vulnerable state."* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

The CCC primary carer in this example helped to support the CCC neighbourhood helpers' spouse with his health condition, highlighting the reciprocal nature of support. This example reinforces how supporting roles in the CCC initiative were not uni-directional, but reciprocal.

CCC neighbourhood helpers also provided informal translation support as a type of informational support. For instance, one CCC neighbourhood helper shared the following photo and story describing the significance of providing informal translation support,



> *"My CCC client lives in the same building as me and also speaks Persian... I think I was one of the only [CCC members] that could speak Persian and could communicate with him in the community, it was really great that I could help him. I think having someone who speaks the same language as you in the community is important because you feel a greater sense of belonging in the community."* (Benesh, CCC neighbourhood helper, individual photo storytelling session)

Another CCC neighbourhood helper echoed the intrinsic value of being able to communicate in your own language, and the importance of this informational type of support not only for communication with professionals, but to feel included in your community:

> *"And as you can see the diversity is huge [in St. James Town]. Which you can call any nation, and they will be right in St James Town. There is all of us here. So that is really nice to have others who speaks your language. So that helps a lot."* (Subira, CCC neighbourhood helper, individual photo storytelling session)

Companionship and friendship

Last, CCC project members also described the variety of ways neighbourhood helpers provided companionship support for isolated CCC community members. Overtime, some of these connections developed into strong friendships. For example, many CCC neighbourhood helpers talked about spending time together by going on walks and talking together. Other CCC neighbourhood helpers spent time together chatting about shared interests, "*Mostly just talk about what's going on at Our Lady of Lourdes, what's happening at the church"* (Margaret, CCC community member, pair photo storytelling session). The two photo and story examples below highlight the different ways CCC members provided companionship and friendship support, such as celebrating special occasions together including holidays and birthdays. Amita shared the following photo and story celebrating the Christmas holiday today with the CCC community member she was supporting,

> *"This was Christmas time, my husband and I had just dropped in, in the season to visit her and generally we have this tradition of making sweets. So we had come home and given her the sweets."* (Amita, CCC neighbourhood helper, pair photo storytelling session)

In addition, Alia also shared another celebratory example of how CCC neighbourhood helpers provided companionship and friendship support celebrating birthdays today,

> *"Sometimes we celebrate. When she turned 90, we did celebrate. Everyone like, you know, contributed to buy a gift for her [CCC member], this is not CCC [program initiated], I did not have budget to do this, but they said, no, we're going to buy for her, I said, OK! So she was soooo happy, so happy, like, this is a moment of happiness actually."* (Alia, CCC community development coordinator, individual photo storytelling session)

At the CCC sharing circle workshop, I also noted a few CCC project members discussing plans for a weekend potluck they were doing at one members house, a get together not organized by the CCC community development coordinator (field note, 2017). Such activities highlight the strength of the relationship between CCC members and how the connections have grown out of the initial connection through the CCC initiative. These examples under companionship support highlight that the relationships between CCC members was not only a transactional support service, but that members genuinely enjoyed each other's company and mutually benefited from this reciprocal relationship.

Summary of Core Functions of The CCC Initiative

Using the CCC initiative as a case study, I identified five core aspects of a compassionate community approach to health promoting palliative care in an inner-city setting. These five core aspects build upon one another and included organizational backbone support at the base, the connecting role of the CCC community development coordinator, training and continuous learning opportunities, and outreach and engagement in the middle, and the social support role of CCC neighbourhood helpers at the top.

These different aspects taken as a whole made up the CCC initiative and explained how a compassionate community approach to health promoting palliative care in a densely populated inner-city setting can build community capacity to support isolated community members living with a life-limiting illness and/or their primary carers. In the following section, I present the impacts of this approach from the perspective of community members and organization staff.

IMPACTS OF THE CCC INITIATIVE: A COMPASSIONATE COMMUNITY APPROACH TO HEALTH PROMOTING PALLIATIVE CARE

The second aim of this research was to use the CCC initiative as a case study to explore the impacts of a compassionate community approach to health promoting palliative care in an inner-city setting. In this section, I present the impacts of this approach from the perspective of CCC project members and organization staff. Impacts were grouped into two overarching themes: impacts on CCC members living with a life-limiting illness and/or CCC primary carers; and impacts on CCC neighbourhood helpers. Within these two overarching themes, I present a number of specific sub-themes.

Impacts on CCC Community Members Living and CCC Primary Carers

CCC project members described a number of different impacts on CCC community members and/or their primary carers as a result of their participation in the CCC initiative. CCC community members and CCC primary carers were grouped together under this overarching theme as both groups were intended as the primary recipients of support (while recognizing the reciprocal nature of the CCC initiative). Within this overarching theme, I identified a number of sub-themes that will be presented below including:

- Increased neighbourly connections
- Feel cared for
- Positive impacts on mood
- Connections to health and social services

Increased neighbourly connections

CCC community members and primary carers increased their neighbourly connections as a result of their engagement in the CCC initiative. For example, one CCC community member who was a newcomer to Canada shared, *"Prior to [joining the CCC initiative], I felt lonely, but now, I don't feel lonely. I feel I have someone"* (Roxana, CCC community member, informal translation, pair photo storytelling session). Similarly, Amita, also shared how since she had been paired with Margaret, a CCC community member living with a life-limiting illness that, "…*a lot of friends of mine in this community now, know [Margaret] through me. And I know a lot of people through her"* (Amita, CCC neighbourhood helper, pair storytelling session). Amita explained her perspective on the significance of the increased neighbourly connections for Margaret,

> *"…I told her, I'm just going to write the names [of all the different people that come to check in on Margaret… that's how you know, it's been an interconnected community here… I wanted to create this group for her, of people, whom she is constantly connected with and beauty is, everyday somebody always is there to call her."* (Amita, CCC neighbourhood helper, pair small group session)

In this example, Amita took a leadership role in identifying all the different people in Margaret's life that were available for support. By bringing everyone together, she helped to formalize an "interconnected community" where there was now always someone to check in on Margaret.

Other CCC project members described how the increased neighbourly connections weren't only a volunteer relationship, but also a friendship and familial-like relationship. For example, Esi, a CCC neighbourhood helper described how the CCC community member with a life-limiting illness she was supporting considered her a friend,

> *"Well Nancy considers me a friend (laughs). Not just a volunteer who is coming, she considers me a friend because she can tell you what is wrong. And what she, she tells me whatever she wants to tell me and sometimes we laugh. She tells me whatever she wants, it's not just like, we've become like friends."* (Esi CCC neighbourhood helper, individual photo storytelling session)

Similarly, Omer, another CCC neighbourhood helper described how John, the CCC community member with a life-limiting illness he was paired with also tried to "be a kind of family" to him as he didn't have family support of his own to rely on,

> *"Well John has [family], but he doesn't see them, or his family is dead, but his sister, they are living in different cities they don't see each other often. So it's just like trying to be a kind of family to them."* (Omer, CCC neighbourhood helper, individual photo storytelling session)

Roxana also described her relationship with the CCC neighbourhood helper she was paired with, like a familial relationship. She shared the following photo and story to represent the strength of their relationship,

> *"Going to community corner, me and my sister."* (Roxana, CCC community member, pair photo storytelling session)

As these stories and photos demonstrate, CCC community members increased their neighbourly connections as a result of their participation in the CCC initiative. In addition, to increased neighbourly connections, CCC community members often described the relationship as a friendship and in some cases like family, underscoring the strength of these connections.

Feeling cared for

CCC community members and CCC primary carers described how they felt cared for by other CCC members in this initiative. For example, Margaret, a CCC community member explained, "*Amita is a nice person to know…someone you can talk to, or if you want anything you can always know that you can count on her, at least for me.*" (Margaret, CCC community member, pair photo storytelling session) Similarly, Esi, a CCC neighbourhood helper explained how the CCC community member she supported, who did not have any family, *"…[can] at least feel confident, oh I have someone I can call and talk to"* (Esi, CCC neighbourhood helper, individual photo storytelling session). Farzana, a CCC primary carer who was also living in a different country from her family also expressed the importance of having someone there for you when you feel alone,

> *"…oh my goodness I don't have any children, who is going to taking care of me. When I'm sick or I'm alone, but when my husband was sick. I was so helpless, when anyone come to call me I feel oh my god, there is someone for me… somebody is there… we are far away from our country, far far away. Here everyone is our relative, right?"*

> (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

Amita, Esi, and Farzana all felt that they could depend on the CCC neighbourhood helper or other CCC members in the group in times of need which made them feel cared for.

Subira, a CCC neighbourhood helper, contrasted the support created through the CCC initiative (i.e., knowing you always have someone to call) with more formal home service support provided by the government,

> *"So some of [the personal support workers] will come for an hour or so. But, imagine if someone needs help and [the personal support worker] comes early in the morning or whatever time, they will go to that person's place for 1-hr and after they left, the other person might need help, but who are they going to call?* (Subira, CCC neighbourhood helper, individual photo storytelling session)

In this example, Subira highlighted the importance of being cared for by an informal support network like the CCC initiative that is flexible and can be depended on in times of need, which can be unpredictable.

Similarly, Farzana, further explained how grateful she was to be cared for by other CCC members in her community. She shared the following story of how Roxana, a CCC community member would frequently check in on her and her husband who was also living with a life-limiting illness,

> *"Even Roxana (CCC community member), unbelievable. She start crying if she doesn't get any news from us, what happened, what happened to uncle? Everybody think if I'm not spending with them, something else with [my husband who is sick]. If I'm not responding the telephone, [they think] something is wrong, so they start knocking the door. So I really have, grateful and I'm really lucky to get this kind of neighbour."* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

In this story from Farzana, the reciprocal nature of the CCC initiative was again highlighted. Not only did CCC neighbourhood helpers provide care and support, but CCC community members did as well in return. The CCC community development coordinator further explained that the care provided is not just a one-on-one support, but that it is a "group concept",

> *"…now if [one CCC member] need to go to hospital, [other CCC members] are helping each other, if they need to go to grocery, they are helping each other. It's a group concept, not one-on-one volunteering. They are coming together, they are cooking together, it's, you can see the strength, dependency, they become like a family."* (Alia, CCC community development coordinator, individual photo storytelling session)

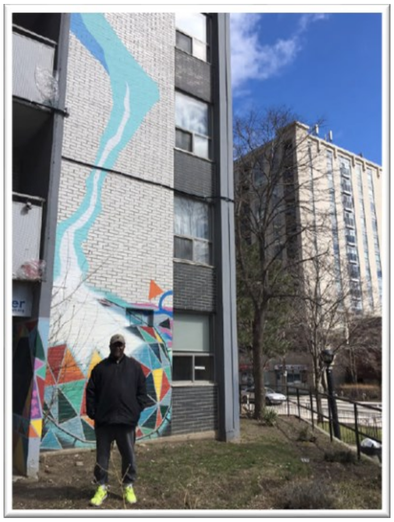
Through the CCC initiative, CCC community members living with a life-limiting illness and primary carers felt cared for by other CCC members in the group. This type of care was characterized as being dependable and flexible in times of need, which was particularly important for CCC community members living with a life-limiting illness and primary carers who did not have any family or friend supports they could depend on outside of the initiative. In addition, the group-based nature of care was another characteristic that helped to create a family-like connection. It is possible that having opportunities to come together as a group and meet over members of the St. James Town community through the CCC Friday Group helped to foster this "group concept" approach to care that led to stronger relationships among members.

Positive impact on mood

CCC community members and primary carers described how being part of the CCC initiative in St. James Town had a positive impact on their mood. Roxana shared the following photo and story to represent how being part of the CCC initiative impacted her mood,

> *"I feel light, I don't feel mental pressure. At home I feel suffocated, but when I go out to The Corner I feel good. If someone is sick we call each other, talk to each other."* (Roxana, CCC community member, informal translation, pair photo storytelling session)

For Roxana, being part of the CCC initiative increased her opportunities to socialize with others in her community which made her "feel light" and "feel good". It also gave her a reason to come and stop by The Corner to visit the CCC community development and other community members. In one of my visits to The Corner to meet with Alia, the Community Development Coordinator, Alia and Roxana were chatting in the office together, and Alia playfully joked that it was Roxana's "daily business" to come say hello and visit The Corner now (field note, 2017). Similarly, Michael, a CCC primary carer, also described how the welcoming attitude of the CCC community development coordinator at The Corner had a positive impact on his mental health. Michael shared the following photo and story,



> *"[People in St. James Town] are very, very friendly. Alia (CCC community development coordinator) will say 'come in, come in, come in'. And for me, it's good because of my mental illness, it's catatonia, but when I'm around people, I don't even think of the fact that I have mental health issues. And the best of it comes from a social environment. I can't imagine living in Scarborough (an east-end neighbourhood in Toronto), where everything is so spaced out. But here, you have to step outside, there's*

> *activities, there is life."* (Michael, CCC primary carer, mini group photo storytelling session)

Similar to Roxana, Michael felt that being around others and having the opportunity to socialize also had a positive impact on his mental health; and that the CCC initiative contributed to creating that positive environment. However, not all CCC community members living with a life-limiting illness were able to get out and connect with others in St. James Town. For example, Helen was primarily homebound due to some challenges she was experiencing with her illness (field note, 2017). However, Helen described how the visits to her apartment by the CCC neighbourhood helper she was paired with "lit [her] candle." She shared the following photo and story of the two of them together,

> *"Leah (CCC neighbourhood helper) put some positive back in where I thought it was all gone. And she accepts me for how I look, tubes in, tubes and everything. I don't have to explain tubes and all this… She lit my candle that I thought was burnt out… There are times prior to before meeting Leah that I just want to give up on everything and knowing her, it's like I look forward to the next day."* (Helen, CCC community member, mini group photo storytelling session)

For Helen, feeling accepted by Leah, despite all the challenges she was experiencing, all contributed to having a positive impact on her mood and looking "forward to the next day".

CCC neighbourhood helpers also shared from their perspective how being part of the CCC initiative positively impacted the mood of CCC community members they supported. For instance, Kamya thought, "*She feels sometimes refreshed [when I come to visit], because she is alone. She feels sometimes bored. But if we meet and if we talk I can see she is very happy*"

(Kamya, CCC neighbourhood helper, individual photo storytelling session). Esi, another CCC neighbourhood helper had a similar reflection. She thought the connection to the CCC initiative "feels good to their hearts,"

> *"Nancy (CCC community member) can have a story that she needs to share with someone and laugh. And she calls me and oh, this is what happened between me and my brother and me and my sister in law today and she will laugh and I will laugh. I will say that is funny. It feels good to their hearts."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

For CCC community members and primary carers, having increased neighbourly connections with others in the community was found to have a positive impact on mood, underscoring the significance of initiatives that seek to build community connections to care for one another.

Connections to health and social services

One of the core aspects of the CCC community development coordinator role was to collaborate with local social and health service organizations to better connect CCC members with relevant supports (as previously articled under the header 'Collaborating with local social and health service organizations to better connect CCC members with relevant supports'*).* The outcome of this aspect of the CCC initiative was that CCC community members and primary carers had increased connections to health and social services as a result of their engagement in the CCC initiative. While a richer description of the types of connections to health and social services was previously described, here I summarize the types of connections made. Connections to these types of supports were important as they support CCC community members in their wish to remain at home by helping to promote independence and inclusion in the community. CCC community members and primary carers were connected to:

- Language support services to help with communication with other services and agencies
- Personal support worker connections to help with basic needs (bathing, light meal prep, administering medication, etc.)
- Social workers
- Primary care (e.g., family physician)

- Mobility supports (walking aids, wheel-transit service with the local transportation authority)

Together with the support of CCC neighbourhood helpers, these services helped to promote CCC community members and/or their primary carers independence and increase connections within St. James Town. In turn, these impacts likely had a role in increasing CCC community members opportunities to be cared for at home.

Impacts on CCC Neighbourhood Helpers

CCC project members described a number of different impacts on CCC neighbourhood helpers as a result of their participation in the CCC initiative. Within this overarching theme, I present a number of sub-themes below including:

- positive impact on mood,
- feeling cared for,
- increased knowledge and skills, and
- professional development opportunities.

Positive impact on mood

CCC neighbourhood helpers also described how their engagement in the CCC initiative positively impacted their own mood. For instance, Esi shared how when she was feeling stressed, she could count on calling Nancy, the CCC community member she was supporting, to lift her spirits,

> *"…even me sometimes when I am stressed out, I don't want to sit down and hear stress. [I think] OK let me just call Nancy [CCC community member] and see how she is doing. 'Hi Nancy, how are you. I'm ok, and you?" I forget about what I was stressed about and we talk and we laugh."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

Amita, another CCC neighbourhood helper also described how Margaret, the CCC community member living with a life-limiting illness she was paired with, was a source of inspiration and positivity in her life that she wanted to share with others,

> *"I love sharing about Margaret [CCC community member] to my friends. Like I always say you know this is a senior, my friend, she is so inspirational – because you know today people need to listen to positive things. Because there is so much negativity around, when you have someone around talking positive or you listen to something positive it makes you feel good and that's the thing about her."* (Amita, CCC neighbourhood helper, pair photo storytelling session)

Similarly, Omer reflected overall on the benefits on mood as a result of getting involved with initiatives like CCC that are focused on supporting the community,

> *"Every society needs this [type of program like CCC], you know. I think it affects people in a positive way. When I see a little bit about volunteers, they are being happy, for what they are doing, and it's nice to see that."* (Omer, CCC neighbourhood helper, individual photo storytelling session)

Overall, CCC neighbourhood helpers reported positive impacts on their own mood from their engagement in the CCC initiative. The stories shared by CCC neighbourhood helpers draw attention to the reciprocity of the CCC relationship. Not only did CCC neighbourhood helpers support the CCC community member and/or primary carer they were paired with, but CCC community members and also provided emotional benefit in return.

Feeling supported

Another impact described by CCC neighbourhood helpers was the feeling of being supported by the wider CCC community (i.e., other CCC members and staff). For example, Kamya, described how the CCC community development coordinator helped her to navigate the educational system when she was applying for school in Canada. She felt so strongly cared for that she was brought to tears:

> *"... [CCC community development coordinator] always encourage me, (laughs) and sometime I think she care me a lot. It makes me like last time I cried because, I have, she cared me a lot more than enough. Ya sometimes I feel like that."* (Kamya, CCC neighbourhood helper, individual photo storytelling session)

In this situation Kamya felt that the coordinator went beyond what was expected in her role. Other CCC neighbourhood helpers also described how an impact of the engagement in the CCC initiative was that they felt supported by other CCC members. For example, Omer shared:

> *"If I have a problem, I ask people [at the CCC Friday Group] what do you think about it? Can you suggest anything, or can you give advice? So that was my benefit thing from this project…."* (Omer, CCC neighbourhood helper, individual photo storytelling session)

Similarly, Nasrin, another CCC neighbourhood helper who was also a newcomer described how if she was having a problem and needed help, she had other CCC members to rely on for support:

> *"… you know, if someone is sick or something, we can call each other, we can talk to each other. If someone says like you know [I have a] headache or something, or I have this [other ailment], people in the group offer local remedy – oh you can make the ginger tea, or something…"* (Nasrin, CCC neighbourhood helper, informal translation, pair photo storytelling session)

In these later reported impacts from Omer and Nasrin their support was drawn from the opportunity to come together at the CCC Friday Group, emphasizing the importance of this aspect of the program for supporting CCC neighbourhood helpers. Overall, these impact stories provide a richer understanding of how CCC neighbourhood helpers feel supported by the CCC initiative, highlighting reciprocal nature of this program. Feeling supported by other CCC members in the group and having neighbours you could depend on helped to build a stronger sense of community among members of St. James Town.

Increased knowledge and skills

CCC neighbourhood helpers reported an increase in knowledge about community resources and skill development as an impact of their engagement with the CCC initiative. For instance, CCC neighbourhood helpers described new knowledge related to palliative care and death, dying, and loss experiences. Amita, a CCC neighbourhood helper, shared how she gained new knowledge about advance care planning such as how to name a power of attorney, "*we had this note on*

Power of Attorney and all that. And I was very happy because what happens with CCC trainings and meetings they give you very good information, you know literature, material" (Amita, CCC neighbourhood helper, pair photo storytelling session). Similarly, Kamya, another CCC neighbourhood helper discussed how she developed new knowledge and skills to support someone who is grieving: "*grieving, what is the grieving, like when if anything happens to client, then what is the process of grieving...*" (Kamya, CCC neighbourhood helper, individual photo storytelling session). In turn, both CCC neighbourhood helpers were able to use this palliative care specific knowledge to support the community members they were paired with.

Not all knowledge and skills developed through the CCC initiative were specific to the field of palliative care. The CCC community development coordinator also facilitated different workshops on different topics selected by CCC members. For example, Kamya shared how during the CCC Friday Group topics she also learned about free income tax clinics the community was offering as well as other opportunities to visit local museums for free through a public library program. In turn, this increased knowledge created an opportunity for CCC neighbourhood helpers to potentially share new knowledge with the CCC community members they were paired with, but also with friends and family highlighting the potential broader reach of the CCC initiative. For example, Esi shared how through her training, she was able to use her knowledge of the Canadian context to help others in the community with getting settled:

> *"You also use [the CCC training] to advise someone, like especially in your commerce you have to say this is how you have to follow these steps when you come to Canada, these are the steps how you have to follow things in order to get into the system and it's good to be involved in order to understand the system and order to be able to move forward."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

While the initial training and CCC Friday Group played a key role in knowledge and skill development, CCC neighbourhood helpers also developed knowledge and skills through their own experience in the CCC initiative. For example, Kamya, shared how through her relationship with Leslie (a CCC community member), she was able to practice her English language skills. At first, Kamya was a bit worried about being able to communicate with Leslie as English was not her primary language. However, Leslie provided encouragement which helped to strengthen their relationship:

> *"I first met her, that time I'm little hesitant because she is Canadian and I have problem to speak fluently to her (laughs). I hesitate (laughing) but she told…I understand what you are telling, don't worry. Then this one makes me to, to help her….Just she told me that one word, don't worry I will understand you, means I understand now what you are saying. So that one makes me close to* here…, *I'm improving my English*." (Kamya, CCC neighbourhood helper, individual photo storytelling session)

Developing Kamya's English language skills was important for being able to communicate with others in the community, but also for her career development. Similarly, Amita also described how she learned more about how to support members of her community through experience and her relationship with Margaret (CCC community member), sharing this photo below to go along with her story:

> *"You know something like this, experience with a senior, sometimes it's the experience that counts. But it's no formal education. It's like you just go along – and as you are with the senior you realize what works and what doesn't work, just test it out. And like they always say experience is the best teacher. And uh, both of us are learning from each other, like my husband jokes and says, who went to support whom? I don't know who is supporting who!"* (Amita, CCC neighbourhood helper, pair photo storytelling session).

The diverse types of knowledge and skills gained through the CCC initiative, from palliative care supports to leisure opportunities in the community was another commonly discussed impact among CCC neighbourhood helpers. In particular, the CCC initial training and CCC Friday Group played a key role in supporting CCC neighbourhood helpers knowledge and skill development. However, as one CCC neighbourhood helpers highlighted, experience by doing was ‘the best teacher’.

Professional development opportunities

Last, professional development opportunities were another type of impact reported by CCC neighbourhood helpers. The opportunity for professional growth was a key aspect of the CCC initiative in St. James Town where many newcomers were trying to re-establish themselves in a new country. Indeed, recruitment posters for the CCC initiative in St. James Town highlighted opportunities for skill development and the opportunity for a reference letter as benefits of joining the CCC initiative (HT recruitment poster document). The CCC community development coordinator explained the importance of offering professional development opportunities for CCC neighbourhood helpers as part of the CCC initiative in the particular context of St. James Town,

> *“This is a diverse community… This is a hub for newcomer, and always people are coming, trying to settle themselves, so like anyway if people can find a reference, they can find a job. So this is all about the settlement. Some people they’re looking for their opportunity, and I’m looking for my opportunity. If I can help someone that is helping me, to train them, you know, evaluating them on their performance of, supporting them, upgrade [their] resume, so like sometime I help them to do this too – I connect them to employment agencies and something.”* (Alia, CCC community development coordinator, individual photo storytelling session)

CCC neighbourhood helpers also described how the opportunities for professional development were an impact of their engagement in the CCC initiative. For example, Esi, a CCC neighbourhood helper shared how she hoped her participation and training in the CCC initiative would help with career advancement:

> *“That training, when I was looking for a job, I also completed that in my resume… I have this kind of training so even though I am here as a part time worker [in my current job], but if they have a position and they ask me and they look at my resume and say oh she has this and she has this, maybe move her from this position and give her another*

> *position. I'm still hoping one day its' going to help me move forward."* (Esi, CCC neighbourhood helper, individual photo storytelling session).

Omer, another CCC neighbourhood helper also explained how his engagement and participation in the CCC initiative was a way to help him decide what he would like to study in school to support his career development,

> *"I found this opportunity [the CCC initiative] from another community. And at that point, and I still, I am trying to figure out is that, as I told you, what I want to study. And I was thinking of studying, community work, like, social work, and stuff, so that's why I was doing my kind of research about it and that's why I decided, volunteering in that field, see how do I like it and see if you like it you can go for it.*" (Omer, CCC neighbourhood helper, individual photo storytelling session)

Similarly, Kamya, who was a nurse in the country she emigrated from, described how she initially wanted to get involved in her new community as a way to learn more about Canadian culture and her neighbourhood. In turn, she hoped that understanding the Canadian system would help her in re-establishing her nursing career in Canada,

> *"…I, came to in the reception [at the Community Corner in St. James Town] and then, actually, my background is in nursing. So I asked the reception, is there any program to care the seniors, to care the children, I need to stick to do that because I want to know the system of here, and also I want to know the culture and the community background.*" (Kamya, CCC neighbourhood helper, individual photo storytelling session)

What these stories from CCC neighbourhood helpers suggest is that one of the reasons for wanting to get involved in the CCC initiative was the opportunity for professional development, whether it was to strengthen their resume, to learn more about a particular field, or to learn more about the Canadian context. Therefore, creating opportunities for professional development was a positive impact of the CCC initiative and a good 'hook' to engage potential community members in the initiative.

Summary of Impacts

While the primary objective of the CCC initiative was to build community capacity to support isolated community members living with a life-limiting illness and/or their carers, it was also CCC neighbourhood helpers that were positively impacted by their engagement with the CCC initiative. CCC community members living with a life-limiting illness and CCC primary carers reported increased neighbourly connections; feeling cared for; positive impacts on mood; and connections to health and social services. Similarly, CCC neighbourhood helpers also reported positive impacts on mood and feeling supported which in turn contributed to building a caring community. In addition, to building a caring community, CCC neighbourhood helpers also reported increased knowledge and skills and professional development opportunities as an impact of their engagement in the CCC initiative. These later impacts were particularly important in the context of St. James Town where many CCC neighbourhood helpers were looking to resettle themselves in a new country. Participation in the CCC initiative helped to build CCC neighbourhood helpers 'Canadian experience' to help with their future career endeavours.

FACILITATORS AND CHALLENGES OF THE CCC INITIATIVE

Together with CCC project members and organization staff, the third research aim was to better understand the specific facilitating and challenging factors that influenced the nature of the CCC initiative in the context of St. James Town, an inner-city setting. CCC project members described a number of factors that helped to facilitate the CCC initiative. Themes specific to facilitating factors included: reciprocity; shared value in the collective good; flexible and organic approach; neighbourhood-based approach; shared interests; and building off community strengths. CCC project members also highlighted a number of challenges that impacted the CCC initiative. Themes related to CCC challenges included: disconnected community; relational issues; CCC neighbourhood helper shortage and sustainability; the informal-formal tension; and lack of steady funding. These themes discussed by CCC project members and organization staff will be presented below.

Facilitators of CCC: A Compassionate Community Approach

Reciprocity

Reciprocity helped to facilitate the CCC initiative in various ways including increasing initial engagement and sustainability, and strengthening relationships between CCC members. The primary intention of the CCC initiative was to build community capacity for the purposes of supporting isolated community members living with a life-limiting illness and/or their primary carers. However, by exploring the impacts on all CCC members, I learned that it was CCC neighbourhood helpers that also benefited through their engagement. For example, CCC community members and/or primary carers, as well as CCC neighbourhood helper, both described how they felt supported and cared for through their participation in the CCC initiative and how it also had a positive impact on their mood. In addition, both sets of groups (i.e., CCC community members and/or primary carers and CCC neighbourhood helpers) were supported by the CCC initiative according to their different goals. In the case of CCC community members and/or primary carers this generally meant a desire to remain at home. In the case of CCC neighbourhood helpers, many saw the professional development opportunities as a beneficial impact of their engagement for their future career goals. This reciprocity element was a facilitator of the CCC initiative as it helped to increase engagement in the CCC initiative, in particular among CCC neighbourhood helpers, and to support sustainability over time (on average, CCC neighbourhood helpers in the CCC participatory case study had been engaged for over 2 years).

Shared value in the collective good

Many CCC neighbourhood helpers shared how their personal values were a facilitating factor that motivated them to participate in the CCC initiative. Interestingly, CCC neighbourhood helpers cited a shared value in the collective good and a desire to give back to their community as a facilitating factor of their engagement in the CCC initiative. For example, one CCC neighbourhood helper explained that her wish to give back to her community was influenced by how she was raised,

> *"I am so grateful with whatever I have and why not share it. That's how I grew up. My background helps with that. My mom, she was very kind and ah, and very giving, and*

> *she was always willing to help others, so, that's what I do."* (Subira, CCC neighbourhood helper, individual photo storytelling session)

Another CCC neighbourhood helper shared the following photo and story describing how she also felt a collective responsibility to care for one another, particularly as her neighbourhood, St. James Town, became more densely populated and diverse,

> *"St. James Town is the most densely populated community in people and high-rise buildings in North America… recent construction projects confirm we are only intensifying our density. If we're really going to define ourselves as an accepting community, indiscriminate of blood or back-story, never has there been a better time to dial up the caring. There is a vulnerability in our increasing diversity and density. We have a responsibility to take care of each other. What we do individually and collectively to help increase accessibility, integration, and support, defines who we are*" (Leah, CCC neighbourhood helper, mini photo storytelling session).

Finally, Omer, a CCC neighbourhood helper described his wish to support others in the community in terms of wanting to leave a legacy,

> *"Like some people only care about other people, they don't care about themselves first, they care about other people…I always feel like I am going to die one day, but I want to do something good for the people. That will be remembered after me."* (Omer, CCC neighbourhood helper, individual photo storytelling session)

CCC neighbourhood helpers had different personal factors that influenced their shared value in the collective good and their desire to support others in their community. The CCC initiative provided an organized avenue for CCC neighbourhood helpers to be part of a larger community with similar values and an opportunity to take collective action.

Flexible and organic approach

CCC neighbourhood helpers described how the flexible and organic approach was a facilitator of their engagement in the CCC initiative. For example, one CCC neighbourhood helper explained,

> *"[The CCC initiatives gives] you an option by the way. They ask if you can commit to at least 6 months to a year, afterwards you can leave. They don't force you to stay. So when you are doing it willingly, you want to do more."* (Subira, CCC neighbourhood helper, individual photo storytelling session)

Similarly, another CCC project member also thought that the flexible approach of CCC was a 'good' approach adding, "*And like [the CCC community development coordinator] never force [you] to do anything. It is optional, so that is also good. Good things*" (Kamya, CCC neighbourhood helper, individual photo storytelling session). Subira and Kamya discussed the benefits of a flexible approach in terms of feeling their participation in the CCC was truly voluntary, which increased their willingness to stay involved.

A former senior Hospice Toronto staff member described the importance of rooting the CCC initiative in a flexible and organic approach using a gardening metaphor. She shared the following photo and story to illustrate this facilitating aspect of the CCC initiative,

> *"…you plant the seeds in soil and you water them and you see how they grow, it's the same thing in the community. Not everyone's going to be involved in the exact same way, but by planting opportunities and support, people can then make those types of investments."* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session)

As the examples in this section demonstrate, CCC neighbourhood helpers had the flexibility to participate in the CCC initiative in different ways and the flexibility to organically test out what worked best for them with the CCC member they were supporting. The flexible and organic nature of the CCC initiative was seen as a key facilitator of engagement in the CCC initiative as it may have helped to facilitate increased ownership in the process.

Neighbourhood-based approach

CCC neighbourhood helpers also discussed how the neighbourhood-based approach was another strength of the CCC initiative. For example, some CCC project members discussed how geographic proximity made it easier to support isolated community members living with a life limiting illness. For example, one CCC neighbourhood helper explained, "*If I have someone in my building, and they let me know, can you check this person, once a day, even after work, I can stop by and say, hey hello how are you doing do you want any help*" (Subira, CCC neighbourhood helper, individual photo storytelling session). Indeed, Leonor, a former senior Hospice Toronto staff member also saw the geographic proximity and density of St. James Town as an asset for the CCC initiative, "*So, that density brings challenges, but it also brings a lot of richness because there are many people around*" (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session). Similarly, Esi, another CCC neighbourhood helper shared how in times of emergency, it was important to be close by to support other CCC members,

> *"it is very important, because when Nancy [CCC community member] called me to tell me she cannot breath… it took me about 10 minutes to get one, to get to the building. But if it is far away maybe you get you don't know what will happen to the clients, so it's good that the services should be around."* (Esi, CCC neighbourhood helper, individual photo storytelling session)

For Benesh, another CCC neighbourhood helper, it made her really happy to run into the CCC community member she was supporting and she described how these neighbourhood run-ins helped to foster what she called "whole care,"

> *"…I see him around the neighbourhood now and he's doing a lot better…it was a bit hard for him in the beginning…he was more at home but ah, he was walking around, he says hi to me, and I say hi to him, and I used to be the one that would ask how he is doing, but now he is asking me how I am, so it just really shows that, it really fosters that whole care, and he really does like care…and it just makes me really happy to see him doing so much better than he was before."* (Benesh, CCC neighbourhood helper, individual photo storytelling session)

For CCC neighbourhood helpers, the neighbourhood-based approach made it easier to check-in on others in their community due to the close proximity of other residents. This was particularly important in emergency situations when time might be a concern. Last, adopting a neighbourhood-based approach also meant there were more opportunities to organically run into, and connect with, other members in your community which helped to strengthen the relationships between CCC members.

Shared interests

Another facilitating factor that helped to increase the strength of the relationships in the CCC initiative was the importance of making matches among community members according to shared interests. Indeed, Helen, a CCC community member, appreciated the effort of the CCC community development coordinator to match CCC members together, *"… she looks at the person that she needs to match up with, and then she checks the volunteer to see which one best match up with that person. And I think it's fantastic the way she did that"* (Helen, CCC community member, mini group photo storytelling session). Similarly, a CCC neighbourhood helper enjoyed being able to discuss philosophy with the CCC community member he was paired with. He took the following photo to help share his story,

> *"Interesting enough, Alia [CCC community development coordinator] told me that he had more than 200 books in his house. He likes to read, he is interested in philosophy, theology, you know, he's that kind of person and I like to talk about those subjects. And it was really nice, so far it's been hard for me to talk and do like brainstorm with people here. Like talking about those things, problems, issues, society, whatever, those subjects. And that guy you know, have experience, all the things, all those years, so that's why it's nice match, I believe."* (Omer, CCC neighbourhood helper, individual photo storytelling session)

Amita, another CCC neighbourhood helper, also described how happy she was to be paired with someone that matched the support she was willing to offer,

> *"And by Feb [the previous CCC community development coordinator] called and she said there is this amazing lady. And she is 94 then. 93, 94. And I was like wow! And she said she is an amazing person, she is a nurse by profession and she loves to go for walks… And she is Catholic… this is the kind of support she is looking for because I*

> *had put a list of things that I would like to do. So she said you know these are the things she is looking for and I was very happy."* (Amita, CCC neighbourhood helper, individual photo storytelling session)

The CCC community development also emphasized the importance of 'connectivity' and finding good matches between CCC members in the context of volunteering, *"It was easy to supervise staff, it's very easy –you are paying them, there is a some code of conduct, they're very bound to all of it. But neighbourhood helpers, this is all about connectivity, and dignified relationship"* (Alia, CCC community development coordinator, individual photo storytelling session). When CCC members had shared interests and things in common, it likely had an impact on strengthening the relationship in a meaningful way which in turn may have helped to increase the sustainability of the support provided.

Building off community strengths

Building off community strengths was another facilitator of the program. Building off the collective power of community members in St. James Town, the CCC initiative was able to support isolated and vulnerable community members living with a life-limiting illness in their wish to remain at home. One of the primary goals of the CCC initiative was to build community capacity to support isolated community members living with a life-limiting illness and/or their primary carers. While one of the challenges of the CCC initiative, presented below, was the feeling of St. James Town being a 'disconnected community', one of the facilitators was that there were members of St. James Town who wanted to get involved in the community and support one another (e.g., having a 'shared value in the collective good'). The CCC initiative was able to capitalize off this strength in the community by creating a platform for people to come together to support others in their community. In addition, collaborating with local social and health service organizations to better connect CCC members with relevant supports was a key aspect of the CCC initiative. Building off community strengths helped to facilitate the CCC initiative as it meant that the CCC initiative was better able to support CCC members across a range of needs drawing on the existing assets within the community without trying to re-invent the wheel. As a former senior Hospice Toronto staff member explained,

> *You might not be the housing expert or the legal expert but you know someone that works at the community legal clinic, or you know someone that works in housing, or you know someone that has the connection to the food bank…"* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session)

Challenges of CCC: A Compassionate Community Approach

Disconnected community

One of the challenges for the CCC initiative reported by different CCC members was the challenge of engaging a disconnected community in the CCC initiative. For example, one CCC neighbourhood helper explained,

> *"So in my culture, you know you're neighbours or if you're in a small town, you know what's going on. The gossip, everything. That's how I grew up. Here, you don't know your next door neighbours. Everybody is very quiet."* (Subira, CCC neighbourhood helper, individual photo storytelling sessions)

Similarly, another CCC primary carer described a similar feeling sharing this photo and story,

> *"I have a neighbour, she was living alone, and nobody talked to her. She was sick, she had a liver problem, liver transplant.... One day I saw her on the scooter and after two, three days, I said I don't see her, where is she? Is anything wrong? Then her son knocked on the door, he said I lost my mother. It was a really shocking thing… And after that I start giving food to her son…Whenever I look at him, I see my nephew there, he lost his father and mother. And I cannot hug him, in this country it's not that easy to*

> *do that."* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

These two stories highlight how CCC members found it difficult to self-initiate care for their neighbours because of what they perceived as a disconnected Canadian culture. For Subira, she felt that neighbours didn't know one another, while for Farzana she wasn't sure if it was appropriate to give her grieving neighbour a hug. Despite the challenge of facilitating a compassionate community initiative in a disconnected neighbourhood, Farzana added that it is for this reason that initiatives like CCC are needed. Farzana shared,

> *"In this country you cannot knock the door and ask help, so you need this kind of organization. So, because, they are great organized. Individually it's hard. So, because they are organized, if you call them, or tell them, oh I see somebody, so this kind of, you know, that's really nice. This is a really good organization."* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

This story from Farzana highlights the importance of creating opportunities for collective approaches to care particularly in an individualistic society like Canada.

Relational issues

While it was more common for CCC members who participated in the CCC participatory case study to describe the relationship with the CCC member they were paired with in a positive light, there were a few examples of relational tensions. For example, one CCC neighbourhood member explained,

> *"Sometimes she [CCC community member] can be moody… Sometimes I will call her and she will tell me that she doesn't want me. I don't take it personal, there is nothing that she deliberately do to hurt me or upset me"* (Subira, CCC neighbourhood helper, individual photo storytelling session).

Subira had a difficult relationship with the CCC community member she was paired with and didn't always feel welcome when she offered to help. However, Subira added that "*Maybe she is upset, maybe something happened…maybe she wanted to get it out. Is it going to hurt me really? It's not*" (Subira, CCC neighbourhood helper, individual photo storytelling session). Subira tried to rationalize the actions of the CCC members she was caring for by acknowledging they may stem from other challenges in her life.

In a more serious example, racism impacted matches between CCC neighbourhood helpers and community members/primary carers. For instance, the CCC community development coordinator explained, *"Then once, one clients' caregiver, said to me I don't want anyone who is (pauses), [going on to] describe my neighbourhood helpers' race"* (Alia, CCC community development coordinator, individual photo storytelling session). Overall, while many CCC members had positive matches, relational issues and racism were also present, which made matching community members difficult at times.

CCC neighbourhood helper shortage and sustainability

Another challenge of the CCC initiative highlighted by CCC members related to not only engaging enough CCC neighbourhood helper to match community requests for support, but also challenges sustaining engagement.

In my visits to The Corner, I learned from the CCC community development coordinator that she would often get requests by other local organization to support an isolated community member living with a life-limiting illness. However, she would frequently have to turn down these requests because there were not enough CCC neighbourhood helpers to match the demand (field note, 2016). One CCC neighbourhood helper commented that part of the challenge in engaging new neighbourhood helpers may have been the lack of community awareness. As Alia, the CCC community development coordinator explained, *"...I'm very careful about you know, expanding the caseload because if I cannot provide them [with CCC neighbourhood helper support], what is the point to, you know?*" (Alia, CCC community development coordinator, individual photo storytelling session). CCC neighbourhood helpers echoed the need to engage more CCC neighbourhood helpers as requests for support were expected to increase with changing population demographics, *"there are more seniors, there are more people getting old, so, they need to more train volunteers"* (Esi, CCC neighbourhood helper, individual photo storytelling session).

One factor thought to impact initial engagement of more CCC neighbourhood helpers was the increasing use of financial incentives by other organizations to engage volunteers in St.

James Town. Leonor, a former senior Hospice Toronto staff member described the difference between the Hospice Toronto approach and other approaches used by other local organizations:

> *"... our incentivizing is building the capacity and giving and receiving from within the community. Versus monetary, we don't, we've never been oriented that way. So, there's been sometimes some undercurrent in regards to that, but yet, it's totally respectable... So you know living in poverty or working class, with limited income…it's very reasonable to understand. And these small incentives that might be monetary…set up that expectation, and that's happened quite a bit within neighbourhoods such as St. James Town."* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session)

Alia echoed Leonor's observations and agreed that paying volunteers had created an expectation among some community members in St. James Town that made it a challenge to engage members in the CCC initiative,

> *"[It's] challenging as I told you, to sustain the volunteer. Because in this community, there are lots of competition. In [another community organization] they have community ambassador. They are saying this is volunteer, but they are paying them lots of money. So they are making the expectation, growing the expectation."* (Alia, CCC community development coordinator, individual photo storytelling session)

As Hospice Toronto had a policy to not pay their traditional volunteers and neighbourhood helpers, both Leonor and Alia felt that the issue of pay made it challenging to engage neighbourhood helpers in the St. James Town context. However, Leonor, a former senior Hospice Toronto staff member also acknowledged that in the context of St. James Town where 36% of residents are considered low income (City of Toronto, 2018), the financial supports provided by organizations to get involved in the community were also "very reasonable to understand" to meet basic needs.

Another factor thought to impact the sustainability of engagement of CCC neighbourhood helpers over time was the impact of new work and school commitments. For example, one CCC neighbourhood helper explained how her new job made it difficult to participate like she had been,

> *"I was just connecting everywhere, so I [was helping] at those places then when I didn't have a job. I was still looking for a job. Now if you give me two seniors [as part of the CCC initiative] I won't be able to handle them"* (Esi, CCC neighbourhood helper, individual photo storytelling session).

Similarly, Kamya, a CCC neighbourhood helper who was starting her nursing training in Canada, also had less time to support the community member she was paired with as she became busier with school and family commitments,

> *"If I live alone, I would be available anytime to her, but I tell her my personal, my real life, so she knows. But really she understands my situation and she always, like, appreciate or what you say, she also help me like. Do study, don't worry. Complete your study (laughs)."* (Kamya, CCC neighbourhood helper, individual photo storytelling session)

While Kamya was increasingly busy with her own studies, she found that the community member she was supporting was very supportive and understanding, a potential indicator of the strength of their relationship. Overall, a climate of financial incentives for community engagement and changes to work and school commitments were a challenge for both engaging new CCC neighbourhood helpers and sustaining continued engagement over time.

The informal-formal tension

Another challenge experienced by members of the CCC initiative was an informal-formal tension; a tension that may be shared by other compassionate community approaches to health promoting palliative care. On the one hand, compassionate community approaches like the CCC initiative are rooted in a bottom-up, community-driven approach to palliative care. Such an approach tends to be more flexible and organic in nature. Indeed, Leonor, a former Hospice Toronto, previously explained this flexible nature, "*Not everyone's going to be involved in the exact same way, but by planting opportunities and support, people can then make those types of investments [in their community]"* (Leonor, former senior Hospice Toronto staff member, individual photo storytelling session). However, on the other hand, this particular compassionate community approach was facilitated by an outside organization (i.e., Hospice Toronto) that had certain obligations and processes it was required to follow. For example, CCC neighbourhood helpers discussed how in their training (some of which overlapped with the traditional hospice volunteer training) there was a lot of emphasis placed on privacy, such as not giving out personal information to the person you are supporting. While this approach to privacy and confidentiality may work in the context of a more formal hospice volunteer relationship, CCC neighbourhood helpers found this approach to privacy difficult in the context of a neighbourhood-based CCC initiative. For example, one CCC neighbourhood helper described,

> *"... we don't allow to give personal contact, including phone number. But, I give to my client, and she also sometimes call me and I called her. If I didn't give her my cell phone number, if need, sometime she also need my help, so then what can she do? That's what I think, and then I gave her my number"* (Kamya, CCC neighbourhood helper, individual photo storytelling session).

Similarly, another CCC neighbourhood helper echoed Kamya's dilemma being unsure of how much personal information to give,

> *"And like first meeting when I went to his place, I was kind of, staying back, just like, protecting myself, at the same time, protecting him. Because, you know, when we were at the training that they gave us, lots of information, like confidentiality things, like you shouldn't share and stuff... but when we have asking like kind of personal questions, I was like, uhhhh... should I answer and stuff? Or I was like trying to change the topic to another thing*?" (Omer, CCC neighbourhood helper, individual photo storytelling session)

These dilemmas highlighted by both Kamya and Omer bring to the surface this tension between a friendship and service-based relationship. In both cases, Kamya and Omer gave as much personal information as they felt comfortable with personally. However, despite this tension, one CCC neighbourhood helper thought the CCC initiative was overall "successful" in balancing the formal-informal tension:

> *"As an organization you're expected to have structure and hierarchy and all these things that create efficiency and order, but, at the same time, with care, it's very, it kind of, disintegrates that hierarchy because caring brings people together and that power difference and that tension it creates. But I feel that Creating Caring Communities it*

> *really, it's successful in that way, it brings them together without that kind of tension, without that kind of disequilibrium, or, like it, it…[brings] those two sides together without conflict."* (Benesh, CCC neighbourhood helper, individual photo storytelling session)

Lack of steady funding

Last, lack of steady funding was another challenge for the CCC initiative. CCC staff members explained that the initiative was primarily funded year-to-year through donations to Hospice Toronto and in some years, through small project specific grants. The CCC community development coordinator explained how the lack of steady funding was a challenge for developing the initiative,

> *"Hospice Toronto doesn't have any funding for that. Even though the sort of work I'm doing, it's supposed to cover 100% [of the St. James Town Community], we don't have the capacity, we don't have the funding, we don't have the like, resources to reach those people. So, this is such a novel work, that it should receive [financial investment]."* (Alia, CCC community development coordinator, *individual photo storytelling session*)

CCC project members also recognized the limited resources the CCC initiative was able to draw upon. For example, Subira stated, "*I don't think [the CCC initiative] has that much and with whatever they have they are trying their best"* (Subira, CCC neighbourhood helper). Similarly, Farzana, a CCC primary carer also echoed the limited resources for CCC and the limitations on what the program is able to do, *"Only one [CCC community development coodintator] is coming here… so it's 2 days… But in my point of view, we need more. I might not need that much now, but it's coming"* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session).

In conversations with Hospice Toronto Staff, I also noted that senior level staff felt that part of the challenge in securing funding related to difficulties in funding opportunities being disease specific (i.e., palliative care for cancer patients). In addition, senior staff also found it difficult to secure funding without having done a formal evaluation to demonstrate the value of this approach to funders (field note, 2016). Funding instability was described at the organizational level as a challenge for the continuation of the CCC initiative. This ongoing challenge highlights that while community capacity to care for others in the community has been developed, it has not been completely self-sustained and still required on-going investment.

Summary of facilitators and challenges

CCC project members noted a number of facilitators and challenges of the CCC initiative ranging from personal factors (e.g., shared value in the collective good) to organizational factors (e.g., lack of steady funding). While the facilitators and challenges noted in this chapter are specific to the CCC initiative in St. James Town, other compassionate community initiative in similar inner-city settings may also be able to learn from these facilitators and challenges.

SUMMARY

In this chapter I presented the findings from the CCC participatory case study. Using the CCC initiative as a case example, these findings outlined the five core components of how a compassionate community approach to health promoting palliative care in a densely populated inner-city setting helped to build community capacity to support isolated community members living with a life-limiting illness and/or their primary carers. These five core components included: organizational backbone support, the connecting role of the CCC community development coordinator; training and continuous learning opportunities; outreach and engagement; and the social support role of CCC neighbourhood helpers. Next, I described the impacts of the CCC initiative on: (1) CCC community members living with a life-limiting illness and/or their primary carers; and (2) CCC neighbourhood helpers. Interestingly, while the primary aim of the CCC initiative was to support isolated community members living with a life-limiting illness, CCC neighbourhood helpers also benefited from their engagement in the CCC initiative as well, highlighting the broader ripple impacts of building community capacity to support palliative care. Last, I presented a number of facilitators and challenges of the CCC initiative to better contextualize the nature and impacts of the CCC initiative. The significance of these findings will be presented in the following chapter.

CHAPTER 8: THE SIGNIFICANCE OF SCAFFOLDING SUPPORT, CAPITAL GENERATION, AND CONTEXT IN INNER-CITY COMPASSIONATE COMMUNITY INITIATIVES

OVERVIEW

The findings from Cycle 2: The Photovoice Project, previously presented in Chapter 7, contribute to an emerging evidence base bettering understanding the nature and impact of compassionate community approaches to health promoting palliative care. Cycle 2: The Photovoice Project makes a unique contribution to the field by adding an in-depth case example from a Canadian and inner-city perspective—two underdeveloped areas of evidence within the field.

In particular, the findings from The Photovoice Project provide rich insight into the broad types of supports that are needed to meaningfully facilitate a compassionate community approach to health promoting palliative care in an inner-city setting. These types of supports were found to extend beyond the scope of typical hospice palliative care (i.e., friendly visits, respite support, etc.). I begin this chapter by discussing the significance of what I call ‘scaffolding support’ in building community capacity to support isolated community members living with a serious life-limiting illness and/or their primary carers. Specifically, I draw attention to the significant types of investments that are necessary in order to: (i) meaningfully capitalize off local community assets and; (ii) address the diverse needs of inner-city community members, in order to build community capacity to support palliative care. While much of the current literature on health promoting palliative care has focused on making the case for the value of community capacity building approaches to palliative care, less attention has been focussed on the types of investments required to provide the infrastructure to support and sustain such an approach. I argue this is highly problematic as compassionate community approaches to health promoting palliative care risk being co-opted by a neo-liberal policy agenda. That is, an agenda focused on downloading community care without matching this change with appropriate support (DeFilippis, 2010). In contrast, the findings from Cycle 2: The Photovoice Project make explicit the types of scaffolding supports needed to meaningfully facilitate compassionate community initiative aims.

Additionally, the findings from The Photovoice Project demonstrate that if these important scaffolding supports are in place, it is possible for compassionate community initiatives to generate both social and cultural capital as a consequence of this approach to palliative care. In the second part of this discussion, I draw on Bourdieu's (1986) capital's theory to explore the significance of the generation of social and cultural capital in an inner-city setting like St. James Town in terms of:

- increasing CCC members opportunities for how they would like to be cared for and supported; and
- increasing opportunities for growth and development (as was the case for CCC neighbourhood helpers, many of whom were immigrants and newcomers looking to settle and establish themselves in St. James Town).

Based on these findings I argue that compassionate community initiatives in inner-city settings should explore strategies to generate different capital resources as a means to increase palliative care options and increase opportunities for neighbourhood helpers.

Finally, I end this discussion by reflecting on the value of case study research in bringing context to the forefront in research and allowing for a deeper understanding of how the broader social context influenced the nature, impacts, facilitators/challenges of the CCC initiative in St. James Town.

THE IMPORTANCE OF SCAFFOLDING SUPPORT IN COMPASSIONATE COMMUNITY INITIATIVES

The importance of scaffolding support was an important learning in my exploration of how a compassionate community approach to health promoting palliative care in an inner-city setting can build community capacity to support isolated community members living with a serious life-limiting illness (*herein after referred to CCC community members*) and/or their primary carers. Scaffold, according to the Merriam-Webster dictionary is defined as "a supporting framework" (Merriam-Webster, n.d.). In this discussion, I refer to scaffolding support as the supporting elements, or the skeletal-like framework, that played a critical role in building community capacity to support isolated CCC community members and/or their primary carers. Specifically, I found that organizational backbone support, the connecting role of the CCC community development coordinator, and training and continuous learning opportunities created important scaffolding to support CCC members. The importance of scaffolding support in compassionate community initiatives is worthy of further discussion for a number of reasons. First, the findings from The Photovoice Project give pause to a commonly held assumption in the compassionate community literature that compassionate community initiatives should ideally be "initiated by community" (Sallnow & Paul, 2014, p. 234) and "citizen-led organizations or neighbors volunteering their own time for their local area" (Public Health Palliative Care International, n.d.-b, para. 2). Indeed Public Health Palliative Care International (n.d.-b, para. 2) explains that compassionate community initiatives are "mostly groups of neighbors living close to each other in villages or suburban areas that come together to organize a way to support people in their own area who are living with life-limiting illness, caregiving or grief and loss." Rather, the findings from The Photovoice Project draw attention to the valuable 'scaffolding support' role community organizations can play, in facilitating compassionate community initiatives in inner-city settings. Second, compassionate community approaches to health promoting palliative care that focus on re-engaging 'community' in experiences of death, dying, loss, and care are becoming increasingly popular in Canada and internationally. With this increasing interest and growth, I argue that we need to adopt a critical lens towards compassionate community approaches so as not to romanticize the role of 'community' and be co-opted by a neo-liberal policy agenda in the process. As I had previously argued in Chapter 2, one of the key considerations in the continued development of compassionate community initiatives in Canada, and internationally, is to not fall into a trap of embracing a community empowerment discourse at the expense of justifying a lesser role of the welfare state (Mowbray, 2005). Rather, I argue that the findings from The Photovoice Project contribute to a more nuanced understanding of the types of supports and investments that are required (e.g., from the welfare state) in order to meaningfully support compassionate community initiatives. In this first part of the discussion, I dig deeper into understanding why these scaffolding supports were valuable in the particular context of St. James Town, an inner-city community. In addition, I also explore how certain facilitators and challenges described by CCC project members influenced the nature of these scaffolding supports.

Organizational Backbone Support: A Key Aspect of Scaffolding in the CCC Initiative

In the CCC participatory case study, I found that the organizational backbone support contributed by Hospice Toronto provided important scaffolding to support the community capacity building aims of the CCC initiative. This organizational backbone support was important in supporting the functioning of the CCC initiative for a variety of reasons. First, Hospice Toronto provided necessary financial support to initiate and sustain the CCC initiative. This financial support was primarily directed at funding a new community development coordinator position in St. James Town to lead the CCC initiative. Second, Hospice Toronto was also able to provide scaffolding support through in-kind resources and experience to support the CCC initiative (e.g., administrative support, experience with death, dying, loss, and care, volunteer training experience, etc.). Third, Hospice Toronto was also able to draw on their organizational connections with other local organizations to support the initiation and development of the CCC initiative. For example, Hospice Toronto was able to secure collective office space in St. James Town at 'The Corner', a community hub, through their relationships with other local organizations. In particular, the financial investment from Hospice Toronto in the form of a dedicated community development position was immensely valuable in supporting the CCC initiative. This dedicated position, albeit only part-time, was important given the time-consuming nature of the CCC initiative process. For instance, the relationship and trust building process with members of the St. James Town community took over a year before the CCC initiative began more formally. These findings are similarly echoed by Labonte (1993, p. 63) who wrote, "We must be patient in this group-building, community creating task. It often takes between one and two years before the first 'group' squiggle may form from the disconnected individual dots, group formation occurring when individual self-identify as 'group members'". As both initiating and sustaining the CCC initiative were found to be time-intensive in nature, a paid position was important. This finding from The Photovoice Project contrasts with calls within the health promoting palliative care literature for compassionate community initiatives to be community initiated and led (Public Health Palliative Care International, n.d.-b; Sallnow & Paul, 2014). Rather than deeming organizational initiated and supported approaches to health promoting palliative care as 'lesser', it is important to understand the local context and determine the best course of action 'starting from where people are at.'

In the context of St. James Town there were a number of contextual facilitators and challenges that made the choice for an organizational initiated and facilitated approach to compassionate communities a valuable decision. In the context of St. James Town where many residents are considered low-income (City of Toronto, 2018), it may not be reasonable or ethical to ask community members to voluntarily take on such a significant un-paid role (i.e., the role of the community development coordinator). In reflecting on some of the deeper issues with the demands of community engagement practices, Chambers (1998, p. xvi) cautions that "poor people's time is not costless." It may not always be feasible for community members to voluntarily take on this role in addition to managing precarious work and caring responsibilities particularly in disadvantaged communities. Rather, policy makers and funders should consider the development of 'soft infrastructure' (e.g., building a community identity through hope and trust) as an essential aspect of community-based health promotion initiatives, and one that requires financial investment to support (Kavanagh, Shiell, Hawe, & Garvey, 2020). In particular, the funding that may be required would be dependent on "geographic and social differences in pre-existing levels of soft infrastructure and community readiness for change" (Kavanagh et al., 2020, p. 3). In the context of St. James Town, CCC project members described that one of the facilitators of their engagement in the CCC initiative was their 'shared value in the collective good'. CCC project members shared how different personal factors contributed to their desire to support others in their community. At the same time however, CCC project members also shared how one of the challenges to adopting a compassionate community approach in the context of St. James Town was a feeling of a 'disconnected community'. As one CCC primary carer and neighbourhood helper succinctly described,

> *"In this country you cannot knock the door and ask help, so you need this kind of organization… Individually it's hard… because they are organized, if you call them, or tell them, oh I see somebody, so this kind of, you know, that's really nice. This is a really good organization."* (Farzana, CCC primary carer and neighbourhood helper, individual photo storytelling session)

Adopting an organizational initiated and facilitated approach in the context of St. James Town was an opportunity to overcome this challenge of a 'disconnected community' by creating a vehicle to harness the individual will of community members to contribute to the collective good of their community.

While the role of the organization in supporting compassionate communities is less discussed in the health promoting palliative care literature, organizational support is a core component in both the self-help (Ibrahim, 2006) and lay health workers literature (South, Meah, & Branney, 2012). These fields, while distinct, share some similarities with the field of health promoting palliative care (e.g., a focus on community capacity building). For instance South et al. (2012, p. 288) found that "adequate infrastructure to support people beyond training" and "adequate programme funding" helped to facilitate effective approaches to supporting lay health workers. Similarly, Ibrahim (2006) explained that while collective action is necessary to create new opportunities for community members, the presence of an external actor acting as a catalyst, along with supportive institutional structures, were essential for both supporting and sustaining these newly created self-help opportunities. One of these supportive institutional structures identified as a facilitator in the CCC initiative specifically was the 'flexible and organic approach' adopted by Hospice Toronto as their facilitating framework. One former senior Hospice Toronto Staff member explained, CCC is about planting the seeds and seeing how things grow, recognizing that "*not everyone's going to be involved in the exact same way*". This flexible and organic approach gave CCC neighbourhood helpers the flexibility to support CCC community members with their own judgement, and it also gave them flexibility to try out new approaches. As one CCC neighbourhood helper stated, "*you just test it out*" (Amita, CCC neighbourhood helper). In contrast, while previous research found that 'prescriptive interventions' were less successful at supporting lay health workers (South et al., 2012), flexible and organic organizational approaches to facilitating the CCC initiative proved effective in this thesis.

Although the literature guiding the development of compassionate community initiatives indicates a preference for community, as opposed to organization-led approaches, the findings from the CCC participatory case study demonstrate the value of organization facilitated approaches particularly in a 'disconnected', lower socio-economic status community. In the context of St. James Town, organizational backbone support was a key component of facilitating community capacity to support isolated community members living with a life-limiting illness and/or their primary carers. Rather than decreasing community engagement, the ‘flexible and organic’ backbone support created a valuable channel to harness community energy for collective action. These findings underscore the importance of understanding the unique context of each community in order to determine the best approach to initiating and supporting compassionate community initiatives.

The Connecting Role of the CCC Community Development Coordinator: Scaffolding Support Through the Social Determinants of Health

Another important aspect of scaffolding in the CCC initiative was the way in which the connecting role of the CCC community development coordinator helped to holistically support CCC members by addressing the social determinants of health as part of the compassionate community approach. Social determinants of health are the social and economic factors that influence individual and population health [including but not limited to: income and social status, employment, education, gender, culture, race and racism, etc. (Government of Canada, 2019)]. Addressing the social determinants of health was necessary in the context of St. James Town where community members, many of whom were newcomers and immigrants, experienced financial challenges, overcrowding, poor housing, among other challenges (The Wellesley Institute, 2010). The findings from The Photovoice Project demonstrate that social determinants of health support was necessary to support CCC community members in their wish to be cared for and supported at home in their community. In addition, this support was also important for CCC neighbourhood helpers as well. While CCC neighbourhood helpers were eager to support their community, they also faced certain challenges and required social determinants of heath support themselves. Supporting neighbourhood helpers as part of the CCC initiative was important, because if neighbourhood helpers experienced too many structural challenges themselves, they may not have been able to support the CCC initiative. What the findings from The Photovoice Project elude to is that addressing the social determinants of health among CCC neighbourhood helpers may be a key part of building community capacity (i.e., scaffolding support) to support death, dying, loss, and care in St. James Town.

The CCC community development coordinator took a lead role in supporting CCC members by addressing the social determinants of health in a variety of ways, expanding beyond the scope of more traditional hospice service supports [e.g., volunteer matching, friendly visits, respite support, etc. (Downe-Wamboldt & Ellerton, 1985; Hospice Palliative Care Ontario, 2018b)]. For example, the findings presented in Chapter 7 highlight how the CCC community development coordinator promoted social inclusion, housing stability, and education and employment opportunities. ‘Building off community strengths’ was a key facilitator of the CCC initiative highlighted in the research that helped to support this social determinants of health aspect of the initiative by making connections to local resources.

While the focus on the social determinants of health was a necessary scaffolding support in the compassionate communities approach to health promoting palliative care in the context of St. James Town, few other compassionate community approaches to health promoting palliative care have explicitly highlighted the significance of tackling the social determinants of health in other compassionate community initiatives. For instance, one other study on health promoting palliative care in Australia, also found that community-based organizations played a role in meeting the basic needs of individuals living with a life-limiting illness through food and fuel vouchers (Mills, Rosenberg, & McInerney, 2014). More commonly however, a systematic review of health promoting approaches to palliative care found that meeting basic needs like shelter and food were typically discussed in the context of low resource settings (Sallnow et al., 2016). While palliative care is about providing whole-person care to individuals living with a serious life-limiting illness and endeavouring for the best quality of life, many of the broader social determinants of health that influence our quality of life are rarely addressed by the traditional hospice palliative care system. Indeed, Reimer-Kirkham et al. (2016, p. 294) have argued for a more explicit emphasis on the need for palliative care to address “the social and structural inequities” that directly influence how we live and die. These authors explain that “palliative care tends to discount the needs of those who can be characterized as doubly vulnerable, being that they are both in need of palliative care services and experiencing deficits in the social determinants of health, and as a consequence live with complex intersecting health and social concerns” (Reimer-Kirkham et al., 2016, p. 294). Similarly, Grindrod (2020, p. 95) agrees that the structural constraints that impact an individual palliative care wishes are “seldom recognised” in both palliative care practice and research. As Grindrod (2020, p. 95) explains, “if those dying wish to remain connected to people, possessions and places that are important to them at the end of life, but their care is provided by health services disconnected from the social setting in which their lives are lived, the very structure of that care limits choice.”

While CCC initiative staff were cognizant of the need to address the social determinants of health among CCC members in St. James Town, this support was typically in the form of making connections to different services. Although making connections to health and social services is important for structurally vulnerable communities in terms of addressing immediate needs, this approach to tackling the social determinants of health is limited as such approaches "can neglect the sources of these afflictions—i.e., living under adverse circumstances—doing little to reduce the need for these services" (Raphael, 2011, p. 266). Rather, Raphael (2011, p. 230) strongly advocates for the need to take a more critical and political approach to tackling the social determinants of health and their distribution by exploring the effects of "the influence and power of those who create and benefit from social and health inequalities." Raphael (2011) explains that certain individuals and groups have lobbied for policies that have resulted in increasing inequalities in income, and growing housing and food security (i.e., changing tax structures that have benefited large corporations, easing labour standard and protections, etc.). In the Canadian context, "the problem is that as their power and influence has increased, there has been declining counterbalances to their influence" (Raphael, 2011, p. 230). To counter these powerful influences, increasing public awareness "of the class-related forces that shape public policy" is needed in order to put pressure on policy influencers to adopt social determinants of health supportive public policies (Raphael, 2011, p. 230). Compassionate community initiatives in structurally vulnerable communities are uniquely positioned to advocate for policies that address the social determinants of health to support palliative care as they have a first-hand perspective of the some of the on the ground challenges and opportunities these communities face.

Understanding the local context of St. James Town was essential in tailoring the development and implementation of the CCC initiative in St. James Town to address local challenges and capitalize off local assets. The social determinants of health play an important role in how we live until we die, including in supporting the development of community capacity to care for community members in St. James Town. The findings from The Photovoice Project highlight that is it not only developing economies that need to consider the social determinants of health as part of their approach, but developed economies also need to consider the social determinants of health to address health inequities.

Training and Continuous Learning Opportunities: Scaffolding Support by Making Caring Collective and Visible

Finally, another key aspect of scaffolding support in the CCC initiative was the initial training and continuous learning opportunities organized through the CCC initiative. In particular, the CCC Friday Group, played an important scaffolding role in developing a collective caring culture in the St. James Town community. In addition, the CCC Friday Group helped to make caring more visible and less of an isolating experience. As described in Chapter 7, the CCC Friday Group was a bi-weekly opportunity for all CCC members to come together, share experiences, and learn from one another. In these sessions, it was also an opportunity for CCC neighbourhood helpers to share any challenges they were experiencing and to ask for help from the group. While other health promoting approaches to palliative care have focused on the importance of the initial training in regard to supporting neighbourhood helpers (Abbey, Craig, & Mayland, 2020; Aoun et al., 2020; Kellehear, 2013), a less common feature discussed in this literature case has been the opportunity to regularly come together as a group for continued learning and mutual support.

The CCC Friday Group addressed one of the more commonly cited challenges with caring for someone living with a serious life-limiting illness: that it can be isolating whether as a primary carer (Pohl, Bell, Woods, & Tancredi, 2019; Tebb & Jivanjee, 2000) or a volunteer (Morris, Payne, Ockenden, & Hill, 2017; White & Gilstrap, 2017). Barnes (2012, p. 3) explains that, “Care is so fundamental to our capacity to live together that we simply cannot see its significance and it becomes possible to ignore it.” Traditional hospice volunteer work has been previously described as an isolating experience as this approach “physically isolates [volunteers] from other hospice workers, especially fellow volunteers from which they might create a shared volunteer-specific culture” (White & Gilstrap, 2017, p. 20). In contrast, the CCC initiative addressed this challenge by creating regular opportunities to socialize and connect as a group (i.e., the CCC Friday Group). As these relationships developed among CCC members through the scaffolding support provided by the CCC initiative, the caring provided by CCC neighbourhood helpers expanded from more one-on-one support, to group based support. In turn, this group-based approached further helped to reduce isolation. Interestingly, in The Photovoice Project, isolation was not a challenge highlighted by CCC project members who took part in the research. Similarly, other research from the peer support field has found that “Being connected to an existing group of network, including maintaining connection with course participation was the most helpful feature in putting [intentional peer support] into practice" (Ley, Roberts, & Willis, 2010, p. 16). In addition, research by South et al. (2012, p. 288) also found that successful approaches to supporting lay health workers included "establishing a learning culture"; "making connections to adult education opportunities"; and creating spaces "for people to have fun".

The CCC Friday Group was a valued aspect by CCC members as it created a space to make caring visible and reduce isolation. Other compassionate community approaches to health promoting palliative, regardless of community context, may also benefit from creating opportunities for frequent social connection and continuous learning as a way to reduce isolation and provide another layer of scaffolding support to benefit neighbourhood helpers.

Reflecting on the Significance of Scaffolding Support in the CCC Initiative

The findings from The Photovoice Project provide insight into the importance of scaffolding support in regard to supporting the goals of one compassionate community initiative in an inner city setting. In addition, the findings from this research also provide practical examples as to the types of scaffolding support that were meaningful in supporting the CCC initiative in an inner-city setting. Specifically, organizational backbone support, the connecting role of the CCC community development coordinator, and training and continuous learning opportunities were core aspects of scaffolding necessary for supporting the development of community capacity to care for CCC community members and/or their primary carers in St. James Town.

Understanding the local context was critical for understanding why these types of scaffolding supports were valuable in the context of St. James Town, an inner-city community (i.e., feelings of disconnect, structural vulnerabilities, etc.). Understanding the local context was also important for identifying levers for change (e.g., facilitators such as building off community strength, and the desire among community members to contribute to the collective good, etc.) While these findings are specific to the context of St. James Town, other compassionate community initiatives in similar inner-city settings may find the lessons learned in this research helpful for supporting the development of their initiatives as well. Finally, these findings also draw attention to the need for financial investment in compassionate community initiatives to help support the types of scaffolding support found beneficial in the CCC initiative. Recommendations for future research, policy, and practice will be further discussed in Chapter 9.

IMPACTS OF THE CCC INITIATIVE: THE GENERATION OF SOCIAL AND CULTURAL CAPITAL

In addition to exploring the ‘how’ aspect of the CCC initiative; I also explored the types of impacts that emerged from this approach. As I reflected on the types of impacts that CCC project members documented in the CCC initiative, I noticed that some of the impacts documented were akin to the generation of social capital and cultural capital. I found this to be a significant finding from a health equity perspective, as according to Pierre Bourdieu, it is “the unequal distribution of structurally-based resources (capitals)” that is at the foundation of inequality in society (T. Abel & Frohlich, 2012, p. 237). In this second part of this discussion I draw on Bourdieu’s (1986) capitals theory to explore the significance of the impacts of the CCC initiative in relation to the generation of both social and cultural capital in the context of an inner-city setting. In addition, I also reflect on some of the new types of impacts reported in The Photovoice Project that have not been previously documented in the existing health promoting palliative care evidence base.

The Generation of Social Capital

Reflecting on the types of impacts documented in the CCC initiative, I noted that some of the impacts on CCC members were akin to the generation of social capital. While different definitions and conceptualizations of social capital exist (Hawe & Shiell, 2000; Rosenberg et al., 2014), here, I draw on the definition by Bourdieu (1986, p. 21) who defines social capital as “…the aggregate of the actual or potential resources which are linked to possession of a durable network or more or less institutionalized relationships of mutual acquaintances and recognitions.” It is through membership in a group that individuals have access to the collectively owned capital which in turn entitles them to “credit” (Bourdieu, 1986, p. 21). However, Hawe and Shiell (2000, p. 873) note that social capital is not only “one thing”, and Nahapiet and Ghoshal (1998) have differentiated between structural (i.e., the overall access to people and resources), cognitive (i.e., development of a shared understanding, language, code) and relational (i.e., trust, respect, friendship developed over a history of interaction) forms of social capital.

Exploring the connection between the impacts of the CCC initiative to the generation of social capital was important, as the positive effects of social capital on mental and physical health are well documented in the literature. Reviews of empirical studies exploring the role of social capital on health have found links between social capital and mental and physical health (Almedom, 2005; Ferlander, 2007; Islam, Merlo, Kawachi, Lindström, & Gerdtham, 2006). Further, while living with a life-limiting illness has been found to reduce social connections (Ferlander, 2007), research has also found that social capital can play a significant role among people who are living with an illness (e.g., a better chance of survival post-myocardial infarction) through the provision of higher levels of emotional support (Berkman, Leo-Summers, & Horwitz, 1992). In addition, other research has also found a positive relationship between sense of belonging in one's own local community (an aspect of social capital) and happiness (Leung, Kier, Fung, Fung, & Sproule, 2011).

In The Photovoice Project, CCC community members, CCC primary carers, and CCC neighbourhood helpers reported impacts related to the generation of social capital. For example, one impact of the CCC initiative was that both CCC community members living with a life-limiting illness and CCC primary carers reported 'increased neighbourly connections' as a result of their engagement in the CCC initiative, a structural form of social capital. These increased connections to neighbours in the community were valuable in the context of St. James Town where social isolation had been cited as a concern for residents (Canadian Public Health Association (CPHA), n.d.), and where over half of seniors live alone (City of Toronto, 2018). In turn, the increase in neighbourly connections contributed to a range of impacts on the health and well-being of CCC community members and/or their primary carers that were important for supporting their wish to remain in their community despite their health challenges. For instance, CCC community members and/or primary carers described 'increased connections to health and social services' as an impact of being a part of the CCC network. This connection to resources through the CCC network was similarly a structural type of social capital. In addition to increased access to community resources, CCC community members and/or their primary carers also reported impacts on their health and wellbeing including: 'feeling cared for' and 'positive impacts on mood', both being relational forms of social capital. For example, Roxana, a CCC community member who was a newcomer to Canada described how, *"Prior to [joining the CCC initiative], [she] felt lonely, but now, [she doesn't] feel lonely. [She feels she has] someone"*

(Roxana, CCC community member, informal translation). In addition, CCC community members and primary carers also reported how they "felt light", didn't feel as much "mental pressure" and how they "felt accepted" and had someone to "depend on" despite challenges with living with a life-limiting illness.

Similarly, CCC neighbourhood helpers also reported positive impacts on health and wellbeing as a result of being part of the CCC network. Rather than CCC neighbourhood helpers describing feelings of isolation in their caring role, CCC neighbourhood helpers reported how their participation had a 'positive impact on mood' (a relational type of social capital). Esi, a CCC neighbourhood helper, described how she would often call the CCC community member she was supporting when she was having a stressful day as a way to relax and laugh. Similarly, CCC neighbourhood helpers also described how they 'felt supported' (a relational type of social capital) by other members of the CCC community when they needed help as well, such as asking for support during the CCC Friday Group session.

The generation of social capital, as an impact of the CCC initiative, was a significant finding as more commonly, caring has been described as a drain on social capital (Horsfall et al., 2012a). For example, Johansson, Leonard, and Noonan (2012, p. 44) explain that,

> *"When there is inadequate funding of aged care services by the state, then social capital may be seen as a substitute for economic and human capital. Caring, therefore, is seen as a drain on capital, whether it be economic or social capital."*

Similarly, other studies have also reported that hospice-palliative caregiving, whether as a family carer or hospice volunteer, can lead to feelings of social isolation among other difficulties [e.g., financial strain, emotional distress, etc. (MacLeod, Skinner, & Low, 2012; Mason & Hodgkin, 2019; Morris et al., 2017)]. In particular, research on care has also found that care work can be particularly isolating and disempowering for racialized women, thereby further decreasing their social networks and agency (Ahmed & Rees Jones, 2008). In contrast however, the findings from The Photovoice Project demonstrate that caring in the community can generate and strengthen social capital for those involved, including minority groups, as was the case in the CCC initiative.

In the context of compassionate communities, the generation of social capital is a commonly cited impact of this health promoting approaches to care (Horsfall et al., 2012a;

Johansson et al., 2012; Rosenberg et al., 2014; Sallnow, 2017). Horsfall et al. (2012a) note that in order to avoid the trap of caregiving being isolating and exploitative, caregiving requires ongoing support. The findings from The Photovoice Project similarly found that the scaffolding support provided by the community development coordinator was essential for providing continuous support to CCC neighbourhood helpers. Similar to the findings of my thesis, Sallnow (2017) also found that reciprocity between community members was a key aspect of generating social capital in their research exploring the impact of a compassionate community initiative. Sallnow (2017, p. 137) also noted that the reciprocity between CCC members was not experienced necessarily in a linear one-on-one relationship, but that "support was often given to one member of the network and received from a different member". In the CCC initiative, this network-based approach to care was also reported, and helped to mitigate some of the isolating experiences of traditional caregiving which in turn supported the generation of social capital.

The Generation of Cultural Capital

In addition to impacts related to the generation of social capital, I also observed that some of the impacts on CCC neighbourhood helpers specifically related to the generation of cultural capital. Cultural capital is defined as "the accumulation of knowledge, behaviors, and skills that a person can tap into to demonstrate one's cultural competence and social status" (Cole, 2020, para 1). According to Bourdieu (1986) there are three forms of cultural capital: embodied (e.g., knowledge/skills), objectified (e.g., cultural goods such as books or pictures), and institutionalized (e.g., educational and vocational certificates or professional qualifications). Interestingly, within the broader health promoting palliative care literature, the generation of cultural capital has not been discussed as an impact of this approach. In The Photovoice Project, CCC neighbourhood helpers discussed two impacts akin to the generation of cultural capital: 'increased knowledge and skills' and 'professional development opportunities' (Chapter 7).

Exploring the connection of the impacts reported in The Photovoice Project to the generation of cultural capital was significant for a number of reasons. While research exploring associations between cultural capital and health is limited (Thomas Abel, 2007), early findings demonstrate that cultural capital has been found to have positive impacts on health (Ohashi, Taguchi, Omori, & Ozaki, 2017; Pinxten & Lievens, 2014; ten Kate, de Koster, & van der Waal, 2017). For example, research has found beneficial impacts of cultural capital on self-reported health, survival and mortality, and mental health (Pinxten & Lievens, 2014). While the mechanism to understand how cultural capital impacts health is less understood, ten Kate et al. (2017, p. 64) suggest that “an individual’s cultural capital shapes a sense of ‘cultural entitlement,’ which entails a sense of being a relevant and legitimate citizens who matters in society.” Indeed, other research has also found that cultural capital strengthens an individuals’ sense of belonging (Ohashi et al., 2017), an influencing factor on health (Kitchen, Williams, & Chowhan, 2012). In addition, research exploring the connection between cultural capital generation and employment success show some positive connections, although this area of study requires additional investigation (Reitz, 2007).

In The Photovoice Project, CCC neighbourhood helpers shared how they developed ‘increased knowledge and skills,’ an embodied form of cultural capital generation. For example, CCC neighbourhood helpers discussed knowledge and skill development related to palliative care such as knowledge around advance care planning, naming a power of attorney, and knowledge and skills around how to support someone experiencing grief and bereavement. This type of impact in the CCC initiative has similarly been a common impact of compassionate community initiatives reported in the literature. For instance, a systematic review exploring the impact of new public health approaches to end of life care similarly found that “individual learning and personal growth” was a common impact of this approach (Sallnow et al., 2016, p. 7). Similar to the CCC participatory case study, this review also identified “knowledge, skills and attitudes to death and dying” as a subtheme in their systematic review of the evidence base (Sallnow et al., 2016, p. 6). In particular, many studies included in this review noted a change in attitude to dying at home with many participants describing how they realized it was a possibility after caring for someone at home at the end-of-life (Sallnow et al., 2016). However, increased knowledge and skills related to death, dying, loss, and care was only one type of cultural capital related impact identified in the CCC participatory case study.

In addition, CCC neighbourhood helpers, many of whom were newcomers, also reported the accumulation of cultural capital that was valuable to helping them settle and establish themselves in St. James Town. As previously reported in the findings, Kamya (a CCC neighbourhood helper who recently immigrated to Canada) described how she accumulated linguistic cultural capital—a type of embodied cultural capital—though her participation in the CCC initiative. She described that through her relationship with the CCC community member she was paired with, she was able to strengthen her English language skills which was important for her goals of becoming a nurse in Canada. Similarly, other CCC neighbourhood helpers, who were also newcomers to St. James Town, also described they developed a better understanding of the 'Canadian context'(i.e., local norms, an aspect of cultural capital) through their participation in the CCC initiative. Specifically, CCC neighbourhood helpers gave examples of how they developed a better understanding of the Canadian context such as how to file income taxes, how to access health and social services, and how to visit local museum and cultural sites, among others. These examples of cultural capital were important for promoting social inclusion among CCC neighbourhood helpers who were newcomers to St. James Town. However, Reitz (2007, p. 30) has also drawn attention to an important critique on the impact of cultural capital in the context of newcomers with respect to cultural assimilation, and in particular "Anglo-conformity". While this critique of cultural capital is valid, it is also beyond the scope of this thesis.

In addition to 'increased knowledge and skills', CCC neighbourhood helpers also shared how 'professional development opportunities' were also an impact of their engagement in the CCC initiative. In the context of the CCC initiative, I considered 'professional development opportunities' to be an institutionalized form of cultural capital [i.e., "the academic qualifications that establish the value of a the holder" (Jeannotte, 2001, p. 38)]. For instance, CCC neighbourhood helpers shared how they felt that being part of the CCC initiative would strengthen their resume, or application for a post-secondary/post-graduate degree, and help them progress with their career and future goals. Indeed, the key value of institutionalized cultural capital is the significance this form of capital has in the labor market (Reitz, 2007). The CCC community development coordinator recognized the role the CCC initiative could play in supporting the accumulation of institutionalized cultural capital, particularly in St. James Town a "diverse community" and "a hub for newcomers" where residents are "trying to settle themselves." As previously highlighted in Chapter 7, the CCC community development coordinator shared that.

> *"…if people can find a reference, they can find a job…. Some people they're looking for their opportunity, and I'm looking for my opportunity. If I can help someone that is helping me, to train them, you know, evaluating them on their performance of, supporting them, upgrade [their] resume, so like sometime I help them to do this too – I*

> *connect them to employment agencies and something."* (Alia, CCC community development coordinator)

According to Bourdieu, the accumulation of cultural capital can, in turn, help to increase the resonance between CCC neighbourhood helpers 'habitus' (i.e., the embodiment of cultural capital) and their field (e.g., the new country they are living in), which in turn can create opportunities for upward mobility and growth (Bourdieu & Wacquant, 1992). As Veenstra and Burnett (2014, p. 188) explain, when there is strong resonance between an individual's 'habitus' and their 'field' (i.e., akin to being a fish in water) a new opportunity is afforded for "creative, adaptive and future-looking practices" (i.e., an increase in opportunities). The generation of embodied and institutionalized cultural capital identified in The Photovoice Project is a unique finding specific to the particular context this compassionate community initiative was situated in. In the St. James Town context in particular, finding opportunities to engage members of the community in the CCC initiative through cultural capital development opportunities was a mutually beneficial aspect of this initiative. The CCC community development coordinator recognized the importance of creating mutually beneficial relationships, indeed, reciprocity was a key facilitator of the CCC initiative identified in this research. The findings from The Photovoice Project expand the scope of potential impacts that can emerge from compassionate community initiatives, particularly in the context of inner-city settings.

Other compassionate community initiatives in a similar inner-city setting may also benefit from incorporating mutually beneficial processes that help to generate cultural capital among newcomer members. Reflecting on the types of core aspects of the CCC initiative that likely played a role in supporting the development of cultural capital, I suggest that the "initial training and continuous learning opportunities" were key facilitators. While training is a common feature of compassionate community approaches to health promoting palliative care (Gomez-Batiste et al., 2018; Kellehear, 2013; Sallnow et al., 2016), there is less discussion on the specific nature of training and the impact both training and continuous learning opportunities can have on those involved (e.g., neighbourhood helpers or community volunteers). In the CCC initiative, the CCC community development coordinator took the time to really get to know the different CCC members, and their aspirations. In turn, she was able to facilitate continuous learning opportunities based on members interests as well as help to make additional connections. Indeed, findings from the peer support literature echo similar benefits of this continuous learning approach. For example, one study exploring approaching to supporting lay people in public heath roles also found that providing learning and professional development opportunities were successful approaches to support lay people (South et al., 2012). In particular, the authors of this study identified three factors related to learning and professional development that were particularly valuable:

- "Designing flexible training packages which enable participation of people traditionally excluded from the education system"
- "Establishing a learning culture in which participants are committed and interested" and,
- "Making connections to adult education opportunities both for self-development and as a route to employment" (South et al., 2012, p. 288).

Similarly, other research exploring the role of community peer support on health literacy and health equity also found that peer supporters "[valued] training when they perceive it to be of personal benefit to them" and when it was "tailored to meet individual and group learning needs" (Harris et al., 2015, p. 71). In the CCC initiative, it is likely that the responsiveness of the training and continuous learning opportunities played a critical role in supporting the generation of cultural capital among CCC neighbourhood helpers.

Reflecting on the Significance of Social and Cultural Capital Generation in Compassionate Community Initiatives in Inner-City Settings

The findings from The Photovoice Project demonstrate that it is possible for compassionate community approaches to health promoting palliative care to generate both social and cultural capital as impacts of this approach to community care. The generation of social and cultural capital was particular significant in the context of St. James Town, an inner city setting, where isolation is high and many community members experience structural vulnerabilities (i.e., low socio-economic status, newcomer status, etc.). These issues can further exacerbate the challenges of living with a life-limiting illness and can limit an individual ability to remain at home in their community. Drawing on Bourdieu's capitals theory, T. Abel and Frohlich (2012) explain that the scope of opportunities available to an individual is directly impacted by their access to different forms of capital. In the context of palliative care, an individual's wish to be cared for in their community and remain at home is limited by their access to economic, social, and cultural capital. Thus, individuals experiencing structural vulnerability who have limited access to economic, social, and cultural capital may subsequently not have the ability to be cared for at home in their community and may not be able to realize their choice.

Therefore, in order to promote health equity in palliative care in structurally vulnerable communities, it is important for initiatives, including compassionate community approaches to health promoting palliative care, to focus on “the promotion of the different forms of capital…that improves the range of options for health promoting agency” (T. Abel & Frohlich, 2012, p. 243). The findings from The Photovoice Project provide an in-depth understanding of the types of processes (including the significance of scaffolding support) that may lead to the generation of both social and cultural capital. How community care is structured and facilitated is critical, as supportive experiences can lead to the generation (rather than then depletion) of social capital in care work. Indeed, Johansson et al. (2012, p. 49) suggests that,

> *“Social capital may be a good litmus test for context of care, because social capital generation requires context that are not coercive, involve trustful community networks, trust and shared values around caring and allow for the exercise of agency.”*

In the CCC initiative, it is possible that the generation of social capital may subsequently increase CCC community members and/or their primary carers options to realize their choice to be cared for at home. For CCC neighbourhood helpers, it is also possible that the generation of cultural capital can also have benefits for upward mobility and growth as well.

Finally, a novel impact of compassionate community approaches to health promoting palliative care identified in The Photovoice Project was the generation of cultural capital among CCC neighbourhood helpers. This was a significant finding in the context of St. James Town where many CCC neighbourhood helpers were hoping to establish themselves in a new country. Increasing CCC neighbourhood helpers cultural capital helped to increase their opportunities for settlement (e.g., new employment/education opportunities). Thus, the CCC initiative was not only focused on promoting the wellbeing and increasing opportunities for CCC community members and/or their primary carers, but the CCC initiative took a whole community approach and also supported CCC neighbourhood helpers as well. It is possible that if potential neighbourhood helpers face too many barriers to engagement, or do not see a mutual benefit, compassionate community initiatives will struggle to build community-capacity to care for others. It is important for other compassionate community initiatives situated in an inner-city setting to focus on both the barriers and drivers for community member engagement in these types of community-based approaches to care. Facilitating processes that generate social and cultural capital may be one such beneficial approach.

THE IMPORTANCE OF UNDERSTANDING LOCAL CONTEXT: THE VALUE OF CASE STUDY RESEARCH

Adopting a participatory case study approach was critical to understanding the nature, impact, facilitators, and challenges of the CCC initiative in context. Poland, Krupa, and McCall (2009, p. 59) define context, broadly, as "the circumstances or events that form the environments within which something exists or takes place." While positivist approaches to research have generally aimed to uncover general laws of cause and effect thereby removing individuals from the contexts in which they live (Raphael & Bryant, 2002); health promotion research is situated in an understanding in which "community context is not a background within which an intervention occurs but is rather the focus of understanding" (Trickett, 2019, p. 206). The Photovoice Project was rooted in a contextualist approach to research guided by an understanding that,

> *"human actions are embedded in a context of time, space, culture, and the local tacit rules of conduct…To unlock the mysteries of what makes an event meaningful we must consider, via methodological and theoretical pluralism, the wider context that "allows" or "invites" the occurrence of that event and renders it socially intelligible" (Rosnow & Georgoudi, 1986, p. 4, in Trickett, 2019)*

The participatory case study approach used in this research provided a more nuanced understanding of why certain elements of the nature of the CCC initiative were vital in the context of St. James Town, an inner city setting. For example, addressing the social determinants of health of CCC members was vital in this context where many members experienced various structural vulnerabilities. In addition, by gaining a deeper insight into the local context of St. James Town, it was possible to explore the deeper significance of some of the impacts of this approach. As an example, the professional development impacts described by CCC neighbourhood helpers (a type of cultural capital) were significant as many CCC neighbourhood helpers were newcomers trying to settle themselves in St. James Town. In addition, understanding the facilitators and challenges from the perspective of CCC project members also helped to provide a richer understanding of what aspects of the local context were important in shaping the nature and impacts of the CCC initiative. As Trickett (2019, p. 206) has long advocated, understanding community context is "perspectival" and is a reflection of diverse perspectives from those involved. Thus, participatory methods, a guiding approach used this in this research, was also important in the case study design in order to gain a deeper understanding of community context from different points of view.

SUMMARY

In this chapter, I explored the significance of the findings of The Photovoice Project in relation to their contribution to enhancing our understanding of compassionate community approaches to health promoting palliative care. In particular, the findings from this research highlight the significance of the 'scaffolding supports' needed in inner-city communities to build community capacity to support isolated community members living with a serious life-limiting illness and/or their primary carers. However, in order to initiate and sustain these scaffolding supports, investment (e.g., from the welfare state) is essential.

In addition, the findings from The Photovoice Project also helped to make the case for why such financial investments in scaffolding support are beneficial. Specifically, this research contributed to an emerging evidence based demonstrating that compassionate community initiatives in inner-city settings have the potential to generate social and cultural capital as impacts of this approach. While more research is needed to confirm these findings, the generation of social and cultural capital, a structurally based resource, helped to increase CCC members opportunities to realize their choices (these goals differed by CCC member). In order to address inequities in palliative care experiences, compassionate community initiatives should look at ways to generate social and cultural capital in order to enhance community members opportunities to realize their choices.

Finally, a participatory case study approach was vital for bringing context to the forefront and deepening our understanding of the nature and significance of the impacts of the CCC initiative through a more complexity informed lens. In Chapter 9, I outline key implications for practice, policy, and research in terms of further developing, and taking action on, health promoting palliative care, including compassionate community approaches.

CHAPTER 9: RECOMMENDATIONS FOR PRACTICE, POLICY, AND RESEARCH FROM THE CCC PARTICIPATORY CASE STUDY

OVERVIEW

In this chapter, I outline a series of recommendations for practice, policy, and research based on the findings from Cycle 2: The Photovoice Project exploring the nature, impact, and facilitators/challenges of the CCC initiative in St. James Town. These recommendations for practice, policy, and research are based on the experiences of CCC project members and organization staff who joined this research project. They are also based on my own reflections as a researcher embedded in the process, and informed by the scholarly literature. However, before outlining this series of recommendations, I briefly debunk a popular myth that it is not possible for a single case to contribute to scientific knowledge and policy development. I also make the case for the value of case study research in furthering our understanding of health promoting approaches to palliative care practice, policy, and research.

THE CONTRIBUTION OF CASE STUDY RESEARCH TO PRACTICE, POLICY, AND RESEARCH DEVELOPMENT

One of the common myths of case study research that continues to persevere is that you cannot generalize from a single case, therefore, case studies are not useful in policy making and scientific development (Flyvbjerg, 2006; Simons, 2009). While there is increasing receptivity in policy-making contexts to objectivist research approaches with large sample sizes and experimental methods "that promise to provide evidence that is conclusive", this is not the only criterion in influencing policy (Simons, 2009, p. 169). Simons (2009, p. 169) argues that "even if findings from large sample studies appealing to objectivist ways of knowing are preferred, case studies provide an understanding of the process and context…that may be needed to accurately interpret the meaning of findings gained through other methodologies." Or, as Flyvbjerg (2006, p. 221) bluntly states, "…in the study of human affairs, there appears to exist only context dependent knowledge…"

Generalizing from the single case is about "portraying the case in its particularity and with sufficient context to enable others, whether policy makers or practitioners, to engage with the issues in the process of generalizing to their own or similar context or for their own purpose" (Simons, 2015, p. 177). This type of approach is rooted in a naturalistic approach to generalization that relies on an individual's tacit knowledge to allow them to identify similarities and differences in the case in order to create new understandings (Simons, 2015). In Cycle 2: The Photovoice Project, the aim was to understand the uniqueness and particularity of the case through an in-depth portrayal of different CCC project member perspectives in context. Simons (2015) argues, it is through an understanding of the particular in sufficient detail that it is possible to discover something universal. This is the paradox of case study research, and while it might not be familiar to those in academic research contexts, it is how we frequently learn from novelists and artists. MacDonald and Walker (1975, p. 3) explain that, "case study is the way of the artist, who achieves greatness when, through the portrayal of a single instance, locked in time and circumstance, he communicates enduring truths about the human condition." It is in this spirit, generalizing from the particular of The Photovoice Project, that the following recommendations for practice, policy, and research are made.

RECOMMENDATIONS FOR PRACTICE

The findings from The Photovoice Project highlight a number of unique aspects of the CCC initiative that may be valuable for other compassionate community initiatives situated within inner-city settings. While many of the lessons learned from The Photovoice Project were previously presented in the findings under facilitators and challenges, here I highlight three key recommendations:

1. Compassionate community initiatives (regardless of setting context) should consider integrating group-based activities as a key component of this approach. In the CCC initiative, group-based activities were valuable for a number of reasons. For example, group-based activities such as the CCC Friday Group, increased the community visibility of care work and decreased social isolation. These group-based activities created an opportunity for all CCC members to share their experiences with others and ask for advice from the group. In addition, the continuous learning opportunities facilitated through the group-based sessions, was a vehicle for the generation of cultural capital. In addition to the generation of cultural capital, these group-based activities created an opportunity for all CCC members to come together which in turn helped to generate

social capital in the process. Compassionate community initiatives should explore strategies to generate social capital (e.g., through group-based activities) as the generation of social capital is the “litmus test” for creating supportive compassionate community environments that are “not coercive, involve trustful community networks…[and allow] for the exercise of agency” (Johansson et al., 2012, p. 49).

2. Compassionate community initiatives in inner-city settings would benefit from building off community strengths (a facilitator identified in this research) in order to holistically support community members from a social determinants of health lens. Rather than re-inventing the wheel, compassionate community leaders should begin by mapping local assets and building community connections among different organizations such as: housing, settlement, health, etc. Addressing the social determinants of health of CCC members was important for supporting community members living with a life-limiting illness and/or their primary carers in their wish to remain at home. Additionally, addressing the social determinants of health of CCC neighbourhood helpers who may also be structurally vulnerable, could be seen as a way to build community capacity for neighbourhood helpers to engage in caring for others in their community. Compassionate community initiatives in inner-city settings should consider strategies to address the social determinants of health as part of a compassionate community approach.
3. Compassionate community initiatives, particularly those in inner-city settings, should also consider including a health equity advocacy component as a key aspect of this approach in order to “[crack] the nut on health equity” (Baum, 2007, p. 90). As I found in The Photovoice Project, the CCC community development coordinator, had an ‘on the ground’ perspective of the various structural challenges many CCC members were experiencing. While the CCC community development coordinator played a critical role in connecting CCC members to various social determinants of health supports, this approach on its own does not address the root causes of these inequities. Community groups or organizations that are helping to facilitate this community approach can use their ‘on the ground’ knowledge and their own organizational position to raise awareness about the inequities in palliative care experiences they are seeing in their community. Further, larger communities of practice, such as the Compassionate Communities Community of Practice in Ontario (Hospice Palliative Care Ontario, 2018a) are even

better suited to lead these advocacy efforts from a larger collective voice. Advocacy is one strategy that organizations or community groups engaged in compassionate community approaches to health promoting palliative care can take to support a health equity mission and contribute to advocating for broader structural changes at the policy level.

RECOMMENDATIONS FOR POLICY

In Canada, the federal government's recent action plan on palliative care includes a statement on supporting "the growth of emerging compassionate communities" and exploring "ongoing work with the compassionate community movement to increase the spread of successful initiatives across Canada" (Health Canada, 2018, p. 3). The findings presented in The Photovoice Project can support the implementation of this action plan by highlighting key considerations for policy that are needed to meaningfully support compassionate community approaches to health promoting palliative care in Canada. These recommendations are as follows:

1. There is a need for meaningful investments in compassionate community approaches to health promoting palliative care. The findings from The Photovoice Project demonstrate the valuable role communities can play in supporting those living with a life-limiting illness. In particular, these supports are essential for those who do not have other family or friend support. The CCC initiative demonstrates the value of investing in initiatives that increase community action to support those living with a life-limiting illness. These types of initiatives take an upstream approach to palliative care by building supports early on. However, these types of collective activities do not just sporadically self-organize. Health promoting palliative care approaches, while community-driven, require leadership support that in turn requires investment (Ibrahim, 2006). Therefore, it is important for palliative care policy in Canada to recognize and invest in "the diversity of contexts in which care happens", in particular for people in which family care is not a possibility (Barnes, 2012, p. 90). Furthermore, an equity focused investment should give priority to investing in compassionate community initiatives that support vulnerable populations.
2. In order to meaningfully support compassionate community initiatives in Canada, a bottom-up and top-down approach is needed. While the federal governments increasing interest in compassionate community approaches to heath promoting palliative care is

promising, it is important that policy support for these initiatives is situated within a broader social determinants of health action plan. The findings presented in The Photovoice Project highlight the types of social determinant of health supports, such as access to affordable housing, that are necessary for reducing inequities in death, dying, loss, and care experiences. While the findings presented in this thesis demonstrate the value of bottom-up approaches to supporting individuals living with a life-limiting illness, top-down approaches are required to address broader structural inequities that directly influence individuals' choices for palliative care. A bottom-up and top-down approach, or what Baum (2007, p. 92) refers to as the "nutcracker effect", is a key strategy to take action on health inequities in palliative care through the social determinants of health. Any policy failure to acknowledge the structural supports needed as part of a compassionate community approach can further encourage a neo-liberal agenda whereby the responsibilities of government are further downloaded on to communities (DeFilippis, 2010).

3. If governments chose to invest in compassionate community approaches to health promoting palliative care, there will be a need to reconceptualize impact (and accountability frameworks) from a health promotion (rather than medical) lens to be consistent with this approach. In particular, funders will need to recognize that health promoting palliative care initiatives take time to build. For example, the CCC initiative in St. James Town, now in its tenth year, took at least one year of relationship building in the community before any formal project could be started. This is not unusual for community empowerment initiatives (Labonte, 1993; Minkler, 1985). As such, health promoting palliative care initiatives in their early stages should be assessed according to changes in group dynamics such as: "stronger group identity, role differentiation within the group, clarity over norms, identification of issues, management of group functions and organization", among others (Labonte, 1993, p. 64). In addition, as health promoting palliative care initiatives develop, there will be a need to identify frameworks that better capture impact that is meaningful to the community, and that also recognizes the organic nature of these community approaches. Using the traditional hospice volunteer accountability frameworks that view hospice volunteers as mini professionals (Guirguis-Younger et al., 2005) (i.e., tracking number of hours spent and visits) does little to

capture broader community impacts. Governments should partner with practitioners and researchers to develop frameworks that better capture what is meaningful to community.

RECOMMENDATIONS FOR RESEARCH

Finally, I reflect on a number of recommendations for future research on compassionate community approaches to health promoting palliative care:

1. While there is a plethora of theoretical literature on compassionate community approaches to health promoting palliative care, there is a need for additional empirical research exploring the nature, impact, facilitators, and challenges of compassionate community approaches to health promoting palliative care. To the best of my knowledge, The Photovoice Project is the first empirical work to document the nature and impacts of compassionate community initiatives in an inner-city setting. Additional research on compassionate community initiatives in inner-city settings would be valuable to make cross-case comparisons of findings. In particular, additional compassionate community research is needed to better understand how this approach can contribute to reducing inequities in palliative care experiences.
2. As part of this empirical exploration, I recommend future research should consider adopting an intersectionality lens. Research from an intersectionality lens assumes that "inequities are never the result of single, distinct factors. Rather, they are the outcome of intersections of different social locations, power relations and experiences" (Hankivsky, 2014, p. 2). Taking an intersectionality lens would address the limited equity considerations taken in the existing health promoting palliative care evidence base, a critique highlighted in Chapter 2. A core aspect of an intersectionality lens is the need for multi-level analyses that connect the experiences of the individual to higher level structures and systems which reveal how power relations are not only shaped, but also experienced (Hankivsky, 2014). Future research in compassionate community approaches needs to situate this approach to health promoting palliative care within the broader social context to acknowledge the role these broader structures and systems play in influencing inequities in palliative care. Hankivsky and Cormier (2019) recommend a number of frameworks for how to incorporate an intersectionality lens to public policy analysis and offer helpful guiding questions for research development as well.

3. Future research should also explore the development of flexible evaluation frameworks to capture the impact and complexity of health promoting palliative care approaches. In addition, a commonly applied framework could be useful for comparing impacts across different contexts. However, any sort of evaluation framework needs to account for the complexity of local context, as "understanding social context is vital for building public health action particularly where communities live in disadvantaged circumstances" (South et al., 2020, p. 12). In Canada, Pfaff et al. (2020) and colleagues have developed "the health impact change model" as an implementation and evaluation framework for compassionate community approaches in Canada. The health impact change model considers population level impacts, community impacts, health system impacts, and patient/care partner impacts (Pfaff et al., 2020). Included in this model is a series of different quantitative instruments that can be used to assess impacts at these various levels. However, these quantitative instruments on their own can be prone to "context stripping" in which "the individual—his or her perspective behaviours and health status—becomes removed from the rich and complex environments, including communities, to which they are linked" (Raphael & Bryant, 2002, p. 193). Qualitative approaches, such as case study or ethnographic methods, are necessary for developing a more complexity informed understanding of the nature and impacts of health promoting palliative care approaches (Raphael et al., 2001; South et al., 2020). One possible approach from an equity perspective would be to explore how different investments in capital (e.g., social, economic, and cultural) increase community members opportunities to live the life that is meaningful for them. For example, for community members living with a serious life limiting illness, this may be the opportunity to stay at home in their community. On the other hand, for neighbourhood helpers who are newcomers, this may mean opportunities for employment. As T. Abel and Frohlich (2012, p. 241) suggest connecting capitals to opportunities that are important to individuals "rather than to pre-fixed and narrowly specified health targets, brings to bear a key aspect of agency that is often neglected in social inequality research and interventions, that is, having options to choose from." Researchers may benefit from drawing on Sen's (1993) capabilities approach. The main claim of the capability approach is that "assessments of the well-being or quality of life of a person, and judgements about equality or justice, or the level

of development of a community or country, should not primarily focus on resources, or on people's mental states, but on the effective opportunities that people have to lead the lives they have reason to value" (Robeyns, 2006, p. 351). In particular, participatory approaches to research may be best suited to explore impact from an 'opportunities' perspective. For Sen, central to the capability approach was creating participatory spaces for individuals to debate and decide what capabilities were meaningful for themselves (Deneulin & McGregor, 2010; Sen, 2004). From this starting point, health promoting palliative care evaluation frameworks could start by identifying the capabilities that were important to the particular group, and use the capabilities that were selected by the group as indicators to assess the impact of the health promoting palliative care approach. Rather than using an a priori framework to assess impact, the capabilities approach helps to guide impact assessment in a context-specific manner putting freedom and agency at the forefront (Ibrahim, 2006).

SUMMARY

In this chapter, I argued that by understanding the particularities of the CCC initiative, it was possible to discover something universal to inform future practice, policy, and research in the field of compassionate community approaches to health promoting palliative care. A theme across these recommendations is the need for those in practice, policy, and research to consider the interconnections between the individual, community, and broader structural systems in order to address inequities in palliative care experiences. The recommendations highlighted in this chapter will support the future development of the field of health promoting palliative care from a health equity lens.

This chapter concludes Cycle 2: The Photovoice Project. In Chapter 10, I use Cycle 1: Grounding and Cycle 2: The Photovoice Project as a case study to explore the ripple impacts that emerged from engaging in a participatory research process.

CHAPTER 10: CYCLE 3—RIPPLE IMPACTS

OVERVIEW

Cycle 3: Ripple Impacts is the final loop in the CCC participatory case study (see Figure 10.1). Using an ecological lens, the purpose of Cycle 3: Ripple Impacts was to:

1. describe how participatory ripple impacts were documented across the CCC participatory case study; and
2. describe the scope of participatory ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of the research and explore connections between ripple impacts.

In this chapter, I define PHR as research done with people whose life or work is the focus of the research in an active and meaningful way across all phases of the research process (Wright et al., 2018). A more thorough discussion of the principles and values of PHR was previously presented in *Chapter 3: Critical Methodological Overview*.

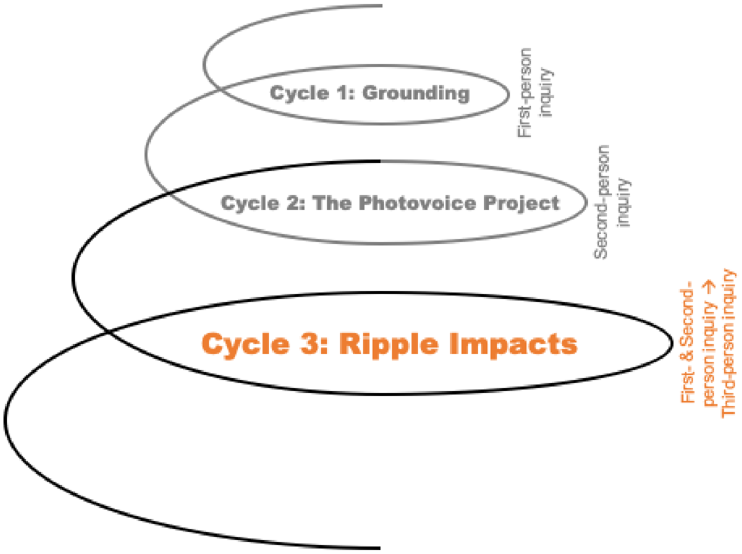


Figure 10.1: Cycle 3 – Ripple Impacts

In this final loop of the CCC participatory case study, I begin by presenting a review of the literature on the current state of evidence on ripple impacts in PHR approaches from an ecological lens. An ecological lens is essential for exploring the ripple impacts that emerge from

PHR processes because of the interdependence, or relational principle that underpins PHR (Trickett & Beehler, 2017). As PHR initiatives aim to create some sort of change in the settings they are facilitated within, change in one part of the setting can cause a system disruption, which can cause ripple impacts across different segments of the specific setting (Trickett & Beehler, 2017). These different segments and settings come together in an ecology surrounding the PHR initiative, necessitating an ecological lens. In this thesis, I use the term ripple impacts (rather than only 'impacts') to highlight the relational or interdependent nature of 'action' in PHR and to expand the search for impacts in PHR beyond individual level impacts, to also include the search for impacts across multiple ecological levels (Trickett, 2019; Trickett & Beehler, 2017).

In the review of literature presented in this chapter, I first start by exploring why it is of particular importance for participatory health researchers to be able to document and articulate the ripple impacts of their own practice. Next, I provide a summary of the different types of participatory ripple impacts that have been previously documented in PHR studies. I conclude this knowledge synthesis by discussing some of the challenges with assessing ripple impacts in PHR. This review of the literature sets the rationale for the focus of Cycle 3: Ripple Impacts.

Next, I use the earlier cycles of the CCC participatory case study (Cycles 1 and 2) to describe how I documented ripple impacts across the study. In addition I present the scope of ripple impacts that emerged during the research using an ecological lens to guide the analysis. In doing so, I assess the catalytic validity of the CCC participatory case study [i.e., the extent to which the research can create new possibilities for social action (Sohng, 1996; Springett et al., 2011)]. As part of this process, I reflect on the ripple impacts that emerged from early cycles of the CCC participatory case study in relation to the participatory nature of this research project. I also explore the connections and relationships between the various ripple impacts at different ecological levels drawing on key concepts from Laverack's (2009) community empowerment framework. This chapter contributes to a growing evidence base exploring strategies on how to document ripple impacts and articulating the types of impacts that can ripple out from a research project informed by PHR principles.

LITERATURE REVIEW

The Pressure to Demonstrate Research Impact

The pressure to demonstrate research impact is not unique to only PHR. Internationally, there is increasing pressure to demonstrate research impact through improvements in policy, practice, and health outcomes in order to substantiate research value to funding organizations and the wider community (Cook et al., 2017; Milat et al., 2015; Penfield, Baker, Scoble, & Wykes, 2013). On the flip side, there is also pressure that policy and practice developments are evidence-based and informed by research (Banks et al., 2017). While research impact has traditionally been focused on counting the number of papers produced, assessing the impact factor of journals, and counting the number of citations on a publication (Milat et al., 2015); it now includes exploring effects, changes, or benefits to the "economy, society, culture, public policy or service, health, the environment or quality of life" (Research England, n.d.). What this shift demonstrates is a change from seeing research as primarily a tool for knowledge collection to seeing it as a means to bridge 'what is known' with 'action for change' (i.e., research into practice) (Springett, 2017). PHR approaches also carry an epistemological and political message, challenging the concept of objective outsider knowledge production by placing primacy on the knowledge and experience of "ordinary people" (Reason, 1996, p. 81).

This shift in the conceptualization of research impact has become interwoven into core activities of the academy as well [e.g., the centralized Research Excellence Framework in the United Kingdom, and funder requirements for knowledge translation plans in Canada (Canadian Institutes of Health, 2012; Research Excellence Framework, 2020)], but not without tensions and challenges (Bayley & Phipps, 2019). The pressure to demonstrate impact raises many questions including: what does research impact look like, what counts as research impact (and for whom), and how can research impact be captured and articulated. For example, within the United Kingdom, the centralized Research Excellence Framework has been criticized for using a narrow definition of research impact that discounts benefits to the academy "and those not arising directly from demonstrably 'excellent' research or from the activities of researchers and graduate students beyond their established bodies of evidence" (Bayley & Phipps, 2019, p. 4). Further, there is also a tendency to measure impact in terms of what can be easily counted rather than assessing what counts in regards to more meaningful impacts, which further limits the documentation of the full scope of research impacts (Milat et al., 2015).

To start to address some of the confusion surrounding research impact, a new concept called ‘impact literacy’ has been developed and articulated by Bayley and Phipps (2019). Impact literacy is defined at the intersection of three key aspects of research impact: “(1) the identification, assessment, evidencing and articulation of impact endpoints (“what”); (2) The practices that create impact (“how”); (3) The successful integration of these by research impact practitioners (“who”)” (Bayley & Phipps, 2019, p. 7). However, any consideration of these three elements of research impact must recognize that in order to effectively create and articulate research impact, researchers must “develop bespoke pathways” rooted in the specific area of their academic work (Bayley & Phipps, 2019, p. 5). Ultimately, these bespoke pathways are shaped by the worldview or paradigm that we explicitly or implicitly subscribe to, and will subsequently influence what we count as relevant impact, and the meanings we attribute to those respective impacts (Kuhn, 1996).

Therefore, in order to identify, assess, and articulate ripple impact in PHR (the ‘what’), and understand the practices that create ripple impacts in PHR (the ‘how’), it is critical that such discussions are rooted in a participatory worldview and reflect the values, principles, and processes of this approach. The following sections of this literature review will provide an overview of current understandings of ripple impacts in PHR, along with the practices that contributed to these ripple impacts. It will conclude with a discussion on some of the challenges with assessing ripple impacts in PHR.

Articulating Ripple Impacts in Participatory Health Research

Enthusiasm for, and use of PHR has increased over the past two decades due to the potential of this approach to “improve health and eliminate health disparities by bridging gaps between research and practice, addressing social justice, and creating conditions that facilitate people’s control over the determinants of their health” (Cargo & Mercer, 2008, p. 326). Despite the use of participatory research methods dating back decades, a recent study from the United Kingdom found that participatory researchers still struggle with articulating the ripple impacts of participatory research and demonstrating links between participatory approaches to research and ripple impacts (Cook et al., 2017).

The struggle among participatory researchers to articulate the ripple impacts of their practice is particularly problematic within the current academic climate of “increased pressure to demonstrate research impact". Furthermore, while PHR approaches have been lauded for addressing some of the dissatisfaction with more traditional research approaches [e.g., community members' dissatisfaction with outside researchers parachuting in to conduct research and leaving without providing information or assistance (Cargo & Mercer, 2008)], it is these same benefits that come with a new set of challenges for demonstrating ripple impacts. For example, PHR can be a time consuming process for all participants (e.g., academic members, community or organizational members, etc.) (Chambers, 1998; Green, O'Neill, Westphal, & Morisky, 1996), and building trust in research relationships can also be a slow process—as previously described in Cycle 1: Grounding. This slower process can be particularly challenging for research partners in academic institutions who are expected to demonstrate outcomes in short research grant cycles (i.e., one to four years). Another challenge is that while research is a core function of academic research partners, the same is not necessarily so for non-academic partners. As Chambers (1998) states, participatory methods, "especially visual ones like mapping, diagramming and matrices, tend to be fun and to engage people's full attention, but sometimes for hours; and poor people's time is not costless". Challenges such as these raise ethical dilemmas among participatory researchers as to whether this approach to research is exploitive. It is these 'challenges' that are part of the PHR process that could potentially dissuade researchers, community groups, and/or funders from using a PHR approach, particularly if it is not clear what the positive impacts, or added benefits, of this approach are. The following sections provide a summary of the types of ripple impacts reported in PHR studies from select key pieces of literature and reviews exploring ripple impacts in PHR.

Types of Ripple Impacts in Participatory Health Research

While research impact is typically conceptualized as impact that is generated at the end of the research study, having been brought about by the dissemination of findings at the end of the project (Pain et al., 2015), impact in PHR needs to be conceptualized according to the values and characteristics of this approach. Specifically, PHR challenges the linear model of research impact which assumes research impact is generated at 'the end' of the study. While PHR projects also generate 'findings-based' research impact, it is the additional ripple impacts that occur at multiple levels of the ecological framework as a result of 'doing research together' that differentiates participatory approaches to health research from non-participatory approaches. In

PHR, ripple impacts are embedded within the research process through continuous cycles of action and reflection (Wright et al., 2018). Therefore, if you wait until the research project concludes to capture ripple impacts, the ripple impacts that are documented may not represent the full scope of impacts that emerged during the facilitation of the project. As 'findings-based' impacts tend to be prioritized by funders and research impact frameworks, ripple impacts in PHR (i.e., impacts that are embedded in the research project) tend to be less well-understood and undervalued (Banks et al., 2017).

However, a few reviews have documented the scope of ripple impacts that can occur when engaging in participatory approaches to health research (Brett et al., 2014a, 2014b; Bush et al., 2017; Catalani & Minkler, 2010; Jagosh et al., 2012; O'Mara-Eves et al., 2015; Rifkin, 2014; Staley, 2009; Viswanathan et al., 2004). In addition, a number of key papers have provided valuable conceptual thinking on ripple impacts in PHR (Banks et al., 2017; Israel et al., 2010; Pain et al., 2015). These reviews and conceptual papers focus on five core areas of ripple impacts: (1) ripple impacts on the quality of the overall research process; (2) personal ripple impacts on project members involved (e.g., community/organizational members and academic researchers); (3) ripple impacts on organizations and coalitions involved; (4) ripple impacts on the wider community; and (5) system and population level ripple impacts. A summary of the positive and negative ripple impacts is presented in Table 10.1 below.

Ripple impacts on the quality of the overall research process

One of the key ripple impacts of PHR is the impact of participation on improving the overall quality of the research across all phases from agenda setting to dissemination strategies (Brett et al., 2014a; Jagosh et al., 2012; Staley, 2009; Viswanathan et al., 2004). For example, a number of reviews reported that participation by those directly impacted by the issue helped to identify topics for research that were more relevant, culturally appropriate, and grounded in everyday experience (e.g., involving mental health patients in research on mental health services) (Brett et al., 2014a; Jagosh et al., 2012; Staley, 2009). Additionally, participatory approaches to health research were also found to: improve engagement of other members (e.g., enhanced recruitment process) by identifying facilitators to engagement (Jagosh et al., 2012; Staley, 2009); and improve research protocols, measures, and tools by using insider knowledge and pre-existing resources (Brett et al., 2014a; Jagosh et al., 2012; Viswanathan et al., 2004). It was also reported that engaging community members in the data analysis process improved the interpretation of findings by identifying themes that researchers may have missed, or correcting misinterpretations in the analysis (Brett et al., 2014a; Staley, 2009). Finally, PHR also had a positive ripple impact on dissemination strategies, for example, by helping to engage the target audience, presenting findings in a more user-friendly format, and enhancing the credibility of the findings by relating them to project members' own experiences (Brett et al., 2014a; Staley, 2009).

Few examples of negative or diminishing effects on research quality were reported in the literature. For example, recruitment bias in research with younger people impacted recruitment if the co-researcher was not liked by their peers (Staley, 2009). Overall, participatory approaches to health research were found to have a positive effect on research quality.

Personal ripple impacts on project members involved

In addition to benefits on the overall quality of the research, participatory approaches to health research were reported to directly impact members of the research team, including both non-academic co-researchers (e.g., community members, coalition members, service users, organizational staff, etc.) and academic co-researchers (Banks et al., 2017; Brett et al., 2014b; Jagosh et al., 2012; Pain et al., 2015; Staley, 2009). According to Pain et al. (2015), a defining feature of participatory approaches to research is that impact is reciprocal: both academic and non-academic partners can be positively impacted by the process of doing research together. This reciprocal process, i.e., 'doing together', stands in contrast to more traditional donor-recipient models of research impact where the academic partner is seen as 'doing for' the community (Pain et al., 2015). The following section will highlight some of the ways that both academic and non-academic partners are mutually impacted by the process of doing research together.

Reviews that explored ripple impacts on non-academic co-researchers identified a number of different impacts such as knowledge and skills development, increased feelings of social connection, and opportunities for financial compensation. For example, non-academic co-researchers have reported developing a deeper level of understanding on the topic being studied and how research is conducted (Staley, 2009). This was particularly the case for PHR projects where training and capacity building opportunities were provided for non-academic co-researchers (Brett et al., 2014b). Skill development was also a reported ripple impact and included skills directly related to research such as interviewing or data analysis skills, as well as general skills such as working in a team, confidence in speaking, and listening in groups (Brett et al., 2014b; Staley, 2009). Further, skill development was reported to improve co-researchers chances of future employment and in taking further community action (Banks et al., 2017; Brett et al., 2014b). Other types of ripple impacts were specific to personal development, such as developing confidence or feeling empowered and valued, as a result of recognizing their own abilities and strengths in the process and having their 'voice heard' (Banks et al., 2017; Brett et al., 2014b; Catalani & Minkler, 2010; Staley, 2009). Formal and informal training opportunities also contributed to an increased sense of empowerment, which in some cases led co-researchers to search for additional training and employment opportunities, and an increased confidence to take further community action (Banks et al., 2017; Brett et al., 2014b; Jagosh et al., 2012). Similarly, non-academic members reported that being able to 'give back' or 'feel useful' contributed to making participation in the research project enjoyable (Brett et al., 2014b; Staley, 2009). Another type of ripple impact experienced by community co-researchers included increased social support such as making new friends, connecting more deeply with their peers, and feeling mutually supported (Brett et al., 2014b; Staley, 2009). In turn, group bonding among project members had a positive impact on increasing co-researchers' capacity to engage with the research project (Lindenmeyer, Hearnshaw, Sturt, Ormerod, & Aitchison, 2007; Staley, 2009). Less discussed in the literature are the emotional and socio-cultural dimensions of generating knowledge together (Oetzel et al., 2015; Pain et al., 2015). For example, feelings of dissatisfaction and frustration were reported to help propel a particular direction of research, while relationships among co-researchers were reported to contribute to feelings of care, empathy, and hope (Pain et al., 2015). Finally, in some cases, engagement in PHR resulted in financial compensation (Staley, 2009).

While there were many positive ripple impacts on non-academic co-researchers, the reviews also drew attention to some of the negative impacts (Brett et al., 2014b; Staley, 2009). Examples of some of the negative impacts included feeling emotionally burdened (e.g., as a result of listening to others' difficult stories), feeling overburdened with tasks, or concerns about being exposed through media attention (Brett et al., 2014b; Staley, 2009). Other negative impacts reported in the literature included not feeling listened to or understood by other co-researchers (e.g., in particular the traditional 'expert' researchers), feeling frustrated with not being able to influence the direction of the research, confusion over why they were being involved in the research, and a failure within the research team to provide feedback on the progress and outcomes of the research to all team members (Brett et al., 2014b; Staley, 2009). Some of these negative impacts could potentially be mitigated through better communication and transparency at the start of the project. In contrast, other types of negative impacts (i.e., being overburdened with work) bring attention to deeper issues such as the demands that PHR places on non-academic members, and what Cooke and Kothari (2001) call the 'tyranny of participation'. Overall, while PHR approaches have demonstrated a number of benefits to non-academic co-researchers, it is equally important to be reflective of some of the negative impacts so as not to 'over romanticize' this approach to research.

While there was some overlap in terms of the ripple impacts experienced by non-academic and academic co-researchers (e.g., enjoyment of working in a group and learning from each other), there were ripple impacts specific to academic co-researchers as well. For example, academic co-researchers who used a PHR approach reported a stronger understanding of community issues and the community context (Staley, 2009). Academic co-researchers also reported feeling less separate from the community, and felt they had a clearer perspective from which to interpret research findings (Staley, 2009). In some cases, these fresh insights into community issues challenged researchers own beliefs and attitudes and ultimately led to a greater understanding of the community they were working together with (Brett et al., 2014b). Further, researchers reported gaining new knowledge and strengthening their research skills, for instance, developing a better understanding of barriers to research, conflict-resolution skills, and improving communication skills (Brett et al., 2014b). Academic co-researchers also reported that the co-production process was 'rewarding' and that working alongside community members brought enthusiasm and energy to the project (Staley, 2009). In some cases, engaging in PHR also resulted in being internally recognized within their academic institutions (Staley, 2009).

Academic co-researchers also experienced a number of negative impacts, mainly the impact that PHR had on time, resources, and funding (Brett et al., 2014b; Staley, 2009). For example, the time needed to build meaningful relationships impacted overall funding budgets as well as timelines set out in funding proposals, which required academic co-researchers to renegotiate research project milestones with funders (Brett et al., 2014b; Staley, 2009). In other cases, some academic co-researchers engaging in PHR reported feeling a loss of power, and had difficulty accepting the views of non-academic co-researchers when views differed from their own (Brett et al., 2014b; Staley, 2009). Last, some academic co-researchers also found having to make changes to their own work practices (e.g., meeting outside of traditional work hours) challenging in order to be meaningfully inclusive (Brett et al., 2014b; Staley, 2009). Conversely, some of the negative impacts reported in the reviews were also seen as positive impacts by academic co-researchers. For instance, some academic co-researchers saw that having their own beliefs and assumptions challenged in the process was a positive aspect of the research (Staley, 2009). Overall, while PHR processes were found to have many positive impacts on researchers, the challenges shine a light on some of the fundamental ways this approach differs from non-PHR approaches, and challenges traditional ways of conducting health research.

Ripple impacts on organizations and coalitions involved

PHR has also had ripple impacts at the organizational and coalition level and among organizational members (e.g., community-based, health care, etc.) in a number of different ways. For instance, organizations and coalitions reported that engaging in PHR approaches increased their organizational capacity as a result of the findings and impacts of the research, and as a result of participating in the research process overall (Viswanathan et al., 2004). For example, the review by Staley (2009) found that organizations reported increased credibility for their projects and activities in respect to being seen as community leaders. Further, when community organizations participated in dissemination activities (i.e., presenting at events or conferences), organizations also reported increased public recognition as a result (Staley, 2009). Additionally—as previously described under ‘Personal ripple impacts on researchers involved’—organizational members developed new skills through informal and formal opportunities for training (Jagosh et al., 2012; Viswanathan et al., 2004). Organizational members indicated general workforce development as a result of taking part in participatory approaches to health research. For example, organizational members reported increased learning from their colleagues, increased knowledge on health or social condition being explored, and improved ability to be reflective in their practice (i.e., developing a more nuanced understanding of the community context or their service-users’ needs) (Bush et al., 2017; Staley, 2009). At an organizational level, the skill building opportunities became assets for the organization or coalition (e.g., in terms of program planning or implementation and enhanced capacity to conduct research) (Jagosh et al., 2012; Viswanathan et al., 2004). Another important ripple impact that was reported by organizational members who engaged in PHR projects was an increased capacity for policy advocacy, specifically developing relevant knowledge and skills to implement the different phases of policy advocacy (Bush et al., 2017; Israel et al., 2010). Engaging in PHR approaches also improved collaborations and communication, not only among organizational members, but also created new alliances which helped to further their research agenda (Bush et al., 2017; Staley, 2009; Viswanathan et al., 2004).

Fewer negative PHR impacts were reported at the organizational and coalition level. For example, Jagosh et al. (2012) found that while disagreements, or interpersonal tensions, generated during the PHR process could result in positive outcomes, they also resulted in negative outcomes for later program planning if they were not worked through in a constructive manner (e.g., a lack of integrated collaboration that led to a lack of insider knowledge being used in program planning, which had negative consequences for engagement). Other negative impacts included an increased workload on organization members, and time constraints (Bush et al., 2017). Despite some of the challenges reported in the included reviews, Jagosh et al. (2012, p. 329) found that in participatory approaches to research "synergy [had] the potential to build over time when the partnership's activities repeatedly [produced] successful outcomes." In some cases this led to additional grant funding being obtained (Viswanathan et al., 2004). In other cases, particularly when there was a gap in funding, the partnership work was able to continue because of the commitment by all project members involved (Jagosh et al., 2012) and feelings of shared ownership (Staley, 2009).

Ripple impacts on the wider community

Reviews on ripple impacts in PHR also explored impact on the wider community. However, before outlining some of these ripple impacts, it is important to define 'the wider community'. For the purpose of this review, 'the wider community' is defined broadly as those community members who were not directly involved in the research project as co-researchers, but share some connection with members of the co-research team. Examples of this connection may include a geographical connection (e.g., living in the same community), a connection to a health issue (e.g., diabetes community), a shared interest in a similar topic (i.e., improving active transportation), or a workplace connection (i.e., work in the same organization or a similar field). Some reviews within the academic literature analyze impacts on the community as those impacts outside of academic contexts, however, there is an important distinction to be made in terms of expected impacts on non-academic co-researchers directly involved in the project, and the wider community in which those non-academic co-researchers share a connection.

One of the commonly cited ripple impacts of PHR at the community level was that participatory processes helped to develop and strengthen trust and acceptability of the research being conducted in the community, which in turn helped to give credibility to the research (Brett et al., 2014b; Staley, 2009). Both historically and even currently, communities have voiced discontent with researchers parachuting into the community, collecting what they needed, and leaving without communicating back findings or providing assistance to the community (Cargo & Mercer, 2008; Dion, Díaz Ríos, Leonard, & Gabel, 2020). As Viswanathan et al. (2004) found in their review, by engaging the community in the PHR process, community members began to see the longer-term benefits of the research, extending beyond the short time period of data collection. This appreciation for the research also helped to increase the acceptability of the research. PHR approaches were also reported to benefit the community by opening the door to new avenues to share findings. For example, non-academic co-researchers were better able to share research findings with the community and target audiences, particularly when non-academic co-researchers became advocates of, and felt ownership for, the research (Brett et al., 2014b; Staley, 2009). In addition, for PHR projects that involved organizational members and community members, such initiatives helped to build better relationships between these two groups (Staley, 2009). As an example, when organizational and community members/service users came together to collaborate, listen to each other, and learn together, the impact was an improvement in program or service offerings, as well as increased engagement by the community in such initiatives (Staley, 2009). Other types of ripple impacts on the wider community included the ability to secure additional funding to continue the research in the community, and job creation as an impact of the collaboration (Viswanathan et al., 2004).

Overall, there were limited negative ripple impacts reported in the reviews. However, Brett et al. (2014b) did report that in some cases, the PHR process can shine a light or create conflict or power struggles within the community which can ripple out to create additional challenges in terms of meaningfully being able to work together. As PHR aims to challenge status quo power structures, it is important for participatory health researchers to be particularly cognizant of the context in which the PHR initiative is situated so as to try and mitigate some of the challenges related to power in a constructive manner.

System and population level ripple impacts

Fewer ripple impacts were documented at the systems and population level in the included reviews and key conceptual papers. In the review by Jagosh et al. (2012), the authors found that many of the participatory relationships had the capability of effecting systemic changes beyond the immediate goals of the research project. One of the key factors that contributed to the possibility for broader systemic change was that the research projects, and project partners, were integrated into the local context, as well as engaged with policy advocates and influential community leaders in the process (Jagosh et al., 2012). Further, as project members developed knowledge, skills, and confidence in policy advocacy activities, new projects and activities were developed, which may have had a longer-term impact extending beyond the immediate research project (Jagosh et al., 2012). For some research initiatives, the success and confidence developed from the initial research project was a launching point for further action. As Israel et al. (2010) highlight, many of the factors that influence our health and create health inequities are beyond any one individual's ability to control. Hence, participatory approaches to health research that incorporate a policy advocacy strategy may be better able to tackle social and economic policy in order to meaningfully address health inequities at the system-level (Israel et al., 2010). In terms of population level impacts on health outcomes, the review by Viswanathan et al. (2004) found that fewer participatory studies reported on health outcomes as a ripple impact of PHR. While some studies showed a modest positive impact, others showed mixed results (Viswanathan et al., 2004). As such, Viswanathan et al. (2004) were unable to conclude whether the modest positive impacts on health outcomes could be attributed to participatory methods. More recently, O'Mara-Eves et al. (2015) conducted a meta-analysis exploring the effectiveness of community engagement in public health interventions for disadvantaged groups. The authors concluded that community-engagement strategies for disadvantaged groups were effective in terms of positive effects on health behaviours (e.g., alcohol abuse, antenatal care, physical activity, smoking cessation, etc.), health consequences (cardiovascular disease, mental health, etc.), self-efficacy pertaining to the health behaviours, and perceived social support in relation to the health behaviours (O'Mara-Eves et al., 2015).

None of the reviews reported negative ripple impacts as a result of PHR processes at the systems or population level.

Table 10.1: Summary of ripple impacts documented within the literature.

Ripple Impact Core Area	Positive Impact	Negative Impact
Quality of the overall research process	• Improved relevancy and culturally appropriateness of research topics. • Improved community engagement in the research. • Improved research protocols, measures, and tools. • Enhanced the interpretation and credibility of findings. • Strengthened dissemination (e.g., engage new audiences).	• Potential for recruitment bias.
Project members involved	***Non-academic co-researchers*** • Knowledge and skills development. • Increased feelings of social connection. • Personal development (e.g., feeling empowered). • Emotional and socio-cultural impacts. • Opportunities for financial compensation.	***Non-academic co-researchers*** • Feeling burdened. • Being exposed through media attention. • Not feeling heard or understood. • Confusion about involvement in the research.
	Academic co-researchers • Stronger understanding of community issues and context. • Better ability to interpret research findings. • Challenged researcher assumptions and beliefs. • Research skill development (e.g., conflict resolution, communication, etc.	***Academic co-researchers*** • Time and resource intensive. • Difficulty with an emergent process and loss of power. • Compromises to be inclusive (e.g., meeting outside of work hours).

Organizations and coalitions involved	• Increased organizational capacity (e.g., knowledge and skills development). • Increased credibility as an organization. • Increased public recognition. • New collaboration, coalitions, and alliances.	• Potential for internal disagreements and tensions. • Increased workload. • Time constraints.
Wider community	• Increased trust and acceptability of research. • New avenues to share findings. • Improvements to services and programs. • New opportunities for research funding.	• Conflict and power struggles. • Risk of maintaining the status quo.
System and population level	• Impact system change by engaging with decision makers. • Policy advocacy impacts from the research process. • Potential for population level health impacts.	• None reported in the literature.

Levels of participation and ripple impacts

Overall, the reviews highlighted the positive and negative ripple impacts of PHR at multiple levels of the ecological framework. However, the reviews also shed light on how different levels of participation contributed to different ripple impacts. For example, Bush et al. (2017) in their review of organizational level impacts found that higher levels of engaged participation (i.e., co-constructed vs. consultation) were connected to more benefits from the PHR process. Similarly, Catalani and Minkler (2010) in their review of photovoice processes and impacts (a common method used in PHR), found differences in the types of impacts that occurred between ‘more’ and ‘less’ participatory photovoice projects. For instance, photovoice projects that were more participatory tended to be connected to stronger, long-term relationships between community members and academic research, in-depth training on photovoice to build community capacity, iterative cycles to reflect and engage in critical dialogue on the research topic, as well as more documented cases of action and advocacy and individual empowerment (Catalani & Minkler, 2010). Finally, in the review by O'Mara-Eves et al. (2015), focusing on participatory interventions, the authors found that interventions that engaged community members in the implementation stage of the intervention were particularly effective, when compared with interventions that only included community members in the design stage.

The reviews and studies included in this literature synthesis outline the scope of ripple impacts that were found to occur as a result of engaging in participatory approaches to health research (summarized in Table 10.1). This synthesis highlighted how PHR processes can have positive impacts on multiple ecological levels. However, this synthesis also drew attention to some of the negative impacts that can emerge. Understanding these negative ripple impacts is important for research project members to identify strategies to mitigate these negative potential impacts.

Challenges of Assessing Ripple Impacts in Participatory Health Research

Participatory health researchers experience unique challenges in assessing and articulating the ripple impacts of PHR. These include the broad use of the term 'participatory' (Cook et al., 2017), when to assess ripple impacts (timing to capture longer term impacts), the challenge of attribution, and finally, perceived lack of appropriate indicators and strategies to assess ripple impacts specific to PHR initiatives (Sandoval et al., 2012). While these challenges exist across the disciplines in which participatory research approaches are practiced, they are further exacerbated in the context of the health sciences—as the health sciences field is strongly influenced by the dominance of the evidence-based medicine (EBM) and evidence-based decision making (EBDM) paradigms.

EBM is commonly defined as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71). Similarly, EBDM encourages decision makers to inform their decisions using the highest quality of evidence (determined by study design) (Hayes et al., 2019). Within these paradigms, evidence is most commonly perceived as quantifiable data. While qualitative evidence has made progress in gaining credibility in public health, "stories" as evidence are still marginalized. Such forms of knowledge have traditionally been characterized within the dominant EBM/EBDM paradigms as subjective and unreliable (Baum, MacDougall,

& Smith, 2006). The impact is that other important forms of evidence within the health sciences such as social efficacy (Rod, Ingholt, Bang Sørensen, & Tjørnhøj-Thomsen, 2013), unanticipated outcomes, intuitive and experiential knowledge (Fleming & Rhodes, 2018; Ledwith & Springett, 2010), and interactions between intervention and context (Goldenberg, 2006; Rychetnik, Frommer, Hawe, & Shiell, 2002) tend to be disregarded. While, as Greenhalgh and Fahy (2015) suggest, the understanding of quality in EBM (and for EBDM) has been misappropriated and distorted by vested interests, they also argue that EBM is maturing from its early focus on epidemiology to embrace a wider range of disciplines and methodologies, including a shift to embracing complexity informed approaches (Greenhalgh & Papoutsi, 2018). Such shifts will challenge a number of potential biases held within EBM/EBDM including the low value given to knowledge through experience, that contributes to devaluing what they term 'the patient and carer agenda' (Greenhalgh & Fahy, 2015).

However this shift towards a more holistic approach is likely to be slow, and consequently, participatory health researchers remain in a dilemma of having to demonstrate scientific merit and impact against quality guidelines and impact frameworks informed by the positivist ontology of EBM and EBDM (South, 2013). The consequence here is that many of the different forms of ripple impacts in PHR (e.g. relational impacts) are not valued under EBM/EBDM's hierarchy of evidence and hence, and end up unarticulated and missing from the evidence base on impact. This contextual challenge is also faced by qualitative researchers, of course, but the effect is particularly acute for participatory researchers working in the health field because of the primacy given to practical and living knowledge in participatory approaches (Heron & Reason, 1997). The following sections elaborate on some of the key challenges of assessing impact in PHR.

The broad use of the term 'participatory'

First, one of the core issues with assessing ripple impacts in participatory approaches to health research is the broad use of the term "participatory" (Cook et al., 2017). As Cargo and Mercer (2008, p. 326) explain, participatory research can be seen as an umbrella term for a variety of research approaches "that share a core philosophy of inclusivity and of recognizing the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users, and stakeholders of the research". This umbrella includes community-based participatory research, participatory action research cooperative inquiry, dialectical inquiry, and empowerment evaluation, among many more (Cargo & Mercer, 2008). Rather than a universal definition for PHR, there are a variety of approaches within this approach to research that may differ according to geographic location (i.e., Northern 'Kurt Lewin' approaches, or South 'Fals Borda' approaches), by health discipline (public health, medical sciences, etc.) or by the type of non-academic researcher involved (organizational, policy, community, etc.). One of the goals of the International Collaboration for Participatory Health Research (ICPHR) has been to explore how PHR is conceptualized and operationalized in different locations and contexts mapping out principles and practices that are common and different among different regions (International Collaboration for Participatory Health Research, n.d.). Members of the ICPHR have begun this work, exploring how regional context has influenced researchers approach to participatory research through a series of case studies (Wright & Kongats, 2018). However, the challenge resulting from the breadth of research approaches falling under the label of PHR is that it is difficult to assess the expected ripple impacts that may result from this approach (Cook et al., 2017).

In order to address this challenge, participatory health researchers should be explicit in describing their approach taken to using PHR. For example, there are a number of different models presenting different levels of participation such as Arnstein's (1969) ladder of participation or Cornwall's (1996) typology of participation. Cook et al. (2017) have developed a matrix of participation to reflect on levels of participation in the research across the different phases from deciding on the research focus, to data analysis to dissemination. This matrix has been used across all cycles of CCC participatory case study, and a completed assessment of the participatory nature of the CCC participatory case will be presented below. Articulating the type of participation in a PHR project using one of these frameworks can help to develop a more transparent understanding of the types of ripple impacts that can be expected.

The issue of timing

A second challenge of assessing ripple impacts in PHR is the issue of timing: When is the best time to assess impact? For example, Morton and Fleming (2013) explain that if the impact assessment is done too early on, the impact of the project may not be fully realized, but if it is done too late then it may be challenging to remember key aspects of the project. From a PHR lens specifically, meaningful participatory processes occur over a long timeframe (e.g., relationship and capacity building), as such, many of the intended and unintended ripple impacts of PHR may not be fully recognized within the short time frames of research funding (Springett, 2017; Wallerstein & Duran, 2010). At the same time, impact in PHR is embedded in participatory processes consisting of iterative mini cycles of action and reflection, and hence cannot only be captured at the end. As impact is embedded in the PHR process, participatory health researchers need to be attuned to recognizing the different types of impacts that can unfold as the project develops. In addition, participatory health researchers may need to consider strategies to capturing impact long after the project has been completed.

The challenge of attribution in research impact

Linked to the issue of timing is also the challenge of attribution in research impact (Morton & Fleming, 2013). The issue of attribution is particularly acute among participatory health researchers in a health systems context because of the dominance of the EBM and EBDM paradigms. Within these paradigms, attribution is typically assumed as linear cause-and-effect causality (Greenhalgh & Papoutsi, 2018), which oversimplifies how impact unfolds in a health context. From a participatory lens, ripple impact occurs through many different channels such as dialogue with others, capacity building, and research findings. Due to the many contributing factors that play a role in ripple impacts in PHR, a study by Cook et al. (2017, p. 483) revealed that PHR "researchers are reluctant to take credit for impact, even if it is an expected outcome of such research" due to the many different factors that may have played a role. As Cook et al. (2017, p. 483) explain, "It is a tendency for those working in this way to want to attribute change as a process of shared endeavours and therefore academic researchers, the people who generally write the academic papers, tend to gloss over this aspect."

Thinking about ripple impacts from a contributions or emergent perspective may be a helpful lens for participatory health researchers. Morton and Fleming (2013) suggest focusing on a research contribution approach, rather than a cause-and-effect approach, as a more useful way to document ripple impacts. The contributions approach "allows an acknowledgment of the complex ways in which research is taken up and used" (Morton & Fleming, 2013, p. 4). Greenhalgh and Papoutsi (2018) also suggest that a new complexity-informed approach to researching health services and systems is needed and suggest a similar emergent causality approach to attribution. Emergent causality, acknowledges that there are various interacting influences that can account for a particular impact, and that it is not realistic to attribute a fixed "effect size" to any one influence (Greenhalgh & Papoutsi, 2018). Another useful approach to address the challenge of attribution in PHR draws from the field of evaluation (Springett, 2017). A results chain or spheres of influence approach may be another useful strategy to thinking about attribution while not implying direct causality (Patton, 2011). Taking a participatory approach, these strategies should start by capturing impacts that are meaningful from the perspective of non-academic co-researchers. As a whole, there are a variety of different approaches to attribution in PHR that participatory health researchers can draw upon without getting stuck in a linear cause-and-effect understanding.

Lack of indicators and strategies to capture links between participation levels and ripple impacts

The fourth challenge with assessing ripple impacts in PHR is the lack of an existing evidence base on indicators and strategies to capture the link between participatory processes and ripple impacts for researchers to draw on. Identifying links between participatory processes and ripple impacts can help researchers demonstrate what the PHR processes added to the initiative and potentially what may have been different without such participatory processes. A literature review by Sandoval et al. (2012) identified 46 different instruments and 224 measures that related to four components of PHR (in this case the review focused specifically on community-based participatory research (CBPR)): (1) context, (2) group dynamics, (3) the extent of the community role in intervention and/or research design, and (4) the impact of these participatory processes on system change and health outcomes. However, of the 224 different measures of CBPR characteristics identified in the literature, only 34 were specific to assessing CBPR outcomes (Sandoval et al., 2012). Of the 34 outcome measures that were identified, indicators primarily focused on capturing outcomes related to empowerment and community capacity, changes in practice or policy, unintended consequences, and health outcomes (Sandoval et al., 2012). However, there were no measures identified in the review that explored changes in power relations, culturally based effectiveness, or cultural revitalisation and renewal (Sandoval et al., 2012), all key aspects of PHR that are subsequently missing from the impact evidence base. Furthermore, the extent to which these indicators and strategies to capture impact start from the perspective of the non-academic co-researcher is unclear and requires additional investigation. While the aim in PHR should not be to mandate a set of standardized indicators to assess ripple impacts, participatory health researchers may find it useful to draw on a library of different strategies and indicators to assess ripple impacts depending on how a PHR project emerges within its respective context. In addition to specific indicators, the processes for capturing ripple impacts are equally important. What ripple impacts are identified, depend on who you ask. Therefore, it is important to engage a wide variety of different voices in the process rather than being limited by preconceived understandings of what counts as impact (e.g., impact standards defined by the academy).

Summary of Literature Review

In this review of the literature I outlined the increasing pressure for participatory health researchers to be able to document and articulate the ripple impacts of their practice. I also provided a summary of the scope of participatory ripple impacts that have been previously documented in PHR studies drawing on key reviews to contextualize the research presented in this chapter within this broader evidence base. Last, I outlined four key challenges with assessing ripple impacts in PHR. In Cycle 3: Ripple Impact (presented below) I begin to explore ways to address some of these challenges.

STRATEGIES TO DOCUMENT RIPPLE IMPACTS IN THE CCC PARTICIPATORY CASE STUDY

In this section, I describe how ripple impacts were documented across the CCC participatory case study (purpose #1 in this final cycle) including first-person and second-person inquiry strategies. Figure 10.2 presents a visual overview of:

- the key phases of Cycle 1: Grounding and Cycle 2: The Photovoice Project;
- how Cycle 3: Ripple Impacts, the focus of this chapter, is situated within the broader CCC participatory case study (i.e., the orange dashed line shows the overlap with the previous 2 cycles and the solid orange line highlights a new part of the CCC participatory case study not previously discussed); and
- the different strategies used to document ripple impacts across the various phases of the CCC participatory case study including first-person inquiry strategies (green line) and

second-person inquiry strategies (blue line). Definitions of first-person and second-person research were previously outlined in *Chapter 3: Critical Methodological Overview*.

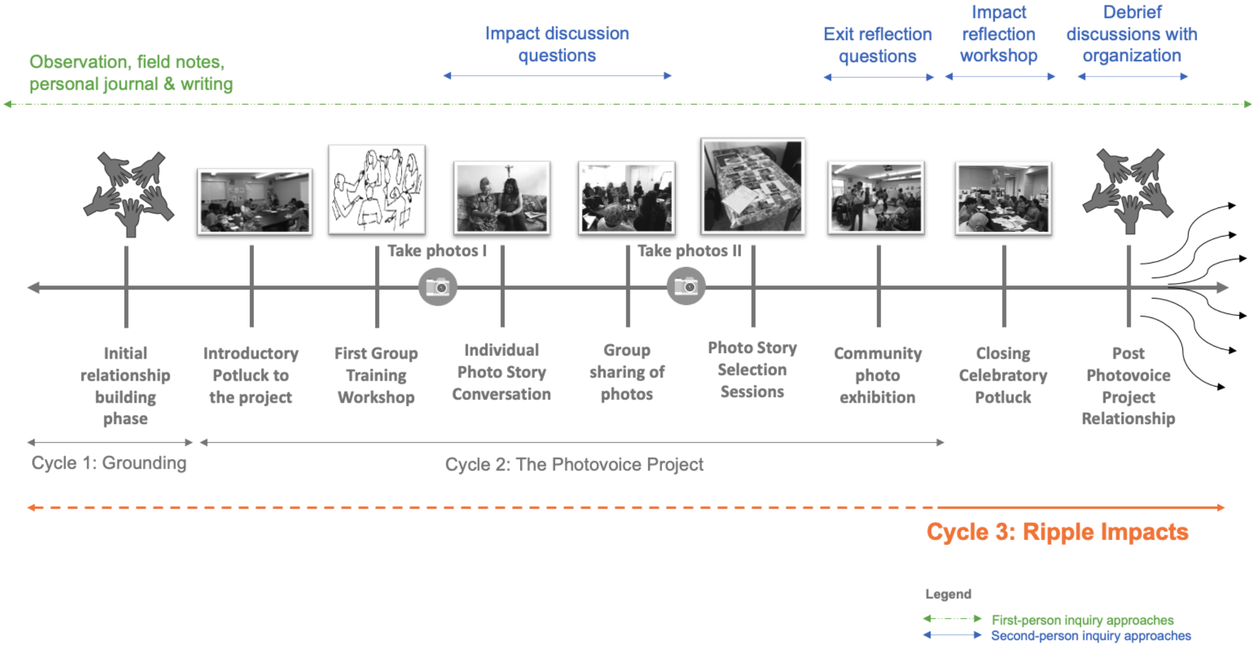


Figure 10.2: First-person and second-person strategies used to capture ripple impacts across the lifespan of the CCC participatory case study.

First-person Inquiry Strategies to Document Ripple Impacts

Observations, field notes, personal journal, & writing

Drawing on first-person inquiry approaches, I used a combination of observations, my field notes, and my own journal entries collected across the entire span of the CCC participatory case study to document ripple impacts (green line in Figure 10.2). In addition, because of my prolonged relationship with Hospice Toronto post-photovoice project, I was also able to document impacts that rippled out after the formal aspect of the research had concluded. This prolonged engagement was a strength in documenting longer-term ripple impacts in PHR.

The first-person inquiry approaches I used were flexible for capturing ripple impacts identified by project members that happened in tangent to the more formal phases of the photovoice processes. For example, during our CCC photovoice reflection workshop, one CCC project member shared with me in passing that another community organization had approached her for a potential community development job opportunity after hearing her speech at the CCC community photovoice exhibition. This wasn't an impact she included in the more formal ripple impact activity I facilitated (explained in the next section), and thus may have been missed if there hadn't been space for informal conversation to occur. With her permission, I made note of this ripple impact in my field notes from the session. In another example, in a visit to The Corner (the shared office space that the CCC initiative is based out of), I learned that one of the CCC project members had gone on to use arts-based research methods in her own studies to explore the meaning of community among youth in St. James Town. While I was no longer in touch with this CCC photovoice member, I didn't know the extent to which participating in the CCC photovoice project influenced her own future project. However, I still noted this observation in my own journaling as a potential ripple impact. As these examples demonstrate, ripple impacts such as these emerged organically throughout the project, and may have been missed from the impact analysis had I not been attuned to noticing potential ripple impacts using these first-person inquiry strategies (i.e., observation, informal conversation, field notes, journaling). In reflecting back on this process, the trust that had been developed over time by being present informally in the community created a space for these ripple impacts to be shared.

Second-Person Inquiry Strategies to Document Ripple Impacts

Discussion questions during photo-storytelling sessions

In addition to first-person inquiry strategies, I also used second-person inquiry strategies to document ripple impacts (blue line in Figure 10.2). First, I included photovoice reflection questions during the individual/mini group photo storytelling sessions and the larger group photo storytelling sessions at the mid-point of the CCC photovoice project. As part of these photo and storytelling sessions, I asked participants to reflect on their experience of participating in the CCC photovoice project, including any facilitators and challenges with the overall process. In these open discussions, many project members included reflections on some of the personal ripple impacts they had experienced at this half-way point. These reflections, captured in the individual and group transcripts, were noted as potential ripple impacts of the CCC participatory case study.

Exit-reflection questions during the public photovoice exhibition

Second, as part of CCC photovoice exhibition, we asked attendees (e.g., community members, health and social service organization staff, decision makers) to complete an exit-reflection survey after viewing the exhibition. As part of this exit-reflection survey we asked attendees to (i) share if there was a photo and story that they connected to in the exhibition, and to share why; and (ii) reflect on what they think are the three most important pieces for building a caring community. This was an opportunity to understand how the CCC photovoice exhibition resonated with the broader community (i.e., another opportunity to capture potential ripple impacts).

Celebratory reflection workshop

Third, all members from the photovoice project were invited to a celebratory reflection workshop after the exhibition occurred (see Image 10.1). The celebratory reflection workshop was an opportunity to come together as a group to celebrate the accomplishments of the group, reflect back on the experience participating in the CCC photovoice project and the ripple impacts, and mark a ‘soft’ conclusion to the project. In total, 10 out of 16 CCC project members took part in the closing reflection. One CCC project member, Helen, had died before the CCC photovoice exhibition, however her primary carer (also a CCC project member) attended this closing reflection.

Image 10.1: Setting up for the CCC Photovoice Celebratory Reflection Workshop.

As part of our celebratory reflection workshop, we asked all CCC project members 'what impacts do you think participating in the CCC photovoice project has had on: (1) yourself; and (2) your community.' We asked project members to write each of their self-identified ripple impacts on separate pieces of card stock paper. As ripple impacts were written down, they were subsequently placed under our large-wall Likert-scale (see Image 10.2).

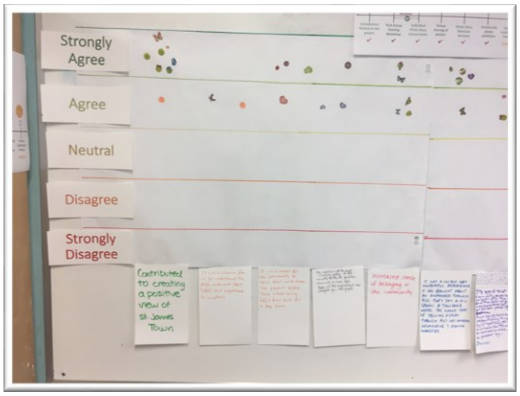


Image 10.2: CCC Photovoice Likert-Scale (vertical) and ripple impacts indicators (horizontal).

Once all indicators were collected, we asked project members to indicate their level of agreement with each of the ripple impact indicators noted by their peers. For example, one ripple impact that was indicated by a project member read, "*contributed to creating a positive view of St. James Town*". Using stickers, each CCC photovoice member was asked to indicate, from their own perspective, the extent to which they agreed or disagreed with this statement (see Image 10.3). In using this Likert-scale process, the purpose was to identify ripple impacts that resonated strongly across the group, as well as ripple impacts that had less support. In hindsight, we weren't able to differentiate between the different ripple impacts as most participants marked such indicator as 'strongly agree' or 'agree', a potential consequence of 'group effect' [i.e., participants censoring or conforming in a group setting (Carey & Smith, 1994)]. To better differentiate the different levels of agreement or disagreement for each ripple impact, future studies should consider limiting the number of stickers, and asking participants to rank their top three to five impacts, rather than using a Likert-scale across all indicators. For example, methods such as 'dotmocracy' can be used to 'nudge' participants to be more selective in identifying the impacts that were most meaningful to them (Diceman, 2013).

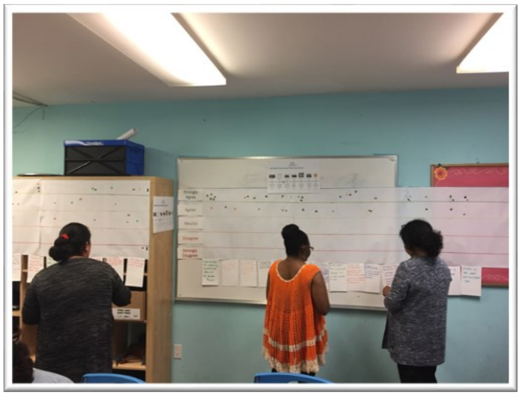


Image 10.3: Identifying level of agreement on ripple impacts in the CCC participatory case study

Debrief discussions with organization staff and a continued working relationship

Last, I also facilitated debrief conversations with Hospice Toronto staff at the 'soft' end of the CCC photovoice project to explore the ripple impacts of the CCC participatory case study from their perspective as an organization. In addition to our formal debrief sessions, Hospice Toronto and I continued an ongoing working relationship related to the CCC initiative. This continued working relationship over time created an opportunity to capture and document some of the longer-term ripple impacts that emerged from the CCC participatory case study after the project had informally concluded.

Summary of Strategies to Document Ripple Impacts

I used a variety of first-person and second-person strategies to document ripple impacts across the CCC participatory case study. Key to documenting the participatory ripple impacts was:

- being attuned to instances of ripple impacts emerging,
- using a variety of different approaches,
- engaging different perspectives across multiple time-points in the project, and
- creating informal spaces for ripple impacts to be shared.

Rather than only trying to assess impact at the end of the project, I was able to make note of potential participatory impacts as they emerged throughout the project. In the following section, I describe the scope of ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of the research and explore connections between ripple impacts using an ecological lens, first describing the analysis approach taken.

ANALYSIS APPROACH

Data analysis of the ripple impacts primarily took place after the various phases of the CCC participatory case were complete. New longer-term ripple impacts were included on a rolling basis as they were shared and documented. As this analysis took place after the CCC participatory case study had already concluded, CCC project members were not included in this stage. Analysis of the ripple impacts in Cycle 3: Ripple Impacts followed a similar deductive-INDUCTIVE thematic coding approach as previously outlined in Chapter 6. In this section, I briefly highlight the key phases of the analysis approach taken in the specific context of exploring the ripple impacts in the CCC participatory case study.

As a first step, I developed a basic codebook as a means to help organize the different ripple impacts according to the different levels of the ecological model. As previously explained at the start of this chapter, drawing on an ecological lens was important to reflect the interdependence/relational dimension that underpins PHR practice. For example, a change in one area of a system (e.g., a neighbourhood or community) can ripple out to impact other facets of a system. In the CCC participatory case study, research done with CCC project members and organizational staff in St. James Town raised the profile of the CCC initiative provincially through different dissemination events. In turn, Hospice Toronto was invited to join a provincial collaborative and influence the direction of compassionate communities at a provincial level. Therefore, an ecological lens is a useful framework to capture the broad scope of ripple impacts that can emerge from a PHR initiate and the connections between levels. I used McLeroy et al. (1988) ecological model for health promotion to inform the development of the codebook. This codebook is outlined in Table 10.2 below. The codebook was subsequently entered into NVivo 12 as nodes. The pre-determined codes used in this codebook were purposefully developed to be broad as the main purpose of this codebook was as an initial organizing tool to bring together similar chunks of data for later inductive analysis.

Table 10.2: Codebook for the analysis of participatory ripple impacts in Cycle 3: Ripple Impacts [adapted from (McLeroy et al., 1988)].

Code name	Description
Intrapersonal	• Impacts related to "…characteristics of the individual such as knowledge attitudes, behavior, self-concept, skills, etc." (McLeroy et al., 1988, p. 355)
Interpersonal processes and primary groups	• Impacts related to "…formal and informal social network and social support systems, including the family, work group, and friendship networks" (McLeroy et al., 1988, p. 355)
Institutional factors	• Impacts related to "…social institutions with organizational characteristics" (McLeroy et al., 1988, p. 355)
Community factors	• Impacts related to changes in the community, which could include "relationships among organizations, institutions, and informational networks within defined boundaries" (McLeroy et al., 1988, p. 355)
Public Policy	• Impacts related to "…local, state, and national laws and policies" (McLeroy et al., 1988, p. 355).

The deductive-INDUCTIVE coding approach to reflexive thematic analysis used had four stages including:

1. *Stage 1 Familiarization:* This involved becoming more familiar with the ripple impact related data from interview transcripts, field notes, workshop materials, meeting notes, etc.
2. *Stage 2 Applying a theoretical lens:* As I read through the participatory ripple impact related data, I sorted the data according to the ecological levels in the codebook. For example, impacts such as 'feeling happy to participate' were coded as an intrapersonal level impact according to the ecological model.
3. *Stage 3 Inductive coding refinement:* After all the participatory ripple impact related data were coded, I went back into each of the ecological levels and inductively coded the text using a combination of semantic (i.e., explicit, high-level) and latent (i.e., implicit, deeper) coding to identify sub-themes within the ecological levels.

4. *Stage 4 Refinement:* I began the process of revising and defining the sub-themes. During this stage, I shared my interpretations of the ripple impacts with Hospice Toronto organization staff (e.g., the CCC community development coordinator and the executive director) to garner their feedback. The analysis feedback process stimulated more discussions about ripple impacts and new ripple impacts were included (e.g., ripple impacts related to the Board of Directors presentation), in addition to changes in theme and code labels. In revising and defining the sub-themes, I followed Braun et al. (2019) guide that themes should have clear boundaries (i.e., there shouldn't be overlap), and that each code should relate to the theme situated over it.

RIPPLE IMPACTS FROM THE CCC PARTICIPATORY CASE STUDY

Using an ecological lens, I describe the scope of ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of the research and explore connections between ripple impacts for the purpose of being able to better articulate the value of PHR approaches (purpose #2 in this final cycle). The CCC participatory case study generated a number of different ripple impacts at different ecological levels including individual-, group-, organization-, and community levels (the labels were modified from the original codebook labels as a result of discussions with Hospice Toronto staff). Figure 10.3 presents a summary of the ripple impacts generated from the CCC participatory case study using the ecological model as an organizing framework.

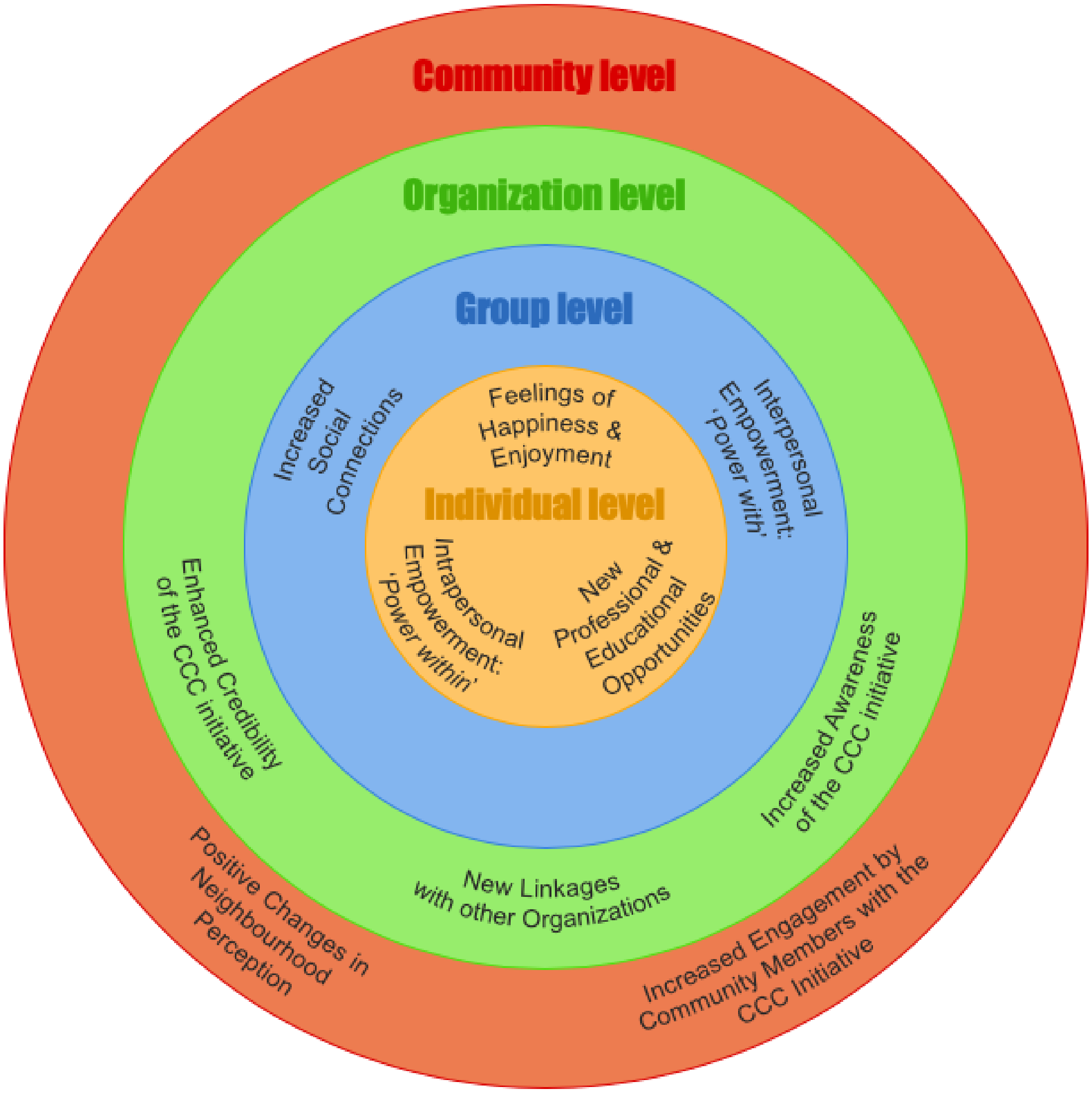


Figure 10.3: Participatory Ripple Impacts of the CCC Photovoice Project from an Ecological Lens

Individual Level Participatory Ripple Impacts

At the individual level CCC project members identified three types of participatory ripple impacts: feelings of happiness and enjoyment, intrapersonal empowerment, and new professional and educational opportunities.

Feelings of happiness and enjoyment

CCC project members identified feelings of happiness and enjoyment through their participation in Cycle 2: The Photovoice Project. In particular, feelings of happiness and enjoyment were most commonly discussed in the context of having the opportunity to connect with others. For example, one CCC project member reflected at the celebratory reflection workshop, "*I feel happy that this project brought everyone together*" (Reflection Workshop). Similarly, another CCC project member commented during the photo storytelling session, "*I really enjoyed this*" (Helen, CCC community member). CCC project members also reported feelings of happiness as a result of having an opportunity to be a part of the research. For example, another CCC project member stated, " *...I'm happy that you considered us, that we can contribute to your project. So that's why we are happy that you included us in your project*" (Nasrin, CCC neighbourhood helper, informal translation). Another CCC project member stated, "*...People don't do enough of this. Sit down and talk about what they have, and what they appreciate to have, what they wish everybody could have*" (Helen, CCC community member).

Finally, CCC project members also expressed enthusiasm and excitement for the arts-based research approaches used in the project. One member stated, "*I'm really excited for the exhibition at the end, and how all these pictures will contribute to your research and your findings and everything*" (Benesh, CCC neighbourhood helper). Similarly, another CCC project member wrote at the reflection workshop, "*The whole idea of telling a story through pictures was amazing, informative and staying connected*" (Reflection Workshop).

Intrapersonal empowerment: power within

In addition to feelings of happiness and enjoyment, CCC project members indicated that intrapersonal empowerment was another individual level impact of participating in the CCC participatory case study. Intrapersonal empowerment is defined as the experience of a strong sense of self and something that increases self-esteem and self-efficacy (Labonte, 1993). In addition, intrapersonal empowerment is the experience of choice, and the power found *within* (Labonte, 1993).

In the CCC photovoice project, intrapersonal empowerment (i.e., the power within) was primarily expressed by members in terms of the power to choose the stories they felt were important to share with their community on collective approaches to care. For example, in one of the photo storytelling sessions, one CCC project member stated,

> "*being able to project the fact that, we have fun. We are both mental, mental health patients, but we can still find time to have fun, or laugh at each other, and see and*

> *express the fact that even though mental patients have a kind of a stigma attached, there is also the lighter side of it*" (Michael, CCC primary carer).

Similarly, another CCC project member stated,

> "*[photovoice] really offers a perspective of taking the pictures and it really shows like what was more meaningful to us and why we took the pictures and showcases how, what was caring for us, and like as members of the community, ya oh that's great*" (Benesh, CCC neighbourhood helper).

New professional and educational opportunities

In addition, two new professional and educational opportunities were noted as tangential potential ripple impacts of the CCC participatory case study. For example, during our CCC photovoice reflection workshop, one CCC project member shared with me in passing that another community organization had approached her for a potential community development job opportunity after hearing her speech at the CCC community photovoice exhibition. Similarly, I learned that one of the CCC project members had gone on to use arts-based research methods in her own studies to explore the meaning of community among youth in St. James Town. While I was no longer in touch with this CCC photovoice member, and therefore didn't know the extent to which participating in the CCC photovoice project influenced her own future project, I still noted that new projects on community emerged, as a potential ripple impact of the CCC participatory case study.

In the participation matrix (Table 10.3), I labelled this last noted potential ripple impact (i.e., new projects on the meaning of community) as a 'collective impact' with a caveat, denoted with a '*'. This new project on 'the meaning of community' was an individually led action (rather than a collective action) however, it was led by an insider (rather than an outsider).

Group Level Participatory Ripple Impacts

At the group level CCC project members identified two types of ripple impacts: increased social connections and interpersonal empowerment.

Increased social connections

CCC project members reported increased social connections as a result of engaging in the CCC photovoice project. For instance, three ripple impacts reported by CCC project members at the reflection workshop included:

- "*CCC members feeling more connectivity with the program and each other*" (Reflection Workshop);
- "*CCC internal connectivity*" (Reflection Workshop); and
- "*Brought us together*" (Reflection Workshop).

Other CCC project members reported that participating in the CCC participatory case study was an opportunity to get to know everyone better through the photo and storytelling sessions. This finding highlights the empathic validity of the CCC participatory case study [i.e., the extent to which the research has increased empathy among those who were engaged in the research together (Dadds, 2008)]. For example, one CCC neighbourhood helper commented, "*I feel like I've gotten to know you guys better in the short span of 45 minutes*" (Leah, CCC neighbourhood helper). CCC project members also discussed how participating in the CCC photovoice project helped to decrease social isolation. As one CCC project member noted in the reflection workshop, the photovoice project helped to "*[break] the barriers of social disconnect*" (Reflection Workshop).

Interpersonal empowerment: power with

CCC project members also reported interpersonal empowerment as a participatory ripple impact of their engagement in the research. Interpersonal empowerment refers to the creation of knowledge and social analysis (i.e., the exploration of a social issue for purposes of taking action) that is rooted in:

- personal and shared experiences;
- strengthening of the critical consciousness in terms of power structures; and
- an increasing sense of self through positive social support that challenges feelings of powerlessness (Labonte, 1993).

CCC project members reflected that through their engagement in the PHR project together, they developed new understandings of their community. For example, one CCC project member reflected that participating in the CCC photovoice project, "*has made me more aware. More* *understanding of seniors staying alone, the joys, sorrows and challenges*" (Reflection Workshop). Similarly, another CCC project member reflected that participating in the project together has "*broadened my view. I have come to know about different cultures*" (Reflection Workshop). In addition, another CCC project member at the reflection workshop wrote that a ripple impact for them was "*to think critically, how can I improve and involve in community?*" (Reflection Workshop).

CCC project members also highlighted how working together on this project brought to the surface the unconscious or implicit knowledge they held. As one CCC project member wrote, participating in the photovoice project "*Made us see what we couldn't see*" (Reflection Workshop), while another project member wrote, "*Realizing how much support and love this community had to offer (the reciprocity of care)"* (Reflection Workshop). In addition, at the CCC celebratory reflection workshop, one CCC project member with an interest in film-making expressed an interest in initiating a videography project with CCC members as he thought it could be a powerful tool to raise awareness about the impacts of collective approaches to care. I did not include this potential 'action' in the Participation Matrix (Table 10.3) as at this time of writing, this project has not been initiated.

Building on these interpersonal empowerment ripple impacts, the CCC community development coordinator reflected on the importance of CCC project members sharing their experience of caring with members of their community as a way to: learn from each other; validate their own experiences; and feel empowered to continue to improve on their contributions to the community:

> *"…Among them, they can see each other to validate their work. [CCC members] might think, oh I'm doing this, is it worth it? Is it connected to the community? … You know, whenever you like know something, you do something by yourself, when you see like the similar work or in a different way or is doing something else, you can validate yourself, like what I'm doing is like, then you can think about it to improve your services, you can learn and something. This is one way to share, and improve among the group*" (Alia, CCC community development coordinator).

Organization Level Ripple Impacts

At the organization level, the CCC photovoice project was reported to have contributed to: enhancing the credibility of the CCC initiative, increasing awareness of the CCC initiative, and creating new linkages with other organizations.

Enhanced credibility of the CCC initiative

CCC project members reported that the CCC photovoice research initiative helped to increase the credibility of the CCC initiative. As one CCC project member reported in the reflection workshop, the photovoice project created "*new visual evidence to support the credibility of CCC to others*" (Reflection Workshop). Building on that ripple impact, a former Hospice Toronto senior staff member reflected, "*you know, my dream would be, we take these experiences and because there is a research element and it is measured and it's consistent that we find outlets to kind of share that*" (Leonor, former Hospice Toronto senior staff member). In this later reflection, research findings were seen as a strategy to increase awareness of the CCC initiative.

Increased awareness of the CCC initiative

The CCC photovoice project also helped to raise awareness about the CCC initiative both internally (i.e., within Hospice Toronto) and externally (i.e., with health and social sector organizations/services in St. James Town). Internally, staff from the CCC initiative were invited to present on the CCC photovoice project to Hospice Toronto's board of directors. Members of the board shared with CCC program staff that they really saw the need for this type of initiative, were impressed with the work completed, and were enthusiastic to identify ways to continue to support this work.

In addition to increased internal awareness, the CCC project also helped to raise awareness externally. According to one project member, the photovoice project "*created a positive image among service providers in SJT and raised awareness*" (Reflection Workshop). In turn, the community development coordinator suggested that this increased awareness of CCC, in particular through visuals, may help to increase collaborations with other organizations to improve the program overall,

> "*If we can connect other services providers, they can see what we are doing. We are telling them, but they can see, they can visualize what are doing. This is one thing. And,*

> *also, if we can tell them, this is, um, very limited resource so if you feel this is worth it for the community, we can expand our hand, we can do it with collaboration, or we can ask for suggestion, like how we can expand this services to the community*." (Alia, CCC community development coordinator).

Last, the CCC community development coordinator and myself had the opportunity to raise awareness about the CCC model by co-presenting at the 5th Public Health Palliative Care Conference in Ottawa, Canada (Public Health Palliative Care International, n.d.-a). This was an opportunity to share a compassionate community approach to health promoting palliative care from a Canadian context to a larger international audience. In the participation matrix (Table 10.3), I categorized this level of participation during the 'action' phase as 'co-learning' (i.e., where both insiders and outsiders share their knowledge, with extra support facilitated by the outside researcher).

New Linkages with other organizations

The CCC photovoice initiative helped to raise the profile of the CCC initiative in St. James Town, and as a ripple effect, Hospice Toronto was asked to join the Compassionate Communities Community of Practice (CoP) in Ontario (Hospice Palliative Care Ontario, 2018a). The Compassionate Communities CoP is facilitated by Hospice Palliative Care Ontario, a provincial palliative care organization. This CoP was an opportunity to connect with other people, groups, and organizations across the province working from a compassionate communities framework in order to: learn from one another, share some of challenges and lessons learned, and explore opportunities for collaboration. In turn, through the Compassionate Communities CoP, Hospice Toronto had the opportunity to contribute to advocating for upstream approaches to palliative care through a larger platform.

In addition, through this Compassionate Communities CoP, Hospice Toronto developed a new partnership with one of the members in Toronto called Neighbours-Helping-Neighbours. The Neighbours-Helping-Neighbours group was developing different interactive workshops and surveys to capture the long-term impacts of compassionate community initiatives across different contexts using primarily quantitative tools. Through this collaboration, Hospice Toronto was able to secure a small pot of funding to support the pilot testing of these evaluation tools in the St. James Town context. Similarly, Hospice Toronto was able to share their photovoice approach to capturing impact with the Neighbours-Helping-Neighbours group to explore using both qualitative and quantitative approaches to the evaluation of compassionate communities.

In the participation matrix (Table 10.4), I categorized this level of participation during the 'action' phase as 'collective action (i.e., where insiders led the action items at this stage).

Community Level Ripple Impacts

At the community level CCC project members identified two types of ripple impacts including increased positive changes in neighbourhood perception and increased engagement by community members in the CCC initiative.

Positive changes in neighbourhood perception

CCC project members reflected that participating in the CCC photovoice initiative contributed to a positive view of the community. For instance, the community development coordinator shared how one of the community leaders in St. James Town was really pleased that the strengths of St. James Town were demonstrated, and that a positive view of the community was being shared in contrast to more common negative stories portrayed in the media. The community leader asked the community development coordinator for posters from the project that could be permanently displayed within the community hub. In addition, the community leader expressed an interest in facilitating a similar project in St. James Town more broadly.

CCC project members also reflected how sharing these positive stories "increased sense of belonging in the community" (Reflection Workshop) and helped to "[weave] a tapestry of community integration" (Reflection Workshop).

The feedback from the exit-reflection survey at the CCC photovoice exhibition also included comments such as "*events like this are valuable in building community. The stories told by immigrant women were inspiring*" (Exit-Reflection Response). Similarly, another exit-reflection read, "*We find we have a lot in common as human beings—it's important to connect!*" (Exit-Reflection Response).

Increased engagement by community members with the CCC initiative

In addition to the photovoice initiative shining light on the positive aspects of St. James Town, Hospice Toronto staff reflected how the CCC photovoice initiative also helped to increase community awareness and encourage community involvement in this initiative. For instance, CCC project members reflected that *"[It was] good to let the community be aware of what is going on with their neighbours and the group and the members are not just about person passing by*" (Reflection Workshop). Another project member shared that the photovoice project may have motivated community members to provide care to their neighbours. Additionally, the CCC initiative was also recognized in the St. James Town Spring Gathering 2017 Summary Report, an event hosted by an organization that links together health and social service in St. James Town. The Creating Caring Communities model to support isolated seniors was identified by community members as a 'meaningful and effective' program, and it was recommended by the community to be 'continued and built upon'. This community endorsement of the CCC initiative validated this health promoting approach to palliative care and encouraged Hospice Toronto to continue to facilitate this initiative, thereby increasing access to upstream palliative care supports.

Summary of Ripple Impacts from the CCC Participatory Case Study

CCC project members identified a number of different ripple impacts in connection to their participation in the CCC participatory case study at varying ecological levels. Individual level ripple impacts reported by CCC project members including feelings of happiness and enjoyment, intrapersonal empowerment, and new professional and educational opportunities. Group level ripple impacts reported by CCC project members included increased social connectedness (and reduced social isolation) as well as participatory ripple impacts related to interpersonal empowerment. At the organization level, engagement in the CCC participatory case study helped to enhance the credibility, and increase awareness of, the CCC initiative in St. James Town. In addition, new linkages with other organizations that led to new projects were also reported. Finally, a few participatory ripple impacts were also reported at the community level including: positive changes in the perceptions of St. James Town as well as increased engagement in the CCC initiative. However, we did not identify any changes at the policy level of the ecological model due to the short time frame of the project.

Reflecting on the participatory nature of the 'action' phase of the CCC participatory case study, most of 'action' items that emerged were led by Hospice Toronto staff (see Table 10.3 below). There was only one example of a potential action that rippled out from CCC participatory case study led by a CCC neighbourhood helper individually. This may have been due to the shorter time frame for reflecting on ripple impacts among CCC community members. In contrast, the continued relationship between myself as an outside researcher and Hospice Toronto staff created more of an opportunity to capture and document actions before the formal timeframe of the project.

Table 10.3: Participation Matrix for the CCC participatory case study: Cycle 3 – Ripple Impacts [adapted from (Cook et al., 2017)].

Type	**Deciding on Research focus**		**Designing research methodology**		**Data Generation**		**Data analysis**		**Report writing**		**Dissemination**		**Action**	
	O	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**	**O**	**C**
Co-option														
Compliance		✓		✓						✓				
Consultation				✓			✓	✓	✓					
Co-operation	✓		✓		✓	✓								
Co-learning	✓		✓				✓	✓	✓	✓	✓	✓	✓	
Collective Action													✓	✓ *

Notes: O = Organization (Hospice Toronto) | C = Community (CCC members) | ✓ * = insider individually-led

EXPLORING THE RELATIONSHIPS BETWEEN PHR PROCESSES AND RIPPLE IMPACTS

In this study, CCC project members, including myself as an outside participatory researcher, collectively identified a number of different ripple impacts at the individual-, group-, organization-, and community level that emerged from the CCC participatory case study. Using an ecological lens was a useful framework to articulate and visually demonstrate the broad scope of ripple impacts that emerged from participatory approaches to research. In addition, applying an ecological lens also provided an opportunity to begin to explore the connections and relationships between the ripple impacts found at different ecological levels. In this discussion section, I reflect on the ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of this research project [i.e., by using the now completed participation matrix as a guide (Table 10.3)]. In addition, I begin to explore the connections and relationships between the various ripple impacts at different ecological levels drawing on key concepts from Laverack's (2009) community empowerment framework.

PHR and Community Empowerment

I used key concepts from Laverack's (2009) community empowerment framework as a way to begin to explore the connections and relationships between the various ripple impacts identified at different ecological levels in the CCC participatory case study. The community empowerment framework was chosen as "action, participation and community empowerment" are central to PHR processes (Abma et al., 2017, p. 493). A key concept in the community empowerment framework is that community empowerment is a continuum made up of five levels of social action: personal action; the development of small mutual groups; community organizations; partnerships; social and political action (see Figure 10.4). Another key concept in the community empowerment framework is that, "Each point on the continuum can be viewed as an outcome in itself, as well as a progression onto the next point" (Laverack, 2009, p. 47).

Figure 10.4: Community empowerment as a continuum [adapted from (Laverack, 2009, p. 48)]

In the discussion to follow, I begin to apply these concepts to explore how the participatory processes across the various phases of the CCC participatory case study led to ripple impacts at different ecological levels that were: intrinsically valuable in their own right; and extrinsically valuable in opening up new opportunities for ripple impacts at other ecological levels.

PHR Processes and Ripple Impacts at the Individual Level

In the CCC participatory case study, one of the early steps in the research process after the research topic and design had been developed was the CCC photo mission (i.e., the 'data generation' phase in the participation matrix, Table 10.3). The photo mission was kept broad to create space for CCC project members to interpret the focus of the data generation stage, within certain boundaries (i.e., a focus on the processes, impacts, and facilitators/challenges of the CCC initiative). As noted in Table 10.3, I characterized this as a 'co-operation' level of engagement as while CCC project members contributed to interpreting the data generation process (i.e., the photo mission) from their own perspective, myself as an outside researcher was responsible for directing the process. While CCC project members did not determine the initial focus of the research, the findings in this chapter emphasize that CCC project members still valued the space to self-identify what they felt was important to share in the photo mission phase of the project. CCC project members noted the opportunity to share their perspective as an individual level impact. Similarly, other CCC project members shared that they were happy to be included in this process and to be able to contribute to this project. The participatory processes of the CCC photo mission phase (i.e., the space to decide what photos to take to document their experience) may have contributed to nurturing a 'power from within' by placing value on the issues that individual CCC project members identified themselves.

While the process of community empowerment (or PHR) can be initiated at any point along the continuum, as was the case in the CCC participatory case study, "for persons experiencing a high degree of 'relative powerlessness' it often starts with a personal action that builds a greater sense of power-from-within" (Laverack, 2009, p. 48). Similarly, other PHR projects have also reported feelings of increased confidence among those involved as a result of project members recognizing their own abilities and strengths and having their voice heard as a ripple impact of the research (Banks et al., 2017; Brett et al., 2014b; Catalani & Minkler, 2010; Staley, 2009).

PHR Processes and Ripple Impacts at the Group Level

Building off the individual photo mission phase of the CCC participatory case study, CCC project members brought their personal photos and stories that documented their experience of being part of the CCC initiative to the larger group. Coming together in this way represented a shift along the community empowerment continuum (Figure 10.4) and created a space for new opportunities for participatory processes and impacts to emerge at the group level. During this phase, CCC project members came together to share their experiences as a group and begin the process of participatory data analysis together by exploring similarities and differences in experiences. In the participation matrix (Table 10.3) I labelled this level of participation as 'co-learning' during the first part of the data analysis phase as both CCC project members and myself engaged in a process of learning from each other. Creating space to come together in small groups and for co-learning levels of participation to occur was valuable for a number of reasons and contributed to new ripple impacts at the group level.

First, CCC project members reported increased feelings of social connectedness among project members as a result of coming together as a group to share experiences. This was an important finding, as previous research has reported that having group support makes it easier for individuals to engage in additional opportunities for social action (Labonte, 1993). Previous research has also found that in participatory approaches to research, group bonding also helped to increased members' engagement with the research project (Lindenmeyer et al., 2007; Staley, 2009). However, the extent to which this social connectedness was maintained after the project came to a close was not captured. Second, CCC project members also reflected on how discussions that happened together at the group level contributed to new understandings of how to support the CCC initiative in St. James Town, in order to improve compassionate community approaches to heath promoting palliative care. Last, coming together as a group to reflect on the impacts of the CCC initiative was also reported to have energized CCC members about their contributions to this initiative. As the CCC community development coordinator reflected, by coming together and sharing experiences it was also an opportunity to "*see each other to validate [CCC members] work*" (Alia, CCC community development coordinator). These ripple impacts at the group level resonated with other literature that has found that through engagement in small groups that individuals create identity and purpose, build connectedness, and validate that they are not alone (Labonte, 1993).

While these ripple impacts reported at the group level were intrinsically valuable on their own, the participatory processes and ripple impacts at the group level created a foundation for new participatory processes and ripple impacts to emerge. As Labonte (1993) has suggested, the work that happens at the group level often represents the locus of social change. In the CCC participatory case study, CCC project members built on the work completed at the group level to develop and launch the CCC community photovoice exhibition. CCC project members (including Hospice Toronto staff members) played a central role in determining the photos and stories to be included in the exhibition (i.e., what I called the 'report writing' stage in a photovoice project). As such, I labelled the level of participation during 'report writing' as co-learning, as I was also engaged in facilitating, and learning from others, in the process. In addition, many CCC project members contributed to preparing for the CCC community photovoice exhibition (i.e., the dissemination phase) and similarly, I labelled this level of participation as 'co-learning' again. The CCC community photovoice exhibition represented a shift in CCC project member focusing their attention inwards (i.e., supporting the needs of the group, learning from one another) to beginning to focus the attention outwards by sharing their collective experiences with the broader community (e.g., community members living in St. James Town, health and social service organizations, and municipal policy influencers including the deputy major of Toronto at the time). This shift from an inward to outward focus subsequently contributed to new opportunities and ripple impacts at both organization- and community levels.

PHR Processes and Ripple Impacts at the Organization Level

As the CCC participatory case study continued to progress, the actions of CCC project members at the group level (i.e., the CCC photovoice exhibition) created new opportunities and ripple impacts at the organization level. This represented another shift along the community empowerment continuum (Figure 10.4) toward higher levels of action. For example, Hospice Toronto (the organizational facilitating the CCC initiative), was able to build off the CCC photovoice exhibition to help raise awareness of compassionate community approaches to health promoting palliative care: internally (e.g., to their own board of directors); and externally to relevant municipal and provincial stakeholders. These dissemination and action activities were labelled as 'co-learning' and 'collective-action' levels of participation respectively in the participation matrix (Table 10.3), as in some cases I helped to facilitate the process, while in others Hospice Toronto took the lead. One of the ripple impacts at the organization level reported by Hospice Toronto staff members was how the CCC participatory case study helped to increase the credibility of the initiative to outside stakeholders. Similarly, other participatory researchers like Parker et al. (2003) have also described gaining public recognition and credibility as an impact of community-based participatory research approaches. This increased recognition and credibility of the CCC initiative created new opportunities for broader engagement at the organization level in supporting health promoting approaches to palliative care. For example, Hospice Toronto was invited to join a provincial community of practice on compassionate community approaches to health promoting palliative care. Being part of a larger network represented a shift from second-person inquiry in the participatory research process (i.e., inquiry in a small group), to a new opportunity for broader third-person inquiry (i.e., inquiring in larger groups). It also created an opportunity for a larger advocacy platform on the value of health promoting approaches to palliative care. In the longer term, being linked into this broader network may loop back to support the group level work of CCC project members and the wider St. James Town community through additional government support and investment in health promoting approaches to palliative care. However, at this time, no ripple impacts related to policy or environmental changes were noted.

PHR Processes and Ripple Impacts at the Community Level

Last, the actions of CCC project members at the group level (i.e., the CCC photovoice exhibition) also rippled out to create impacts at the community level. For example, a few community level impacts including positive changes in neighbourhood perception, and increased engagement by community members with the CCC initiative were two ripple impacts that emerged from the work of CCC project members at the group level.

Facilitators of Ripple Impacts in PHR

In reflecting on the ripple impacts that emerged from the CCC participatory case study in relation to the participatory nature of the research project, as well as the connections and relationships between ripple impacts, I noted a few facilitators of ripple impacts in PHR. Factors that facilitated ripple impacts (which share similarities to key concepts in Figure 10.4) included:

strong group identity and cohesion, nurturing connections between opportunities for action at different ecological levels, connecting the personal with the political, and higher levels of participatory engagement by project members.

Strong group identity and cohesion

A strong group identity and an existing level of social cohesion among CCC project members helped to facilitate ripple impacts in the CCC participatory case study. On average, CCC project members that participated together in the CCC participatory case study had been a part of the group for a year and a half (see Chapter 6). As there was already an existing group identity, the CCC participatory case study did not have to spend time working to build group cohesion. As a result, even within the relatively short project timeline of the CCC participatory case study, CCC project members were able to move from more individual to collective efforts more quickly. If this CCC photovoice project had been organized with a new group of individuals, the ripple impacts that would have emerged may have been more limited in scope in the same time frame.

It is important for researchers, practitioners, and funders to realize that the group-building process is slow and requires patience and commitment (Labonte, 1993). As Minkler (1985) highlighted in the Tenderloin Senior Outreach Project, which aimed to build supportive ties among inner city seniors, it took one year of standing in the hotel lobby talking to senior roomers, providing counselling and a listening ear before the first group started to form. This slow group building process is important to emphasize in PHR initiatives which aim to create social change—particularly in a climate where funders expect to see new initiatives and groups move to social action and public policy impacts within a short time period (Labonte, 1993).

Nurturing connections between opportunities for action at different ecological levels: connecting the personal with the political

Another important facilitator of ripple impacts in the CCC participatory case study was nurturing connections between opportunities at different ecological levels. In order to move toward the outer level ripple impacts (i.e., community or policy impacts) in the CCC participatory case study, it was not feasible for one person, group, or organization to possess both the skills and time that were required to meaningfully work across all levels. Rather, it was important to nurture connections between opportunities at different ecological levels and build off the strengths of different partners. For example, organizations (e.g., Hospice Toronto) have a number of characteristics that can be of value for promoting the actions of smaller groups in terms of developing partnerships and focusing on social and political action. In addition, organizations have a more established structure and functional leadership that can help smaller groups by mobilizing members and resources to support outward focused goals (Labonte, 1993).

Nurturing connections between opportunities at different ecological levels is also important for both academic and non-academic co-researchers to consider. Indeed, Björn Gustavsen (2003) has argued that action research (an approach that falls within the PHR umbrella) will be limited in its influence and impact if researchers continue to only think in terms of disconnected single cases. Rather, Björn Gustavsen (2003), like Labonte (1993) and Laverack (2009), argues that participatory health researchers should be thinking about how to create or support social movements by looking for opportunities to make connections between cases or events. However, while Reason (2003a, p. 282) also agrees with the importance of this type of larger scale inquiry (which he calls 'third-person' inquiry practice (Chandler & Torbert, 2003)), he argues that it is equally important to "engage in transformations of consciousness and behaviour at personal and interpersonal levels." As Reason (2003a) explains, it is not feasible to make systematic change solely on the basis of single cases, just as it is not feasible to build large political networks without developing the capacities for critical inquiry among the individuals, groups, and small communities which make up these larger networks. In contrast to Björn Gustavsen (2003) however, Reason (2003a) doesn't see larger networks as being more important for social action and impact, rather each level of social action has value in terms of contributing to broader social action. As such, the emphasis should be on making connections between 'the personal' and 'the political' (Reason, 2003a).

In our participatory ripple impact analysis on the CCC participatory case study, we were able to demonstrate how PHR processes (or actions) and impacts at various ecological levels opened up new opportunities for social action at different ecological levels. Therefore, the findings from the CCC participatory case study suggest that academic and non-academic co-researchers should look for ways to connect 'the personal' with 'the political' in order to build a strong foundation for addressing important social issues. In the context of the CCC participatory case study initiative, this was to begin to raise awareness on the value of compassionate community approaches to health promoting palliative care.

Higher levels of participatory engagement by project members

Last, this reflection exploring the relationships between PHR processes and ripple impacts begins to show some early evidence that higher levels of participation in PHR initiatives may lead to more ripple impacts, echoing findings from previous reviews on the impact of PHR processes (Bush et al., 2017; Catalani & Minkler, 2010; O'Mara-Eves et al., 2015). In the CCC participatory case study, participatory engagement at the organizational level was relatively high across the various phases of the research (see Table 10.3). Among community members (i.e., CCC members) participatory engagement levels increased over time, with lower levels of engagement in the initial planning phases of the research. While this study did report a variety of ripple impacts across ecological levels, it is difficult to compare the ripple impacts in the CCC participatory case study to other PHR initiatives with lower or higher levels of participatory engagement as there are limited studies within the literature that have explored this connection. Furthermore, strategies to assess levels of participation are not consistent across the literature, which further compounds this challenge.

SUMMARY

The ripple impact analysis of the CCC participatory case study presents the broad scope of ripple impacts that emerged over the course of the research project from the perspective of co-researchers involved in the project. While it is too early to assess how the nature of participation influenced the ripple impacts that emerged, this study presents one case example that has potential to contribute to a broader multi-case exploration of impacts. These findings contribute to a growing evidence base on better articulating the value of participatory approaches to health research, particularly in a climate where there is pressure to demonstrate tangible impacts from research. Rather than using a priori indicators to assess research impact, a strength of this study was that co-researchers involved in the project determined what impacts were meaningful to them (a discussion on strengths and limitations of the CCC participatory case study will follow in Chapter 11). Not only is this important from an epistemic justice perspective, it is also important in terms of broadening our understanding of the scope of ripple impacts that can emerge from participatory processes. In addition, by using both an ecological lens and drawing on key concepts from the community empowerment continuum, I was able to demonstrate how ripple impacts at individual and group levels [i.e., impacts that tend to be considered ‘micro’ and hence undervalued (Banks et al., 2017)] formed an important foundation by creating new opportunities for social action at different ecological levels. An ecological lens and the community empowerment continuum may be useful organizing frameworks to better articulate to funders the connections between levels of social action and the importance of connecting ‘the personal’ with ‘the political’. In addition, we identified a number of facilitators of ripple impacts in PHR including having a strong group identity, nurturing connections across ecological levels, and higher levels of participatory engagement.

Finally, our case study also provided a practical example for how to go about assessing ripple impacts in a PHR initiative which may be useful for other participatory health researchers looking to articulate and demonstrate impact. Our approach to capturing ripple impacts is a first attempt at beginning to explore different strategies to overcoming some of the unique challenges in capturing impact in PHR (e.g., issues related to broad definition, time frames, etc.). Future research could begin to bring together case studies such as ours to look for patterns linking levels of participation with different types of impacts in order to more fully understand this approach. Indeed, the International Collaboration for Participatory Health Research is working on developing an Interactive Knowledge Base to map the relationships between participation and impact, the scope of impacts that can be expected, and how these impacts manifest in different context of health research (i.e., different issues, locations, people involved, etc.) (International Collaboration for Participatory Health Research, n.d.). This endeavor will make an important contribution to understanding participatory ripple impact in PHR on an international scale.

Cycle 3: Ripple Impacts was the final cycle of ‘action and reflection’ in the CCC participatory case study. In the last chapter to follow, I provide a summary of the research and reflect on the strengths and limitations of the CCC participatory case study.

CHAPTER 11: CONCLUSION

BRINGING IT ALL TOGETHER

This thesis is a representation of my journey, taken together with CCC members and Hospice Toronto staff, into the CCC participatory case study. This participatory research journey started as an exploration into the CCC initiative to learn more about the nature and impact of compassionate community approaches to health promoting palliative care within an inner-city setting. As the research planning unfolded, I saw a unique opportunity to reflect on, and explore, the participatory nature of the research processes used to explore the CCC initiative. By studying my thesis experience as a whole, I was afforded the opportunity to make a contribution to both the field of health promoting palliative care and PHR.

In Cycle 1: Grounding, I critically reflected on my experience initiating and building a participatory research relationship with Hospice Toronto. Building this participatory research relationship formed the foundation of the CCC participatory case study. However, despite the importance of this initial relationship building process, it has not received as much focus in the literature. Like many other students who engaged in a participatory research process before me (Burgess, 2006; Grant, 2007; Klocker, 2012), I soon realized the map detailing the process of initiating and building a participatory research relationship was only half sketched out within the literature. With the support of my supervisor, I had to trust the emergent process and learn to initiate a participatory research project ‘by doing’. Letting go of a concrete destination was personally challenging. However, using first-person inquiry was an opportunity to document what I had learned along the way; lessons that I will bring with me on my next participatory research journey. For example, I critically reflected on various factors that facilitated my experience initiating and building a participatory research relationship. Some of these facilitators included: identifying potential partners who were ‘participatory’ research ready, identifying small concrete projects to work on together, organizational capacity to engage in a PHR project, and getting to know the community slowly. I also experienced challenges along the way including navigating relationship expectations and boundaries, as well as my own internal tension of negotiating institutional timelines with participatory principles. By presenting my experience initiating and building a participatory research relationship, I was able to provide a more transparent account of the early phases of engaging in a participatory research project. In doing so, it was my hope that other doctoral students beginning their participatory journey feel encouraged to trust the process and may also be able to draw on some of the lessons I learned along the way to support their own journey.

By developing a strong foundation with Hospice Toronto and other members of the CCC initiative in Cycle 1, we were able to move to Cycle 2: The Photovoice Project. Together, we engaged in a 10-month photovoice project to explore the nature, impact, facilitators and challenges of a compassionate community initiative in an inner-city setting using the CCC initiative as a case study. The findings from Cycle 2 provide a deeper understanding into how a compassionate community approach to health promoting palliative care in an inner-city setting can build community capacity to support isolated community members living with a serious life-limiting illness and/or their primary carers. In particular, the findings from this research draw attention to the need for ‘scaffolding supports’ (e.g., organizational backbone support, focusing on the social determinants of health, and creating spaces for co-learning and connection to occur) in order to meaningfully support a compassionate community initiative. While bottom-up community driven approaches to health promoting palliative care demonstrate many positive impacts (discussed below), top-down support (i.e., from the welfare state) is necessary to meaningfully bolster these initiatives. In addition, the findings from Cycle 2 contribute to a limited evidence base exploring the impacts of compassionate community approaches to health promoting palliative care. From an inner-city perspective, CCC project members identified a number of impacts resulting from their engagement in the CCC initiative. For example, CCC members reported increased neighbourly connections, ‘feeling cared for’, and positive impacts on mood, in addition to increased knowledge and skills and professional development. In reflecting on these impacts, I noted that many of these impacts were akin to the generation of social and cultural capital (i.e., structurally based resources). This was a significant finding from a health equity perspective, as this research highlighted how compassionate community initiatives in inner-city contexts have potential to increase community members’ resources. In turn, this expansion in resources can increase community members’ opportunities to realize their preferred choices for palliative care. While additional research is needed, these findings highlight how compassionate community approaches to health promoting palliative care may be able to reduce health inequities in palliative care experiences if they are meaningfully supported.

Finally, Cycle 3: Ripple Impacts formed the final loop of the CCC participatory case study. As I shared in Chapter1, I was drawn to PHR approaches as I was motivated to engage in a research process that could foster change and lead to improvements in the palliative care experience. Reflecting on the participatory nature of the research across the previous Cycles 1 and 2, I experimented with strategies to capture and document the impact of the CCC participatory case study process using an ecological lens. Rather than determining the impact of the CCC participatory case study using a priori indicators, I drew on different first- and second-person inquiry approaches that brought the perspectives of those involved in the research to the forefront. By engaging non-academic co-researchers in determining the impacts that were meaningful to them, we were able to document a broader range of ripple impacts across multiple ecological levels (e.g., feelings of happiness, interpersonal empowerment, new organizational linkages, and positive changes in neighbourhood perceptions of the CCC initiative). Traditionally, individual-level and group-level impacts (i.e., feelings of happiness, interpersonal empowerment) have tended to be less valued by research funders (Banks et al., 2017). However, using Laveracks' (2009) community empowerment continuum I demonstrated how ripple impacts at lower levels of the ecological model were necessary for opening up opportunities for higher level impacts. Based on these findings, I concluded that in order for participatory research to contribute to both personal change and higher-level structural change, academic and non-academic co-researchers should consider participatory research processes that aim to connect 'the personal' with 'the political'.

STRENGTHS AND LIMITATIONS

One of the strengths of the CCC participatory case study was the opportunity to capture my thesis experience as a whole from the early stages of developing the research relationship, to engaging in The Photovoice Project, and finally to reflecting back on the participatory ripple impacts that emerged along the way. By exploring my thesis experience 'as a whole', I was able to draw attention to parts of the research journey that tend to be brushed over (e.g., initiating and building a participatory research relationship) despite their significance to the process. By focusing on my research experience as a whole, I was able to provide a more transparent account of the CCC participatory case study, including all the messy action-reflection loops along the way.

Cycle 1: Grounding

One of the strengths of the first-person inquiry in Cycle 1: Grounding was the opportunity to critically reflect on some of the limitations of the participatory nature of the relationship building process I engaged in. This inquiry provided a space to stop and reflect on what I would aim to do differently in the future. With this experience under my belt, in future research I want to be more mindful of power imbalances in the participatory research process and explore strategies to better equalize the distribution of power in participatory research projects. For example, in determining the focus of the research, I will be more cognizant of who may be missing from these conversations that should be at the table.

Cycle 2: The Photovoice Project

In Cycle 2, one of the strengths of The Photovoice Project was the flexible PHR method used. Together with Hospice Toronto staff, we were able to adapt the method to maximize the participation of different CCC project members, including those who were unable to attend group sessions at the community corner due to health or mobility reasons. I found photovoice to be an inclusive research method to engage CCC community members living with a life-limiting illness. In our CCC photovoice project, the vast majority of CCC members already had access to a camera which helped increase the accessibility of this method. We also found the camera to be a powerful tool for communication with CCC project members who were not as confident communicating in English. Wang and Burris (1997) have described photovoice as an inclusive data generation tool, as anyone can learn to use a camera. Previous photovoice research has also shown the potential and value of photovoice in engaging vulnerable groups on topics from political violence to discrimination (Catalani & Minkler, 2010) and including end-of-life care (Horsfall et al., 2012a). While the majority of CCC project members were CCC neighbourhood helpers, we still had good participation from both CCC community members and CCC primary carers which helped to increase the diversity of experiences that were included in the project—another strength of this study. In addition, the socio-demographic profile of CCC photovoice project members was diverse, reflecting the diversity of the broader CCC membership base and the St. James Town community.

Further, the CCC Photovoice Project was an engaging method that helped facilitate CCC member engagement across the entire research process despite the time intensive commitment. In The Photovoice Project, every project member stayed committed to the project until our final reflection workshop, which we found to be a strong indicator of CCC members' support for the project. While a limitation of our study was that CCC members were not directly involved in determining the focus of the research (as previously described in Cycle 1), like Nykiforuk et al. (2011), we kept the photo mission broad to allow CCC project members the space to express their own interpretations of the photo mission.

In addition, photovoice was a useful method to bridge the gap between research and action (Wang & Burris, 1997). The photos and stories created an opportunity to raise awareness of the value of collective approaches to community care in St. James Town by highlighting the often 'invisible nature' of this work (Barnes, 2012). For example, the community photo storytelling exhibition in St. James engaged a diverse group of different stakeholders including health policy makers, municipal elected officials, community members, and other local social and health services organizations. One community leader in St. James Town praised the efforts of CCC members for countering the negative portrayal of St. James Town by shining a light on the strengths of the community. This community leader expressed a desire to explore a similar project on a larger scale in St. James Town.

Finally, in terms of opportunities to generalize the findings from The Photovoice Project to other health promoting palliative care contexts, a strength of our study was the use of rich descriptive re-telling of CCC photovoice project members stories. The findings from the CCC photovoice project may be particularly valuable to other community groups in inner-city settings. In Chapter 9, I outlined a series of recommendations for practice, policy, and research based on the findings from The Photovoice Project

Cycle 3: Ripple Impacts

One of the strengths of Cycle 3 was that this ripple impact analysis on the CCC participatory case study provided a practical example of how to begin to overcome some of the challenges reported in the literature on how to assess ripple impacts in PHR.

First, I adapted Cook et al. (2017) dimensions of participation matrix to reflect on the nature of participation in the CCC participatory case study across the various phases (Table

10.3). In using this matrix, I was able to provide a more contextual and transparent understanding of the types of ripple impacts that emerged given the participatory nature of the research. While I adapted the matrix to denote participation levels among different groups (i.e., the organization and community), I noted a number of challenges in regard to assessing participation with this matrix. One of these challenges was that the phases of the research (outlined horizontally on the matrix, see Table 10.3) were broad and didn't always reflect particular nuances of the CCC participatory case study. For example, while CCC members played a key role in preparing for the photo exhibition, it was unclear where to note this level of participation in the research process. I ended up noting that 'preparation for the exhibition' was akin to 'report writing'. In addition, the classification of participation levels was also a bit vague making it difficult to differentiate between levels. Using this matrix highlights some of the challenges with creating an assessment tool that is broad enough to use in different context for comparison purposes, with the need for a flexible tool to capture the nuances of different PHR processes. Indeed, South and Phillips (2014, p. 694) suggest that evaluation on community engagement processes "needs to build a thick description and explanation of the nature of participation." This thick description and explanation is important to provide a more nuanced and transparent account of the participatory nature of the research.

Second, we were able to begin to address some of the issues related to 'timing' in PHR by purposefully assessing ripple impact across the timeline of the project, rather than waiting until 'the end'. As Wadsworth (1998, p. 7) agrees, change in PHR is not something that happens at 'the end' of the process, but that it occurs throughout. In this study, we explored ripple impacts: during our photovoice individual and group story telling sessions; at the photovoice exhibition; during a special workshop dedicated to reflecting on impact; and by drawing on my own researcher observations, field notes, and journal entries that captured impacts more informally as they organically emerged or were highlighted. Further, I was able to stay connected with Hospice Toronto staff after the soft closing of the CCC participatory case study which allowed for longer term ripple impacts to also be included in the analysis (e.g., organizational ripple impacts specific to partnership opportunities such as joining the HPCO Community of Practice). Exploring ripple impacts across the timeline of the participatory project, and beyond, created an opportunity to build an ongoing memory, and capture the breadth of ripple impacts, that may have been lost or forgotten if they have only been assessed once the project had concluded.

Third, we followed Morton and Fleming's (2013) recommendation to explore research impact from a contributions perspective as opposed to a cause-and-effect perspective. We used an ecological framework to present our ripple impact findings which allowed us to present our findings from a 'spheres of influence' perspective. For example, ripple impacts found at the core of the model were more of a direct impact of the participatory research (i.e., individual level impacts), while impacts on the outer circles (i.e., the community level) were more of an indirect ripple impact of the research. This framework may be useful for other participatory health researchers in terms of organizing the various ripple impacts that emerged from a PHR process.

I also identified a number of limitations of our ripple impact analysis. First, while we were able to capture a breadth of different types of ripple impacts, across different timepoints and from diverse perspectives, we were unable to go into much depth. For example, when one project member indicated in our closing reflection workshop how one of the ripple impacts from participating in the CCC Photovoice Project was '*breaking the barriers of social disconnect*', it would have been beneficial to ask additional follow-up questions. Due to constraints of the research (e.g., time limitations of project members juggling many responsibilities) we were unable to explore deeper into some of these findings. Ideally, it would have been beneficial to do our closing reflection workshop over a day rather than a few hours, as uncovering some of those deeper discussions can require more time.

Further, while we were able to capture longer term impacts at the organizational level in terms of partnership building, it was more difficult to capture longer term impacts at the individual and interpersonal level as I was no longer in direct communication with many of the project members after the project had concluded. Again, this limitation should be interpreted within the constraints of the research (e.g., ethics processes that limit longer term communication after the project had concluded). Future studies could explore opportunities to bring together project members after a year has passed to explore longer term impacts at the individual and group levels.

Finally, another strength of this study was the value of including a diversity of perspectives in the ripple impact analysis. In our CCC participatory case study these perspectives included project members directly involved in the study, Hospice Toronto staff perspectives, and impacts reported in the broader community (i.e., at the photovoice exhibition). This was valuable as it allowed us to understand the range of ripple impacts across different levels of the ecological model from individual level impacts to organizational and community level impacts and present a much more holistic understanding of the scope of ripple impacts. In particular, South and Phillips (2014) have also recommended that any evaluation of community engagement, whether qualitative or quantitative needs, to be directly rooted in the experience of participants involved; as was the case with the CCC participatory case study.

CONCLUDING REFLECTIONS

I conclude my thesis journey drawing inspiration from a quote by Esther Perel, *"Relationships are the fabric of our society."* In the CCC participatory case study, it was relationships that were the thread weaving together the three cycles of my thesis journey. In Cycle 1, relationships formed the foundation from which the research in Cycle 2: The Photovoice Project was possible. In Cycle 2, together with CCC project members and organization staff, we learned about the significance of relationships and social connection in keeping people living well until the end-of-life. Finally, Cycle 3 drew attention to various research ripple impacts and action for change that can occur when people come together to explore an issue of mutual importance. The significance of relationships and connection is a key learning from my thesis journey that I will take forward in my research career. This will be valuable as Minouche Shafik, director of the London School of Economics predicts: "*In the past, jobs were about muscles, now they're about brains, but in the future they'll be about the heart*" (Alain Elkann Interviews, 2018).

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APPENDIX A: HEALTH PROMOTION AND PALLIATIVE CARE—A PARADOX?

The field of health promotion has historically avoided researching and practicing in the field of palliative care (Kellehear, 1999b). Even at present, there are few examples of health promotion researchers or practitioners exploring issues related to death, dying, loss, and care (Whitelaw & Clark, 2019). This is problematic as the principles, values, and strategies of health promotion can make a valuable contribution to addressing many of the critiques and challenges of current approaches to death, dying, loss, and care (e.g., the medicalization and professionalization of palliative care). While health promotion's limited engagement in these issues may be a result of the historical dominance of the biomedical paradigm in claiming the field of palliative medicine (Clark, 2002), health promotion has historically been more focused on disease prevention (Antonovsky, 1996).

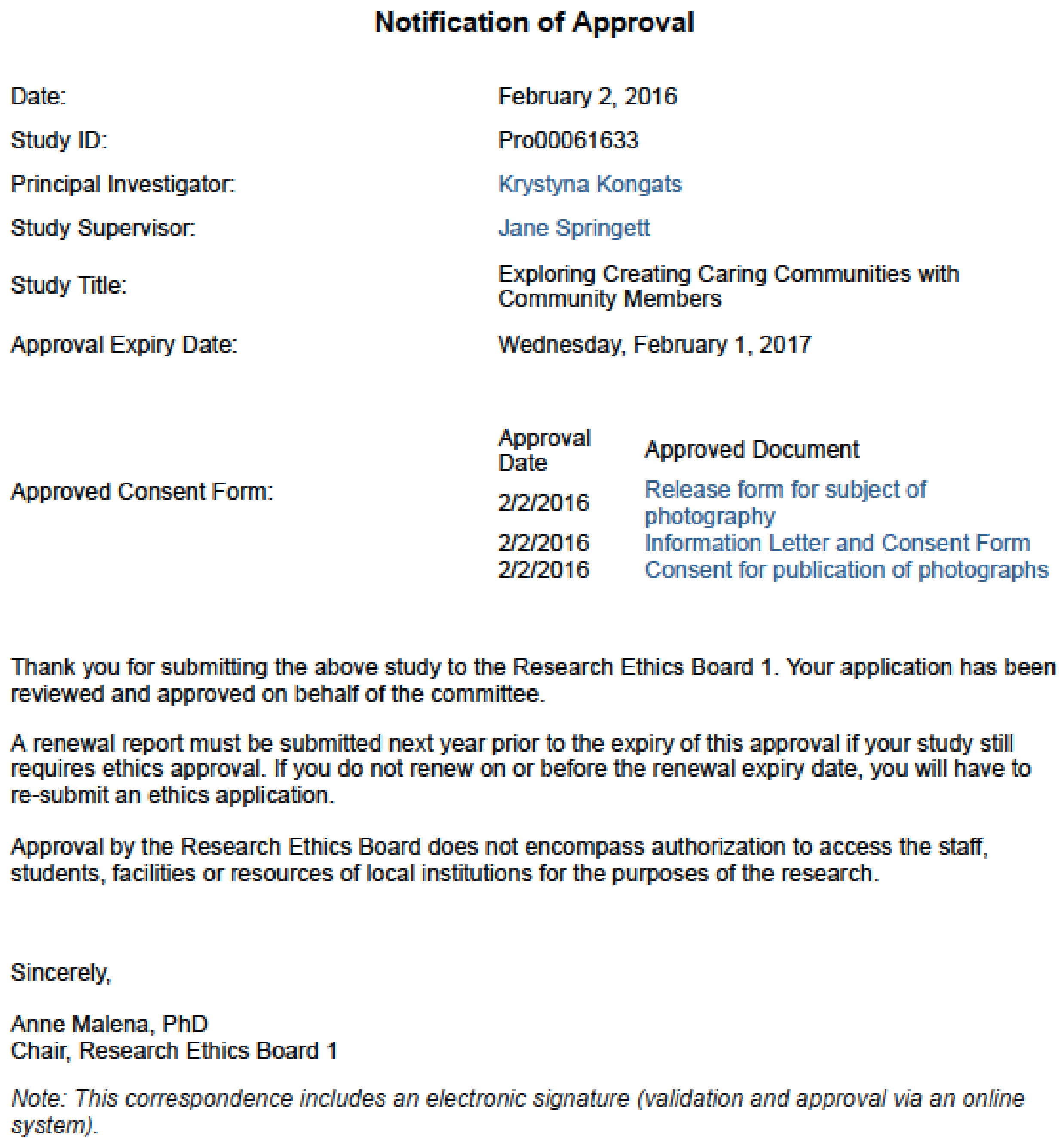
The focus on disease prevention in health promotion is illustrated in the well-known health promotion/public health river parable (National Collaborating Centre for Determinants of Health, 2014). As the story goes, a witness sees a man stuck in a river current and rescues him on to the bank only to see that there are many others also caught in the current coming downstream. The man decides to walk up stream on the bank to figure out why so many people are ending up in the river in the first place. This popular parable is commonly used to differentiate the purpose of health promotion (i.e., identifying how to stop people from falling into the river) from the purpose of curative medicine (i.e., rescuing those who have already fallen in and need saving) (National Collaborating Centre for Determinants of Health, 2014). At either end of this spectrum however (i.e., prevention vs. cure), experiences related to death, dying, loss, and care have fallen though the cracks.

However, Antonovsky's (1996) salutogenic approach to health promotion creates an opportunity for the principles, values, and strategies of health promotion to positively impact the experiences of death, dying, loss, and care. Antonovsky (1996) had challenged the field of health promotion to expand beyond a pathogenic orientation that categorizes individuals as healthy or sick, to a salutogenic orientation rooted in an assets-based approach. This salutogenic approach to health promotion can reframe the popular river parable by dissolving the divide between 'healthy' and 'sick' to seeing all living systems, including humans, as inherently flawed. From this perspective, it is assumed that all humans will experience events beyond their control, that everyone is ultimately subject to an unavoidable death, and consequently, all humans are somewhere in the river along the "healthy/dis-ease continuum" (Antonovsky, 1996, p. 14). From this perspective, a salutogenic approach to health promotion in palliative care asks: how can we make the river a better place to be for experiences of death, dying, loss, and care (e.g., through healthy public policy and settings-based approaches); and how can we learn to swim better in the river to make these experiences more positive (e.g., by developing our own capabilities). This shift creates an opportunity for the field of health promotion to apply the principles, values, and strategies of this field to positively impact health and well-being at any point along the healthy/dis-ease continuum, including supporting experiences of death, dying, loss, and care.

APPENDIX B: ETHICS MATERIALS

1. Ethics Letter of Approval
2. Information Letter
3. Consent Form
4. Anonymous Demography Survey
5. Consent for the Publication of Photographs
6. Release Form for Subject of Photography

ETHICS APPROVAL LETTER



Notification of Approval

Date:	February 2, 2016	
Study ID:	Pro00061633	
Principal Investigator:	Krystyna Kongats	
Study Supervisor:	Jane Springett	
Study Title:	Exploring Creating Caring Communities with Community Members	
Approval Expiry Date:	Wednesday, February 1, 2017	
	Approval Date	Approved Document
Approved Consent Form:	2/2/2016	Release form for subject of photography
	2/2/2016	Information Letter and Consent Form
	2/2/2016	Consent for publication of photographs

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Anne Malena, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

INFORMATION LETTER

Study Title: Exploring Creating Caring Communities with Community Members

Research Investigators:				Student Supervisor:
Krystyna Kongats Research Student [redacted]	**Minara Begum** Community Dev. Coordinator [redacted]	[redacted] Director, Clinical Services [redacted]	**Dena Maule** Executive Director [redacted]	**Dr. Jane Springett** Professor [redacted]

***@hospicetoronto.ca**

Background

You are being invited to participate in a collaborative photo and storytelling project to explore the Creating Caring Communities (CCC) initiative in St. James Town because of your contribution as a [insert relevant: CCC helper/client/carer/community leader/staff member]. Hospice Toronto provided me with your contact information as they thought you would be a good fit for the study and may have an interest in joining. This study is being done together with Hospice Toronto and the University of Alberta. It is part of my thesis project in health promotion.

Purpose

The purpose of this study is to explore the impact of Creating Caring Community in St. James Town from the perspective of community members who are involved in this initiative. We are doing this project because there is very little known about the impact of community led initiatives that help people with serious illness or other conditions.

Study Procedures

If you would like to participate in the project, you will be invited to join a photography and storytelling project called ‘photovoice’ to show and tell others how being part of a caring community in St. James

Town impacts your daily life. Your experience and knowledge as a [insert relevant: CCC helper/client/carer/community leader/staff member] would be a strength to the research project. If you would like to join the project, you will be invited to participate in:

- An introductory meeting to learn more about the project (either at your home or close-by at the Community Corners in St. James Town)
- A 1-hr individual interview to share your photos and stories at a time and location convenient for you
- *[Optional]* 2 group meetings to share photos and stories with other community members to discuss similarities and differences in photos and stories and think about how to share these photos and stories with others (for example: at a photo exhibition in the community).

If you feel more comfortable with extra English language translation support to participate in the project, please let us know and we will do our best to connect you with a volunteer!

With your permission, we would also like to audio record the interviews and workshops, these sound recordings will be kept confidential and will only be used to help us remember what was said, they will not be shared with others. There are no costs to participating in this study.

Benefits

We cannot promise any benefits to you from your participation in this community research process. However, community members who have participated in past photovoice projects said that they developed new knowledge and skills in community research. As a small thank you, you will get to take home copies of your photographs. We also hope that the information we learn by doing this study together will help other communities who want to develop a similar community-led approach to caring for persons who are ill in the community.

Risk

The potential risks for participating in this research are minimal and no greater than what you would experience in your daily life. There is a small chance that you may feel uncomfortable sharing your story about your experience being part of a creating caring community and how it has supported you or someone you know. You do not have to answer any question you do not want to. As the research activities have an optional group component, complete confidentiality cannot be guaranteed. However all community members who join the project will be asked to keep confidential what others share in the group.

Voluntary Participation

You are under no obligation to participate in this study, your participation is completely voluntary and will not impact your relationship with Hospice Toronto. You are free to choose how much you would like to participate. Even if you agree to be in the study you can change your mind and leave at any time or change your how much you want to participate. All you have to do it contact **Krystyna Kongats** or **Minara Begum** to let them know about the changes you wish to make. If you would like to remove your photographs and written stories from the project, again, all you have to do is contact **Krystyna Kongats** or **Minara Begum** to let them know. The last date to remove your photographs from the project will be prior to the start of our group sharing and analysis workshop (we will send you all dates once we know what works best for the group).

Confidentiality & Anonymity

The findings from this research (i.e. the photos and stories you share) may be reported in: a final report to Hospice Toronto, policy makers and/or community representatives; academic journals; conference presentations; multimedia public platforms (e.g. websites); public presentations; and/or public exhibitions (e.g. photo display exhibit). As this is a collaborative research project you will have the option of whether you would like to have your name listed as a contributor to the project.

All research documents will be securely stored by the student principal investigator in a locked cabinet or a password protected file for a minimum of 5 years following the completion of the research, after which they will be safely destroyed. Only the student investigator, supervisor and university ethics board will have access to all files.

Further Information

If you have any further questions regarding this study, please do not hesitate to contact myself, **Krystyna Kongats** (Student Researcher) by phone: [redacted] or email: [redacted] or **Minara Begum** (Community Development Coordinator) by phone: [redacted] or email: [redacted]

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

CONSENT FORM

Project Title: Exploring Creating Caring Communities with Community Members

Do you understand that you have been asked to be in a research study?	Y	N
Have you read and received a copy of the attached information sheet?	Y	N
Do you understand the risks and benefits involved in taking part in the study?	Y	N
Have you had an opportunity to ask questions about the study?	Y	N
Do you agree to have the interview & optional workshops audio (sound) recorded?	Y	N
Do you understand that you are free to leave the study at any time, without having a reason?	Y	N
Has the issue of confidentiality been explained to you?	Y	N
Do you understand who will have access to the study data?	Y	N
I agree to participate in the study.	Y	N

Who explained the study to you? ____

Signature of Participant____

Printed Name____

Date____

Signature of Investigator____

Date____

Creating Caring Communities Photovoice Project

ANONYMOUS DEMOGRAPHIC SURVEY

These 8 questions help us to understand who took part in the photovoice project. Answering these questions are **anonymous** and **voluntary**. You can choose "prefer not to answer" to any or all questions. This will not affect your relationship with the CCC program or Hospice Toronto.

1. Role:

☐ Client
☐ Carer
☐ Volunteer
☐ Staff
☐ Community Leader

How long have you been involved with CCC: _____________years, _____________ months

2. Gender:

☐ Male
☐ Female
☐ Transgender
☐ Other:
☐ Prefer not to answer
☐ Do not know

3. Age:

☐ 18-29
☐ 30-39
☐ 40-49
☐ 50-59
☐ 60-69
☐ 70-79
☐ 80-89
☐ 90-99
☐ Do not know
☐ Prefer not to answer

4. Were you born in Canada?

☐ Yes
☐ No If **NO**, what year did you arrive in Canada? ________________________________
☐ Do not know
☐ Prefer not to answer

5. What language(s) are you most comfortable speaking? (Check ALL that apply):

☐ Amharic
☐ Arabic
☐ ASL
☐ Bengali
☐ Chinese (Cantonese)
☐ Chinese (Mandarin)
☐ Czech
☐ Dari m
☐ English
☐ Farsi
☐ French
☐ Greek
☐ Hindi
☐ Hungarian
☐ Italian

☐ Karen
☐ Korean
☐ Nepali
☐ Polish
☐ Portuguese
☐ Punjabi
☐ Russian
☐ Serbian
☐ Slovak
☐ Somali
☐ Spanish
☐ Tagalog
☐ Tamil
☐ Tigrinya
☐ Turkish
☐ Twi
☐ Ukrainian
☐ Urdu
☐ Vietnamese
☐ Amharic
☐ Arabic
☐ Do not know
☐ Prefer not to answer
☐ Other: ____________________

6. Which of the following best describes your racial or ethnic group? CHECK ONE ONLY

☐ Asian - East (e.g., Chinese, Japanese, Korean)
☐ Asian - South (e.g., Indian, Pakistani, Sri Lankan)
☐ Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
☐ Black - African (e.g., Ghanaian, Kenyan, Somali)
☐ Black - Caribbean (e.g., Barbadian, Jamaican)
☐ Black - North American (e.g., Canadian, American)
☐ First Nations m
☐ Indian - Caribbean (e.g., Guyanese with origins in India)
☐ Indigenous/Aboriginal not included elsewhere
☐ Inuit
☐ Latin American (e.g., Argentinean, Chilean, Salvadorian)
☐ Métis
☐ Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
☐ Mixed heritage (e.g., Black- African and White-North American)
☐ White - European (e.g., English, Italian, Portuguese, Russian)
☐ White - North American (e.g., Canadian, American)
☐ Other: ______________________________
☐ Prefer not to answer
☐ Do not know

7. What was your total family income before taxes last year?

- ☐ $0 to $29,999
- ☐ $30,000 to $59,999
- ☐ $60,000 to $89,999
- ☐ $90,000 to $119,999
- ☐ $120,000 to $149,999
- ☐ $150,000 or more
- ☐ Prefer not to answer
- ☐ Do not know

8. How many people does this income support?

- ☐ _________ person(s)
- ☐ Prefer not to answer
- ☐ Do not know

CONSENT FOR THE PUBLICATION OF PHOTOGRAPHS

Exploring Creating Caring Communities with Community Members

I ____________________________________ (print name) give my permission to Krystyna Kongats and Hospice Toronto for the specified photographs to appear in print, online, and other types of display as part of the research project "Exploring Creating Caring Communities with Community Members" and for further dissemination (such as academic journals, final reports, media release, multimedia platforms, public gallery). I have reviewed all photographs that I took during the research study and obtained consent from all subjects in the photographs. I understand that my name will not be used unless I agree to have it published.

I understand that I can contact Krystyna Kongats anytime about this project at [redacted] or her supervisor Jane Springett at [redacted] if I have any concerns or complaints about the project. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Please place an `x` next to your response:

______ I consent that **all of the photographs** I have taken may be used as part of the research and for academic and public publication either in print or online.

______ I consent that **only certain photographs** I have taken (specified below) may be used as part of the research and for academic and public publication either in print or online (e.g. journals, community presentations, gallery display, websites).

Title/subject of photograph: ____
Title/subject of photograph: ____
Title/subject of photograph: ____
Title/subject of photograph: ____
Title/subject of photograph: ____

Please place an `x` next to your response:

______ I **want to be identified** as the photographer of my photograph(s) in this research project and in academic and public publications either in print or online (e.g. journals, community presentations, gallery display, websites).

______ I **do not want to identified** as the photographer of my photograph(s) under any circumstances

______ I only want to **<u>be identified under the following circumstances</u>** (please outline):

Signature of community member: ____

Date: ________________________________

Informed and adapted from: Castleden, H. E. (2007). *As sacred as cedar and salmon: A collaborative study with Huu-ay-aht First Nation, British Columbia into understanding the meaning of 'resources' from an indigenous worldview* (Order No. NR32933). Available from Dissertations & Theses @ University of Alberta. (304793390).

Pryma, P. A. (2013). *Women framing their journey from interpersonal violence to positive growth* (Order No. NS27672). Available from Dissertations & Theses @ University of Alberta. (1504616358).

RELEASE FORM FOR SUBJECT OF PHOTOGRAPHY

Exploring Creating Caring Communities with Community Members

I ___________________________ (print name) give permission to the project "Exploring Creating Caring Communities with Community Members" to collect and use my name and photograph of myself in any format of public, academic or media presentation or publication. I understand that a community member is taking a photograph(s) of me that represent their understanding of the impact, value and/or contribution of Creating Caring Communities in St. James Town. I also have the option of receiving a copy of the photograph taken of me and a summary of the findings from the final report.

I understand that I can contact Krystyna Kongats (Student Researcher) anytime about this project at [redacted] or her supervisor Jane Springett at [redacted] if I have any concerns or complaints about the project. The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Please indicate your response with an 'x' (choose only one):

______ I want my name identified on any captions associated with my picture in this thesis and future dissemination such as journal articles, community presentations, media releases or public displays.

______ I do not want my name identified on any captions associated with my picture under any circumstance

______ I only want my name identified under the following circumstances (please describe):

Please indicate your responses with an 'x' (select all that apply):

______ I want a copy of the photographs mailed or emailed to me

______ I want a copy of the summary findings of this study mailed or emailed to me

Person in photo (signature): ____

Date: ____

Adapted and informed by: Castleden, H. E. (2007). *As sacred as cedar and salmon: A collaborative study with huu-ay-aht first nation, british columbia into understanding the meaning of 'resources' from an indigenous worldview* (Order No. NR32933). Available from Dissertations & Theses @ University of Alberta. (304793390).