Unpredictable Paths into Care: Examining HIV and MS Care Relationships in Southern Ontario

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UNPREDICTABLE PATHS INTO CARE

UNPREDICTABLE PATHS INTO CARE: EXAMINING HIV AND MS CARE RELATIONSHIPS IN SOUTHERN ONTARIO

by

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Wilfrid Laurier University, 2021

DISSERTATION

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Abstract

In Canada, we often speak of caring for others as more than a social obligation; it is part of how we conceptualize ourselves and our humanity. Family/friend relationships can become strained, however, when providing care and support for people with complex and unpredictable chronic episodic illnesses, here termed episodic care. Relational impacts may be understood as influences and impacts directly related to the relationship between the carer and family member/friend. The purpose of this study is to create a middle-range grounded theory of episodic caring based on the relational impacts of carers for people living with HIV and MS.

Conducted in southern Ontario using qualitative constructivist grounded theory methods, this dissertation examines the development of relationships between carers and family members/friends living with episodic illnesses and documents the resulting social, emotional, and relational impacts on carers. To better understand how family/friend episodic care relationships emerge and progress, this dissertation project was guided by the emergent research question: What are the relational impacts of episodic care on HIV and MS carers? Findings from semi-structured interviews with 18 HIV and MS carers highlight the development of a relational identity as carers navigate shifting illness episodes over time. The relational model of episodic care developed in this study presents an alternative conceptualization of carer identity development by integrating episodes of illness and wellness into chronic illness care. The model illustrates the intimate, evolving relationship between the carer and family member/friend living with an episodic illness.

The study findings describe a phased approach to relational identity development involving entries into care, navigating unpredictability, and redefining the care relationship. This
develops into an identity of essential carer or reciprocal carer, or carers may choose to exit care. Resolving relational tensions that arise from performing care activities creates an opening for changes in how carers understand themselves through their care relationships. In addition to how episodic carer identities influence how carers perceive themselves within a relationship, social factors such as gender, income, and culture impact care experiences, at times creating additional challenges in the lives of episodic carers. To reduce carer strain, a re-visioning of family/friend care as community-centred and family/friend-supported will help re-focus episodic care as an option instead of a duty.
Acknowledgements

This dissertation highlights the quality and strength of enduring relationships that persist through the most challenging of times. The study participants’ demonstrated the stability of episodic caring relationships through quiet acts of service, repeatedly performed, which are at the heart of caring for family members/friends. The participants spoke truth to an often undisclosed form of care with poignance but without pity for their circumstances. In their honour, this dissertation is dedicated to all who provide episodic care yet seek support and balance in their efforts, hoping for a more inclusive way of navigating the unpredictability inherent in care. Now walking in a carer’s shoes, the participants’ words are in my thoughts each day.

In turning to my supports throughout the project, I’d like to acknowledge my family’s ongoing encouragement, especially my primary cheerleader, my mom. By asking ‘when will you be done?’ too many times to count, she helped me remember that we can always anticipate good things, even when they seem far off. Though she departed this life shortly before the final draft of the dissertation was completed, her spirit helped drive forward the work to the end. I may not be able to tell her directly, but I can say here, ‘it’s done, mom.’

A special thanks to the ever-patient committee that guided the project directions. To my advisor, Dr. Eliana Suarez for her positive perspective and vision of where the work could go. To Dr. Magnus Mfoafo-M’Carthy for his calm, steady, reassuring presence. To Dr. Michael Woodford who aims to bring out the best in all who work with him. And to Dr. Susan Cadell who shared her passion for a humane approach to care work that honours people over process.
Credits are also due to a supportive Ph.D. cohort who were always encouraging. I’m grateful to have walked this journey with women of talent but more importantly of integrity. There is indeed great strength in unity. I will continue to cheer them on wherever their professional journey takes them.

As well, thanks to the students I’ve taught throughout my Ph.D. tenure. I may not understand why the Part-time Appointment Committee (PTAC) repeatedly offered me research courses to teach. Still, the students’ challenging questions improved our classroom experiences and my dissertation work by further stretching my ideas.

Completing a dissertation takes the proverbial ‘village of people’ to move from concept to final product. How grateful I am to lift and, in turn, be lifted by incredible people.
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Chapter 1: Introduction

Acts of care are all around us. We donate to support a favourite cause, make soup for a friend with the flu, and even take extra shifts at work when a colleague has a baby. In Canada, we often speak of caring for others as more than a social obligation; it is a part of how we conceptualize ourselves and our humanity. We support those in our inner circle and those we meet for the first time on the street alike, with small acts of kindness that are often purposeful and meaningful. However, care work is becoming increasingly common as increased responsibility to support people with complex chronic episodic illnesses is placed on the shoulders of family members/friends, here termed *episodic care*. Due to the unpredictable and chronic nature of episodic conditions, many carers provide supports over extended periods with a mix of times when no or little care is needed and times when high levels of care are required. Episodic care is on the rise in recent decades resulting from changes to our social fabric and healthcare systems, including strategic political and economic policy shifts at the federal and provincial levels (McGetrick, Raine, Wild, & Nykiforuk, 2019). The outcome has been an increasing system-wide gap in supporting people living with episodic illnesses (Keefe, 2011), with the burden primarily falling on family/friend carers.

In the context of episodic illness, care is often provided by partners, family members, friends or significant others who feel a sense of compassion and duty toward their loved one. These feelings facilitate action as relationships expand to include care duties. The resulting direct or indirect effects of episodic care can be felt in various ways, including emotionally, within personal relationships, and socially, impacting community involvement, for example (Canadian Working Group on HIV and Rehabilitation, 2006). The activities of care are multi-faceted,
including a system of morality fraught with challenging decisions regarding acting in the best interest of another (Brabeck, 1993). At its core, the term implies the provision of help or support, but given the relational nature of caring, both the carer and the recipient are involved in the co-production of care (Rummery, Glendinning, Halliwell, Jacobs, & Tyrer, 2000).

Like episodic illness, episodic care can vary week-to-week and month-to-month and over time, including times of severe illness and other times of relatively good health. Care recipient involvement in care provision is not passive, but rather is complex involving multidirectional flows, which benefit both the carer and recipient. Thus, the emotional impacts experienced by the carer, at times, bringing strength or additional burden (Milligan, 2000). Although the breadth of socio-emotional impacts is not well understood, episodic illnesses and their inherent unpredictability alter the lives of episodic carers (Whitehead & Lero, 2014; Wolbring, 2011). At present, episodic care is under-represented in care research, policy, and practice; this lack of awareness is having significant, long-term, multi-faceted impacts on the health and well-being of carers.

1.1 Statement of Purpose and Research Question

While examining issues from a systems approach, social work practitioners and researchers are mindful of the welfare of individuals and groups impacted by often disconnected socio-political systems (Siegler & Brennan-Ing, 2017). While impacts on quality of life remain central, this perspective illustrates the interactive dynamic of the person affected by their surroundings and, in turn, influencing the systems around her. Social work researchers are well suited to research complex issues of under-recognized populations that focus on social justice. At
present, there is a limited understanding of episodic care as a form of care provision and as such episodic carers are left out of social policy and program planning for carers. This research will help better understand the experience of relational episodic care to improve recognition of the multiple challenges faced by carers and ultimately carer access to supportive resources.

This dissertation research is exploratory, with the intent to develop an enhanced understanding of the breadth of experiences and generate theoretical constructs to conceptualize episodic care in Ontario. The purpose of this study is to create a grounded theory of episodic caring based on the experiences of carers of people living with Human Immunodeficiency Virus (HIV) and Multiple Sclerosis (MS). During the participant interviews, as early data analysis was completed, a distinct common theme reappeared in the stories of episodic carers which brought the relationship between carer and the person living with an episodic illness (PLWEI) to the forefront of the discussion. In keeping with the emergent nature of constructivist grounded theory research, the research question shifted to reflect the central topic raised by the participants. To better understand how unpaid episodic care unfolds, this dissertation project is guided by the emergent research question: *What are the relational impacts of episodic care on HIV and MS carers?* Toward answering this question, a model was developed showing the phased development of a relational episodic carer identity.

This theme of relational impacts will be explored as both reflective of the relationship between the carer and the PWED, as an interpersonal experience, but also as how the relationship between carer and PWED changes how carers then engage with the social world around them. Social construction theory is used to frame the impacts of care within the social context of carers. In addition, neoliberal ideology will be discussed as a factor influencing the
rise of episodic care. Background literature for social construction theory and neoliberalism will be presented in Chapter Two.

Note that all data collection, analysis, and elaboration of findings were completed prior to the COVID-pandemic. The global pandemic may have additional relational impacts on episodic care beyond those described in this dissertation.

1.2 Discussion of Key Terms

The following section will define and explain the terms relevant throughout the dissertation. Note that additional terms related to the Relational Model of Episodic Care developed in this project and associated constructs are presented in the Findings and Discussion chapters.

Care supports occur in various ways, including tasks for supported living, such as housework or administering medications, known as Instrumental Activities of Daily Life (IADL) (Huang et al., 2019). There are also tasks related to the fundamental elements to sustain daily life, often called Activities of Daily Living (ADLs), including bathing, dressing, eating, walking, and toileting (Tochel et al., 2019). This language is heavily task-orientated and focused on the performative or doing aspects of providing care (Chappell & Reid, 2002). While the terms are useful for describing the task work done by carers, they lack contextual and relational aspects of care that humanize the day-to-day activities.

From a social work perspective, language use matters not only to represent an expert viewpoint but also to include the views of underrepresented people and groups. A definition of family/friend support in episodic care needs the social and relational components inherent in the
intimate labour of care provision. For this reason, the terms informal or unpaid caregiver that is often used for family/friend caring fall short of a relational definition (Harding, 2004). Another common term is caregiver; although when used, the relationship between the person receiving assistance and the individual providing the supports is blurred, as the label applies to both professional paid carers and carers with pre-existing relationships (England, 2010).

Throughout the study, the term carer is used, which is common to academic care literature from Great Britain and a term familiar to people who provide care (Hirst, 2001; Molyneaux, Butchard, Simpson, & Murray, 2011). To further explain the term carer, there are two central features, caring for and caring about. Caring for describes the task-oriented aspects of care provision. In contrast, caring about highlights the emotional investment in the process, both by the individual providing care supports and the person receiving care (Grant et al., 2004). Emotional intimacy in the relationship increases as the carer becomes increasingly attuned to the well-being of the family member/friend in need of care, while the carer carries out a variety of individually-tailored care duties (Kulik, Cregan & Bainbridge, 2013). In this study, the term episodic carer will describe individuals who provide any form of support to a family member/friend of someone living with HIV or relapsing-remitting MS. Note, the term episodic will be discussed further in Chapter Two.

In the study, relationship describes a meaningful involvement of two or more people but not necessarily with the promise of continuity or reciprocity. However, long-term relationships are common in care work (McNamee & Hosking, 2012). There are multiple ways that episodic care relationships may be described, from a perspective of the two people involved, within care circles involving several people, or as a community of carers. In this study, carer relationships will be explored from a person-to-person perspective. The terms partnership, couple, and dyad
are commonly used to describe this one-on-one element of care relationships. However, *partner* places the focus on the relationship, at times indicating an official commitment that may include a contractual focus; *partner* is too formal to describe the emotional breadth of episodic caring relationships. *Couple* also focuses on the committed emotional investment between people but may also imply a sexual relationship. Whereas, *dyad* centres on the interpersonal relationship between the carer and family member/friend that may take multiple forms. Thus, the term *dyad* will be used as a reminder of the interpersonal nature of episodic care. As episodic care relationships are unique to the dyad, the constellation of effects on the care relationship will be unique and are discussed in the Findings chapter. Depending on how episodic carers experience and interpret relational impacts, carers form relational identities. In the discussion chapter, the development and progression of relational care identities will be examined in the complex environment of care.

Lastly, as the research question explores care-related impacts on the various life areas of episodic carers, access to social determinants of health will be defined. Social determinants of health are factors affecting wellness outside of public health systems, such as income, housing, and employment (Public Health Agency of Canada, 2018). The influence of episodic care on access to social determinants of health will be explored throughout the Findings and Discussion chapters to frame the individual and social contexts of episodic care.

### 1.3 Location of Self within the Work

This section has two purposes, one written in a spirit of disclosure, as an act of bringing myself into the project; the second is to connect with the constructivist lens of the research,
which integrates lived experience and theoretical knowledge to frame and interpret research data (Frost et al., 2010).

I come into this project as a person who has spent the majority of her life in Ontario. The historical, geographical, and socio-political contexts of the study are familiar. Growing up, Windsor was home, an area replete with a production-based economy focused on the auto sector. Prior to 1995, Windsor had a higher per capita income than the Ontario and Canadian averages, but by 2015 had fallen below both, with nearly 25% of residents living below the poverty line (Statistics Canada, 2017a). The city is now known for its income polarization and higher than average crime rates (Statistics Canada, 2019a), preceded by growing poverty issues. In other words, a city with *haves* and *have nots*. During my time living in Windsor, while social services were available, access varied. Many Windsor residents needed to drive to London or Toronto to access more comprehensive supports. As a result, access to services was a common discussion topic.

Having lived in Toronto for the past 15 years has changed some of this perspective. Large urban centres, smaller cities, and surrounding counties all have their challenges with resource sufficiency. While cities have a wider array of resources, there are challenges of waitlists, transportation, and privacy (to name a few). In all areas, the services provided never seemed to be enough; often there were too few community resources to meet individual/family needs, particularly as politicians, advocates, and researchers also struggled to address the root causes of public problems. The demand for services always seemed to be greater than the availability, with the louder voices seeming to have greater access to the limited supply. These observations informed my growing interest in the practical side of social justice work.
With respect to episodic care, I connect to this work through my family of origin experiences. By the age of 9, I found myself taking on adult roles, with a parent who spent long periods in the bedroom dealing with mental illness, having some better days, interspersed with challenging periods of days, weeks, or even months. As a pre-teen, I would shift what I would do when I came home from school-based tasks to how my parent was doing that particular day. While the additional work of dishes, laundry, and preparing meals impacted my free time and how much effort I put into homework, the more significant impacts came through the mental and emotional shifts I experienced as a young carer.

At the time, I did not feel emotionally ready to have a parent who could not hear about my school challenges or in my life, generally. Learning to cope on my own by relying on myself was difficult. During parent/teacher interviews, my teachers would talk about how, although I was doing well in the class, I was not an active contributor to discussions and group work. I wonder if the emotional separations I was dealing with at home filtered into my elementary and high school experiences. This pattern of unpredictable episodic illness experienced by my parent continued throughout my youth. The typical teenage separation of self from family became even more potent for me, as I would do what was necessary to keep the basics of life running for the family while spending more and more time on my own. I came to think that if I wanted to make things happen, I needed to act for myself. While I learned to be self-reliant, I also experienced changes in how I interacted with my parents, similar to a parent-child role reversal. Today, I have regular contact with my parents. I love my parents, who have done a tremendous amount for me despite my non-traditional childhood.

These experiences, coupled with my current social justice orientation as an educator and social work practitioner, are woven into this project. My research training helped me understand
how I enter into a research space together with the participants, co-constructing the interview experience. Reflection on my research has helped me learn to listen first, reserving judgment to hear the carers’ stories, with less filtering and greater emphasis on the meanings of care from the perspectives of the study participants.

1.4 Summary

Carers in Ontario struggle on an ongoing basis to step in where health and social supports have increasingly stepped out. This dissertation tells their stories, as often as possible in their own words, to protect the meaning intended by participants. Thus, I strive to share multiple angles of the complex environment of relational episodic care while focusing on the people at the centre.

The dissertation is organized into chapters, first describing the socio-political circumstances influencing episodic care and then relating the current social landscape to the day-to-day experience of episodic carers in Canada. Beginning with social constructionism as the theoretical backdrop and the growing influence of neoliberal healthcare ideology, the paper will highlight systemic factors impacting carers and contributing to the rise of episodic care in Canada. The Findings and Discussion chapters extend existing knowledge about episodic care within Canada by exploring the experiences of a sample of episodic carers in Ontario across a wide variety of life and health circumstances. The findings include the development of theoretical constructs describing episodic care provision as part of an ongoing relational identity development process. The thesis concludes with recommendations for public policy and social
work practice improvements to acknowledge and support the unpredictable care work performed by episodic carers.
Chapter 2: Theoretical and Empirical Context

This chapter outlines the theoretical and empirical foundations of this research inquiry. It starts by highlighting the main principles of social construction theory as the guiding framework of this study. The foundational principles of neoliberalism, presently a dominant ideology influencing decision-making in the public sector, are examined next with an aim to understand the impacts of neoliberal policies in healthcare delivery driving the swell of episodic care in Canada. Following this foundational context, a historical overview of care provision from a national perspective is offered, including the rise and scope of episodic care. The chapter concludes with an overview of HIV and MS care literature from a Canadian perspective.

While there is no consensus about the role of theory in qualitative research, there is standard agreement on two functions of theory: first, as informing the choice of methodology; and second, as a basis for developing new theory after data collection (Anfara & Mertz, 2014). This fluid approach allows the model developed in this study to be explained and interpreted through existing theory while being based on the lived experiences of participating episodic carers. Therefore, additional theoretical lenses help to frame the findings in the Discussion chapter. This sets the stage for understanding the various social attributes and interactions of episodic carers, as socialization is an integral experience of care.

2.1 Central Tenets of Social Construction Theory

As humans, we connect with and influence the social environment. Showcasing how people and environments interact to influence one another, social constructionism is a
metatheory utilizing a person-in-environment perspective to explore how people connect together and with the world around them (Charmaz, 2014). Berger and Luckmann (1966) frame the importance of the social environment on forming and sustaining relationships by stating, “to be in society is to participate in its dialectic” (p. 129). Thus, people are active participants engaging and altering the social world around them.

Another aspect of social construction theory is the influence of context on interaction. In this sense, the contextual setting includes social, historical, political, and cultural forces that intersect in various life experiences (Burr, 2015). People are social beings who interact with each other within the socio-political sphere (Fiske, 2018). As such, social constructionism brings together people with their environment; each interaction between individuals is part of a contiguous series of events where the personal and collective histories are brought into the next experience, thereby carrying the history forward into subsequent interactions (Burr, 2015). At times, one contextual aspect may be more relevant than another, for example when a racially-motivated crime occurs and underlying tensions surface in the community (Gergen, 2001). This temporal historicity connects the past with the present (Lock & Strong, 2010). Thus, people do not enter into experiences with others tabula rasa but rather with a diversity of experiences influencing their social presentation and engagement with others (Gergen & Davis, 2012). Social constructionism provides a useful theoretical lens to discuss the historical and contextual bases of how people understand the social world, including the experiences of episodic caring.

In considering a constructivist lens, debates arise regarding reality (Lee, 2012). Firstly, in response to the central epistemological question concerning what is knowable, there is a literal, temporal experience of day-to-day life (Gergen, 2009a). People exist, as does the world around them; objects are also real (Cupchik, 2001). This reality is both discernable and knowable,
though heavily impacted or constructed by social relations (Houston, 2001). People have become and will yet change through relational interactions (Hosking, 2011). Thus, each relationship and how we understand ourselves are products of co-creation (Goffman, 1959).

Living in a social environment, we experience the world through our communication and interactions with others from which shared knowledge based on experience is produced (Hibberd, 2006). Relational interactions are the foundation of society; people occupy an ongoing dialectic space of discourse and exchanging ideas (Laible & Thompson, 2015). Interpersonal communication happens in verbal and non-verbal ways, including the spoken word, written narrative, body language, eye contact, and use of language. In the process, people are changed through dialogue, as well as by what has been seen and felt (Goffman, 1959; Hacking, 1999).

Thus, people continually change through social relations throughout life (Greene & Blundo, 2017). When considered from a life course perspective, people are influenced by engagement with the social world while also impacting that same social environment (Berger & Luckmann, 1966).

People are, therefore, complex social beings embodied by centuries of history and socialization into a particular culture, place, and time (Gergen, 1994). Cultural traditions are passed down during our developmentally formative years and internalized throughout life (Galbin, 2014). This subjective view of knowledge is ultimately local, although some similarities exist across cultures and similar social circumstances (Kim, 2001). Communities are socialized similarly through how people interact with one another and transmit these ways of being from one generation to the next (Potter, 2008). With this understanding, people are an unfinished work in progress.
The perspectives with which we understand the world are temporally bound and inherently subject to change. For some, constructivist standpoints can result in feelings of uncertainty with the world becoming a fragile and shifting place (Demeritt, 2002; Nightingale & Cromby, 2002). For others, constructivist perspectives can be liberating, both within the mind and through the ongoing presence of possibilities for social action and change (Gergen, 1994). For episodic carers, the construction of their social reality can be challenging, as carers navigate the unpredictable health needs of PLWEIs, and edifying, as care relationships can bring benefits to carers’ lives. Social construction theory opens doors to understanding the relationships and identities of episodic carers (O’Toole, 2013), as identities are relationally constructed (Gergen, 1994). Most importantly, this interpretive approach toward understanding human development does not attempt to reflect an accurate picture of the world (Cunliffe, 2008; Gergen & Thatchenkery, 2004; Houston, 2001) but rather how the lived experiences of carers shift and change as carers move in and out of care responsibilities. As such, social constructionism fits well as a theoretical lens for this project and as a backdrop for understanding the relational changes arising through unpredictable episodic care.

Social environments are indeed central to understanding the experience of episodic care. HIV is a prime example of how living with an illness has social implications. An HIV diagnosis is associated with its modes of transmission through the transfer of bodily fluids connected with socially-bound conceptualizations of morality or addiction (Canadian AIDS Society, 2003). Social and value-based judgments may define people living with HIV, and these labels can follow people living with HIV throughout life (Harpur, 2012). Depending on the nature of the supports available to the carer and the personal response attributes of the carer, stigma-by-
association can become a significant issue over time if experiences of discrimination are repeatedly internalized (O’Brien, Bayoumi, Strike, Young, & Davis, 2008).

Social constructionism also influences how disability is understood. According to the World Health Organization (2011), disability results from a complex interaction of life impairments with the broader social environment. As such, disabling impacts can be physical, limiting the performance of activities of daily living and engaging in social aspects of life such as community involvement (Varecamp, Heutink, Landman, de Vries, & van Dijk, 2009). Impairment is a functional limitation in body function or structure; an activity limitation is an executive difficulty performing an action or a social participation restriction. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person’s body, mind, and the aspects of the society in which she lives (Wilkinson & das Nair, 2013). Traditional models of disability, also known as individual-level models, focus on the physical/mental limitations of living with a disability (Wolbring, 2011). Problems exist in the person, resulting in participation restrictions in society. Thus, disability becomes an embodied experience where the body is the central focus of challenges experienced at any level, whether activity-based or in broader aspects of social participation such as employment (Watson, McKie, Hughes, Hopkins, & Gregory, 2004).

Over time, disability activists and representatives of academic circles have come to reject the notion of disability as located in the person (Shakespeare, 2013). Situating the experience of disability within the individual places the prime responsibility for the day-to-day management of challenges on the PLWEI (Barnes, 2013). Social disability theorists consider this a myopic essentialist argument that fails to consider the influences and constraints society places on the individual (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012).
From a social disability perspective, the narrow, individualized focus of disability fails to account for societal responses to barriers to participation that persons with disabilities often encounter (Anastasiou & Kauffman, 2013). Disability results from shortcomings of social systems, policies, and practices that prevent people from engaging with their environment (Barnes & Mercer, 2004). This significant change removes the focus on shortcomings as located within the body by placing the onus to adapt and accommodate disability in the social environment (Crow, 1996). Episodic illness disabling impacts occur directly on PLWEIs and indirectly on carers. As such, a social disability perspective aids in understanding the experience of providing care by highlighting the socio-systemic factors, such as discriminatory practices or participation-limiting social policies, which create barriers to active participation.

2.2 Neoliberal Context of Care

No decision-making body acts in a vacuum. There is no tribunal, public bill, or enacted policy independent of the ideology of the day. Ideology may be defined as “a shared way of thinking based on a set of ideas that reflect values, beliefs, attitudes, and experiences of a particular person or group” (Graham, Shier, & Delaney, 2017, p. 69). At the community level, shared systems of thought influence how people engage with their social environment. At the macro level, ideology influences the role of government in economic, political, and social matters. At times, governments and policymakers, with some assistance from the public, initiate policy responses to social problems (McKenzie & Wharf, 2016). All social policy develops from ideology, and, as such, has long term implications for intended beneficiaries and groups excluded.
from social policy decisions (Lightman & Lightman, 2017). In recent decades, neoliberalism has become the ideology influencing political and economic decision-making across Canada.

Beginning with the Second World War, a time emerged of rapid expansion and growing public sector funding with an increasing focus on the public sector to develop a nationalized healthcare program (Marsh, 2018). The public sector was at its most expansive, focused on galvanizing Canadians in support of the war. At this time, a significant emphasis was placed on delivering services and supports in certain aspects of society, including employment, financial aid, economic aid to war-related business initiatives, food delivery, and, to a limited extent, community-based services (Clark, 2002). Following the conclusion of the war, the government invested in public infrastructure and social structures, such as roads, civic offices, and social programming, to maintain the masses.

Post World War Two, the focus of the country shifted from full-scale war-related investment to peace-time activities (Brodie, 2002). The public sector grew throughout this period, with strong social support in Canada to develop safety-nets such as financial welfare programs to support individuals and families when employment opportunities were limited (Cox, 2013). The economic theory of John Maynard Keynes fueled the growth of social policy in Canada (Harvey, 2005), including the development of financial support programs such as Unemployment Insurance, the Canada Pension Plan, Canada Pension Plan – Disability, and provincial income replacement programs for Canadians with low levels of employment and people living with disabilities. This was a time of heightened trust in government and fellow citizens, characterized by policies at the federal and provincial levels to curtail the broad powers of the market (Clark, 2002).
Now let us consider neoliberal ideology. This ideology may be enacted in multiple ways, including a macroeconomic theory, a purposeful collective of policies and practices that showcases the doctrine of extreme market liberalization, a mechanism for the (re)production of the class system, and a force of capitalism (Ferguson, 2009). Harvey defines neoliberalism as:

a theory of political economic practices that proposes that well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade. (2005, p. 2)

This definition of neoliberalism offers a retrenchment from traditional economic conceptualizations of liberality, which in economic circles involve distancing government from marketplace regulation (Braedley & Luxton, 2010). Friedman, in turn, theorized and supported the uptake of economic liberality (Rodrigues, 2018). His approach does not necessarily result in deregulation; the decision-makers within the economy may introduce regulatory mechanisms of their own, focusing on the reduced influence of governments on national and international business environments (Springer, Birch, & MacLeavy, 2016). The narrowed focus on employment and production under the umbrella of a market-centric ideology includes reduced stress on the financial impacts of workers engaged in an unstable employment environment (Harvey, 2007).

Among conservative neo-classic economists, there is a more singular focus on the fundamental principles of market liberalization and the free-market economy, including removing tariff and trade barriers limiting the flow of goods in commercial activities (Harvey, 2007). Neoliberal capitalism implies “going back to a more rough and tumble kind of capitalism in which governments play a smaller role in regulating the economy and protecting social
interests” (Stanford, 2008, p. 48). Many of the essentialist concepts of free-market economics influence the shifting movement toward the globalization of markets. Yet, in reality, neoliberalism has come to mean opening markets in select areas across the globe, especially in the Global North (Peck, 2002).

In recent decades, Canada's successive political decisions have moved across the country, embracing neoliberal political ideals federally and provincially (Braedley & Luxton, 2010; Springer, Birch, & MacLeavy, 2016). These ideas have, at times, conflicted with political ideologies, depending on the leadership in power (Baines, 2015). Despite political differences and the ensuing reductions associated with the neoliberal influence, public governance has come in line with market principles of efficiency and market-oriented business ideologies (Innis, 2018). Policy decisions made by federal and provincial governments have reduced access to social programs since the 1990s and into the present through financial cutbacks and raising thresholds for social program access (Marsh, 2018). In the process, policy decisions have shifted the public mindset toward a sense of inevitability for the ongoing evolution of neoliberal ideology, thereby adding to the strength of neoliberal influence in many facets of life (Wilson, 2017).

Neoliberal ideology has reshaped the political right and left over the past several decades and is exerting waves of influence within economic and social circles at all levels in Western countries (Iyall Smith, 2013). Free market forces play a substantial role in shaping our current economic environment in Canada, and this will likely continue over time (Whiteside, 2009) by reducing union and pro-labour movements across Canada and weakening the leverage of workers (Peck, 2008). Many employees find themselves in tenuous positions, as negotiating personal needs for workplace flexibility impacts competing demands experienced by employers (Furrie &
In turn, this may decrease opportunities for workers to negotiate individual accommodation needs in employment environments. For populations facing multiple barriers, such as women, the complexity of these issues increases (Fraser & Bedford, 2008; Vick, 2013).

Changes to health and caring supports, as well as the social context for community-based programming, have been influenced by expansive movements toward individual self-reliance and personal responsibility for illness (Galvin, 2002). Individuals and families are relegated to the role of consumer, viewed in light of their prospects to contribute to economic development. For those less able to contribute to the new greater good, the state provides support only when necessary to intervene. People are more frequently left to fend for personal assistance, scattered amidst a fragmented system of public and commercialized services and often with heavy administrative burdens (Denton & Spencer, 2010).

As discussed above, reductions to community-based care programming have been influenced by the tenets of the global and highly influential neoliberal economic theory. In recent decades, the sway of neoliberal ideologies in the Western world has increased in both impacts and reach (Baines, 2015). The effects of neoliberal constructs on the healthcare industry continue to negatively influence the growth of episodic care delivery by leaving family members/friends with few other options except to provide care themselves (Labonté & Stuckler, 2016). The following section focuses on the pan-Canadian healthcare context where neoliberal principles drive the rise of episodic care as policy trends shift toward personal responsibility for health and well-being (Madden & Speed, 2017).

Healthcare, although still considered an essential service, is now viewed more as part of the industrial complex than as a public service (Robson, 2018). The resulting shift toward managerialism within both the federal and provincial jurisdictions has impacted people in
Canada by altering healthcare service delivery and the types of services available (Romanow, 2002). As a result, increasing pressures are placed on family/friend carers to provide in-home supports previously carried out in hospitalized settings (England, 2010). Healthcare systems have examined ways of improving efficiencies and eliminating corporate excess, thereby facilitating changes in accessing various supportive services (Moraros, Lemstra, & Nwankwo, 2016). Healthcare practitioners are asked to do more with less and frequently perform near-heroic feats in the interests of the public they serve (Wu, Singh-Carlson, Odell, Reynolds, & Su, 2016). These changes have placed boundaries upon and increased the regulatory processes of healthcare in Canada (Marsh, 2018). The result has been a system-wide shift in the placement of the duty of care onto individuals, families, and communities (Tang, Browne, Mussell, & Smye, Rodney, 2015). As a result, individual-level impacts are becoming increasingly noticeable as increasing numbers of people fill healthcare roles previously performed by the state (Hande & Kelly, 2015).

Canada has a multi-faceted social fabric with values to protect the greater public good; socialized access to primary medical care is part of the collective Canadian identity (Lewis, Donaldson, Mitton, & Currie, 2001). Despite a longstanding tradition of social consciousness, as described above, ideological tides have shifted in Canada (Graham, Shier, & Delaney, 2017). Healthcare coverage is central to Canadian identity, with many believing that the dissolution of the medicare system in Canada would change how Canadians identify themselves (Tuohy, 2018). Values underlying who should access services and the responsibilities of governments in protecting the public good have undergone sweeping changes. As noted, presently, neoliberal ideals abound within the industrial healthcare complex, including the integration of market liberalization, deregulation, reduced governmental intervention, and individual responsibility for health (Chernomas & Sepehri, 2018). In response to the oft-cited challenges of resource-wasting
within the healthcare system, Whiteside (2009) refers to a crisis of accumulation as prominent due to home-based care becoming a market-based service. As such, the quality of the services provided and the changing structure of healthcare delivery in Canada are called into question as current tenets of neoliberal ideology impact healthcare delivery (Drummond, 2015). Values of *citizens as consumers* and *purchasers of services*, with a market-oriented focus on healthcare as a service instead of a fundamental human right, are creating change in the healthcare system. Increasingly, treatments are available only to those who can pay set fees (Ranade, 2018). These changes have moved Canada’s socialized medical program away from single-tiered medicine toward increasing care commodification (Raphael, 2015).

The uptake of neoliberal values has varied from region to region, with some provinces integrating more comprehensive policy and programmatic changes than others (Levesque et al., 2015). In viewing these changes from a national perspective, Ontario is somewhere in the mid-range. The continued attempts by proponents of market-oriented healthcare in Ontario at increasing privatization have been successful although undertaken with stealth (Kirst, Shankardass, Singhal, Lofters, Muntaner, & Quiñonez, 2017). Since 1995, Ontario has restructured funding for services considered non-essential or non-critical (Marchildon & Hutchison, 2016). The previous focus on restorative supports for the general public, such as rehabilitation in its various forms, has been altered to increase public reliance on third-party purveyors of rehabilitation supports commonly offered through employer health insurance plans (Strumpf et al., 2012). Provincial programs aimed at preventing illness and its more socially-oriented counterpart of social wellness initiatives continue to see cuts to services (Barnes, 2014; Ruckert & Labonté, 2014). Healthcare in Ontario is moving toward a two-tier delivery system.
where universal services comprise the lower tier available to all while the upper level of services is possible through a fee-for-use system (Skinner, Joseph, & Herron, 2016).

Many Ontarians continue to embrace the idea of available and accessible healthcare for all. During the writing of this dissertation, not all of the proposed changes to privatize Ontario healthcare have moved forward. However, these changes continue to impact family/friend carers as nursing care and rehabilitation once offered in-hospital are expected to be delivered at home (Canadian Healthcare Association, 2009; Coyte & McKeever, 2016; Gilmour, 2018). Supports that were previously the domain of public health systems, such as preventive and treatment-oriented outpatient physiotherapy, are now provided on a fee for service basis or provided by family/friend carers (Baker & Axler, 2015; Wojokowski, 2017).

2.3 The Rise of Episodic Care

The following section discusses the rise of family/friend episodic care in Canada in recent decades. The section also explores how and where episodic care is provided, as well as intersections of episodic care and existing social policy. Afterwards, the existing literature on HIV and MS care is reviewed.

2.3.1 Understanding episodic illness and episodic care.

Episodic illnesses are complex chronic conditions that vary over the life course (Antao et al., 2013). For many, the diagnosis is permanent, involving ongoing illness experiences that, unlike stable health conditions, are changeable from week to week, month to month, or year to
year (Proctor, 2002). When ill health occurs, the length, occurrence, and degree of severity of the episode are uncertain (Canadian AIDS Society, 2003). The unpredictable nature of the illness-related symptoms can result in periods of good quality of health and then poor health (Vick & Lightman, 2010). Thus far, the terminology used to label episodic illness has been inconsistent, with terms hidden or invisible illness commonly used without a standardized meaning (Vickers, 1998). Forms of common episodic conditions may include mental illness, such as generalized anxiety and other conditions, for example, arthritis, diabetes, migraines, chronic fatigue syndrome, cancers, or HIV. Traditionally, illness groups have self-selected to use the label of episodic or a related term (Canadian Working Group on HIV and Rehabilitation, 2006); thus, any chronic illness that manifests unpredictably may be self-defined as episodic. For a more comprehensive list of episodic illnesses, see Appendix A.

To understand the incidence of episodic illnesses in Canada, the rates of several common conditions are described. The Canadian Community Health Survey data notes that 3.5 million Canadians experience a mood disorder, with many diagnosed with major depressive disorder; another 2.4 million people meet the threshold for Generalized Anxiety Disorder over the lifespan (Pearson, Janz, & Ali, 2013). In Ontario, rheumatoid arthritis rates doubled between 1996 and 2010, reaching 97,500 people in 2010 (Widdifield et al., 2013). Diabetes rates have also shown an upsurge, with more than 3 million people in Canada living with the illness (Public Health Agency of Canada, 2019). Diagnoses of episodic forms of cancer, such as breast cancer, are also on the rise (DeSantis et al., 2015). Furrie and Crawford (2010) reported that 46.4% or 1,140,500 of the adult population with disabilities indicated they live with at least one of the 27 conditions associated with episodic illness. Episodic illnesses occur in people of varying ages, educational backgrounds, genders, and social strata, impacting individuals and families during the prime
working years when many episodes occur (Stapleton & Tweddle, 2008). As seen above, living with an episodic illness has become an issue of relevance to millions of Canadians with carers providing supports in addition to meeting personal, employment, education, and community demands.

Toward understanding commonalities in the episodic illness experience, in 2008, a Canadian research team developed the Episodic Disability Framework to explain the unpredictable experience of living with HIV, including possible health and social impacts (O’Brien et al., 2008). See Appendix B for a graph of the framework. This framework is useful to form a general understanding of the effects of episodic illnesses. Within this framework, during the pre-episode phase, people living with episodic conditions experience relative health plateaus, where symptoms are both manageable and consistent (O’Neil, 2012). With the onset of an illness episode – phase two – a descent into an uncertain health trajectory begins, where health is unstable in three primary ways: the episode length, the episode’s degree of severity, and when the next change will occur (Canadian AIDS Society, 2003; Jennings, Callahan, & Caplan, 1988). In the final phase, after each illness episode, health may return to a level similar to before the episode, health status may have deteriorated, or health might even improve (Dewa, Goering, Lin, & Patterson, 2002). Impairments from the illness episodes are also variable over time (Antao et al., 2013), which may result in disability. Although predicting when an illness episode will happen is challenging, the framework and its graphical representation are useful for visualizing the peaks and troughs associated with the experience of living with an episodic illness (O’Neil et al., 2012) and for highlighting the varying times when care may be needed.

Though no two illness episodes are experienced the same way within an illness group and from one episode to another for a PLWEI (Denton & Spencer, 2010), this framework
demonstrates a beginning, a middle, and a conclusion to individual episodes (Canadian Working Group on HIV and Rehabilitation, 2006). The utility of the Episodic Disability Framework exists not in its predictive value, as the precise timing and severity of illness episodes are challenging to determine, but rather in the perspective provided. As shown, multiple intersecting factors contribute to each illness episode and the experience of the disability over the life course (Balderson et al., 2013). One aspect is the increasing rate of comorbid diagnoses alongside the episodic illness diagnosis, which has medical, social, and caring impacts (Bahm & Forchuk, 2009; Gadalla, 2008). Additional intersecting factors are based on timely access to inadequate social determinants of health, such as financial stability, quality housing, and access to system navigation supports (Cockerham, Hamby, & Oates, 2017). A further significant factor involves ongoing access to medical diagnoses and treatment (Sav et al., 2015). The utility of the framework stems from its generalizability across illnesses, representing the overall experience of episodic illness; however, it does not include the role of caregivers as important actors in the care of episodic illness, which is the focus of the current study.

The non-apparent nature of many episodic illnesses can prove challenging to obtain and maintain ongoing access to medical resources (Hay, 2010; Overman & Selak, 2012). For example, in traditional forms of impairment, for someone living with a mobility limitation, using a cane or a wheelchair becomes a visible indicator of the impairment. However, in episodic care, while a PLWEI may be living with one or more forms of complex, chronic illness, disability may not be readily visible (Banks & Kaschak, 2014; Santuzzi, Waltz, Finkelstein, & Rupp, 2014). Because of the invisible nature of many episodic illness episodes, doubts regarding the legitimacy of the illness may persist in the social environments of PLWEIs and their carers. Trust can be eroded for carers, and personal difficulties may result, including barriers to employment
access and career progress (Beatty & Joffe, 2006). This unpredictability, or *not knowing* makes episodic illnesses challenging; carers may feel unsettled for years (Bove, Zakrisson, Midtgaard, Lomborg, & Overgaard, 2016). People living with episodic conditions can experience episodic health fluctuations long before receiving a medical diagnosis.

Episodic illness diagnoses often occur during the prime of life, between young adulthood and middle age (Whitehead & Lero, 2014). During this period, many people are engaged in life activities, including education, employment, career advancement, and managing family demands from both children and aging parents. The onset of episodic illness creates vulnerabilities that are challenging to overcome, such as maintaining a living income level while grappling with a health course in an ongoing state of flux (Berg & Upchurch, 2007). Connected to the often-invisible nature of episodic illness, many people living with episodic conditions have the external appearance of wellness, despite the internal storm of health impacts that can be physical and mental health-related (Venville et al., 2016).

In addition to experiencing illness symptoms on any given day, individuals living with episodic illnesses often have to deal with multiple appointments, medication changes, workplace accommodations, barriers to stable income, as well as housing, daycare, and other personal needs (Kleinman, 2012). Juggling such tasks and ensuring one’s needs are addressed is often too great to bear alone (Li, Shaffer, & Bagger, 2015; Taylor & Quesnel-Vallée, 2016). Frequently, help is needed, creating feelings of loss of control for the PLWEI while bringing the supportive carer into a new role with fluctuating time demands and uncertainties (Grant et al., 2004).

Across all forms of illness, 8 million people in Canada will provide care supports (Sinha, 2013). Based on Statistics Canada data, between 2007 and 2012, the number of people relying on care-related supports increased by a dramatic 20%, bringing the total number of carers in Canada
to 4.5 million (Sinha, 2013). The provision of support by family and friends accounts for approximately 80% of the hours devoted to attending to the needs of individuals with chronic health conditions and disabilities (Fast et al., 2002). Thus, as the prevalence of episodic illness increases, corresponding increases to the numbers of people providing intermittent, ongoing support to those living with episodic illnesses are anticipated (Lehman & Dixon, 2016; Manderson & Warren, 2016; Watkins, Assari, & Johnson-Lawrence, 2015).

As discussed, supporting people living with episodic illness through a unique but complex and fluctuating system of needs are family/friend carers. Episodic care provision impacts the lives of thousands of Canadians of various ages and socio-economic backgrounds (Sinha, 2013). Presently, there is no universal definition of episodic care, and as many arrangements for providing episodic care may exist as there are people (Ankuda & Levine, 2016). Due to the nature of episodic illnesses and related needs, many carers provide supports over extended periods, ultimately becoming part of an unpredictable cycle of sickness and wellness (Keefe, 2011). Though often unrecognized, episodic carers are integral to the healthcare team.

Literature in the field of informal or family/friend care differentiates between types of care supports (Beach et al., 2005). One area of research examines the differences between the delivery of direct services, whether physical or emotional, and coordinating or management services (Casey, Crooks, Synder, & Turner, 2013). Managerial functions are indirect forms of care support. Often comprising fewer hours than direct care, managerial tasks may include mediating, supervising, and planning. In recent decades as trends to adopt neoliberal values have influenced health policy, some tasks previously performed by community-based organizations (CBOs), healthcare providers, and others involved in care planning have shifted to the
responsibility of carers (Rosenthal & Martin-Matthews, 2009). Although commonly overlooked as part of the care process, these functions form an integral part of the delivery of care (Barbosa, Figueiredo, Sousa, & Demain, 2011; Turner & Findlay, 2012). For carers, balancing personal demands and providing ongoing supports can place one in a precarious position (Chen, Ngo, & Park, 2013). Many carers experience challenges, being caught between two lives, resulting from the low social value placed on care work (Fraser & Bedford, 2008). Social isolation for carers can also impact quality of life (Hayes, Hawthorne, Farhall, O’Hanlon, & Harvey, 2015). At present, across most of Canada, family/friend care is not financially compensated, leaving many carers torn between multiple systems of paid and unpaid work to sustain daily life for both themselves and family members/friends under their care (Duxbury, Higgins, & Smart, 2011).

Given the fluctuating nature of episodic illnesses, intermittent carers are called upon, often on short notice, to provide support for an indefinite period. The activities of daily life are impacted for the person living with the episodic illness and the carer who might need to take time off of work or school to provide supports (Bassi et al., 2014; Kulik et al., 2013). Care services are often needed unpredictably, and being available on-demand may add to carer burden (Keefe, 2011). While repeating care activities may become necessary due to ongoing health episodes, challenges for both the carer and the PLWEI will likely persist in understanding specific triggers of illness episodes (Hudson, 2000). This study aims to examine the unfolding nature of care as a process responding to the evolving nature of illness.

The following section on policy and service gaps further explores the pivotal moments which drove the development of early Canadian public health policy and programs which influence the context of episodic care today.
2.3.2 A historical review of care in Canada.

Care has a longstanding tradition in Western culture. Historically, care was often delivered through a multi-generational family, including extended kin relationships (Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011). Families were often large, comprised of members dedicating not only their time but the essence of their lives to the survival of all (Rutty & Sullivan, 2010). Within families, the division of labour cut across age and gender (Cunningham, 2014). Distribution of work was allocated based on age, physical capacity, and for some tasks by gender, with everyone who could work becoming involved in communal life activities (Fuller, 1998). With many hands to complete the chores to be done, there was a culture of work flexibility (Stoller, 2018).

This capacity to adapt to the shifting needs of family members enabled support from birth through death (Glenn, 2010). Focus on the overall well-being of each member was considered essential to meeting the needs of the family unit, and this required bringing a diverse array of human and natural resources to each successive challenge. Early intervention was possible when needs arose, as family members lived and worked together (Bengtson, 2001). A cooperative living style persisted for centuries amongst hunter/gatherer and later agrarian communities; this involved productive labour by all available participants (Neysmith, Reitsma-Street, Baker-Collins, & Porter, 2004). Historians of family structure consider multi-generational families the norm and desired form of family, with the current nuclear family format, commonly with two generations of parents and children, as an unstable family format (Sussman, Steinmetz, & Peterson, 2013).
With the advancement of the industrial era, communities of single or two-generation families were increasingly common. Also, average family sizes shrunk, placing greater responsibilities on the few (Williams & Crooks, 2008). For decades, people traded out homesteads for economic stability in the cities (Morgan, 2016). Members of households worked and socialized alongside one another but with an overall culture shifting away from collective needs toward greater personal independence and interpersonal competition as people gathered in larger urbanized environments (Glenn, 2010). Family decisions centred increasingly on employment opportunities and a search for enhanced resource stability (Kertzer & Barbagli, 2001). This shift in living arrangements affected care relationships as traditional community and familial systems became increasingly transient (Polivka, 2005). With the changes in settlement patterns and the movement of peoples from other countries and continents into the Canadian territories, new ideas on social care patterns emerged.

Post World War Two, as employment and war-related injury and illness increased, healthcare delivery became increasingly available in the public sphere (Marchildon, 2013). The British North America Act was examined for possibilities to expand medical access, including indigent members of society who frequently could not afford privatized healthcare (Fuller, 1998). This spurred a movement in Canada toward a nationalized system of healthcare supports (Prince, 2018). Initial developments grew into a patchwork system of healthcare resources that varied across the country. Heated debates arose concerning the purpose, the jurisdiction of oversight (federal versus provincial), and the degree of private profit-making until the Medical Care Act was passed in 1966 based on the ground-breaking work of Saskatchewan Premier Tommy Douglas (Thompson, 2015). Although imperfect in scope and reach, a universal healthcare system was established.
A gap in access to stable financial supports resulted in the creation of the Canada Pension Plan (CPP) and her sister plan, the Quebec Pension Plan (QPP), in 1966 (Beland & Koreh, 2017). Afterwards, the Canada Pension Plan Disability (CPP-D) provided long-term partial income replacement for people living with severe and prolonged disabling impairments who could no longer perform job duties (Torjman, 2002). The Canada Health Act in 1984 guaranteed universal access to healthcare services provided by a physician across the country, with the provinces responsible for implementation (Fuller, 1998; Rutty & Sullivan, 2010). With the growth of primary medical care, long-term home-based care needs also increased.

Two forms of family/friend care are presently recognized in our current social programs and the broader community (Buyck et al., 2011; Heller, Gibbons, & Fisher, 2015). One form of care delivery includes providing supports to children living with a disability, most commonly by parents or close relatives (Fast, Niehaus, Eales, & Keating, 2002). Delivery of ongoing care to aging family members is another form (Hollander, Chappell, Prince, & Shapiro, 2007; Turner & Findlay, 2012).

In recent decades, there has been a steady shift toward increased individual responsibility to provide for personal and family health needs; this shift has been accompanied by a sense of culpability aimed at those living with preventable illnesses (Hughes, 2017), as certain chronic illnesses are perceived as avoidable. Thus, the person living with the illness, such as HIV or addiction, is considered at fault for behaviours leading to the condition. With this shift toward the blaming and shaming of people living with episodic conditions, there has been a reticent attitude to deliver supports to improve the quality of life for PLWEIs (Hankivsky & Christoffersen, 2008). As a result, there are gaps in providing for physical and mental health-related needs, the most pressing health problems in Canada since the 1990s (Urbach, 2018).
Tensions result as people in Canada, healthcare professionals, and policymakers grapple with the gaps between what professional medical teams can deliver and what supports family/friend carers can reasonably provide.

The subtle shift is moving the responsibility of care away from formalized healthcare systems and increasingly onto the shoulders of family/friend carers. This change demonstrates the value placed on the individual as the primary attendant of care and purveyor of supports, a reductionist approach instead of a community care ethic (Drummond, 2015). Although reasons for the shift are intersecting, factors include: evolving political tides toward neoliberal market-driven initiatives (as discussed earlier), devolution of healthcare to provincial and local regions, reduced access to hospital-based supports, and decreased funding for community-based initiatives supporting people living in their communities (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). In many cases, family/friend carers are viewed by policymakers as being different from professional paid caregivers, thereby limiting the public visibility of care work and access to existing community-based carer supports (Lunsky et al., 2014). Care invisibility widens the gap between the haves and the have-nots in the care world (August, 2009; Neysmith & Reitsma-Street, 2005).

Among the social factors influencing care provision, gender, and place of residence have prominent roles. In Ontario, people across genders, cultures, sexualities, and socio-economic strata provide care supports (Sinha, 2013). Carers have different citizenship identities, years living in Canada, ethnicities, occupations, age groups, and income levels (Armstrong & Kits, 2004; Duxbury, Higgins, & Schroeder, 2009). In North America, women provide the highest amounts of care provision, comprising 54% of all carers, and they contribute the most hours to care (Fast et al., 2002; Xiong, Biscardi, Nalder, & Colantonio, 2018). However, the gender
The divide is shrinking as higher numbers of men become active providers of various care supports (Baines, 2015; Sevenhuijsen, 2003b). The reasons for these shifts continue to be explored, including differences in diagnostic rates of complex chronic illnesses between the genders, with women experiencing higher rates of illnesses such as depression, anxiety disorders, fibromyalgia, and MS (Roberts, Rao, Bennett, Loukine, & Jayaraman, 2015; Schneider, Steele, Cadell, & Hemsworth, 2011). Increases in the number of male carers may contribute to the changing social acceptance of who provides care.

The diverse geographies of Canada impact the capacity to provide care supports. Concentrating community supports in urban centres often presents challenges for carers living in rural areas who experience transportation and financial barriers to accessing resources (Goodridge & Marciniuk, 2016). Of note are the differences in the types of services available and the distance. These can amplify the challenges of transportation access and travel time requirements, especially if the PLWEI requires assistance with travelling (Gessert et al., 2015). As well, access to communication technologies and medical services is often limited in rural areas (Skinner & Rosenberg, 2006). However, emerging communication technologies now include remote support through Telehealth and other programs, although access continues to vary by region (Ray, Young, & Lindsay, 2018). In the study of geographies of care, location makes a significant difference in the support available.

2.3.3 Social policy impacts on episodic illness and episodic care.

Much of Canada’s policy response to health-related issues over the past century has been reactive, with health challenges arising and, subsequently, responses developed (McKenzie &
For example, the Compassionate Care Benefit (CCB) is an accessory program of Employment Insurance developed in 2016 for carers providing supports to terminally ill family members; the program was developed after advocates lobbied to improve resources for carers. Although designed for carers providing ongoing *intensive* forms of support, episodic carers are likely unable to access the benefit due to the intermittent nature of the care they provide (Giesbrecht, Crooks, Williams, & Hankivsky, 2012).

Concerning income support, episodic illness impairments do not often meet the threshold of disability as outlined in provincial and federal disability income support programs. The definitions of disability vary widely, and many do not include illnesses, which, although chronic, have a *relapse and remit* illness trajectory (Lightman, Vick, Herd, & Mitchell, 2009). Provincially, when PLWEIs apply for provincial income support programs not designed as income supplements for people who can engage in the labour force, such as the Ontario Disability Support Program, people living with chronic illnesses may be denied because the illness impacts may not meet definitional requirements for consistency (Ho, Kuluski, & Im, 2017). At the federal level, the Registered Disability Savings Program (RDSP) requires a consistent daily experience of illness symptoms for 90% of the time to access the program (Government of Canada, 2019b). To qualify for disability status under the Canada Pension Plan (CCP-D), one’s symptoms and life impacts must be both severe and prolonged (Torjman, 2002). Thus, someone living with a fluctuating episodic illness would be ineligible for financial supports when employment becomes challenging for intermittent periods because of ill health. In short, while the day-to-day health impacts of episodic conditions are significant, the threshold for access to public income supports is higher. On a somewhat positive note, within the last decade, CPP-D has altered definitional requirements for PLWEIs who attempt to return to work but are
unable. In this case, the rapid reinstatement provision facilitates an automatic return to the financial benefit when employees cannot continue due to illness (Campolieti & Riddell, 2012). This decision by the federal government demonstrates a recognition that PLWEIs need flexible supports to obtain and sustain employment.

Barriers PLWEIs face accessing income support during times of illness can have ripple effects on episodic carers who assist with the PLWEI’s financial and other needs. Carers, in turn, may face economic challenges as they financially support the PLWEI. Further, episodic carers may also seek non-financial supports, such as restorative respite, which involves contextual opportunities to reconsider and internalize care experiences (Chiao, Wu, & Hsiao, 2015; Silverman, 2018). At the community level, access challenges to community support programs exist for episodic carers across Canada. The unique challenges of episodic carers are often not recognized in our communities, and resources such as information and community supports are sparse (Casado, van Vulpen, & Davis, 2011; Lilly, Robinson, Holtzman, & Bottorff, 2012). For some carers, the process of applying for various forms of support is akin to navigating a policy maze.

Barylak and Guberman (2016) advocated for a rights-based approach to carer policy based on the central role that carers provide in social healthcare, as well as by positioning support as a fundamental human right. This approach has not yet been realized; thus, advocacy continues. Advocacy has a longstanding tradition in developing social policy in Canada. Still, at present, gaps exist in public policies to support episodic carers as well as those living with episodic illness. Amidst increasing pressure to provide supports to PLWEIs, episodic carers have many needs for support as they fulfill the carer role, yet policies remain unresponsive. It is hoped that
the results of the current study will increase understanding of episodic caring and contribute to efforts to advocate for provincial and federal policies that address their diverse needs.

2.3.4 Considering HIV care.

This section reviews the existing literature on providing care to a family member/friend living with HIV/AIDS.

HIV has long associations with controversy, since the early years of the virus, as an illness physically and socially devastating to individuals and communities living on the margins of society (Herek, Capitanio, & Widaman, 2003; Whiteside, 2016). Early in the crisis, physicians and community medical practitioners noted a cluster of uncommon conditions such as certain cancers and pneumonia — illnesses commonly associated with immune compromise (Benson et al., 2009). Becoming infected with the virus meant grappling with a disease that could indiscriminately ravage the body; for many, this ended in death (Rife & Salemi, 2015). The illness spread quickly across the world with uncertain modes of transmission that fueled community fears about transfer from person to person (Heller, 2015). Due to the high incidence rates among gay men in the 1980s, living with HIV came with the social stigma which had historically kept gay communities from living openly (Stall, Friedman, & Catania, 2008).

During much of the 1980s and 1990s, determined community activism drove research initiatives with levels of fervour and immediacy having few parallels in the 20th century (Doka, 2014; Kippax & Stephenson, 2012). The growing incidence of HIV was accompanied by efforts to search for causes, prevention options, treatment options, and the possibility of a cure (Rushing, 2018). HIV was identified in 1984 following a combined effort by French and
American researchers (Sabin & Lundgren, 2013). Shortly afterwards, in 1985, a rapid identification test for HIV was developed, making detection possible at any point following infection (Esparza, 2013). But without medications to stem the damaging effects of the virus, people living with HIV/AIDS (PLWHAs) would experience a variety of comorbid illnesses that move through the body with remarkable speed, from body wasting to cancers to pneumonia (Rushing, 2018).

Since the latter half of the 1980s, targeted medications have reduced the body’s immune system response to HIV. The mid-1990s marked a significant breakthrough in HIV pharmacological development when highly-active antiretroviral (HAART) treatments became available (Killen, Harrington, & Fauci, 2012). As HAART medications became more accessible, PLWHAs experienced a dramatic shift, with many living longer lives — albeit with fluctuating illness and wellness (Solomon, O’Brien, Wilkins, & Gervais, 2014). As a result, since the HAART era began, HIV has increasingly become an episodic illness (Canadian Working Group on HIV and Rehabilitation, 2006). Although death still occurs, often due to comorbid conditions resulting from immunodeficiencies common to HIV, much of the lived experience of HIV is chronic for PLWHAs with stable access to HAART medications (Erlandson, Schrack, Jankowski, Brown, & Campbell, 2014). In Ontario, public coverage of HIV medications continues to be part of the provincial drug formulary, thereby making HAART medications publicly accessible (Government of Ontario, 2020). With the update of HAART medications, HIV illness episodes often continue to change as health needs shift (Gallagher et al., 2013). As such, an HIV diagnosis comes with the uncertainty of an unknown future, death, and living with an illness that may take over the body.
Presently, while pharmaceutical developers continue to work the labs, much of the daily work of living with HIV happens in homes and hospitals where partners, friends, and family members care for PLWHAs, including some carers living with HIV who themselves sometimes need care. HIV care can be intensive when illness occurs; at other times, there are few symptoms requiring support (Mignone et al., 2015). HIV care is often unsung work, as carers navigate illness episodes, which may strike with little warning.

With respect to carers, studies early in the history of HIV care focused on the experience of stress and the emotional well-being of carers who provided supports to someone grappling with debilitating HIV symptoms or who had recently lost a loved one to HIV (Folkman, 1997; Rosengard & Folkman, 1997). During the early years of the disease, families, friends, and local communities lived on the alert, wary of contracting the new illness and often living apart from mainstream society (Wilkie, 1992). For carers of people living with HIV themselves, experiencing a lack of control over life circumstances was common (Cadell, 2003). Despite the distress experienced by HIV carers from the loss of loved ones, research suggests that many carers engaged in a reflection process that led to post-traumatic growth and wisdom (Cadell, 2007; Cadell & Haubrich, 2006; Cadell & Sullivan, 2006). In a Canadian study of HIV carers, posttraumatic growth was associated with access to meaningful social supports (Cadell, Regehr, & Hemsworth, 2003). From the study by Cadell and colleagues (2003), the experience of growth seems to involve making meaning, forming an understanding, adapting, and setting boundaries associated with the ongoing experience of providing care.

The relational bond between the carer and PLWHA acts as a motivator for carers to build care-related skills to improve the quality of support (Wrubel & Folkman, 1997). To find meaning in care relationships, mental distinctions between care and other aspects of life assist carers with
maintaining perspective (Carlisle, 2000). Wrubel, Richards, Folkman, and Acree (2001) further explored the nature of relationships in HIV care by describing three variations of HIV carer relationships: engaged carers, conflicted carers, and distanced carers. Engaged carers are involved in an ongoing provision of care while learning new skills to benefit the PLWHA. However, conflicted carers wrestle with how to care for themselves while continuing to provide care. Conflict occurs through tensions from the uncertainty of continuing to provide care while navigating personal demands. Distanced carers provide the third form of care; when a health decline triggers preparations for end-of-life care, carers begin to mentally and emotionally prepare themselves for the loss of a loved one.

Reynolds and Alonzo developed a model of HIV care in the early years following enhanced treatment access, studying both longitudinal and cross-sectional reviews of care. The study examined the phases of care following the HIV diagnosis: transitions to care, living the burden, and facing the void (Reynolds & Alonzo, 1998). The final phase looked at facing a relationship void resulting from ending care, which could either result in emotional challenges associated with severing a relationship due to strain or facilitate growth as carers adjusted to the demands of care and saw enhanced capacity within themselves. This final category highlights the uncertainty inherent with HIV care. Additional HIV care research has noted that carers benefit from finding meaning in care tasks and using insightful phrasing, such as living with HIV, to gain perspective during the illness episodes (Anderson, 1992).

Due to the highly stigmatized nature of HIV, carers have often come from in-group supporters who acknowledge the stigma associated with HIV transmission (Cahill & Valadéz, 2013). The stigma can create concerns when reaching out to the broader community for potential supports (Roger, Migliardi, & Mignone, 2012). Further complicating the situation is the
possibility of stigma-by-association experienced by the carer (Kulik, Bainbridge, & Cregan, 2008). Canadian families of youth living with HIV have reported barriers to status disclosure due to perceived stigma (Fielden et al., 2006). In some instances, HIV carers live with HIV themselves, presenting multiple barriers that persist over time and may impact the health of the carer.

As partners, family members, and friends, including PLWHAs, increasingly provide supports with assistance from community organizations, HIV care is becoming less stigmatized (Harris, Veinot, & Bella, 2010). Although PLWHAs continue to die from illnesses connected to HIV, most HIV care has shifted to longer-term support of a chronic illness (Balderson et al., 2013). HIV care continues to have unique challenges, primarily due to potential health complications resulting from opportunistic infections (Cahill & Valadéz, 2013). In addition to illness episodes, HIV medications often cause significant health impacts such as nausea, gastrointestinal distress, and sleep and eating changes (Treisman & Soudry, 2016). Additional medication side effects include fatigue, insomnia, diarrhea, and neuropathy, which may increase the need for supports (DiBonaventura, Gupta, Cho, & Mrus, 2012). Appointments with physicians, dentists, dieticians, and various specialists require care coordination in a shifting landscape of health (Flickinger, Saha, Moore, & Beach, 2013). Although not all PLWHAs experience significant health impacts, the many who do experience these impacts along the illness journey tend to initiate family/friend HIV care. In this process, carer well-being impacts occur to income, health status, discrimination, multiple life losses, dispositional optimism, effective coping mechanisms, and feelings of personal empowerment (Fredriksen-Goldsen, 2007; Valjee & Van Dyk, 2014).
Much of the existing HIV care literature was developed before the availability of HAART medications in the mid-1990s. There is thus a gap in available HIV care literature, during which time the experience of HIV has changed from a focus on palliative care to chronic episodic care.

### 2.3.5 Considering MS care.

Next, the discussion focuses on MS care. Canada has a higher-than-average incidence rate of multiple sclerosis (MS) infection, with approximately 77,000 people currently living with MS (Government of Canada, 2019c). Furthermore, per capita diagnoses are anticipated to rise in the coming decades (Nana et al., 2017). MS is a last resort diagnosis, meaning that a diagnosis of MS often occurs after extended periods (even after decades) of living with the illness (Giovannoni, 2016). Many live with changing symptoms of MS for 5 to 10 years before a diagnosis is received (Palace, 2001). MS is a degenerative neurological disease that often occurs in early adulthood (Disanto et al., 2011). Of those diagnosed with MS, 85% live with relapsing-remitting MS, resulting in motor-neural impacts that shift over time with periods where symptoms remit (Spain, Cameron, & Bourdette, 2009). In relapsing-remitting forms of MS, the course of illness mirrors the experience described in the Episodic Disability Framework (Goldenberg, 2012). Some signs of MS may not be readily visible, such as fatigue, depression, and cognitive impacts (Charvet, Kluzer, & Krupp, 2014). The physical and mental health impacts of living with MS are significant and long term.

The prolonged emotional and physical toil of MS results in a life-long, uncertain illness course that bears the hallmark characteristics of episodic illness (Buhse, 2008). For people living
with MS, care provision is likely, especially during episodes of illness, with MS carers describing periods of challenge followed by periods of relational stability as *peaks and troughs* (Boland, Levack, Hudson, & Bell, 2012). According to a meta-review of MS carers, life impacts occur across multiple life areas, including physical and psychological well-being, social life, work-life, and finances (McKeown, Porter-Armstrong, & Baxter, 2003). Carers function in highly unpredictable circumstances in a search to both manage symptoms and complete activities of daily life. Learning to accept the long-term nature of MS care assists with the relational adjustment for carers navigating a new aspect of their relationship (Pakenham & Samios, 2013).

For people living with MS, carers are often family members/friends who provide 80% of all care supports (Hillman, 2013). Perhaps due to the higher rates of incidence of MS in women (Jobin, Larochelle, Parpal, Coyle, & Duquette, 2010), higher than average numbers of male MS carers have been reported, with half or more MS carers identifying as male (Lee, Pieczynski, DeDios-Stern, Simonetti, & Lee, 2015; McKenzie et al., 2015). In MS care, internalized constructions of gender roles influence carers’ perceptions of responsibilities. Traditionally gendered activities such as lawn care or home maintenance fall outside of the regular activities for female carers, with male carers noting meal preparation, shopping, or laundry as unexpected tasks performed (Hughes, 2016).

When a spouse is living with MS, the relationship between the carer and PLWEI can be negatively impacted (Buchanan & Huang, 2011). For some carers, the socio-emotional relationship between the carer and PLWEI loses focus as care activities become more prominent than the relationship (Sullivan & Miller, 2015). For MS carers, feeling compelled to care is common and may reduce the relationship quality (Hughes, Locock, & Ziebland, 2013). Timely psychosocial supports can help MS carers, who can benefit from counselling following the MS
diagnosis (Lorefice et al., 2013). Carer well-being is positively associated with understanding the illness course and is inversely associated with how carers process negative emotions (Bassi et al., 2016). Interestingly, carer mood is not related to the degree of MS illness severity (Pooyania, Lobchuk, Chernomas, & Marrie, 2016).

Among the topics researched in MS care, carer burden is common (Akkus, 2011; Dunn, 2010; Ertekin, Özakbaş, & Idiman, 2014). In MS care, the increased likelihood of carer burden is associated with education at a high school level or below, residing with the PLWEI, a higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in becoming a carer (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). When PLWEIs experience increases in physical symptoms, such as loss of bladder control, this can also increase the burden upon carers (Buchanan, Radin, & Huang, 2011). MS carers experience more strain than non-carers and Alzheimer’s carers, with more impairment to daily life activities, increased visits to the emergency room, and hospitalizations (Gupta, Goren, Phillips, & Stewart, 2012). For male carers, the perception of burden is linked with mental health status (Buchanan, Radin, & Huang, 2010). Generally speaking, MS carers accept the co-existence of illness and wellness with family members/friends. This understanding may serve, at least in part, to counterbalance the negative impacts of providing care (Bassi et al., 2014).

2.3.6 Similarities and differences between HIV and MS care.

The next section discusses HIV and MS care together, exploring the similarities and how the context of care may differ. The discussion concludes with the broader social influences impacting HIV and MS carers.
Beginning with similarities between HIV and MS, the triggers of illness episodes are shifting and variable for both (Hempel et al., 2017; Mohr, Hart, Julian, Cox, & Pelletier, 2004; O’Brien, Bayoumi, King, Alexander, & Solomon, 2014). Opportunistic illnesses seen in HIV are frequent and severe due to immunosuppression, resulting in illness episodes such as pneumonia, encephalitis, or tuberculosis (Colvin, 2011; Kaplan et al., 2010). Similarly, as stated above, approximately 85% of people living with MS experience relapsing-remitting episodes, often with changing symptoms, for uncertain periods (Mitchell, Benito-Leon, Morales Gonzalez, & Rivera-Navarro, 2005).

As explained above, throughout the experience of living with HIV, illness episodes are often not directly connected to HIV but are instead episodes of comorbid conditions (Brashers et al., 2003; Douek, 2005), including mental illnesses such as depression or anxiety disorders (Treisman & Soudry, 2016). Similarly, relapsing-remitting MS is episodic for much of the illness experience, primarily impacting the nervous system and commonly experienced with comorbid illnesses (Confavreaux, Vukusic, Moreau, & Adeline, 2000). This complicates considerations when comparing the two illness groups, as carers may be providing supports for comorbid illnesses in addition to a primary diagnosis (Hastrup, Van Den Berg, & Gyrd-Hansen, 2011). Divisions between the conditions grow blurred, with no exact way to differentiate between the care needs of PLWEIs living with multiple illnesses. For carers, illness episodes add to the learning curve of adapting to a constantly changing experience of care provision.

However, the types of physical experiences associated with HIV and MS are different; for example, episodes of MS may impact vision or functioning in the legs, and moving from place to place may be challenging (Razazian et al., 2016), which are not seen in HIV. Additionally, genetic factors affect people living with MS by contributing to the development
and progression of the illness (Hempel et al., 2017). While relapsing-remitting MS has episodes for years, often decades, most people living with this type of MS eventually see disease progression, which ultimately becomes debilitating (Bergamaschi, Berzuini, Romani, & Cosi, 2001; Confavreux & Vukusic, 2006). Thus, in MS care, the illness experience is episodic for years, possibly decades, with a likely future progression. HIV, in contrast, may continue as episodic with medication adherence and ongoing physician support.

Additionally, medication adherence may impact the care one needs. In Ontario, PLWHAs have publicly-funded coverage of highly active anti-retroviral medications (HAART), which have a significant stabilizing effect on the illness course of HIV (Government of Ontario, 2020). For individuals who may not be taking medications regularly or as prescribed, the level of unpredictable HIV-related illness impacts immune strength (Ingersoll, 2004) with higher viral levels noted in the bloodstream even following a single missed dose (DeMasi et al., 2001). Despite this, factors impacting medication adherence include IV drug use, mental health conditions, and housing and food security; these factors can result in skipping doses of medication or periods where medication is not taken (Garcia & Côté, 2003). In a study of factors related to HAART adherence in British Columbia, only 56% of participants were optimally adherent to prescribed medications (O’Neil et al., 2012). This percentage of sub-optimal adherence is high, which may have ripple effects on carers who support people living with HIV.

In MS care, non-optimal medication adherence may occur, although for different reasons and other impacts than in HIV care. In a multi-year Canadian study, one-quarter of all participants living with MS followed over two years were non-optimally adherent to prescribed therapies (McKay et al., 2017); a large European study found similar results (Devonshire et al., 2011). The reasons for sub-optimal medication adherence in MS are different from HIV, with
injection anxiety being a primary factor for those living with MS (Turner, Williams, Sloan, & Haselkorn, 2009), along with treatment fatigue, perceived lack of efficacy, and adverse treatment events (Costello, Kennedy, & Scanzillo, 2008). These treatment barriers present persistent challenges for carers who may become involved in motivating PLWEIs to follow treatment regimens.

Social determinants of health strongly impact the provision of HIV and MS care. In addition to the physical and emotional aspects of episodic care, there are social impacts experienced by carers either directly through the care or indirectly when PLWEIs experience challenges to accessing personal social determinants of health (Shier, Ginsburg, Howell, Volland, & Golden, 2013). This discussion is especially relevant as HIV incidence is linked to social determinants of health access (Auerbach, Parkhurst, & Cáceres, 2011), such as reduced income, housing impacts, and barriers to employment (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013). As the carers become part of the lives of PLWHAs, carers may also assist with finding solutions to barriers to accessing social resources (Topcu, Buchanan, Aubeeluck, & Garip, 2016).

In summary, at present limited evidence is available on how HIV and MS carers provide episodic care supports and, in turn, are influenced by the process of administering care. Family/friend care commonly redirects carers in their life course as care responsibilities become part of the carer/PLWEI relationship (Torjman, 2011). Episodic care, which may expand or limit potential future professional and personal opportunities for carers, calls for additional investigation — a call responded to by this study. The next chapter describes the methods and methodology of the study toward developing a model of the long-term, lived experience of relational episodic care delivery.
Chapter 3: Research Methodology and Methods

This chapter outlines how a *constructivist grounded theory* (CGT) approach informed the methods of the study. The chapter begins with a review of the philosophical underpinnings of CGT, followed by details on the use of CGT in the study design, sampling, data collection, procedures for data analysis, knowledge mobilization, and the involvement of a project advisory committee during the project.

The following question initially guided the research: *What impacts do adult carers experience as a result of unpredictable illness episodes?* However, as described in the next chapter, a more salient question emerged in the process of conducting the study: ‘*What are the relational impacts of episodic care on HIV and MS carers?’* This question became the focus of the study and the resulting model of relational episodic care to be developed in the Findings chapter.

### 3.1 Introduction to Grounded Theory (GT)

Since its ‘discovery’ five decades ago (Glaser & Strauss, 1967), GT has become a growing influence as a qualitative methodology. For qualitative and quantitative researchers alike, CGT conjures sentiments, some favourable, some in opposition to its positivistic origins which embrace a rigorous set of methods (Bryant, 2002; Cunliffe, 2008; Tolhurst, 2012). Perspective differences abound regarding the nature of research (Popkewitz, 2011), research value, and present and future applications (Mills, Chapman, Bonner, & Francis, 2007). These debates have spurred the refinement of CGT methods, strengthening CGT as a meaningful
offering at the metaphoric research table, growing its range of applicability while enhancing its popularity. While the future may bring additional CGT options, in the present, CGT has three primary approaches: Glaserian (Glaser, 1999), Straussian (Strauss & Corbin, 1990), and Constructivist (Charmaz, 2014). The next section will review the development of CGT.

3.2 Origins of a Social Constructivist Grounded Theory Approach

As a methodology, CGT has experienced several fundamental shifts from the early origins in the work of Glaser and Strauss in the late 1960s (Glaser & Holton, 2004), which occurred through internal differences of opinion within the field of CGT research. These changes included how to arrive at the point of theory and whether or not the final product can be considered an accurate representation of what has occurred or is influenced by contextual factors such as history, time, power dynamics, and the influence of the researcher on the process (Mills, Bonner, & Francis, 2006). As social constructionism grew in acceptance, its use widened into theory development (Holstein & Gubrium, 2013). Scholars such as Kathy Charmaz (1990) raised concerns about the decontextualized, atheoretical nature of grounded theory research (Henwood & Pidgeon, 2003). After studying under Glaser and Strauss, she proposed Constructivist Grounded Theory as an alternative method, bringing together a constructivist epistemology with GT methods (Holstein & Gubrium, 2013). The new theory relied on interpretations of the key actors, including researchers and community members. Under this umbrella, a new lens emerged for the data analysis and interpretation processes, the perspectives of the research participants who may be involved in various ways during the research process.
CGT represents a frameshift within grounded theories, allowing for the researcher's presence within the work itself while providing the methods-driven structure necessary to develop mid-level theory from context-bound data (Charmaz, 2014). This shift moved GT toward a context-influenced, relational approach embracing a more fulsome understanding of the social world by using constructivist principles. CGT represents a bold proclamation and departure from the origins of GT by calling into question research as purely an organic creation, by claiming that theory generation cannot exist devoid of historical, political, and socio-cultural factors. The methodology involves rich, descriptive, recurring data reviews, which extend beyond meaningful explanation to theoretical development, exploring why a phenomenon occurs (Corbin & Strauss, 2014). CGT is developing a rich tradition within social work for examining issues of relevance to individuals, communities, and societies, with the inclusion of relevant social conditions. Beginning with a construct to explore, CGT approaches utilize an inductive inquiry, comparative logic, abductive reasoning, and interaction throughout the research process, which engages the researcher throughout the research process (Charmaz, 2008). This multiphase process utilizes inductive inquiry in a situated abductive logic (Charmaz & Bryant, 2016).

Abductive analysis “consists of assembling or discovering, based on an interpretation of collected data, such combinations of features for which there is no appropriate explanation or rule in the store of knowledge that already exists” (Reichertz, 2010, para. 14). Thus, an analytic review is done with the openness to challenge existing conventions, which can result in the “cultivation of anomalous and surprising empirical findings against a background of multiple existing sociological theories and through systematic methodological analysis” (Timmermans & Tavory, 2012, p.169). This process occurs within the local socio-historical, cultural, and political environment (Charmaz, 2008).
CGT research is not atheoretical but instead comes from a place of informed but unsettled inquiry. As researchers cannot unlearn previous knowledge or dissociate from personal axiologies, existing theory is part of all scientific inquiry (Henwood & Pidgeon, 2003). This positioning may be called theoretical agnosticism (Thornberg, 2012). The process proceeds with an ethos of discovery as methods themselves are considered emergent throughout the data gathering (Charmaz, 2008). As data gathering progresses and new areas of relevance are identified, the questions posed to participants change. This process recurs until two points of theoretical saturation are reached, in response to the questions posed and, more broadly, the central themes under inquiry (Charmaz, 2014). Data gathering is often semi-structured, allowing the participant flexibility to discuss contextually relevant themes (Charmaz & Belgrave, 2012). Alongside an iterative review process, including open and thematic coding (Corbin & Strauss, 2014), a comparative process creates a higher-level explanation of the research in the form of a new construct-driven middle-range theory (Charmaz, 1990). CGT embraces variance of experience, including outliers in the analysis (Charmaz & Bryant, 2016; Charmaz, 2014), exploring the what and how of a topic (Charmaz, 2008). New theory can exist at multiple levels, ranging from specific to a broader application to the general population (Akesson, Braganza, & Root, 2018). Middle-range theory development involves a theoretical outline for use in a specific context (Gurd, 2008).

Following CGT principles, the focus of this project was to develop an interpretive middle-range theory, which provides an organizing framework for episodic care that integrates the personal, social, and political environments locally (Glaser & Strauss, 2017). The project utilized a concurrent data gathering and analysis method, coding directly from the interview data, constant comparison of codes, ongoing construction of theory as the data builds, memoing, and
theoretical sampling. CGT involves the concurrent processing of data alongside the analysis to explore emerging themes (Birks & Mills, 2011). Although data gathering and analysis are described separately in writing, in line with CGT processes, they co-occur and are commonly referred to as constant comparative method (Creswell & Poth, 2016). The use of constant comparative methods influenced the direction of the project, as participants spoke of often the importance of relationships between carers and PLWEIs.

The constant comparative method uses a reflective, iterative process to compare code levels with one another, including as new data continues to be added (Charmaz, 2014). Thematic analysis of the interview transcripts involved flexible, constructivist grounded theory strategies, including constant and comparative analysis, review of interview notes, initial coding, secondary coding, comparison of coding, development of categories and emerging theory from the data (Charmaz & Bryant, 2016; Strauss, 1987). These methods moved the data beyond a description of what happens by examining patterns, developing new concepts, and ultimately moving those concepts to the realm of theory development (Glaser, 1978; Glaser & Strauss, 1967). Coding involved looking for actions throughout the text (Charmaz, 2014). The analysis examined the carer-PLWEI relational impacts, as well as ways care provision impacts the life of the carer, including social determinants of health — factors of interest related to the unpredictable illness course, the hallmark characteristic of an episodic illness. While neither the MS nor HIV carer communities are large in Canada, both are considered episodic illnesses due to the unpredictable nature of each illness course.

The theoretical sampling involved completing the first several interviews and reviewing the transcripts for questions that were not of relevance, as well as concepts discussed by participants not included in the original interview guide. As a result, several questions were
added to the interview guide to understand the carer sense of responsibility for the PLWEI, the types of boundaries placed by the carer on the relationship, and the ways carers understand their relational identity. The revised interview guide was submitted and approved by the REB (See Appendix H). During this process, memoing, in conjunction with transcript coding, connected ideas from participants toward developing the theoretical concepts. Constant comparison guided thematic development throughout the data gathering and analysis phases.

3.3 Framing the Social Constructivist Approach to the Research

Social constructionism is a way to understand and find meaning in interactions, understandings of the world, and the decision-making that is part of our daily experience (Thornberg, Perhamus, & Charmaz, 2014). Drawing on the ethos of CGT, this research adopted a constructivist approach informed by the work of Kathy Charmaz (2014), integrating the CGT methods outlined above for the data gathering and analysis. Constructionism is the orientation of the project, ontologically interpretive and epistemologically postmodern (Charmaz, 2008). Through integrating the perspective of care as a relational task, care becomes a situated experience. Diversity arises by allowing situations to unfold as they will, then evaluating relational exchanges within their contexts. Thus, a natural tension exists in generating a middle-range theoretical model and its potential use in other settings. A research project is inseparably bound to historical, social, and political contexts, limiting the range of application. The relevance of the final product to its audiences should be evaluated within the original research setting and then considered within the applied context.
In research, CGT comes from a positioned standpoint, as with other types of qualitative investigation (Bryant & Charmaz, 2007). Researchers using CGT methods integrate purposeful self-reflection into their work, enhancing the research process through explicating the origins and development of their work via a self-reflexive lens (Turnbull, 2002). Locating a project in the context of CGT can involve self-reflection on the area of study, with personal reflexivity being a vital aspect to the development of internal cohesion of the work (Alvesson & Sköldberg, 2018). In essence, this involves a process of retaining focus or ‘keeping the main thing, the main thing,’ to reduce the likelihood and potential impacts of scholarly drift from the original purposes of a project by examining the relationship between researcher and participant (Etherington, 2007). Reflexivity also provides ongoing opportunities to explore future directions of a theory (Lawler & Bilson, 2012).

3.4 Sampling

Here carer is defined as someone who provides temporal, managerial, or social supports to a family member/partner/friend living with a complex chronic episodic illness. Often a pre-existing relationship exists with the care recipient before the onset of care-related tasks. In this project, both the carer and the person living with the episodic illness are adults, with the carer being a family member/friend. To meet the study criteria, carers were presently supporting or had supported someone living with either HIV or relapsing-remitting MS.

Below is a listing of study inclusion criteria. In keeping with the constructivist orientation of the project, participants self-identified as a provider of care-related tasks for someone living with either HIV or relapsing-remitting MS in Southern Ontario.
Table 1

*Study Inclusion Criteria*

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<th>MS/HIV Participants</th>
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<td>Adult 18 years or older</td>
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<tr>
<td>Provides unpaid support to a partner/family member/friend with unpredictable health</td>
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<tr>
<td>episodes</td>
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<tr>
<td>Living in southern Ontario</td>
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<tr>
<td>Caring for someone living with relapsing-remitting MS or HIV</td>
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Study participants were recruited based on the following criteria: diagnosis of a partner/family member/friend living with either HIV or relapsing-remitting MS and residing in Southern Ontario. Eligible study participants supported someone living with HIV or MS in the past or the present while living in Southern Ontario and were at least 18 years of age. Specific to HIV, since the advent of anti-retroviral drugs or HAART medications in the mid to late 1990s (Hogg et al., 1998; Johnston et al., 2010), the illness experience of HIV has become increasingly episodic as pharmacological interventions improve longevity and quality of life (Gakhar, Kamali, & Holodniy, 2013). People currently living with HIV may experience periods of living with AIDS, and then with treatment AIDS symptoms may remit (Deeks, Lewin, Havlir, 2013). Still, an AIDS diagnosis was not an exclusion criterion. Recruiting similar numbers of MS and HIV carers provided balance representation across the carer groups. The southwest Ontario region was selected for two main reasons, first, as in the area where I live, and second, Ontario is the province with the most people per capita in Canada delivering family/friend care supports (Sinha, 2013).
To respect constructivist grounded theory methods, theoretical sampling was used throughout the interviews as participants shared common themes about the importance of the carer/PLWEI relationship to providing episodic care.

3.5 Ethics Review

As the research involved human participants, the Wilfrid Laurier Research Ethics Board (REB) provided the ethics review and clearance before initiating data collection. The project received approval (REB 4933) in Summer 2016, with recruitment starting shortly after. As the relationship between the carer and the person living with the episodic illness became increasingly relevant to the study, a second ethics clearance allowed additional participant queries about the inter-personal impacts of episodic care and individual constructions of the self as a carer. Overall, the ethics review modifications were completed three times during the project.

3.6 Recruitment

Recruitment documents to reach potential participants used plain language at the standard eighth-grade reading level to reduce participation barriers. The phrase someone who provides supports expanded the possible audience by describing how caregivers may identify themselves instead of ascribing the label of carer.

Recruitment proceeded using a purposive sampling strategy. Purposive sampling involves selecting participants often because of a unique characteristic or experience (Engel & Schutt,
2017). In this study, the two-group sampling approach focused the search on carers of someone living with HIV or MS. This strategy involved leveraging existing professional and personal relationships via a request to CBOs serving populations of interest and referrals from pre-existing contacts. Purposive non-probability sampling is typical of qualitative research due to smaller overall sample sizes (Engel & Schutt, 2017).

Email via partner listservs helped establish credibility with participants through pre-existing relationships with the partner organizations and allowed for broad reach to potential participants. To further broaden the recruitment base, the Hassle Free Clinic, AIDS Committee of Toronto, and 519 Community Centre, all located in Toronto, agreed to post recruitment flyers. Other organizations assisted with disseminating information, including Wellesley Community Centre, St. Michael’s Hospital HIV clinic, and Sunnybrook Hospital. Contact was also made with the MS Society of Ontario to assist with outreach to local chapters. Still, the initial request did not meet the MS Society requirement of receiving external funding for the project. Following an unsuccessful attempt to post the study on the National MS Society Research Portal, in the Summer of 2018, the MS Society contacted me to post the study information. In addition to the MS Society Research Portal post, several MS Society chapters in Southern Ontario agreed to disseminate information on the project to their members via social media platforms.

Realize Canada, the national Episodic Disabilities Forum (EDF), the Ontario Caregiver Coalition (OCC), Ontario Women’s Health Network (OWHN), and Women’s Health in Women’s Hands (Toronto) distributed recruitment emails to their member listservs. One MS Society Chapter, the Grand River Society, agreed to distribute information to a caregiver support group. A personal Facebook account helped recruit via a status update post about the project.
Where opportunities arose to speak about the project within personal, community, and academic circles, progress was shared, accompanied by requests for referrals to potential participants.

An initial wave of door-to-door canvassing yielded opportunities to post recruitment flyers at HIV organizations across the city of Toronto. At the same time, email requests went to HIV organizations across Southern Ontario. Of these, the AIDS Committee of Windsor posted a flyer sent via standard mail in an information package. Inside the Faculty of Social Work, posters also aided recruitment efforts. As an outreach strategy, I also volunteered for six weeks at a food bank supporting people living with HIV run by the Toronto People with AIDS Foundation. Volunteering served two purposes to give back to an organization that assisted with the project and invited community-based conversations about the project.

Potential participants, community workers, and persons with study-related questions contacted me via a Laurier email address or telephone. All inquiries received a response as soon as possible, within 24 hours of the initial contact. Recruitment and data collection continued through referrals from contacts and members of the dissertation committee. Community organizations representing the interests of people living with HIV and relapsing-remitting MS assisted with the recruitment. A previously established partnership with *Realize Canada*, a leader in episodic illness research, policy, and practice in Canada, assisted with networking and recruitment and agreed to disseminate final results.

To compensate participants for their time and expertise, each received an honorarium for participating. The Laurier Faculty of Social Work provided a stipend of $500 to assist with project costs incurred through honoraria payments. When recruitment slowed, through strategizing with Dr. Suarez and several HIV experts, the honorarium amount was increased. A modification request increased the honorarium amount from $15.00 to $30.00, which was
otherwise in line with the honorarium amount per interview in the Greater Toronto Area.

Afterwards, recruitment continued, following a suggestion to contact the Toronto Public Health HIV clinic who disseminated via their listserv.

3.7 Data Collection

Where participants felt comfortable with the process, expressed interest in participating, and met the inclusion criteria for the study, a date for an interview was scheduled at a time and place convenient to the participant. Participants received directions and parking information as needed. Interview locations were private, including meeting rooms at the Wilfrid Laurier Faculty of Social Work, Realize Canada boardroom, and private homes. Participants selected an interview location convenient for them, with all interview sites offering sufficient privacy to conduct the interview comfortably. Participants could ask questions before, during, and after the interviews.

On the day of the interview, participants were first thanked for participating, followed by a review of the informed consent document (see Appendix F). Participants initialled each page, as well as signed and dated the form before the interview. Before each interview, study participants completed a demographic information sheet to understand the socio-cultural characteristics of family/friend episodic carers (see Appendix G). The purpose of the information sheet was to understand the backgrounds and experiences of the study participants better. Responses to the demographic fact sheet were optional, with participants responding as appropriate to their identity and circumstances. As a qualitative study, this information is useful
for understanding the socio-demographic diversity of episodic carers and creating an enhanced *picture* of how and where episodic care occurs in Ontario.

The interview protocol was then reviewed, including confirmation the participant was comfortable with recording the interview and a reminder the interview could be paused or stopped at any time. During the interviews, occasional check-ins were done with participants to determine if they were emotionally well and confirm their comfort with continuing. Participants could take breaks at multiple points during each interview. The semi-structured interviews followed the outline of the interview guide focusing on the changeable nature of the carer role over time. To view the informed consent statement, see Appendix F. The interview guide for participants is available in Appendix H. Interview participants were asked questions as outlined in the interview guide.

Interview questions focused on three areas, the episodic nature of care provision, personal impacts resulting from the care, and self-perception of the caring role. Examples of questions about the episodic nature of care included, *How might you describe your experience with providing episodic supports to your family member/friend with an episodic illness? In what ways do episodes of illness and wellness impact how you provide supports? What types of caring supports do you provide? Have these supports changed over time? If so, in what ways?*. Using constant comparative methods during the interview process, themes emerged related to how the relationship unfolds and a relational episodic carer identity develops. Examples of questions about relational shifts and impacts while providing care included, *How do you understand your role/s as an episodic carer? To what degree do you feel responsible for the well-being of your family member/friend? What boundaries/limitations currently exist in your caring relationship? Are there any boundaries/limitations you would like to change?*
Participants responded based on the relevance of the question to their personal experiences. As such, each interview explored the questions most relevant to the participant and their care experiences; no two interviews were identical. Participants continued responding to a question until exhausting further comments (Roulston, 2010). As a result, participants spent varying amounts of time on the interview questions depending on their lived experiences with episodic care. Based on participant responses, probes such as can you tell me more about that or do you have anything else to add invited additional examples. The interviews lasted from 45 minutes to 2 hours in length, with many lasting around 90 minutes.

Following the interview, a final check-in allowed participants to discuss their comfort level with the overall process and determine the need for follow-up support. Where applicable, participants received a resource list of local community-based supports. Participants were thanked for their time and provided the honorarium. Each participant received a copy of the receipt, with an additional copy retained for project bookkeeping. Following the interview, each participant received a thank you email for their time. Data collection continued until theoretical saturation occurred (Birks & Mills, 2011).

All interviews were audio-recorded and transcribed verbatim, including a description of the interview environment. Transcripts included the date, the type of care relationship (either HIV or MS), an assigned interview number, with timestamps at intervals of approximately 15 minutes. Edits to improve transcript quality included removing pauses and non-word fillers, such as uhmm or ahhhh.

Each interview offered an opportunity for reflective journaling, also referred to as memoing in CGT (Charmaz & Bryant, 2016). Two journals provided a forum to put thoughts to paper, capturing moments of questioning as well as insights. While one journal contained a
catalogue of themes discussed during individual interviews, including new content and repeating themes, the other served as a place for theorizing, questioning, and analytic inquiry. The theoretical journal helped progress the theory by recording insights as they came, allowing for a progression of ideas built upon one another. Over time, the theoretical journal became more valuable in moving forward the conceptual model's development, although both journals were useful. The synchronous writing processes and reviewing the journals shifted the focus of the project from the breadth of impacts carers may experience to the relational effects occurring between carer and PLWEI. The Findings chapter explores these themes further.

3.8 Confidentiality of Data

In line with REB protocol and to protect participants, data confidentiality occurred via several mechanisms. Signed consent forms and participant information sheets, including identifying information, were stored in a locked cabinet. Audio files were transferred from the digital recorder to a computer, then saved as protected files using encryption software. Subsequently, audio files were deleted from the recording device. Data analysis occurred in a private area. As established in the ethics protocol, safe storage of all files will continue following the project for seven years, after which they will be deleted.

3.9 Project Advisory Committee

Elements of participatory research have been successfully integrated into grounded theory research in the past when Teram, Schachter, & Stalker (2005) used participatory methods
to explore the experiences of female survivors of childhood sexual abuse. In line with the constructionist theoretical approach, an advisory committee provided feedback into the conceptual model. Relationships with Realize Canada and the Toronto HIV/AIDS Network aided with finding advisory committee participants. With representation from multiple audiences, including episodic care policy, practice, and lived experience, the committee provided input into the following: data analysis and knowledge translation to various relevant stakeholder groups. Integrating analysis to connect research to relevant stakeholders, including the community, was key to the project.

The intention of involving a cross-sectoral, representative grouping of individuals, including episodic carers, provided guidance and insights from representatives with interests in various areas of work in the episodic care community. The committee provided a *check and balance* during the analysis and knowledge mobilization phases and guided the next steps after the project. The advisory committee strengthened the data analysis by providing feedback on the new learnings from the project.

Study participants also received an email invitation to provide feedback on the final data analysis. Available participants reviewed a draft project discussion paper and then commented on how well the results fit with their personal experience. This data review process with the advisory committee and project participants was used as forms of member checking to determine if the model met the experience of episodic carers and allied health professionals working with carers. Providing feedback was voluntary, with no compensation given.

### 3.10 Data Analysis Procedures
A first reading was conducted by hand, without software; subsequent analysis used the qualitative data analysis software ATLAS.ti version 8. ATLAS.ti software is an analytic package that offers a wide range of qualitative data analysis options. Previous experience with data analysis in ATLAS.ti helped move forward the analysis process. Reviewing the participant transcripts identified 165 unique codes. Afterward, the codes were grouped into themes for more in-depth analysis (see Appendix I)—the findings chapter organizes participant quotes for ease of review. Later in the discussion section of the paper, the meanings of central themes are presented in greater detail.

Memoing was used throughout the data gathering and analysis to record immediate and reflective observations and insights throughout the process. The reflexive process of memoing allows for description and expansion of an experience (Mills et al., 2006) and memos based on previous insights. This process moves a purely experiential analysis of the development of a theoretical framework. Through this memoing process, the framework developed and shifted, based on the experiences of episodic carers in the course of being an episodic carer (Charmaz, 2014; Martin & Turner, 1986).

### 3.11 Knowledge Mobilization

As a project in an emerging research area, ongoing communication with all stakeholders in this field continues to be a necessary pathway to advance knowledge in the area. Contributions to academic and community-centred discussions about care are central to the project work from the point of data collection through the end of the project and will continue beyond. This process is referred to as catalytic validity, which brings researchers into their work
as non-neutral participants while privileging the lived knowledge of community members (Baines, 2015). The Social Sciences and Humanities Research Council (SSHRC) understands knowledge mobilization as a process that involves ‘reciprocal and complementary flow and uptake of research knowledge’ (SSHRC, 2015). This flow of research information moves in multiple directions with new knowledge delivered and acquired by researchers, community members, social work practitioners, and policy audiences throughout knowledge mobilization.

The intent is to begin the process of knowledge translation early in the project and continue distributing information following completion of the work. Dissemination of research findings began during the data analysis phase, including a presentation at a student-oriented research conference at the University of Guelph. Dissemination plans include academic and community presentations, a summary report in plain language posted to websites of collaborative agencies and distributed through electronic mailings, as well as peer-reviewed articles in relevant journals. At the time of this paper, the project findings were presented at the 2018 Engage Graduate Student Conference and the 2019 Global Carework Summit. Partnerships and networks developed during the project with the Ontario Caregiver Coalition and the Canadian Caregiver Coalition will be maintained while seeking additional knowledge mobilization opportunities following the project's completion.
Chapter 4: Research Findings

This chapter presents the key findings from the analysis of the semi-structured qualitative interviews conducted in the study, which informed the development of a Relational Episodic Care model. The data collection initially aimed to answer the research question: What impacts do adult carers experience as a result of unpredictable illness episodes of family members/friends? However, throughout the interviews, the relational experience between episodic carers and PLWEIs became the most prominent theme. Thus, following the evolving nature of qualitative inquiry methods (Bryant & Charmaz, 2007; Punch & Oancea, 2014), the emergent findings led to a shift in the study question to, What are the relational impacts of episodic care on HIV and MS carers? This revised question, which focuses on the relational effects of episodic care, frames the emerging carer identities that inform the relational model presented at the end of the chapter.

During the analysis, separating the findings of the MS and HIV carer groups versus combining the groups into a single review was considered; however, similar patterns of relating between carers and PLWEIs occurred across both illness types. The two groups are explored together in the following chapters to represent a combined episodic carer perspective.

The present chapter is organized by the thematic findings identified in the data analysis. Key study themes include types of episodic care defined by how care is provided, entries into episodic care defined by when care is provided, carer navigation of unpredictability, how relationships are redefined throughout episodic care, and the subsequent relational identities taken up by episodic carers. Each of these topics is discussed in the order of appearance in the
relational model of episodic care presented at the end of the chapter. The chart below shows the chapter organization.

Table 2
Organization of the Findings

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
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<tr>
<td>4.2.2 Collective Care</td>
<td></td>
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<td>4.3 Episodic Care Beginnings: Entries into Episodic Care</td>
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<tr>
<td>4.4 Navigating Unpredictability</td>
<td></td>
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<tr>
<td>4.4.1 Navigating Emotional Changes</td>
<td></td>
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<td>4.4.2 Navigating Complex Care Environments</td>
<td></td>
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<tr>
<td>4.4.3 Navigating Access to Social Determinants of Health</td>
<td></td>
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<tr>
<td>4.5 Redefining the Care Relationship</td>
<td></td>
</tr>
<tr>
<td>4.5.1 Essential Care</td>
<td></td>
</tr>
<tr>
<td>4.5.2 Reciprocal Care</td>
<td></td>
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<td>4.5.3 Exiting Care</td>
<td></td>
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<td>4.6 Toward a Model of Relational Episodic Care</td>
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</tbody>
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4.1 Participants: Demographic Information and Narrative Profiles

The following is an overview of the participants at a glance. Episodic carers in the study come from various identities and circumstances, and in common with other care and caregiving studies, many respondents identified as female (Duxbury & Higgins, 2012). Participants were
primarily working-age adults between the ages of 45 and 64 years. Although most participants lived in urban areas, several participants identified as living in a rural area. Respondents had slightly higher education levels than the Canadian average (Ferguson & Zhao, 2011), with many having completed post-secondary degrees or graduate programs. For ethno-racial identity, most participants indicated one of two groups – European or African/Caribbean. This composition contrasts with the Canadian national averages for both groups (Statistics Canada, 2017c), with people of European ancestry less represented in the study and African/Caribbean participants more strongly represented. Annual income leaned toward the lower end of income earnings in Canada, with most participants earning less than $30,000 annually (Government of Canada, 2019d). Sexual identities were also more diverse than the Canadian average, with one-third of all participants identifying as LGB+ (Statistics Canada, 2017d). Half of the participants self-identified with a disability, which may create a context where episodic carers navigate social barriers, as well as personal health challenges, while also providing care supports. See Appendix G for the list of demographic questionnaire options.

The following table presents an overview of participant demographic information.
### Socio-Demographics of the Sample

<table>
<thead>
<tr>
<th>Demographic Factors</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>Male</td>
<td>6  (33.3)</td>
</tr>
<tr>
<td><strong>Age, years</strong></td>
<td></td>
</tr>
<tr>
<td>18-44</td>
<td>3  (16.7)</td>
</tr>
<tr>
<td>45-54</td>
<td>8  (44.4)</td>
</tr>
<tr>
<td>55-64</td>
<td>4  (22.2)</td>
</tr>
<tr>
<td>65+</td>
<td>3  (16.7)</td>
</tr>
<tr>
<td><strong>Type of Community</strong></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>1  (5.6)</td>
</tr>
<tr>
<td>Town</td>
<td>2  (11.1)</td>
</tr>
<tr>
<td>City</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>Large Urban Centre</td>
<td>3  (16.7)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>5  (27.8)</td>
</tr>
<tr>
<td>Below Bachelor</td>
<td>1  (5.6)</td>
</tr>
<tr>
<td>Bachelors/college</td>
<td>8  (44.4)</td>
</tr>
<tr>
<td>Masters</td>
<td>4  (22.2)</td>
</tr>
<tr>
<td><strong>Ethnocultural Identity</strong></td>
<td></td>
</tr>
<tr>
<td>African/Caribbean</td>
<td>5  (27.8)</td>
</tr>
<tr>
<td>Demographic Factors</td>
<td>Frequency (%)</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>European</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>Latino</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>Income (in thousands)</td>
<td></td>
</tr>
<tr>
<td>&gt;20</td>
<td>5 (27.8)</td>
</tr>
<tr>
<td>20-30</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>30-40</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>40-50</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>50+</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>Sexuality</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>LGB+</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>Experiencing a Disability</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (50.0)</td>
</tr>
<tr>
<td>No</td>
<td>9 (50.0)</td>
</tr>
<tr>
<td>Relationship to PLWEI</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>Spouse</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>Parent</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td>Friend</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Multiple</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (5.6)</td>
</tr>
</tbody>
</table>

Years of Experience as Episodic Carer
The following narratives provide additional details on each of the carers who contributed their time to an interview. To protect individual privacy, participants selected a pseudonym for the report.

_Eddie_ is retired, a heterosexual of Latin American descent, and living in a town. He has supported a family member with MS for more than 20 years. He has a post-secondary diploma and worked in a business environment. He is a Canadian citizen living in Canada for more than ten years who identifies as a Christian.

_Peter_ is married, living in a city, who describes his sexual identity as questioning. He retired from work in a government agency and is married. He has supported a family member with MS for 12 years. His religious affiliation is Christian, and he has two bachelor’s degrees. Peter was born in Canada and described his background as English-Scottish.

_Becky_ is unemployed, identifies as heterosexual, is between 35 and 44 years old, and previously worked in not-for-profit environments. She is a single Christian of African descent with a bachelor’s degree. She is a Canadian citizen who has been in Canada for more than ten years and supports multiple people living with HIV.
KC is a Canadian citizen living in Canada for more than ten years who has been supporting multiple people living with episodic illnesses for more than ten years. He has previously worked in healthcare and is between the ages of 55 and 64 years. He is a single person of African descent living in a city, and lives with a disability. He has a college diploma and describes his sexual orientation as Other.

JW is currently unemployed, separated, and worked for a non-profit agency in the past. He is between 45 and 54 years old, lives in a city, and describes his spirituality as Aboriginal. He is Canadian and has a high school diploma. He identifies as bisexual and has been supporting multiple people living with episodic illnesses for 2-3 years.

Katmod is retired and lives in a city. She has been supporting a family member for 8 years and used to work in a business environment. She identifies as heterosexual and Christian, holds a high school certificate, and lives with a disability. She is Canadian-born.

Gonzo is unemployed and has been supporting a family member with an episodic illness for 15 years. He previously worked in the service sector. He is a single Canadian between the ages of 45 and 54 years. He is gay and Christian, has a college diploma, and lives with multiple disabilities.

Daphne is employed, works in administration, and lives in a city. She has been supporting a family member with MS for 22 years. Daphne is a married Christian with a college diploma and is of European descent. She is Canadian-born, heterosexual, and between the ages of 45 and 54 years.

Neville is married and lives in a city. She is employed full-time in healthcare, identifies as a Christian, and has a master’s degree. Neville is Canadian-born and identifies as heterosexual.
Nikola is unemployed and lives in a large urban centre. She is single, between 45 and 54 years old, and has been supporting a family member with MS for more than 20 years. She identifies as an atheist, has a bachelor’s degree, and is of Eastern European descent. She is heterosexual, Canadian, and living with a disability.

Cheyenne is unemployed and between the ages of 18 and 24 years, living in a city. She identifies with no religious affiliation, has a college diploma, and is of Jamaican descent. Cheyenne lives with a disability and has supported a family member with an episodic illness for ten years. She is heterosexual and Canadian-born.

Lisa is employed, working in a non-profit agency in a large urban centre. She is between the ages of 55 and 64 years, is single, and is affiliated with Judaism. Lisa has a master’s degree and has supported multiple people living with episodic illnesses. She is heterosexual and Canadian-born.

Fifi is a single person of African descent who has been supporting a friend with an episodic illness for two years. She was unemployed at the time of the interview but previously worked in a non-profit agency. Fifi is living with a disability and has a high school diploma. She is heterosexual and a landed immigrant who has been living in Canada for 5-10 years.

Zebra is an employed widow who works in manufacturing. She is between the ages of 45 and 54 years and lives in a city. She lives with several disabilities and is of African descent. She has a high school diploma and identifies as trans. She is a Canadian citizen living in Canada for 5-10 years.

Ragnar is retired and has supported a family member with MS for 35 years. He previously worked in manufacturing in a city. Ragnar is a Christian with a master’s degree. He is heterosexual, married, and born in Canada.
Jane Alexander is between 35 and 44 years and has supported a family member with an episodic illness for more than 25 years. She is employed part-time in sales and service and lives in a town. She is living with a common-law partner and has a trade certificate. She lives with multiple disabilities, is bisexual, and Canadian-born.

Isabella is a married homemaker between the ages of 45 and 54 years living in a rural area. She has a high school certificate and identifies as Christian. She is heterosexual, Canadian-born, and has supported a family member with an episodic illness for 16 years.

Libby is currently unemployed and has supported a family member living with an episodic illness for five years. She is between the ages of 55 and 64 years and married. Libby previously worked in the non-profit sector. She has no religious affiliation and a master’s degree. She lives with a disability and is Canadian-born and heterosexual.

Several participants reported having care-related experiences outside the scope of the study. These experiences ranged from the experience of being a young carer to providing supports to someone living with another type of illness or disability, aside from MS or HIV, as well as participants who provided care support to another PLWEI, either in other provinces or abroad. The care experiences help illustrate the complexity of care environments and the lives of episodic carers. Thus, social circumstances in the past and the present are part of the story of an episodic carer. Where participants made the transition from child to an adult carer, the interview focused on the period of care after the participant turned 18 years old. The interview conversation focused on episodic care experiences within Ontario for participants who had previously lived and provided care in another jurisdiction.

To help maintain participants’ anonymity, direct participant quotations do not include identifying information, such as location, original name, or background information such as type
of disability, or information about associated family members. To preserve the authenticity of the participant’s voice, quotations reflect the participant’s language and manner of speaking.

4.2 Forms of Episodic Care: Single Dyad Care and Collective Care

The following section will explain the approaches to episodic care shown by participants. To contextualize the relational aspects of care provision as reported by the participants, two types of episodic care will describe the nature of episodic care, either in sequence or concurrently. The first type is termed single dyad care, where an individual carer supports an individual PLWEI in a single one-to-one dyad and where the carer and PLWEI relational roles are distinct. The second type will be called collective care, where carers may concurrently support multiple PLWEIs.

Episodic care is delivered relationally, between a carer and a family member/friend, where health-related, social, and emotional investments exist between carers and PLWEIs. The study participants’ experiences and context led to developing forms of episodic care based on the situational arrangements of care. Participants also shared that through relationships, episodic care takes on additional meaning for carers and PLWEIs. The purpose of episodic care is also enhanced through the reciprocal nature of care, where both carers and PLWEIs receive benefits despite the challenges related to caring over time.

The following sections describe the study participants’ experiences of single dyad and collective care; in each section the form of care will be defined, including who is involved and how care relationships develop, the direction(s) of the care between carer and PLWEI, and the types of supports provided.
4.2.1 Single Dyad Care.

Single dyad care is common in the care literature (Coeling, Biordi, & Theis, 2003; Lyons, Zarit, Sayer, & Whitlatch, 2002; Wight, Aneshensel, Murphy, Miller-Martinez, & Beals, 2006) and may develop from an existing family/friend relationship or post-diagnosis. Where relationships begin post-diagnosis, they may evolve through a personal connection or a CBO. Single dyad carers are often spouses or partners, neighbours, friends, or children, all of whom are interested in the well-being of the PLWEI. Single dyad care may involve a single one-to-one dyad or a carer supporting more than one PLWEI either in sequence over a period of time or concurrently, with care provided in a one-to-one dyad. Note that while single dyad carers may or may not be living with a disability, the care provided is primarily unidirectional, done by the carer to assist with meeting the needs of the PLWEI. Twelve participants were classified as providing single dyad care.

In this study, carer participants who engage in single dyad care reported that the individual carer–PLWEI relationship is often long term, although variables such as carer availability, personal health and well-being, employment demands, financial stability, and desire to continue supporting the PLWEI influence the relationship length. Carer investment in the relationship does not depend on the time spent providing episodic care. Carers may experience deep, meaningful relationships, even within a short time.

He started to tell me about it, and we were instantly friends from then on. At the time that was, that felt unusual. Later on, that didn’t feel unusual at all. But these were really intense friendships. They were, there was a really deep bond more or less instantly. (Lisa)
This quote speaks to an emotional intensity connected to unpredictable episodic care.

Personalized care supports provided by single dyad carers may include socio-emotional or managerial ADLs. Providing transportation and support for medical appointments is also common for single dyad carers. “She manages her appointments…. She keeps track of when she’s supposed to go to the dentist, the doctor, whoever…. I just have to make sure I’m available to get her there” (Peter). In addition, organizational tasks are common to the range of supports provided.

If it’s paperwork he needed, something I had to download on the computer, then I could just drop it in an envelope to him and then pick it up with whatever he needed done or to contact somebody. He’s on disability assistance through the Ontario government, so there was always things, forms and stuff that had to be filled out and sent away. So, you know, at that time, it wasn’t as dire as it is now. So, … doctors’ visits and things that he needed to go to and then I would have to go and do it for him or do it with him. (Katmod)

The caring process sometimes involves less desirable activities such as toileting or cleaning necessary to sustain life. Hence, carers have to push through these types of tasks, which can be challenging over the long term. Single dyad carers often need to be flexible and responsive to the changing needs of PLWEIs and find themselves changing care-related tasks over time, even from one day to the next.

For single dyad carers, additional members of a care circle may contribute to providing supports to help balance the ongoing provision of episodic care by spreading the work across multiple people. Here, a care circle connotes the idea of inclusive, integrated supports that surround the PLWEI (Collins & Schwartz, 2011; Dupuis, Reed, Bachmann, Lemke, & Pichora-
Fuller, 2019). Multi-carer arrangements may reduce the temporal burdens of care, although complex circumstances may alter the emotional impacts of care.

She [mother of person living with MS] would come over and help with some household activity, maybe volunteer to take the kids if my wife was fatigued…. Most recently, our daughter and her children live quite close, and my daughter is quite happy to come over whether she’s asked or not. (Ragnar)

For additional care circle members, support is provided less frequently than the person who views themselves as the primary carer for the PLWEI. Generally speaking, carers have one or more people in the care circle, often children, neighbours, or extended family. The relevance of the care circle would be worthy of further investigation to understand better how episodic care circles function and what contributes to a supportive experience for everyone involved.

4.2.2 Collective Care.

Participants discussed how episodic care might occur when the role division between carer and PLWEIs is blurred, as care is reciprocal. This arrangement, seen in HIV care, will be called collective care (Barnes, 2012). Many carers providing collective care are also living with HIV and are thus carers at times and PLWEIs at other times, depending on situational needs. Although seen less frequently than single dyad care in the literature, a previous HIV care study also described a similar dynamic (Knowlton, 2003). Six carers in the study participated in collective care arrangements.

More men participated in collective care in the study than women, with half of the male respondents participating in collective care. Male participants engaged in transient forms of care
that were shorter-term in nature, lasting several months to several years, while the one female who provided collective care supports had longer relationships lasting many years. Collective-style carers provided supports for several reasons, out of interest in this style of relational care, or involuntarily, not seeing an alternative to accessing the range of supports needed to maintain their health. While there is no evidence to suggest men are less dedicated care providers than women, these findings call for exploring further whether men and women participate in different styles of episodic care.

In collective care, carers search for reciprocity of support, where a carer lends support and, in turn, anticipates receiving help from others when needed; this results in developing a network of relational support where carers assist a range of people and also receive support in turn.

Definitely, if I put myself out, I can expect somebody else but that same person to help me back; I just have to know that if I’m willing to do this for someone that maybe down the line, somebody else will be willing to do something for me when I need it. (Nikola)

Further, collective carers may have an expanded support network for themselves when an episode of illness arises. Carers view their relationships as personal and meaningful, even when caring for multiple people. This network may provide a protective function when support is needed. A range of people is available to provide supports; if one person is unavailable to assist, someone else may be accessible. In contrast to single dyad care, collective care relationships appear to develop from previous relationships, although many begin following the diagnosis.

The level of involvement in collective care varied, with some carers viewing their roles as casual. In contrast, others displayed a high level of personal commitment to the ongoing care of the PLWEI.
This is not about numbers. This is about relationships. Many people have one that they, that they’re using to, or that they’re part of in terms of support, and these are just people’s stories about what the impacts have looked like, what the good has looked like, what the struggle has looked like in a lot of what we’ve talked about. (KC)

Many carers talked about the relationship between themselves and their family members/friends as having a positive quality.

Next, the unique entry into collective care will be described, which is different from single dyad care as carers and PLWEIs move through a process to participate in the relationship. Carers often limit the types of supports provided early in the collective care relationship, with some setting boundaries from the outset. This boundary setting seems to reduce the burden experienced by collective carers by creating protections on appropriate interactions to avoid losses in the relationship. Collective care relationships begin by developing the basis of a relationship before providing additional supports; thus, the new relationship often takes time to build a foundation of trust.

Participants highlighted the process of transitioning from casual acquaintance into a collective care relationship, which occurs through successive boundary testing. Boundary testing involves exploring the limits of a potential carer’s willingness to provide supports and happens through a series of progressive relationship tests here called bids. A bid is a simple support request, with reciprocation anticipated. Early in the relationship, the transactions are initially small (Erchul & Chewning, 1990; Mikulincer & Shaver, 2012; Pepler & Lynch, 1991). Bidding often begins with emotionally innocuous requests, such as purchasing a coffee or asking for a cigarette but can evolve into greater requests, such as providing temporary living space or
assistance with paying rent. Returning a bid will likely result in a bid from the other person, in a *give-and-take* fashion.

Increased relationship trust occurs through repeated interpersonal boundary testing over time. For some carers, trust is so essential to the collective care relationship that carers develop personal systems to *explore the potential* of a new acquaintance. Hence, the cycle may recur multiple times before the other PLWEI carer feels *safe* to take the relationship to a more personal care level, one in which the carer may become more vulnerable. When a relationship reaches the point of initiating care, bids often shift from safe requests to addressing the person’s illness-related needs. The bidding process serves to reduce the experience of relational vulnerability. Collective carers view susceptibility to being hurt in a collective care relationship as a disadvantage. Establishing commonalities between the carer and the PLWEI may help to develop a collective care relationship.

Collective carers believe that if they support others, there may be a carer available to assist them in a time of need. In this sense, care becomes a form of insurance against a more difficult time, where participants accrue social *points* by supporting others, which might be *redeemed* later (Knowlton, 2003). With each petition for support with a positive return, increased trust develops. Once someone is willing to provide more innocuous types of assistance, future requests may include assisting with care-related tasks, such as support to attend an appointment or providing a meal when needed. For some, bargaining may even help with basic survival tasks, like eating that day or having a place to stay for the night. The trust built is fragile, subject to breaking if favours stop being reciprocated, if the other person makes repeated demands without providing support, or if the person makes high demands, such as for intensive care supports. Of
note is that the frequency of contact within collective care relationships may shift over time as boundaries are negotiated and renegotiated.

Similar to single dyad care, supports provided by collective carers involve assistance with completing daily life tasks like delivering coffee, washing dishes, assisting with mobility, and cooking. In addition to activities of daily living, care may be personally tailored. “Sometimes, when she is not feeling well, I go to do laundry for her; I go do shopping for her. I braid hair, so sometimes I go braid for her” (Zebra). Another participant described how communication forms a part of providing support to PLWEIs.

Basic dialogue. Recognizing that there might be a need. Listening before speaking and just sort of checking the climate out to see if it’d be ok for me to move forward or say, “I know something, a little something about that. Might I be of assistance to you? Or do you think, yeah?” Yeah, gradual steps, baby steps, and listening to what people aren’t verbalizing. (KC)

Thus, the supports provided vary depending on the need. As is relevant to the PLWEI, support may include arranging medical appointments, meal preparation, cleaning, or health-related advocacy. Collective care supports also extend into personally or culturally meaningful life areas, ranging from conversations to preparing culturally traditional meals or providing a make-over.

What differentiates collective care from other types of care are several features, including a reliance on the support person for needs in the moment in the short and long term, whereas in single dyad care the care duties tend to stabilize over time. Expectations of longevity in collective care are also less common, with the relationships viewed as potentially transient. The primary difference is the requirement for reciprocity of care. The carer could become the person
cared for, with the responsibilities shifting back and forth in an unpredictable manner, similar to the episodic illness itself. Collective carers may provide supports in the longer term or the short-term, depending on circumstantial needs, which is different from single dyad carers who commonly provided care for longer periods, including decades.

Off and on like, maybe like 15 years. About 15 years here and there. Not a steady thing every day, you know. (JW)

Thus, the frequency of providing collective care supports varied from carer to carer, creating a wide range of possible mutually supportive care arrangements.

The social environment may play a significant role in collective care, as seen in the types of supports provided, ranging from necessities to health-related assistance, and the immediacy of the needs. Poverty may be a factor in developing collective care relationships, as carers may have decreased stability in financial, employment, and housing aspects of life, with potential ripple effects on illness episodes. Thus, the types of supports provided in collective care are more likely connected to social determinants of health. Exploring the intersections between poverty and episodic care may add detail to the economic experience of care provision. Also significant is the potential for role confusion experienced by collective carers, as carers both provide and receive support (Barnes, 2012). Thus, the division lines between the care and interpersonal relationships become quite blurred, with carers entering into relationships with the expectation of personal gain in return for support provision. Additional research will improve the understandings of carer role negotiation and relational boundaries.

Neither single dyad nor collective care is inherently better than the other, as carers and PLWEIs may receive relational benefits from either form. Forms of care are different because
circumstantial needs vary, and individual preferences vary. The existence of more than one type shows an evolution beyond what may be considered the traditional care dyad.

4.3 Episodic Care Beginnings: Entries into Episodic Care

The following section describes the carers’ feelings of responsibility as care support begins. This shift initiated episodic care identity development for study participants, which is here termed an Entry into relational episodic care.

Episodic carers may live and work close to PLWEIs. Carers often live in the same city, neighbourhood, or household, consistent with previous research (Duxbury, Higgins, & Smart, 2011; Dwyer & Miller, 1990; Himes, Jordan & Farkas, 1996). For episodic carers, physical proximity to the PLWEI is an outward indicator of their inward commitment to the care relationship. Episodic care translates into sacrifices by the carer, including time spent, personal funds, pursuit of educational and career opportunities, altered personal plans, including travel, and emotional strain, all of which contribute to an emerging relational identity.

Reasons for entering episodic care relationships vary from person to person. Carers may feel a sense of duty to a partner or the community or a desire to maintain a relationship with the PLWEI (Feeney & Collins, 2003). For some, satisfaction comes from assisting one or more PLWEIs, while for other carers, the emotional bond created with the PLWEI can be a primary motivation. For some, a combination of the above may underpin them becoming a carer. By providing supports, many carers receive benefits, including learning new skills, a deeper understanding of self, social opportunities, and/or enhanced connections within the community.
(Collins, Ford, Guichard, Kane, & Feeney, 2010; Ironson, 2007; Mikulincer, Shaver, Gillath, & Nitzberg, 2005).

A care entry may occur at the start of a relationship or happen in the context of an existing relationship.

We had a longstanding relationship before anything happened…. It was a caring relationship, like a caregiving relationship before he got really sick…. It was as it was needed; it was really hard to say where it began and ended. (Lisa)

Entering into a new care relationship is a distinct process from that seen with an existing relationship. In new relationships, developing trust is of central importance, and in turn, developing trusting relationships facilitates care supports. Note the importance of a trustworthy relationship in the following quote.

There’s a trust factor. There’s a bonding factor or being able to communicate things he needs to do…. It’s got to have compassionate people. They actually have to be willing to spend time, be willing, be able to communicate. (Gonzo)

For carers, looking backward at the changes can be part of the process of bringing into awareness the ongoing need for care provision and the transition into the carer role.

Alternatively, for carers who enter into care relationships after the diagnosis, the care aspects of the relationship may initially take a more prominent role in their lives. The shift into more emotional aspects comes later, with time spent together and the increase of trust. “I feel like she was like my mother. She [was] not anymore somebody I go to help” (Fifi). For carers, social aspects of relationships matter. “While I was helping people do their daily activities, you know because I was fresh, you can call ‘fresh on the block,’ like I used to always like being
around somebody” (JW). The bonds forming between carer and PLWEI reach various levels of emotional intimacy.

Generally speaking, carers provide voluntary supports, yet there may be many undesired care-related tasks performed by the carer. In these circumstances, carers draw upon the strength of existing relationships to continue through the challenging tasks.

So, I said, “you know what, I’m going to put her shoes [on] and suppose this happened to me. Would I like to be a burden? Would I like somebody to be scared of me?” And so that’s how I get the courage, I prayed, and I didn’t see it as a big deal even to clean her, to put the diaper, to clean the mess. It wasn’t easy. (Zebra)

Care tasks are often provided at the physical, mental, and emotional expense of the carer, at times overtaking other aspects of the relationship. “This caring has actually pulled us apart as a couple. Because it’s become the number one priority for him” (Daphne). Accompanying the developing identity is an awareness that the episodic illness will likely continue, resulting in care provision becoming part of the present and future relationship. Despite the challenges, carers often continue the relationship.

Within collective care relationships, trust is slowly built but may quickly erode. Carers may feel burned by experiencing some form of breach of trust, whether through a loss or the failure to receive desired support from the relationship.

I always give people the benefit of the doubt, and they screwed me over. So I test them.

A couple of times, I do something, and they say, “I’ll pay you back whatever and all that.” Then they start ignoring you and this and that. (Gonzo)

Here, trust is central to continuing the care relationship. For some carers, maintaining an emotional guard is essential to avoiding personal harm.
So, I have to feel needed. I can’t be taken [for granted]; I’m very careful about not being taken advantage of; it has to be for real. (Nikola)

Thus, care relationships may involve an ongoing negotiation of sensitive relational boundaries.

There are times where CBOs, such as AIDS Service Organizations (ASOs), facilitate the connections between carers and PLWEIs. This adds a unique aspect to the carer relationship, as the carer is also serving in a community-organized, volunteer-based relationship. In this role, the carer receives support from the organization to transition into caring and continue forward, including training before meeting the PLWEI and ongoing training and peer support from other volunteers.

I really appreciate all this training that I’ve gotten here in Canada…. That has made it easy for me to care for my friends here. (Zebra)

Thus, an arrangement between the carer and the CBO develops to facilitate supports to a PLWEI while carers receive support from the community organization.

As a protective function, CBOs may set boundaries around the nature of the relationship between the carer and the PLWEI. Boundaries may include specifying when and how carers can provide care, as well as the types of tasks involved. Some carers view these organizational policies as limitations to the care relationship, for instance desiring to make contact when best fits their schedule.

The policy for all the organization they put big barriers between somebody you want to help to bring back her life and then, and it’s too late….Barriers it means policy. I want to do this first but supposed to wait, and I have a limitation. For example, I wanted to bring food to her house…. She’s in the bed. But because of a policy, I can’t go inside the house. (Fifi)
At times, carers wish to do more than is currently possible under the CBO running the volunteer program.

While acting as brokers of person-to-person care, CBOs serve as connection points between semi-professionalized carers and PLWEIs, who may have few other personal support resources, while offering training to engage with PLWEIs as well as ongoing emotional support. As part of their oversight role, CBOs function as regulatory bodies, creating standards for the timing and nature of interactions between carers and PLWEIs. Of note, in many areas across Canada, CBO-arranged services do not exist, and thus potential carers may seek out care relationships elsewhere.

As seen here, care entries are contextually-bound and vary from carer to carer. Entries represent a transition where care becomes an integral and evolving aspect of the relationship between the carer and PLWEI. Sometimes this transition is at the start of the relationship, and for others, it is a change in an ongoing relationship to include a care component. Commitment to the developing carer identity reconciles the unpredictability of how episodes of illness and wellness will impact a decision to continue providing care and will be discussed further in upcoming sections. This recognition integrates flexibility as care activities continue to shift over time as PLWEI health needs change.

4.4 Navigating Unpredictability

In this section, the experience of unpredictability will be discussed, beginning with the uncertain nature of the episodic illness course and transitioning to how these experiences over time contribute to relationship changes between carer and PLWEI. During the interviews,
participants shared many experiences that highlighted the unpredictability of episodic care. This section sets the stage for the upcoming discussions on navigating emotional changes, how carers navigate complex factors in the care dyad and the broader social environment that impacts care, and how episodic care provision impacts carer access to social determinants of health.

Within the care dyad, indicators of illness episodes may take multiple forms, unique to the PLWEI and the carer. Indicators may include changes in affect or physical signs of decline, resulting from responses to a medication regime, seasonal impacts, or stress-related triggers. Factors that can exacerbate the severity of an illness episode include health-related factors such as co-occurring illness, addictions, the absence of social supports, social stigma, and the lack of individual coping strategies (Butler, Koopman, Classen & Spiegel, 1999; O’Brien et al., 2008).

For carers, the episodic, unpredictable nature of the care relationship is more than a series of performative tasks; it is also an experience of mind, body, and spirit. Moreover, the uncertainty of episodic care weighs heavily on the relationship between carers and PLWEIs. For carers, not knowing what will happen next presents challenges to responding to illness-related needs as well as continuing the relationship with the PLWEI. In the early years of episodic care, carers function without knowing how or when to act, doing what seems possible, given the circumstances.

Some carers use the metaphor of a *roller coaster* to describe the at-times fast-shifting health variations. Health states were consistently viewed as non-permanent, indicated by time markers such as *right now*, with carers sometimes living in the moment. The support changes may include the types of care activities, frequency of care supports, and the appropriateness of the support to PLWEI health needs. These changes felt at times beyond the carer’s control, as the ups and downs of the episodic illness came without warning and changed over time.
Doing all of the other care that’s required, other than the person that you’re caring, so I don’t want to say it’s been a huge roller coaster, but it’s been difficult, difficult, and different at times. (Daphne)

This uncertainty also becomes part of the relationship between the carer and PLWEI, which has also been noted previously in HIV care (Cadell & Marshall, 2007).

What’s going to be around the corner? What’s coming up? That unknown piece, in the beginning, that was the stressful part. Now it’s unknown, but it’s unknown for all of us of what’s around the corner. (Neville)

Personal preferences of the PLWEI add additional layers of complexity to the uncertain relationship of care.

Carers in this study stated that navigating unpredictability should not be understated, especially when uncertainties about the illness course seem like a labyrinth to navigate.

You would be told when you went into something what the expectation was, but no, there was really no line. (Lisa)

Carers may struggle to find themselves in the changing relationship, especially if the care demands shift the relational balance toward meeting the needs of the PLWEI.

You see it happening, and yet you’re limited; you feel helpless at times that you can give the care and help that they need. Yet you’re there for every doctor’s appointment and all the research. (Isabella)

Carers in this study pondered questions about how the episodic illness was evolving, including how to act, when to respond, when the next episode would occur, how to complete care-related tasks, how to obtain a balance between providing care and personal needs, how to access supports, or what to do in the face of limited medical information. As noted by participants,
questions often resurface as carers continue to provide supports that require familiarity with the illness, along with an understanding of individual and circumstantial needs.

In coming sections, three specific areas that relate to the experience of unpredictable episodic caring will be explored, including how emotional shifts in the relationship are experienced and later reduced, how complex social factors impact the relationship in the care dyad, and how throughout episodic care, the carers’ quality of life is affected, as ripple effects from care lessen access to social determinants of health.

4.4.1 Navigating Emotional Changes.

This section discusses how carers experience a range of emotions from unpredictable episodic care relationships over time and how the emotional connection between carer and PLWEI impacts care.

Change is a constant aspect of episodic care relationships as carers navigate the emotional and physical ups and downs of assisting PLWEIs. The range of emotional impacts on carers varies widely, with carers in this study discussing positive and negative effects on the relationship.

There’s so many changes I can’t … verbalize them all because a lot of them are just inside, you know. Won’t come out because I think that’s part of the sometimes that anger you keep inside. And but, oh yeah, it’s changed in many … ways for me. And it’ll continue to change. And I hope in more positive ways than negative. (Katmod)

The types of supports provided change over time as the health needs of PLWEIs fluctuate; the relationship continues while the social environment of care changes.
Diagnosis may become a point of relief at having a direction and possible answers, or an emotional and psychological weight as carers acknowledge the long term nature of the illness and need for ongoing care. Where the carer is the only person aware of a diagnosis, the burden rests on the carer to fully understand the needs of the PLWEI.

She was emotional all the time, but I didn’t know what [would] happen…. So, after that, she go[es] to HIV tests and she was HIV positive. We discuss a lot and then she said, “Nobody didn’t know I was HIV positive.” (Fifi)

Among the challenges is recognizing how care provision has been emotionally burdensome for carers in the past and may continue to be over time.

It can be hard, even emotionally for her. She hasn’t admitted it to me yet; I kind of just found out when my brother was born. I always kind of knew. (Cheyanne)

Doubt concerning the benefits of choices made in the past or the potential for making suitable future choices persisted in the long term for many episodic carers. “I am more worried now. I’m more of a worry wort now” (Daphne). Navigating illness episodes involves a range of emotional impacts on carers, influencing the quality of the relational experience between carer and PLWEI.

I don’t think it [personal radar to detect episodes] really ever shuts off. I think I’m always having to think ahead for the next step…. I don’t always do it right. (Isabella)

Wanting to provide supports in the correct way can negatively impact the care relationship by setting unattainable standards given the ongoing, shifting nature of episodic care.

So, I think it was tough because I never really knew what the right thing to do was. I remember actually telling the person I was seeing about that. Hoping that she would be able to tell me, “do it this way. This is better.” And they just sit there. (Lisa)
Episodic care involves the infusion of time and mental and emotional energy in supporting another person, and emotional separation from care activities becomes increasingly tricky.

Mental health impacts are common to the experience of episodic care. As such, the emotional burden may build over time as illness episodes continue.

I started having anxiety, and it just created a whole thing because I’ve just seen my mom. I’ve seen her almost dying. There’s times where she’s almost died. I don’t even know how she’s living sometimes. (Cheyanne)

Feeling the burden of emotional strain is not connected to a particular set of activities. Still, it can result from any task where carers bear the emotional weight in the care relationship.

When you help people with HIV, even basic things like taking them to the grocery store or taking them to the store, it’s the stress that comes with it. (JW)

Episodic care is emotionally heavy, as the carers vicariously experience the PLWEIs day-to-day challenges, along with impacts to the carer’s own emotional and mental health.

Carers may use a variety of coping strategies in response to the emotional strain of episodic care relationships. “I push the emotions away. It’s so bad; it’s not a good feeling to push it” (Becky). Unresolved emotions can build over time, creating challenges to continue the relationship.

Because if you don’t, everything just balls up in here and something in your life that’s bothering you, you take it out because a lot of people snap. And … it’s like “no, I want to be patient, I want to be considerate, empathetic.” (Gonzo)

Carers wrestle with maintaining focus on the PLWEI, speaking to the desire for improved balance in care relationships.
The emotional burden of care may shift over time, and these shifts may have disruptive relational impacts that create change in care delivery.

I’ll get calls, “I have to do this. I have to go to the hospital.” [She] need[s] a blood transfusion. So, I’ll have to rush out there to go help the kids. There’s times where she may be in the hospital for a few weeks, and so I’ll have to manage the kids, and I’ll help just take care of her. I’ll bring her food and maybe give her emotional support. It’s very moody. The past few years, it’s gotten a lot more distant with me. (Cheyanne)

The roller-coaster analogy used previously is applicable from an emotional perspective as well as a psychological perspective used to understand the shifting care situation. Carers may feel limited control over the situation and experience shifting, uncertain feelings.

I’m Jewish; it’s entirely normal for Jews too, offers of food are offers of love, that’s deeply engrained, … the food …was my way of focusing on something that I could do something about. There were so many things that were outside of my control. (Lisa)

Episodic carers manage co-occurring emotional and physical impacts while providing care.

“Very hard on you emotionally, physically, it’s draining” (Gonzo). Carers may reach out to various support sources to help navigate the ongoing changes, including friends, community supports, or spiritual resources.

For the first few days, I was scared, and I felt like … this is not what I’m supposed to do, but then, every time I would think, “how about, let me put myself in her shoes” because if this happened to me, I’ll also need somebody to help. We have nurses working [in] the hospital; that is what they do. Am I so special to do it? And I pray to God, and I say “God, let me not vomit when I do that.” (Zebra)

Despite complex demands, carer dedication to the relationship often remains high.
Where relationships existed between the carer and PLWEI before the diagnosis, carers begin the care journey with a history, including patterns of communication and interaction that carry forward into the changing relationship. In existing relationships, carers may fear a loss of the connection, as noted in this comment.

I asked the question in a variety of ways about “what’s bugging you and what’s going on?” “Well, there’s nothing.” Except that after 2 or 3 weeks, she would say, “yeah, here’s what’s bugging me.” I think it’s probably related to “if my MS gets bad enough, my husband will pick up and leave and then I’ll be in a fix.” I think that her fear of abandonment was really what was bothering her the most. (Ragnar)

Carers or PWEIs may test the durability of the relationship throughout care, mainly when the previous relationship changes significantly.

It’s emotional; it hurts because you want your mother; you want to have some sort of relationship with her other than just doing things for her. … I had a little bit of a mother, and now it’s totally gone. (Cheyanne)

The loss of reciprocity in the relationship is a heavy weight to bear for episodic carers.

In contrast, not all emotional impacts experienced by carers are negative. Providing care speaks to a committed investment of self to the well-being of another person.

I suppose she’s more open with me than others. She’ll call and ask me to drive her places. When we go places, we’ll chat. It’s a social kind of thing. It’s episodic in that it’s not so much based on the disease when I care for her; it’s based on what she’s doing for the treatment or care for that disease. It’s not like she has a crisis of health that she’s suddenly bed-ridden, though I would hope that if it comes to that, that she would ask. (Libby)
At times, benefits come in the form of strengthened relational bonds; focusing on the relationship aids with continuing forward despite how the illness unpredictability impacts the carer.

   We’re getting closer. Like any other marriage, we agree and disagree, especially the more disagreement because we are two different cultures. I come from Latino, and she is from Canada here; it is totally different culture. But one thing that we realize that our relationship, we got … closer now. (Eddie)

Commitment levels to the relationship between carer and PLWEI are generally high, evidenced by the ways many carers navigate challenges, looking to work through issues rather than moving on from the relationship.

   Additional benefits to carers may include becoming more comfortable socially through providing care. “Yeah, it gets me out. I get to go visit people sometimes when I need to or when they invite me…. I’m not shy anymore, which is great” (Nikola). Thus, carers may also experience personal growth, in addition to relational benefits, at times in unexpected ways.

   I’ve grown a lot. Before, I was upset about a lot of things; I didn’t handle my emotions very well. I guess time just has gone on and I … realized so much…. I’ve learned a lot from her mistakes, as well. (Cheyanne)

Learning to separate emotions from personal experiences from those of providing care is another area of carer growth.

   Carers could see the time spent providing support as having benefits for themselves or their relationships with the PLWEI.

   Sometimes she [would] call me to come on Sunday. But if it’s possible, I can see [her] all the time, and then we laugh and then, you know if it’s like that they think somebody is strong and then it go[es] down (Fifi).
Note how, for some carers, mutual benefits from care develop over time. “I’d be willing to bet that it’s been very significant … in my personal longevity, spiritual, mental, and otherwise” (KC). Emotional connections between carer and PLWEI may become more influential as care continues.

It make[s] me to be happy because our connection is very totally connected. The first time I saw her is not the same as she is now. The first time she saw me is not the same. It means we help each other. (Fifi)

Carers thus process their experiences in many ways, recognizing some positive aspects to the changes triggered by episodes, even though the ups and downs are often challenging.

**4.4.2 Navigating Complex Care Environments.**

In addition to the unpredictability of episodic care, study participants also reported being challenged by the evolving, complex health problems of the people they support. In this section, the impacts of multiple factors on the experience of care are discussed, including the health system, comorbid illnesses and care, and how carers respond to the numerous factors in their environments that impact the quality of the care relationship.

From a health-systems perspective, challenges may arise with respect to carer access to health-related information as health professionals may privilege protecting privacy over sharing information with members of the care circle (Hunchak et al., 2015). Limited access to information can complicate decision making, leading carers to provide support with incomplete information. Results may include delayed responses to an upcoming episode or a potentially inappropriate response to PLWEI needs (Kitson, Price, Lau, & Showler, 2013). Barriers to
information access about PLWEI health needs or treatment options place carers in a perpetually reactive position by reducing the potential to plan future health episodes.

For others, complex care involves supporting not just one health condition but multiple illnesses. Comorbid conditions, including various physical and mental health challenges, are becoming increasingly common for people living with episodic conditions such as HIV (Guaraldi et al., 2011; Schouten et al., 2014), as well as MS (Marrie et al., 2015; Redelings, McCoy, & Sorvillo, 2006).

We had been dealing with him with depression…. So, it was like, “ok great,” this is another thing that can come and go. So, I think there’s times where you go, you go along feeling like “ok everything is fine” and then there would be a bump in the road and it would be a flare-up, and then try to look at it, “is this MS-related or is this not MS-related.” (Isabella)

Attempting to differentiate symptoms of one illness from another may add confusion to the process of providing care. In response, carers may manage health shifts by accommodating a worst-case scenario, as noted in the following quote. “I think at that point in time, I was ready to move to a one-floor house. I envisioned a wheelchair… so that panicked me” (Neville). As issues arise, carers may feel an increased pressure to prevent issues from arising in the future.

Because that was my mistake once…. We parked at a certain place, and I get out from my side, and she get out from the other side, and all of a sudden, “where are you?” She fell; as soon as she [got] out of the car, she fell. So that was the first and the last time.

(Eddie)

The pressure to provide high-quality care can increase time requirements as well as leave carers wondering about what the future holds for the relationship.
A unique aspect of the dynamic experience of providing episodic care is the blurring of boundaries between professionalized roles and family/friend episodic care provision. One example of these blurred lines is illustrated in the following quote from Zebra: “you cannot just tell somebody ‘get out, go get medication.’ You have [to] first of all do counselling. So, I counsel people.” These semi-professional supports may be demanding and include psychosocial counselling, medication administration, maintaining sanitary conditions, or maintaining safe conditions with sharps or medical equipment. As the carer takes on unfamiliar tasks that stretch their capacity of available time, energy, and resources, implications arise for the carer–PLWEI relationship.

Over-extending in these areas may result from limited access to beneficial community resources and may worsen existing relationship strain. Challenges to accessing resources may stem from multiple factors, such as limited availability of support resources for episodic carers, lack of awareness of available resources, and challenges with using available resources. Over time, this added strain on the relationship, especially without re-balancing the relationship, can contribute to a possible care exit.

Trying to regain control over a continually shifting situation is common as carers search for stability where there may be little. Although responses to illness episodes may feel haphazard and reactive, a process unfolds during the early months and years of providing care. Illness-related insights can assist with putting supports in place earlier to mitigate the impacts of illness episodes. Carers may seek out security by planning for alternative options for delivering care. This strategy raises questions about what forms contingency planning may take, how to make decisions, who makes decisions, and how the planning process shifts over time. When these changes occur, for example, if a PLWEI becomes ill the day following a treatment, this may be
manageable day-to-day. Toward this end, carers may develop new skills to provide care as PLWEI needs unfold.

I’m learning to cook now. Something I’ve never done, and I don’t like it. I don’t like it.

My brother cooks, my nephew cooks, but I don’t, so, but now I’m forcing to learn how to cook. I don’t mind just doing the house chores, like doing the laundry, the dishes, cleaning the house. (Eddie)

Whether preventive or responsive, supports may take a wide variety of forms, including rest, medication, alternative therapies, rehabilitation, or social supports.

4.4.3 Navigating Access to Social Determinants of Health.

In this section, the personal impacts on carers with respect to accessing essential social determinants of health, including food security, education, employment, and finances are discussed. Carers may use private funds to provide supports. “It’s time-consuming and also a little bit on the financial side” (Katmod). Purchasing supplies for a PLWEI may be limited to when funds are available. “I don’t have money but sometimes buy milk, buy tea, if she’s thirsty. If I have money, I do that” (Fifi). Therefore, it is difficult for carers to set individual priorities as they must decide to privilege their own needs or support for the family member/friend.

Relational impacts may also arise while making decisions about when to intervene to provide additional resources. Tensions may result when a PLWEI asks for financial support to meet basic needs, such as buying medications.

So, here is an example. That lady’s calling me, she needs something, vitamins; she doesn’t have money. When she gives me a card when she’s not feeling well, I go and
[find] “insufficient funds.” Are you going to come back without any medication if she needs it or milk or anything? So, you’re going to end up using your own money. Do you think you’re going to go and tell that sick person that you need money when she is sick? (Zebra).

The continuing need to provide the necessities of life creates challenges to care provision.

Financial resource limitations can also reduce access to the PLWEI, especially where carers live apart from the PLWEI. “For me, it’s just like financial. Are you able to transport yourself from one point to another, like I’ve been driving most of the time I was here in Canada” (Becky)? When personal finances are limited, carers may reduce the types of supports provided or limit time spent with the PLWEI. When carers cannot give support according to the standard of care they envision, feelings of inadequacy may result.

You’re jobless, and it’s very hard financially there, hard emotionally, hard physically on both of them because if you’re stressed out and you don’t do self-care and they see it. And then they feel more like they’re burdening you. And you don’t want that. It’s very, very awkward. (Gonzo)

Financial matters are a source of relational tension as carers may struggle to meet personal financial needs and manage additional financial burdens from providing care.

Episodic carers may provide time-limited or ongoing financial support. The financial assistance is, at times, so taxing that carers may experience personal debt or even bankruptcy. I got in so much debt I ended up about five years ago I declared bankruptcy because I ended up so much debt. Mostly from that time, just basically living on credit. Even when I got on ODSP, I wasn’t getting enough money to pay all the bills, so it was slowly
creeping up and eventually, I just had; I was $42,000 in debt and had to reset everything.

(Jane Alexander)

The weight of the financial burden varies depending on personal income and financial resources. Financial support may contribute to the carer questioning whether they can continue to provide at the current level if needed. In response to ongoing pressure, carers may set relational boundaries around decisions to provide financial assistance or withhold funds.

Some people have a game, there’s been people I’ve felt burned, and I stay away from them. So, especially lending money. I’ve learned not to lend money. When you don’t have money, you really know that you can’t lend money because you don’t have money to lend (Nikola).

Financial challenges can be ongoing as carers continue to juggle work with care provision, renegotiate support, or receive support requests that require financial contributions.

Another social health impact involves barriers to education due to care provision. Time constraints due to care-related activities, the unpredictability of care needs, and the emotional burden of care can alter educational plans.

So, it’s always been up and down. I did miss a lot of my high school because of my mom. So I did never finish high school. I went to do a couple of courses after, and I had my second son. (Cheyanne)

Depending on where the episodic carer is in their life journey, episodic care impacts make challenging personal circumstances more difficult, at times limiting personal development opportunities for carers.

Repeated employment impacts are typical while providing supports over time but may vary from person to person. “You’re working, and you have to take time off work to do stuff to
help them out” (Gonzo). Carers with supportive work environments may be more able to arrange shifts to facilitate their employment responsibilities and care-related activities. “It didn’t affect me at home. I just had to fit [it] in my schedule. If I’m not able to, I just say I’m not able to come this day, let’s work on these other days. That’s what I do” (Becky). The challenge is finding a responsive employment environment and flexible job responsibilities that fit with the unpredictable nature of episodic care.

Access to a helpful employer often occurs by chance. While some carers have positive experiences with employer accommodation, others experience difficulties, including loss of employment, due to the irregularity of health needs. “So I had a hard time with work. They weren’t really that understanding” (Cheyanne). For carers, conversations with employers can be riddled with doubt, with carers hoping for leniency and flexibility, not knowing how the request will be received. These issues create a scenario where employment may be an ongoing source of stress for carers. Disclosure preparation may include self-questioning about what details to disclose or concerns about accidental disclosure of personal information. In addition, the episodic carer may develop doubt about their ability to progress in their career. They may decide to stay in their current position if the employment relationship is reasonably supportive, delaying career aspirations.

In situations where multiple social determinants of health are impacted, carers may incur losses. Carers may face bankruptcy, job changes, or personal physical and mental health issues throughout care. For carers experiencing multiple barriers to social determinants of health, the challenge of responding to health needs grows more complicated. In circumstances where carers respond to numerous changes, sometimes on an ongoing basis, carers navigate an environment of
additional instability and uncertainty, along with strained relationships, especially if PLWEI health needs broaden beyond the primary diagnosis.

Every time she got worse, I would get worse. Now every time she gets bad, I’m not so affected by it because there are support systems that people at the [long-term] home recognize what’s going on. (Katmod)

The personal circumstances in which carers provide support vary widely, with carers having differential access to educational, occupational, and financial resources. Where resources are available, this may also reduce the burden faced by carers, who then can better support their family member/friend.

The next section discusses how carers redefine the care relationship through the challenging experiences of episodic care.

4.5 Redefining the Care Relationship

The participants’ narratives show that an episodic carer may fill care-related roles over extended periods without necessarily adopting a carer identity. For some carers, grappling with the identity is ongoing, as carers struggle with shifting relational identities. For carers in the study, internalizing the label of carer came from one of two sources. The carer herself began using the term, or as was the case for Katmod, when a disability organization applied the carer label to her. If the identity is socially derived, carers choose to internalize or reject the label, or perhaps even use the name occasionally, as fits the circumstances. Taking on a carer identity is associated with accepting the ongoing tasks and relational aspects of care. These are a central
part of the transition from being a responsive family member/friend who helps out when needed to become a regular part of the care team for a family member/friend.

Thus, episodic care provision involves a process of *becoming*. Becoming an episodic carer may involve multiple relational roles, including providing physical support to improve mobility, or acting as a personal coach, socio-emotional support, psychosocial counsellor, healthcare manager, system navigator, medication specialist, interpreter/translator, volunteer, or social activist. Daily life activities are also frequently part of care responsibilities, such as grocery shopping, cleaning, or providing stability when walking.

I’m sure down the road, my caring hat will look different, I don’t know. I mean, nobody knows. But right now, we’re managing the best way we can…. Caring comes in many different forms, and right now, it’s more the emotional than the physical. (Isabella)

For episodic carers, taking on multiple roles can be challenging to the care provision, perhaps the point of considerable uncertainty in providing care.

Care activities place an array of resource demands on carers, including time, personal finances, sleep, other physical requirements, or emotional and mental wellness. These demands may result in delayed personal goals, career progress, educational pursuits, socializing, and the pursuit of private interests. Although many of these difficulties are not co-occurring, the ongoing, recurring nature of care requirements can place a relentless weight on carers’ shoulders over time. Taking on additional responsibilities may change how carers perceive their relational identity — for many carers, identifying as a carer requires time to understand the role and what the mantle will mean for them.
Each episodic care journey is unique as no two carer relationships are identical. The individualized nature of episodic care is further amplified by the variable course of episodic illness, even for those with the same diagnosis.

When somebody’s in difficulty and people will call and they honestly, when they say, “if you need anything, please just give me a call.” And they mean it, they do mean it. But no one ever offers to scrub the toilet. They always offer to do something that’s kind of fun. One of the things that I learned was that you have to, you should be very careful that you don’t actually take away the thing that they enjoy, right? (Lisa).

Carers spend time as well as mental and energy absorbed in the process of supporting another person.

Many carers have multiple functions, often concurrently, including advocating with health systems on behalf of the PLWEI.

She knows I’ve got her back if something happens when she’s been in homes where there have been abusive staff. I’ll go to bat for her. (Jane Alexander)

Carers also spoke often of taking on managerial roles to monitor healthcare appointments or responsibilities in the community.

I basically became his secretary during that whole time. I kept track of the money that had come in…. I mean, it was overwhelming for him with all the, what was going to be involved, and I basically just took over and kept track of everything. (Isabella)

Becoming a personal coach or counsellor is another role. Initiating supports is challenging when information on what is available is limited. Carers may act in additional roles when resources are inadequate.
Carers offer supportive counselling in a variety of areas, including health and personal decision making. At times counselling may encourage PLWEIs to access illness treatments and continue with wellness supports.

Then always complaining about the side effects of the medication and so always comparing notes at that time. It’s just not delivering medication like a delivery boy. Also, it’s the time you connect [to] the person, you sit there, and then you talk more. (Becky)

Some carers view their role as making a vital difference for PLWEIs who had no other support systems. “But really, to make up a human who was in bed is to make [an] effort and to encourage that person to bring her back [to] life” (Fifi). Taking on the emotional and mental wellness of a PLWEI, in the absence of a professional, is a role carers may not be prepared to assume.

Some carers experience a sense of fate or a higher calling, which may be an initial draw to participate in episodic care.

I feel like it’s a big calling. With the training that I got in Canada for being a personal support worker, I’d rather take care of people living with HIV and AIDS than just other people because there is nobody who wants to take care of them. (Becky)

Carers who practice spirituality in their personal lives may also see spiritual connections to the experience of providing care.

The time we start to talk about [spirituality], is my spirit and her spirit were connected.

Because she was emotional, she don’t have nobody, and nobody was interested in her. If in the community, but after I came, it was everything…. So, it means our spirits human to human [they were] connected before. (Fifi)

Many carers note that the spiritual aspect of their relationship with the PLWEI extends beyond the care relationship.
In anticipation of a health change, carers may be on guard, in a state of readiness, for an illness episode. “That is my main concern now, for her that I need to be 24 hours with her” (Eddie). Carers start by examining the situation, listening to the expressed needs of the PLWEI, and looking for signs of the need for assistance, which may be unspoken. When there is no precedent for an episode, continuing forward in the absence of a pattern is challenging. Carers are uncertain of how the episode may proceed or what might be considered useful supports. This uncertainty is also seen in chronic mental illness care (Biegel, Milligan, Putnam, & Song, 1994; Moller-Leimkuhler & Wiesheu, 2012).

Carers who provide support for more extended periods can think retroactively when an illness episode occurs, looking back to times of similar patterns. This retrospective approach considers what worked previously and what alleviated some of the episode-related issues. With each carer on a unique course, there is no clear precedent in episodic care, only the wisdom that comes from hindsight and understanding the triggers of health changes.

Change in the relationship is frequent, as carers often navigate more transitions than anticipated. Regardless of how the relationship begins, the presence of the illness is an influential factor. The illness becomes an omnipresent third member of the relationship between the carer and PLWEI, influencing how the carer and PLWEI interact and what they do.

I never thought that I could be a caregiver. I never thought I could be a nurse or could be a [in] home carer. I never thought about it until step by step or just minute by minute I start doing it. Now going back, I said, “how my life changed.” (Eddie)

During this phase, the influence extends beyond the illness to the socio-emotional aspects of the relationship. The provision of episodic care adds to the uncertainty experienced between carer and PLWEI as the relationship shifts. Thus, the relational balance may become distorted in an
episodic illness context, as the carer role becomes more prominent, shifting the dynamics of the relationship. This shifting is often unintentional and unplanned.

I don’t know what that is because, in your mind, you’re always wondering is this the time that it doesn’t bounce back and get better. You don’t want to promise something that can’t happen (Ragnar).

Instability persists as illness episodes recur, and the carer/PLWEI dyad responds to the episodes. Sometimes when you’re raised to be independent, you keep that to yourself too because you don’t want to show your vulnerable side, you don’t want to show your weak side, and yet when you start talking, you realize that there’s other people out there that go through things that are the same or a lot worse and they understand and so. It’s just getting to that point. (Isabella)

The changes may be undetected or considered to be inconsequential until the carer recognizes an imbalance.

In care relationships, uncertainty can take the form of anticipating what to do, how the PLWEI wants a particular task done, what the PLWEI wishes to do for themselves, and what the PLWEI still enjoys doing. Additional questions carers may pose include: What is coming next? What community supports may be needed? Episodic care provision is consistently forward-thinking, looking at what health changes might be approaching.

I think I was more anxious and worried about every little thing. I was kind of like the protector. I can give an example of every time we do it, “are you sure? Are you sure you should be doing that?” (Neville)

This future-looking perspective may reduce the enjoyment of the present moment and being with the PLWEI.
But you know, I’m dealing. I’m trying to deal with it on a daily basis. And not looking till tomorrow and what happened yesterday, happened yesterday. Just file it away.

(Katmod)

Toward this end, carers may attempt to minimize the impact of the illness on the relationship.

As health changes repeat throughout the illness course, role shifts also occur. Shifts in carer roles can also cause personal tension when preparing and planning for future care needs. Although role shifts may be challenging, they are not inherently negative, and may have positive impacts as carers develop various skills in the process. Among the ways that carers deal with these shifts is through the setting of care-related boundaries. Boundary setting becomes a tool for carers to see the carer identity as part of their overall identity without becoming consumed by care demands. Despite ongoing challenges, carers express a high level of commitment to continue care provision.

Carers may attempt to rebalance the relationship when imbalances occur in the give and take of the relationship. In these instances, maintaining the relationship is necessary but is coupled with a desire to negotiate change. For some carers, attempting to assert influence over the relationship results in an uncomfortable conversation. Evaluative discussions sometimes lead to the development of relational boundaries, as carers and PLWEIs discuss what is most beneficial for the dyad and which aspects of care someone else could provide, including shifting responsibilities to the PLWEI. These conversations are examples of the non-static nature of episodic care relationships.

Redefining the care relationship is a unique experience for carers and PLWEIs, with an indeterminate timeframe. Carers may move through a peacemaking process toward accepting the unpredictable nature of the relationship.
I used to get upset at her. “Why would you do that to me?” … But now, as I got older, I’ve gotten more understanding about her situation. I’m a lot more understanding and just not getting upset about it. Just well, “that’s not nice…. I’m not gonna meet you, or we’ll find other arrangements for you to bring the kids.” I just try to work around her.

(Cheyanne)

Navigating the journey is a day-to-day process located in a particular place and time. Frequently, carers continue forward despite the fluctuations, looking for the best way to maintain the relationship with their family member/friend.

You do have to realize that life is still to live, and you have to try to find the best way to do it. It just takes a little more investigating, a little more creativity on your part.

(Isabella)

The carer/PLWEI mutual commitment to the relationship aids with continuing forward despite the challenges.

To continue providing supports, carers use strategies that include positive ways of coping with ongoing care provision.

I had to commit myself to do that, but it was challenging, and also I felt for her because she could be running to the bathroom every 5 minutes, every 5 minutes; it affected me because I would ask myself, “why not me?” (Zebra)

Examples of mental strategies used by carers include considering the experience of needing care from the perspective of the PLWEI and believing the carer may need support at some point. By providing supports, the favour may one day be returned.
I would say that introspection was probably a good thing. Sometimes it was a bit painful but more of a growing experience than anything negative impacts. It was just a really hard time. It was just a really, really hard time. (Lisa)

These strategies may be influenced by personal values, with different forms potentially used by the same carer, depending on the circumstance. Strategies are beneficial to supporting family/friends as they mitigate unpredictable circumstances and emotionally thorny aspects of episodic care.

Care relationships are central to providing various types of support to PLWEIs, as focusing on relational patterns in episodic care shifts the focus from task-based ways of conceptualizing care to person-centred aspects of interactions. This focus on the episodic care relationship will be called *Relational Care*, where carers engage in activities of “encouragement, personal attention, and communication in ways that endorse a mutual sense of identity and self-worth” (Milligan & Wiles, 2010, p.738). The identity shifts described previously provide insight into the multiple ways in which carers construct episodic carer identities.

The following sections will further explore how care relationships develop or shift during care, as well as a discussion on why approaching episodic care from a relational standpoint is useful. Upcoming sections examine aspects of the interpersonal nature of episodic care, here called *essential care* and *reciprocal care*, including how both types connect episodic carer relational identities to broader social circumstances. The third section shares reasons for *Exiting care* relationships.

### 4.5.1 Essential Care.
In essential care, carers often function as primary carers for a single PLWEI. Essential carers are frequently engaged early in the development of the illness; however, they may also become involved at some point following the diagnosis. Essential carers often feel the weight of being a central, care-related decision-maker, which may be a heavy burden to bear. The term *essential* focuses on basic needs, consistency, and dependability, and comes with a perceived duty to care. Care provision is sympathetic and compassionate to the needs of the PLWEI but with a limited feeling of receiving personal benefits through providing care. In essential care, providing supports may be viewed as a sacrifice by carers, who often feel a sense of loss at *what might have been* if the illness had not occurred.

In essential care, the relational carer identity may transcend socio-emotional aspects, as illness-related needs become a central aspect of the relationship. Maintaining relational ties becomes secondary to the illness response, which places additional burdens on carers as the role becomes more important than the relationship. Focus on the work of care may continue to the point where carers may feel care provision has almost entirely overtaken the relationship, resulting in a primarily task-oriented experience from day to day, with limited emotional support.

That I have no choice. That I have to do this. That this is life. That this is literally life…. Maybe somebody else might say, “have more time to yourself. You’ll be able to do other things…. You could go on vacation without thinking about it.” Because my heart belongs to him and I don’t want that…. I don’t want to know what life is without him. (Daphne)

Essential care is focused on commitment to continue providing care despite the emotional, financial, time, or activity demands.

In some instances, the carer steps voluntarily into the identity of an essential carer. However, in other situations, the carer feels there is no other option (Hoffmann & Mitchell,
1998), believing no one else could provide supports of the same quality. This essentialized carer identity may, in turn, influence how carers interact with and feel about the PLWEI through the months and years of care. Carers may experience loss of choice, with less personal time available as the care duties became more prominent. The needs of the PLWEI would begin to overshadow carer needs in the relationship, leaving some carers to set aside activities, such as vacations or social events. For some carers, personal sacrifice extends further into their own basic needs, such as sleep, exercise, or eating habits.

Sometimes it would be nice just to say, ok, you take care of me for a while…. It’s not that he takes everything, and I don’t get anything back, but I feel sometimes that’s part of my control because then I know what’s happening, and I know that there are some things that I have no control over. (Isabella)

Essential carers may experience higher levels of emotional burden and difficulties with balancing care and personal responsibilities. Carer motivation may shift over time, with the duty to support becoming a prominent aspect of the relationship.

This feeling of lack of agency within the essential care relationship feels emotionally constraining.

I always stepped in and did what was necessary, and my sister always stayed back and said, “I’m going to do my own thing.” When she went off to university, she said, “I kind of feel guilty leaving you here” and I said, “if you can get out, go. Take care of yourself, live a life. Because I can’t.” I’ve always felt that I couldn’t. (Jane Alexander)

Essential carers may think that if they are not available, there will be negative consequences to quality of life for the PLWEI.
Essential carers who feel solely responsible for providing care may not recognize other potential members of the care circle. Research indicates that access to social supports benefits the carer’s capacity to continue with care responsibilities (Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014). Where access to social supports is limited, the impacts on the carer are negative, increasing the emotional burden (Clair, Fitzpatrick & La Gory, 1995). Although the carer–PLWEI relationship persists in essential care, carers may overlook vital social supports.

For carers, community-based supports can provide relief and a portion of the resources needed for the individualized challenges of episodic care. Community supports may include other carers, health providers, employers, third-party insurers, childcare supports, educational institutions, community service organizations, and restorative respite opportunities, depending on the specific needs of the PLWEI.

If you’re in a family situation, that’s kind-of fraught or very emotionally tangled anyway; I don’t know how you’d manage to carve out some time for yourself or to say to the person, “look, I need an hour to get out of the house.” (Libby)

Carers may feel disconnected from their local environments during essential care and may struggle to reach out for additional support. This wrestle may continue until the emotional burden reaches levels where carers feel obligated to continue to provide support. At this point, the provision of care is exacting physically, mentally, emotionally, and spiritually.

The care-centred focus may progress so subtly that the shift may become entrenched in relational patterns, leading carers to stop providing care when the relationship feels imbalanced.

And don’t get me wrong, I have left because, you know. I have left. I left him for a couple of days plenty of times. I’d go to my mom’s. “I’m not dealing with this anymore.”
He would become angry and very unreasonable. We would fight, and I would be like, “what’s the point?” (Daphne)

For some carers, the shift is so encompassing that providing care is no longer a viable option, preceding the end of the care relationship, the focus of section 4.5.3 Exiting Care.

When the impact of the illness becomes increasingly present in the relationship, the PLWEI may feel uncertain about continuing the connection long term.

The idea of becoming a burden to the extent that they [PLWEI] say, “I can’t cope, I’m sorry but out of here.” I’ve had that discussion probably half a dozen times over 10 or 15 years where she’s in a rotten mood, or a quiet mood or uncharacteristically withdrawn, and we’ll finally talk about what’s bothering her, and I’d say “that isn’t something you ought to be concerned about.” It seems like eventually, she’s not concerned about it until the next time. (Ragnar)

Thus, the carer steps in to reassure the long-term stability of the relationship, which places additional stress on the carer. Although providing care is a prime focus of the relationship, essential carers may experience personal benefits outside the relationship. These benefits may include the feeling of making a difference in the life of another person or fulfilment in taking care of people from within their community.

I feel like it’s my calling, my passion to take care of people. I’m a mother. I don’t feel like it’s a burden; it’s not a burden to take care of somebody living with HIV and AIDS (Becky)

In essential care, the socio-emotional relationship between the carer and the PLWEI plays a lesser role, with some carers finding an identity and purpose as a contributor to their community.
Even though some essential carers may have conflicting views of the value of the care identity, many continue forward.

The following figure provides a visual of the essential care identity. In this relational identity, the carer identity is a more significant aspect of the relationship than in reciprocal care. Note that in the following diagram, the distancing of social supports does not represent a lack of availability of various systemic supports but rather the degree to which the carer identity overtakes the relationship, which overshadows the ability to recognize and reach out to community supports.
Figure 1

Visualizing the dynamics of essential care relationships

Care identity as prominent in the relationship
4.5.2 Reciprocal Care.

The next relational episodic care identity to be discussed is *reciprocal care*. As the name reciprocal suggests, a central characteristic of reciprocal care is the notion of *give and take*, of finding an acceptable balance between the work and emotional labour of care, of the giving done by the carer, with relational benefits that compensate for the sacrifices made by the carer. Thus, the activities performed between carer and PLWEI are less central to how the carer and PLWEI perceive their relationship. In reciprocal care, the carer sees the relationship as having lasting, personal benefit beyond the day-to-day care activities. Consistent with the situated, constructivist view of the research, there is no prescribed way to achieve balance in the months and years of providing reciprocal care.

Reciprocal care may be seen in care relationships both before after a diagnosis and occurs in both HIV and MS carers. Single dyad and collective carers may experience reciprocity while providing care. Reciprocal care harnesses the existing relationship between the care provider and PLWEI to the benefit of both. It involves a striving for a balance of the integration of the concerns and issues manifest in care with individual autonomy and connection between the carer and PLWEI central to the relationship (Avivi, Laurenceau, & Carver, 2009; Neff & Harter, 2003). “We want this to be an experience of MS, not ruining us, like taking over us (Isabella).” Where reciprocity is not a static state but rather an ongoing effort involving both carer and PLWEI to strengthen their socio-emotional relationship while navigating the care relationship, the carer's individuality is maintained alongside the relational carer identity.

Time is often a factor in developing a reciprocal care relationship, requiring both carer and PLWEI to strive for emotional balance in the relationship. For carers, an understanding of
the importance of the self amid the illness episodes is vital. Thus, in a reciprocal care relationship, the role of carer does not overwhelm all other purposes. The carer does not come to lose personal identity in the process of care provision (Eifert, Adams, Dudley, & Perko, 2015). This focus may enable the carer to maintain perspective on the relationship, resolving issues together with the PLWEI as they arise. As a result, both carer and PLWEI can function with reduced strain on personal resources and the carer–PLWEI relationship, reducing care-relationship stress. A factor related to achieving balance is the amount of social and economic privilege experienced by some carers. For carers with limited physical, financial, or geographic access to resources, achieving the relative balance in reciprocal care is difficult.

Once I realized that it wasn’t keeping him down, then I was able to let go a bit, so I think it was a gradual process for me. It was definitely a very emotional piece; I think I’m very protective too. (Neville)

Many carers learn through providing care which aspects are comfortable and which are uncomfortable.

One noteworthy requisite for reciprocal care is the boundary setting between carer and PLWEI. Boundary setting occurs as carers are disappointed with relational patterns that unfold during care provision during and between episodes of illness, placing limits on activities and focusing responsibility for care on both the carer and the PLWEI.

If I don’t want to do it, I’m not going to do it. Again, anybody who knows me really well would say, well, “she’s finally come to her senses.” Because, you know, you just gotta put a line in the sand and say ‘no’ and mean it. (Katmod)

Boundary setting may occur through conversations between the carer and PLWEI or through decisions made by the carer alone to limit certain aspects of the care. The processes for
determining what might become of care relationships when boundary-testing occurs are individual. “I’ve been living in proximity to people that are always needing, always need help, and I’ve learned to differentiate and protect my own energy and resources” (Nikola).

Carers may be more likely to set boundaries after being slighted or feeling a substantial imbalance.

So, you pick up on things. The way they talk to you. The way they socialize with you and everywhere you go, you see them every day. I’m over at [ASO name], this guy I never talked to in 3 days, “got a cigarette, got a cigarette, got a cigarette….” Why should I break down and give you something I paid for, and you’re being a real idiot. Really bitter about it. You don’t reward bad behaviour. (Gonzo)

A hallmark of reciprocal care is the negotiations about which care tasks will be completed by whom, and how often. Boundaries are viewed as part of the care relationship’s evolution, as carers intend to preserve the relationship quality.

The following figure shows the dynamics of episodic care relationships when community supports are available, and a reciprocal relationship exists between carer and PLWEI. It should be noted that the intersecting concentric circles are not static. There may be shifts to the degree of overlap between the carer and personal identities. Still, generally speaking, balance is maintained, allowing the carer and PLWEI to find meaning in the relationship.
A common feature across the spectrum of reciprocal carers is the valuing of supportive community resources. Carers either access community supports or believe access is possible if needed. This perceived capacity to access supports lends reciprocal carers a psychological advantage as they provide care with a sense of security that support is both available and attainable if needed. A state of balance, represented in the centre of the concentric circles, comes
from a working understanding of the episodic illness machinations, seeking meaning in the relationship for both carers and PLWEIs, and reaching beyond the dyad for additional supports.

4.5.3 Exiting Care.

Exiting care involves ending the care aspects of a relationship, such as coordinating appointments, supporting system navigation, or meal preparation. These physical, managerial, and organizational aspects of care are fundamental to care provision and the development of a carer identity. But when the doing aspects of care, which often involve extensive giving on the part of the carer, overtake what the carer receives from the relationship, the carer identity may become a difficult burden to bear, which results in some carers exiting the care relationship. Thus, exiting care involves a purposeful distancing of the carer from the carer identity. Unlike the often-gradual transition into an episodic care identity that occurs subtly and often below the carer's awareness, exiting care is often an emotion-filled, profoundly personal decision, carefully considered before moving forward.

Whereas the previous sections discussed the carer’s intent to continue providing care, care relationships may also end. Exiting care could also include distancing from the socio-emotional aspects of the relationship. The decision to end the care relationship often comes following the transitional period of defining the relational identity, as the carer and PLWEI recognize the long term direction of the care needs, especially where the carer identity forms the main focus of the relationship. The carer receives few benefits from the relationship, or the demands of providing care outweigh the perceived relational benefits. As such, care tasks may result in little remaining energy to perform tasks for other aspects of a carer’s life.
They’re having to spend so much mental and physical energy on being sick that they just don’t have a lot left over for anything else. It was a little bit, toward the end, he really only wanted to be with family, so I stopped going, and that was a little bit tough on me.

(Lisa)

There are various reasons for exiting care, including lack of trust, increasing burden of care, shifts in health, or increased focus on personal needs.

Following a care exit, carers may view the past relationship from either a positive or a negative perspective. Carers may feel they have been burned, or that their willingness to support others has been over-extended. As a result, some carers become cautious about when and with whom they might begin caring again. A carer’s decision to bring the relationship to a close is emotionally exhausting and often follows a period of careful consideration of available resources and potential benefits of continuing the care relationship. Carers often experience a sense of loss after the relationship finishes, struggling to find closure.

Of note, this category was seen only in the HIV interviews and where there were no pre-existing relationships between carer and PLWEI before the HIV diagnosis, with relationships formed through community connections or an HIV organization. Given the separation of the carer from a care identity following an exit, former carers may not have identified with the study criteria when the study call was issued. This may have limited the experiences of exiting care gathered during the interviews to carers providing collective care. Understanding the circumstances leading to a care exit may help with decision making and transitioning from being a carer.
4.6 Toward a Relational Model of Episodic Care

The following discussion brings together the previous sections of entries into episodic care, navigating unpredictability, and redefining the care relationship into a relational model of episodic care. The model shows how care extends well beyond the acts of care to become a unique relational journey between carer and PLWEI through which a relational care identity develops. This identity is non-linear and may involve returns to earlier phases of the process, depending heavily on how the carer experiences are internalized and processed. Resource support availability is also central to resolving the uncertainty.

A theoretical model is historically and contextually bound (Charmaz, 2014). A useful model moves from the experience of sensations or constructs to examine relationships between those constructs, ultimately to a level of abstraction that explains how constructs and relationships combine into an overarching social theory (Anfara & Mertz, 2014). Based on this study, a model of the emerging relational carer identity was developed and is explained below. The model consists of three phases: Care Entry, Redefining the Carer Identity in the Shifting Relational Context of Episodic Care, and the Development of a Relational Care Identity – either essential carer or reciprocal carer. Carers may also choose to exit care if demands become unduly heavy, resources are challenging to access, or carer priorities shift.
UNPREDICTABLE PATHS INTO CARE

Figure 3

A Relational Model of Episodic Care
The model illustrates the inseparable connection between the socio-emotional nature of the episodic care relationship and the evolving relational identity. The confluence of these two aspects of episodic care, the contextual and the relational components, are ongoing throughout episodic care. Each phase brings relevant experiences that contribute to the developing relational carer identity. Next, the section will expand on each aspect of the model, moving from left to right.

Helping is part of a relationship and is what you do with someone in need; episodes may not initially be considered part of an ongoing illness. Multiple entry points exist to the episodic carer identity. Care Entry may start at the start of the relationship or through an existing relationship as the carer slowly recognizes the illness as ongoing after responding to previous health episodes. Initial responses to health episodes such as someone with MS symptoms temporarily losing the ability to stand, or a severe bout of the flu for someone living with HIV, are often done to assist a family member/friend. Illness episodes commonly precede diagnosis and may trigger further testing by medical personnel. Diagnosis may initiate a connection of the illness episodes as part of a chronic condition. Recognition of the chronic nature of the illness and the need for evolving care is part of the transition into the carer identity; of note is that a carer may provide supports, even for extended periods, without connecting with a carer identity.

In addition to the experience of illness episodes, a care entry is a heightened period of ambiguity as a new relational care identity develops, often taking time to transition into an enduring role identity. At this time, carers are beginning to recognize unpredictable illness episodes as part of a larger pattern of illness. Thus, adopting the carer identity is more likely at the individual level, although it may originate in the social environment. While others may
recognize the carer as a carer, this is secondary to how the carer identifies herself in the relationship.

The next phase involves *experiencing the relational impacts of episodic care* while *redefining the relational care identity*. This phase consists of experiencing illness and wellness episodes becoming part of the relationship for carers, with a growing awareness of the carer role. During the early months and years of an episodic illness, as episodes of illness and wellness fluctuate, so does the understanding of the developing relational identity. Episodes occur but are not permanent, persisting for a time but followed by periods of improved health. This main difference between episodic and degenerative forms of illness is noteworthy. What is often challenging is the inability to anticipate the illness path, especially during the early years of care. The PLWEI may return to a wellness level similar to before the episode. For some, however, the return to health may not be back to an original state of wellness but rather to a state between the pre-episode health level and health declines related to the episode (Whitehead & Lero, 2014).

Health patterns vary in length from months to years, involving a cycle of experiencing and redefining, which continues until repeated illness triggers recur. During this phase, the search for identity continues until there is sufficient experience for the carer to *locate herself* in the carer identity. Patterns in the care relationship develop through responses to episode triggers, which are experiences or events that initiate or exacerbate a current episode. These triggers push the potential for an illness episode past the *tipping point* where a downward health trend occurs. Triggers may include medication changes, impacts from a comorbid condition, or delays in accessing treatment. A catalyst may also be environmental, such as financial stress or issues related to housing stability (O’Brien et al., 2014). The movement toward a lasting carer identity develops with time and experience with the episodic illness, accompanied by looking in
hindsight to reconcile the care relationship; through repetition in navigating health episodes, relational identity shifts toward an enduring construct.

During this phase, individual life circumstances are also a prominent element in providing care. Meeting daily needs, work, personal health, family, community, and social demands all compete for the carer's time and attention. Thus, planning for the future can become challenging due to the changeable nature of episodic care, which may leave carers in an extended limbo period where they continue to function reactively to meet care demands. At this time, carers may begin to develop an outreach plan in case care requirements increase and community supports are needed. Suppose carers feel additional supports are inaccessible for any reason. In that case, the weight of this realization may impact the relationship with the PLWEI, possibly leaving carers feeling trapped in a situation with few options for improvement.

Also of note is the quality of the socio-emotional relationship between the carer and PLWEI. The emotional burden of care is counterbalanced in part by what the carer receives from the relationship. These benefits are by no means a transactional accounting as might be seen in a balance scale, a *one for you, one for me*, but rather the feeling of contentment with the existing imbalance in the relationship. The perceived quality of the relationship is an essential factor in how the relational carer identity will develop.

The next phase involves the development of a lasting relational carer identity. The first identity to be discussed is *essential care*, where the relational identity centres on the caregiving aspect of the relationship. Care is central to the relationship identity, which results in disruptions to the social aspects of the relationship, as well as reciprocal benefits that may come to the carer. The interpersonal relationship shifts as care activities form the central focus of the relationship. Note that the degree of emotional and temporal burden in essential care relationship varies from
carer to carer. In essential care relationships, the carer may experience a heavy load and reconsider the type of relationship and subsequent carer identity. When this occurs, the carer identity returns to the previous phase. At that point, carers and PLWEIs determine if and how they would like the socio-emotional relationship to continue.

In contrast, in reciprocal care, some carers develop mutual feelings in the relationship as both receive socio-emotional benefits from the care relationship. Care thus forms part of the relationship identity but is not central to the relational identity. Both carer and PLWEI give and receive socio-emotional benefits from the relationship.

And she’s more mellow in that regard now. Or if I don’t get something done right that minute, it’s not so bad anymore where it used to be. She would want an instant answer or something done right away. So, in that regard, I think maybe the relationship has gotten a little better in some regards. (Peter)

Access to additional supports often plays a significant role in reducing the relational imbalance experienced by carers. As seen in essential care, carers with reciprocal care identities may return to a state of relational uncertainty if care demands shift significantly to where feelings of mutual gain occur less frequently.

A third option exists when the carer decides to end the care aspects of the relationship. As shown in the model by the double-sided arrow between essential care and the developing relational identity, where the carer identity obscures the relationship’s social aspects, carers may choose to end the care relationship. This is known as exiting care, which involves a decision to end the caregiving aspects of the relationship, and may also stop the social aspects of the relationship. The decision to close out the care activities may dissolve the connection if the individuals go their separate ways. While it may be possible to set boundaries on care activities
to focus only on the relationship's social aspects, this was not seen in the study. Of note is that exiting care is seen in the study with carers who began the relationship following the diagnosis of HIV, although there is reason to believe that exits could happen across illness groups (Daly, 2016; Rohr, Wagner, & Lang, 2013).

The Relational Model of Episodic Care presented here provides a visual of the relational transitions of episodic care, including Entries into Episodic Care, Navigating Unpredictability, and the resulting carer identities of essential carer or reciprocal carer involved in Redefining the Care Relationship. These identities are non-static, shifting as the relationship continues throughout the months and years of care.

The discussion chapter will develop a deeper understanding of the context in which relational care identities develop by, first, expanding on the situational factors that influence how episodic carers experience relational episodic care; second, situating the study findings within the context of previous research; and third, discussing the limitations and implications of this study.
Chapter 5: Discussion and Conclusion

The Relational Model of Episodic Care developed in this study presents an alternative conceptualization of carer identity development by integrating illness and wellness episodes into chronic illness care, highlighting the intimate, shifting relationship between the carer and PLWEI. The model describes entries into care as the often-protracted period of incongruence between carer activities throughout the months and years of illness unpredictability and the transition into a carer identity. During this process, carers strengthen a developing care identity with each care-related activity. In episodic care, the prognosis is different from progressive illness forms of care, as both carers and PLWEIs are not preparing for health declines over time, instead anticipating improvements following each episode. As a result, episodic carers often move through periods of uncertain identity while grappling with the unforeseeable health reversals common to episodic illness. Episodic care brings together PLWEIs and carers, often in complex environments. Over time, through their interactions, perceptions, and co-constructions, a relatively stable relational identity develops, although it may shift as carers and PLWEIs navigate the uncertain, changeable landscape of episodic care.

Throughout this process, carers experience a range of quality of life impacts on social and psychological determinants of health. Thus, the socio-cultural environment influences the relationship through repeated actions and shared experiences (Greene, 2017). The range of impacts varies from carer to carer, with common impacts on finances, employment, personal time, and social supports, as well as physical and mental health. All carers in the study experienced multiple social influences. As such, the Relational Model of Episodic Care as
contextualized in the lives of episodic carers responds to the revised research question, *What are the relational impacts of episodic care on HIV and MS carers?*

This chapter examines the situated impacts of episodic carer relational identity development, building on the Relational Model of Episodic Care introduced in the Findings chapter. Situated impacts, including socio-environmental influences of gender, and cultural values and practices on carer identity, will be explored in greater detail. Implications for research, policy, and social work practice will then be considered, followed by concluding comments on the relevance of social care principles to the future of episodic care.

### 5.1 Episodic Care as a Relational Identity

Health-related uncertainty impacts episodic carers in multiple, intersecting ways; indeed, navigating the unpredictability of health changes is often a primary concern for the HIV and MS carer participants. Factors that can exacerbate or mitigate the severity of an illness episode include health-related incidents such as co-occurring illness, addictions, the presence of social supports or stigma, as well as individual living strategies and personal attributes (Butler, Koopman, Classen, & Spiegel, 1999; O’Brien et al., 2008). Unmanaged stress may also impact the overall experience of any episode (Delgado, 2007). Each of these challenges acts as a potential barrier for carers to personal, socio-emotional, and economic well-being. When carers perceive the demands of episodic caring as ongoing and substantial, the nature of the relationship begins to change (Kulik, Cregan, & Bainbridge, 2013). This relational re-construction involves significant transactional elements, such as personal shopper, healthcare aide, or appointment manager, and has implications for the carer as the relationship shifts from primarily interpersonal.
and mutually-supportive to a series of task-oriented activities with altered reciprocity for the carer (Rosenthal & Martin-Matthews, 2009). The relationship between carer and PLWEI can develop a relational asymmetry, where the carer shifts from acting on perceived reciprocity common to many episodic care relationships to recognizing the ongoing imbalance in the care relationship (Milligan, 2000). This changes how the carer sees both herself and the family member/friend (Hornsey, 2008).

As shown in the model of Relational Episodic Care, identity is not fixed but instead develops through the experiences of a carer in relationship with a PLWEI, as people are inherently social beings (Gergen, 2009b; Overton, 2013; Shotter, 2017). Relational development, or the ability to relate socially, happens throughout a lifetime (Deanow, 2011). Relationships involve values-based, cooperative well-being (Held, 2006), achieved through connection and responsibility to others by prioritizing balanced, supportive relationships (Brabeck, 1993). Carers come to a relational sense of self by interpreting cues from PLWEIs and responding based on perceived needs; for example, when carers look beyond the needs of a PLWEI to also provide meals for the children of the PLWEI. In the context of episodic care, relationships evolve in a specific time, place, and culture (Carpendale & Lewis, 2010).

Relational identity theory is a framework that expands on the concept of an evolving relational identity, as suggested by the study findings. This framework attributes its early origins to Henry Stack Sullivan (1940), who proposed the idea of a relational matrix, inclusive of past and present relationships, as the organizer of the self. The concept of a relational self is different from a collective self and suggests that identity development occurs within an interpersonal relationship, as opposed to a socially derived identity (Brewer & Gardner, 1996). This
developing identity was observed in the study, as many carers did not initially view themselves in a carer role despite performing care-related tasks.

Carers and PLWEIs function in distinct ways in relationships but do not act independently of one another (Mascolo, 2019). Relationality takes place “in context …. It views the self as more fluid than fixed, and as shaped in interaction relative to social or interpersonal settings and backgrounds” (Hadley, 2008, pp. 205-206). In contrast, identity involves an internalized construction of the self as a preferred representation to the social world (Dutton, Roberts, & Bednar, 2010). Of note is that identity is different from identification, which is acceptance of a particular role and “the extent to which one defines oneself in terms of a given role relationship” (Sluss and Ashforth, 2007, p.11). In the study model, relational identification follows transitioning into care, occurring when family members/friends accept care as an ongoing aspect of the relationship. As shown in the model, over-identification with care tasks may transition the carer who was previously acting as a good partner, family member, or friend to develop a different relational identity. In the model, this focus on the transactional elements of care commonly transitioned into an essential carer identity.

Within relationships, identity formation occurs through five mechanisms, including individual action, the direction of the effort, the response(s) of another person, the use of culture and related symbols to mediate activity, and the extended sociocultural system, which includes socially accepted meanings, practices, and artifacts (Mascolo, 2005). For example, participating carers supporting a partner appear influenced by Western marital vows to care for each other in sickness and in health, which may reinforce acting out of a duty to care. In her interview, Daphne noted the transition from seeing care as part of the relationship to functioning primarily
in the carer role. Her devotion to her partner was no longer reciprocal, as care activities became a responsibility borne by her throughout the physical and emotional ups and downs of care.

Relational identity is further influenced by mediated action, meaning the ways people use cultural tools to relate to others around them, most commonly in the form of natural language (Wertsch, 2017). For example, communication in episodic care relationships is central to carers understanding the needs of PLWEIs, seen as carers frequently inquire about the health challenges and support needs of PLWEIs. Beyond the transactional aspects of care, a deeper relational identity develops through the emotion-focused parts of care provision. Eddie spoke to how he and his spouse are growing together emotionally by learning better interpersonal communication, talking about care needs, watching for changes in energy level, providing balance when walking or standing, or during temporary loss of body function. Through verbal communication and ongoing watchfulness, the couple is developing a more profound relational intimacy.

Similar to essential care, Noddings (2013) spoke to a form of care known as receptive, where the carer becomes immersed in the needs of the family member/friend. In this sense, the carer role becomes the dominant role in the relationship, overshadowing the often beneficial and mutually supportive socio-emotional aspects. This focus on the relational identity may create a loss of social support for the carer as carers focus on the relationship with the PLWEI over other aspects of life. This relational shift may be subtle, occurring over time, as the demands of providing care continue in the longer term.

All study participants reported benefits from the relationship with the PLWEI, although the types of gains and the frequency varied from carer to carer. As noted in the model, carers who view care support as subordinate to the socio-emotional relationship receive from and give to the relationship. A self in relationship with an other [person] has been critiqued by feminist scholars
who reject the concept of a separate other, instead reframing the relational self as part of an intersubjective mutuality which involves *give-and-take* in the relationship (Freedberg, 2009). In contrast, Noddings (2013) describes the “dynamic potential for mutuality in caring” (p.87), which speaks to the ongoing, changeable nature of relationships. These dynamics are reflected in the study model, both when carers navigate the unpredictable circumstances and the potential for shifts in carer identity after a relational identity settles.

Even as patterns arise in care and relational identities seem more evident, the balance within the relationship continues to shift, as shown in the Venn diagrams for essential and reciprocal care. As seen in this study, carer experiences differ in the types of care activities performed, resources accessed, carer perceptions of influence over their environment, and, importantly, how episodic carers come to construct a relational identity. Each episodic care relationship is unique in the amount of *giving* to the PLWEI. Still, the mutual experience continues over time for both individuals through the interpersonal relationship, although to varying degrees (Li, Shaffer, & Bagger, 2015).

Movement toward mutuality lies at the heart of relational development. Rather than viewing people as primarily motivated by a need for self-sufficiency and personal gratification, a relational perspective acknowledges our deep need to establish connections with other people (Jordan, 1991, p.1).

Through mutual interaction with others comes enhanced understanding of self (Downie & Llewellyn, 2012). This deeper self-understanding is part of the developing relational identity. In discussing the benefits of relational identity, the acts involved with the care relationship can have restorative purposes for both carers and PLWEIs through their mutual relationship (Miehls, 2011). A Canadian study used factor analysis to explore the main aspects of growth in parents of
children with a life-limiting illness where care-related stress is ongoing, and unpredictability is present in the illness course. The study findings pointed to making meaning of experiences as a key contributing factor to post-traumatic growth, aided by additional factors such as higher self-esteem, optimism, expressions of spirituality, and lower depression (Cadell et al., 2014). Meaning-making also facilitates the creation of deep, meaningful connections between carers and PLWEIs in this study.

Carer identity and roles are intertwined as part of a process where carers perform tasks that may lead to taking on roles. As seen in the study, actions may include learning to communicate in meaningful ways, paying attention to detail, or performing care tasks without haste. Role repetition over time may reinforce the changing self-concept as part of identity formation. As such, roles are consciously adopted (Newell & Shanks, 2014), similar to the decision-making by carers to thoughtfully continue to provide care despite the growing presence of care provision in the relationship. In the study, care roles became thoughtful parts of the relationship when carers had developed a relational identity. This is different from the early period of care when supports are provided based on need and are not considered part of the ongoing relationship. The period of change, where carer identity is undergoing a revisioning process, occurs as part of the phase *Redefining the Relational Identity* in the model. Even following this phase, the relational care identity is not a fixed construct. Self-concept may shift, noted when essential carers transitioned from the carer role during a care exit.

In contrast, a model of carer identity development by Montgomery and Kosloski (2009) shows an alternative way of conceptualizing how family members/friends eventually define themselves as carers. Based on Caregiver Identity Theory, the model identifies caregiving activities as increasing over time as carers respond to *progressive care needs* (Montgomery &
Kosloski, 2013; Montgomery & Kwak, 2008). Based on an assumption of family member/friend health decline, the carer identity becomes increasingly more prominent over time. Accordingly, there are ongoing increases in care activities, altering how the carer views her self-concept as she steps further into the care identity (Montgomery & Kosloski, 2009).

Additionally, carers in this study spoke about personal growth experiences through episodic care via bidirectional flows of support between carers and PLWEIs. Although caring may be perceived as unidirectional within partner/family/friend relationships between adults, as noted in the current study, support is often given and received from both individuals (Grant et al., 2004). Influence in the care relationship is felt two-ways as carers themselves become changed through the process of care (Freedberg, 2009). In support of this approach, Fisher and Tronto (1990), in their exploration of care relationships, reported care as not passive nor one-sided. The carer does not hold all the influence, as the PLWEI holds significant power to impact not only what happens in the relationship but also how (McPherson, Wilson, Chyurlia, & Leclerc, 2011). Interestingly, growth has been noted in carers who experience distress associated with care relationships and responsibilities (Cadell, 2007).

Next, several social factors will be discussed that influence the development of a relational care identity. These factors include the importance of care circles, carers who live with chronic illness, experiencing stigma-by-association, and the identity implications of assisted care arrangements via community-based organizations (CBO).

Care is often provided with additional help, as seen in the study, with multiple family members or friends offering support. As they are sometimes referred to, these care circles provide episodic carers with potential outlets for sharing the burden of care (Mckinlay, 2001; Price & Lau, 2013). Care circles refer to the relational linkages between the care providers
through existing relational ties or a shared commitment to providing care for the PLWEI (Louw, Dunbar-Krige, & Fritz, 2010). As observed in the study findings, participation in care circles may be voluntary, or care circle members may feel a personal or community duty to participate in care activities. The potential value of care circles is in the *re-distribution of care* among the members as different members may occupy different roles (Dong, Samavi, & Topaloglou, 2015).

Among the roles noted in this study and complementary literature includes carers as care recipients. This important aspect of the non-static, multi-directional flows of care was noted in a study on caring in the context of mental health where people considered to be receiving care were reported to be meaningful providers of care within their families and communities (Williams & Mfoafo-M'Carthy, 2006). Similarly, as noted in the study, collective care delivery became a means of survival for PLWEI carers with limited access to family members. However, the relationships are often more transient than in commonly stable forms of single dyad care. As such, the balance between providing for the self and others is critical (Ulrich, 1996), which, in an episodic illness context can make deciding between caring for personal needs or the needs of the PLWEI difficult. Carers may also become ill; the assumption that episodic carers themselves are consistently well is inaccurate (Grady & Rosenbaum, 2015). Self-care becomes difficult to practice when carers identify in two places – as carers and PLWEIs – striving to meet their own needs while also attempting to meet the needs of family members/friends. This was noted in the study, particularly for carers living with one or more illnesses, which may also blur the relational identity (Mignone et al., 2015). The strain on the emotional and physical health of carers challenges care planning and the flexibility required to respond to the needs of PLWEIs (Sullivan & Miller, 2015).
Additionally, there are vicarious impacts on the lives of carers of people living with stigmatized illnesses, such as HIV or mental illness. To reduce the social stigma, some PLWEI carers would not discuss the diagnosis of their family members/friends to avoid negative perceptions of the family member or themselves. This form of stigma, which occurs in various social environments, is known as stigma-by-association (Goffman, 1963). Social stigmas can be damaging for carers who experience stigma-by-association during everyday social interactions, such as within the employment environment or grocery shopping (Kulik, Bainbridge, & Cregan, 2008; Pryor, Reeder, & Monroe, 2012). Stigma-by-association effects can also result from negative interactions with colleagues, which can turn the workplace into an unsupportive environment (Kulik et al., 2008). Thus, carers may experience socially ascribed stigma and be left managing its socially and emotionally damaging effects, which, in the study, included isolation and concerns about disclosure.

As noted in this study, stigma is relational, often involving more than one person. While MS-related stigma is documented (Grytten & Maseide, 2006), the source is primarily a perceived stigma, internal to the PLWEI. In other words, it is often the interpretation of how people living with MS believe others to view manifestations of the illness, such as hand tremors (Cook, Germano, & Stadler, 2016). In HIV, the experience of stigma is differently impactful due to (mis)understandings of how the virus spreads and associated moral judgments of people living with HIV (Earnshaw & Chaudoir, 2009). Stigma related to HIV also impacts carers through association with people living with HIV and AIDS (PLWHA) (Mignone et al., 2015; Wright, Aneshensel, Murphy, Miller-Martinez, & Beals, 2006).

The stigmatized nature of some episodic illnesses may also play a role in how carers approach providing supports. Both HIV and MS carers in the study discussed avoiding
conversations with people outside of their care circle as a means to reduce negative social perceptions from other family members, friends, or community members. Although the silence allowed carers to distance themselves from social commentary, in some instances, the silence eroded the quality of existing relationships as carers focused more on the PLWEI. In other cases, carers supporting PLWHAs might attempt to insulate the PLWEI from the social burden arising from stereotypes about HIV and other episodic illnesses (Logie & Gadalla, 2009; Mak & Cheung, 2012). This additional burden of care provides a protective function for PLWEIs as carers vicariously experience negative stereotypes instead of the PLWEI (Ho & Mak, 2013).

This, in turn, increases the emotional weight of care and may increase the emotional distancing between the episodic carer and PLWEI, as the carer faces a burden not shared with the PLWEI. Of note, the carer’s stigma may be challenging, especially within vulnerable populations such as minority groups or people living in poverty (Mignone et al., 2015).

Herek (2009) defines HIV-related stigma as a form of prejudice, discounting, discrediting, and discrimination directed at people living with HIV and at associated individuals or communities. Stigma can have a silencing effect on many chronic illnesses but is particularly salient amongst PLWHAs due to ongoing misunderstandings of how HIV spreads from person to person, as well as moralistic judgments of activities connected to HIV transmission. The silencing experienced by HIV carers may come from being associated with the HIV community, with an additional layer of stigma related to being a male carer (Florom-Smith & De Santis, 2012; Poindexter, 2005). Further silencing can happen when carers do not speak about their concerns or when supports are challenging to access (Ussher & Perz, 2010).

Galvin (2002) describes the challenges related to the moral culpability of chronic illness by saying,
it is becoming less acceptable to enter and remain in a physically incapacitated state: it clashes too uncomfortably with the image of the “good citizen” as someone who actively participates in social and economic life, makes rational choices and is independent, self-reliant and responsible. Chronic illness is increasingly viewed as culpability in the face of known risks, an instance of moral failure that requires the intervention of a range of political technologies (p.108).

Thus, social tolerance is decreasing for illness, as health becomes the normative standard for judging quality of life and social productivity (Fries, 2008). The construct of the model member of society is deeply embedded in the persuasive, broad-minded reach of neoliberal ideology where capacity defines the individual, and limited work capability is connected to moral reprehension (Moore & Robinson, 2016). Moral culpability occurs when blame is attributed primarily to the individual as the cause of illness as though individuals are responsible for the illness, without consideration of the social origins of disease (Dodd, 2013). As such, increasing personal responsibility rests on the individual for her maintenance and care (Springer, Birch, & MacLeavy, 2016). Carers bear some of this moral burden through association with people living with episodic illnesses (Pryor, Reeder, & Monroe, 2012).

Notably, the study findings agree with previous research showing care provision as a blend of positive and negative relational experiences. A study of Alzheimer’s patients that examined outcomes of care found that relationally-oriented carers are more successful in the longer term and showed more positive coping skills (Lewis, Hepburn, Narayan, & Kirk, 2005). Throughout this process, carers experience emotional benefits in addition to the challenges of care. Some of the relational highs include becoming more emotionally in tune with one another or feeling relief when an episode is ending. Thus, care provision may not continuously be a
stressful experience. In the present study, some carers experienced increases in feelings of attachment and affection for the PLWEI. For individuals who are not related, the relationship came to feel more like family, where carers came to see the PLWEI as a meaningful, long term, stable part of their lives. This process of making meaning also occurs for carers who have lost a family member/friend/partner, with an increased understanding of the relationship and the carer role (Cadell & Marshall, 2007).

The decision to provide family/friend care often stems from external factors beyond an interest in caring for another person (Ciani, 2012; Meng, 2012). As noted with HIV carers in this study, where carers connect to a PLWEI via a community-based organization, this process may influence how the relational identity begins. Where CBOs are involved in connecting carer and PLWEI, there is a sense of carer identity from the outset of the care relationship; this is a noteworthy difference from existing family/friend relationships where the illness becomes part of the relationship after months or years of a social relationship. Heard and Lake (1997) call this careseeking in a model of caring based on Attachment Theory. Thus, the entry into episodic care is automatic, even though carers still move through the doubt and uncertainty of navigating the care tasks ahead. Although many carers expressed gratitude for the CBOs acting as a point of connection between carer and PLWEI, which allowed for care relationships to develop, the organizational standards, although intended to protect carers, also had undesired impacts on carer-PLWEI relationships. These included limitations to the frequency of visits or the types of activities provided, for example. Although strong relational bonds are common in CBO-facilitated carer-PLWEI relationships, obligations to uphold organizational regulations may present boundaries and frustrations for the carers who feel constrained in what they can do for PLWEIs.
To mitigate the burdens of care, carers may seek personally meaningful spiritual connections. Carers with spiritual beliefs may have an additional means to make meaning and continue forward while providing episodic care. This was noted throughout the interviews as carers discussed accessing spiritual supports of various kinds to maintain perspective. Intersections between spirituality and care are growing in the literature, as carers cope with the emotional weight of care throughout the process of providing care, including following the loss of a family member/friend. Where care continues into a decade or more, spirituality may add meaning to banal care tasks (Robinson, 2013). Spirituality may even facilitate growth in various personal domains during and after the experience of care (Cadell, 2012). Spirituality has been noted to help carers grapple with the diagnosis of the person they were caring for, mortality, the social world, and their relationship with the PLWEI (Cadell & Haubrich, 2006). For carers who feel they have the knowledge and resources to provide care and connect to a meaningful form of spirituality, an additive effect between self-efficacy and spirituality may reduce carer depression (López, Romero-Moreno, Márquez-González, & Losada, 2012).

Additional supports to mitigate burdens of care can come from early training of carers in the expectations of the unfolding carer role and relational shifts. Kalra et al. (2004) found that carers who were identified and provided with structured training had improved care experiences in the months following the training. Toward reframing the perception of who is a carer, a model of the carer as “expert, focusing on the production of caregivers as empowered self-regulating subjects, who develop expertise in primarily the technical skills of caring” was proposed (Sadler & McKeivitt, 2013). Considering carers as experts within their environments of care, with information, skills-based, and relational knowledge shifts the situational power experienced by
carers who may experience disadvantages when advocating for PLWEIs or functioning as system advocates, as shared in this study.

5.2 Episodic Care and Gender: Considerations and Implications

Gender is a topic of increasing interest in care-related literature. To date, much of the Care literature has been written from a gender-binary perspective. A search on the experiences of non-binary or trans carers yields sparse results, so the following gender discussion uses currently available information. Although much of the existing literature focuses on care in the context of permanent or debilitating illness, there are insights relevant to episodic care, where complex social factors intersect with the relational processes of care. This section discusses how the approaching-parity gender dynamics of episodic care intersect with historically derived social roles of men and women, including conceptualizations of masculinity, and provides contrasts and comparisons of the Relational Model of Episodic Care with the currently available literature on gender and care.

Revenson et al. (2016) claim a discussion of care without discussing gender is incomplete. Gendered participation in care is changing as increasing numbers of men accept care roles (Greenwood & Smith, 2015), as noted in the current study, where one-third of participants identify as male. While I was writing this dissertation, the 2018 General Social Survey data on Caregiving and Care Receiving was still being prepared for release, and recent Canadian data is limited. Of the recently available studies, a Canadian national survey showed 54% of family/friend carers are female, with 46% percent identifying as male (Sinha, 2013). Comparatively, in 2008, the gender breakdown in care provision was 60% female, 40% male
(Cranswick & Dosman, 2008). Studies from the United States show similar trends with increasing numbers of male carers over the past two decades (Wolff et al., 2018). This changing gender dynamic represents a significant change toward understanding who provides care while raising questions about the support needs for carers of various genders in a *culture of care* that traditionally recognizes women as carers.

The carer identity has deep social roots extending back centuries, placing women as nurturers, attendants, and emotional supports who put the *needs of others* above the *needs of self* (Singer, Biegel, & Ethridge, 2014). Women continue to perform traditional care tasks such as cooking, homemaking, or bathing PLWEIs, despite increased flexibility in allocating household tasks between men and women in the West (Esplen, 2009). Women still provide most care in Canada, although the participation rates are changing as more men are stepping into care roles (Sinha, 2013). Female primary carers contribute more hours of care than male carers. However, no difference is seen in care hours between male and female secondary carers (del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012).

Researchers have responded to the historically gendered care analysis by introducing a masculinity lens to understand care and care provision (Russell, 2007). Masculinity studies often focus on the constructed experience of men in the context of their lives, including within institutions, such as providing care alongside formal employment. Broader social norms are also relevant, such as normative care delivery based on Western male social identities (Gardiner, 2002; Williams, 2010), including care as protection of the PLWEI (Kumpula & Ekstrand, 2009). As such, male carers may experience tensions with internalized social identities, such as expressions of compassion by men (Bridges & Pascoe, 2014). In the study, male participants identified increased empathy as an outgrowth of ongoing care activities and infrequently as an
initial part of care, connecting with the idea that male carers struggle with emotion-focused care aspects.

Relational approaches to care delivery may vary across genders. While the number of male carers is increasing, men may provide care in less visible ways. As noted in the study, men tend to normalize PLWEI illness symptoms instead of connecting symptoms to illness and thus are slower to access community resources. Still, once symptoms are acknowledged, men may reach out for assistance more quickly than women (Hayes, Zimmerman, & Boylstein, 2010). Although not seen among single dyad carers in the study, male carers may experience increased anxiety about their PLWEI partner, potentially leaving the relationship, compared with female carers (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). For male carers with emotionally distant relationships with the PLWEI, self-esteem is negatively impacted while providing care (Chappell, Dujela, & Smith, 2015). Male carers who identify as having a poor relationship quality with a PLWEI are more likely to institutionalize a family member/friend than males with an overall positive relationship quality (Winter, Gitlin, & Dennis, 2011). Sons who provide care may assist with activities of daily living, but men may also be apt at supporting parents working through emotional aspects of an illness, such as uncertainty (Collins, 2014). For men who provide collective care, where care-related decision-making is interrelated by an interconnected system of care providers, as seen in this study, men more commonly change their care network, especially if female carers are involved (Davey & Szinovacz, 2008; Gerstel & Gallagher, 2001).

Consistent with current literature, gendered differences in care provision are also noted in the study findings, particularly concerning how carers navigate unpredictable social changes. While men and women experience care-related burdens, women tend to experience increased impacts from what may be termed secondary stressors, such as relational and financial
challenges (Silverman, Brotman, Molgat, & Gagnon, 2020; Swinkels, Tilburg, Verbakel, & Broese van Groenou, 2019). Women, who provide the brunt of care supports, are more likely to experience employment impacts (Lee & Tang, 2015) and bear a more significant financial burden when providing care (Duxbury, Higgins, & Smart, 2011). Being employed while providing care has also been shown to increase carer burden for women (Schrank et al., 2016). In complex situations, carer burden is also associated with being female, a spouse, and living with a care recipient (Kim, Chang, Rose, & Kim, 2012). Increased burden is also experienced by female carers when problem behaviours are encountered, such as PLWEI anger or dependence in performing necessary activities of daily living (Bédard et al., 2005). In contrast to these findings, a study found male MS carers at risk of a more significant physical health burden (Adelman et al., 2014). Toward better understanding the demands of care provision, Collins and Swartz (2011) suggest using multiple carer evaluations to understand the shifting factors connected to carer burden over time and considering the importance of contextual elements to more fully understand the effect of care-related duty (Bastawrous, 2013).

The socialization of women into care roles may create different expectations for male and female carers (Anjos, Ward-Griffin, & Leipert, 2012). Female carers in the study experienced additional social pressure to care not only for the PLWEI but also for other family members, completing tasks such as cooking for the family, assisting with the hair and grooming of the children, or providing transportation. Trying to remediate the immediate challenges of the PLWEI and difficulties within the family system was discussed by female carers as an additional burden.

The type of relationship between carer and PLWEI may also impact the care provided, as noted in the friend-based collective care in this study. A U.S. study found that PLWEIs who
receive care from a son have one or more unmet care needs (Beach & Schulz, 2017); although the reasons for the unmet care needs are unknown, this may indicate differences in the types of care provided rather than negligence in providing care. Among women caring for partners, the degree of burden and depressive symptoms may reduce sexual satisfaction, impacting the physical and emotional quality of the relationship (Davies, Sridhar, Newkirk, Beaudreau, O’Hara, 2012). Another study found that adult-child carers experience more stigma and care-related burden than spousal carers (Kahn, Wishart, Randolph, & Santualli, 2016). Penning and Wu (2016) found that caring for a partner or a child increased caregiving stress for both men and women compared with care of other relational types. Each of these studies speaks to the complex dynamics of care provision that extend beyond a gender dichotomy to influence relationship type on the experience of providing care.

Additionally, care-related responsibilities shift as male and female carers are increasingly performing similar care tasks (Calasanti & Bowen, 2006). Women and men experience common challenges related to care delivery, including reduced self-esteem (Chappell, Dujela, & Smith, 2015), work and career limitations (Colin Reid, Stajduhar, & Chappell, 2010), and emotional burden from care (Friedman & Buckwalter, 2014; Sharma, Chakrabarti, & Grover, 2016), all of which increase as care continues (Morais et al., 2012; Pavalko, 2011). Both men and women may experience employment impacts, although in different ways; male carers may reduce work hours as care responsibilities intensify, whereas women may attempt to balance care and work duties or exit the workforce (Gomez-Leon, Evandrou, Falkingham, & Vlachantoni, 2019).

Although studies show mixed results on gender-based differences in approaches and impacts to providing care (Martin, 2000; Navaie-Waliser, Spriggs, & Feldman, 2002; Sharma, Chakrabarti, & Grover, 2016), gender is valuable to consider in episodic care relationships.
Although much of the current literature available relates to traditional forms of elder care or caring for a child with a disability, family/friend episodic carers may find insights to help guide their understanding of navigating challenges related to episodic care. The current study highlights the need for literature specific to episodic care, as unpredictable aspects of care are not well explained in existing care-related literature.

As Ontario continues to become a culturally diverse province (Statistics Canada, 2017c), addressing these issues will become increasingly crucial because episodic care provision is not a one-size-fits-all experience. Thus, researchers and community supports can assist by acknowledging and accommodating carers of various cultural backgrounds and understanding community needs and priorities. This is discussed in the next section.

5.3 Episodic Care and Culture

The body of research examining the individual experiences and values involved in care provision is shifting away from the micro focus on dyad-based care as a Western social norm (DeForge et al., 2017; Funk, 2015). As increasing numbers of carers collectively support, alleviate suffering, investigate issues, advocate for rights, prevent problems, and nurture PLWEIs, family/friend care provision is developing a culture of care (Revenson et al., 2016). This section will discuss the study findings against the framework of a culture of care, including ethic of care values, as well as the influence of cultural values and practices on the experiences of providing episodic care.

Gilligan (1993) was an early proponent of connecting relational theory with a morally based ethic of care used to explain women’s roles in the social world. By focusing on gender,
Gilligan’s work offered a female view on morality, whose perspective was unrecognized as different from theoretical models of moral development and reasoning based on men (Blum, 1993). The circular model begins with a focus on care for the self, then shifts outward to the needs of others (Larrabee, 1993). In reaching out to care, women recognize that for relationships to continue, carers need to make conscious decisions about when and how to provide care, as many carers experience limitations on time and capacity to offer care supports (Friedemann-Sánchez & Griffin, 2011). Over time, carers may accept that not all PLWEI needs may be satisfied through the care relationship (Clement, 1996). This finding is similar to the boundary setting done by carers in the present study.

Gilligan’s model was an initial effort to foreground gender as an aspect of care, yet the model uses an essentialist perspective, representing a single voice that fails to capture the breadth of women’s experiences (Phillips, 2010; Witt, 2011). In contrast, a constructivist lens integrates variations in circumstances, contexts, and cultures to provide insight into an array of care experiences. The relational constructivist perspective of this study calls for more expansive concepts of care culture, including the experiences of anyone providing care, toward reducing the risk of repeating the reductionist error identified by Gilligan and further silencing marginalized voices. Questioning the value of a gendered ethic is useful today, given the ongoing shifts in who identifies as a carer.

Caring for another is a uniquely moral experience (Kleinman, 2012). Virginia Held (2006) describes moral care as “the compelling moral salience of attending to and meeting the needs of the particular others for whom we take responsibility” (p.10). In speaking to the values connected to an ethic of care, Hankivsky (2004) speaks to the interdependence of individuals who, via thought and action, connect to their social environment. Additionally, relational
sensitivity to connections is needed between carer and PLWEI due to the changeable nature of human needs, “since people are sometimes autonomous, sometimes dependent, sometimes providing care for those who are dependent; humans are best described as interdependent” (Tronto, 1993a, p.162). Individual autonomy or independence is a myth when the interconnected nature of care delivery is understood (Fineman, 2004). Interdependence is a relational concept, with mutuality less by choice than by circumstance (Kittay, 2011), as care is connected to physical proximity and is critical to the development of mutuality in a relationship (Milligan & Wiles, 2010).

Toward describing the morality of care, Tronto (1993a) describes four values forming the basis for an ethic of care. First, attentiveness involves both recognizing and being aware of a need for care. In the context of episodic care, this study shows that attentiveness requires awareness of change in the PLWEI, especially at the onset of another episode of illness. For example, Eddie described being constantly aware, even to the point of losing sleep, while looking for indicators of an upcoming episode. Connecting attentiveness to action involves moving beyond a feeling of responsibility for the PLWEI to respond to individual PLWEI needs. From a social perspective, accessible care is a social justice issue, as care is “conditioned by cultural and ethical understandings and by economic and political circumstances” (Kittay, Jennings, & Wasunna, 2005, p.443).

Next is the value of support for the person assisting, the carer. Feelings of obligation can be powerful motivators to continue care, potentially creating a burden on the carer in the process. This was especially noted among essential carers in the study, who felt the care activities had overtaken the reciprocal socio-emotional aspects of the relationship. The third value is competence, which refers to the performance of care with the necessary skills and capacity to
provide care (Barnes, 2012). In the study, with limited community options for support, many carers felt compelled to develop new skills, which is both empowering and burdensome at the same time. Lastly, responsiveness refers to relational sensitivity as carers notice how care is received; responsiveness may also involve reflection on the experience from the perspective of the PLWEI (Visse, Abma, & Widdershoven, 2015). The majority of carers in the study provided reciprocal care, which offers more care/life balance and offers greater socio-emotional reciprocity in the care relationship. To further this analysis, the concept of asymmetrical reciprocity recognizes relational imbalances while allowing carers to be open to change in care experiences, allowing for multiple subjectivities. Relational openness may facilitate a mutual understanding between carer and PLWEI (Sevenhuijsen, 2003a). This concept is similar to the welcoming interchange between carer and PLWEI in reciprocal care. Toward a more expansive set of values, Sevenhuijsen (2003b) also adds plurality, communication, trust and respect, and solidarity between carer and PLWEI as foundational parts of developing and maintaining the relationship between carer and PLWEI. The central role of trust in the carer/PLWEI relationship is also central to the present study among all care relationships. Of note is the purpose of trust among collective care relationships, where trust is considered vital to initiating a connection and maintaining a care relationship.

An ethic of care is not a guiding theory with a fixed set of steps for carers to resolve conflicts or pattern personal care work but rather uses guiding principles for application in context, which may be called a contextual ethical metatheory (Tronto, 1993b). For episodic carers, where the lived, daily experience of care shifts continually, some principles may be of greater use at specific points and lesser value at other times, as noted in the above discussion on trust in the relationship. The values explored are not exhaustive, as additional precepts may be
involved in particular circumstances (Tronto, 2013). For example, in the study, episodic carers spoke of respecting the capacity of PLWEIs by not overstepping the bounds of what PLWEIs wished to do for themselves or helping when assistance is unwanted, thus showing the importance of respect during the care process.

In considering additional values, the capacity to set boundaries is also central to episodic care. Carers are inherently vulnerable during care as focus increases on the needs of PLWEIs, with carers paying less attention to personal needs. This was shown in how study participants navigated the unpredictability of social, emotional, and health needs. Kittay (2011) introduces the concept of “moral harm as … the consequences of failures in responsibility and responsiveness” (p.53). Moral harm may occur where carers feel the ongoing primary responsibility for care, coupled with limited access to supplementary supports.

If the preservation of a web of relationships is the starting premise of an Ethic of Care, then there is little basis for critical reflection on whether those relationships are good, healthy, or worthy of preservation (Tronto, 1987, p.660).

Although dedication to supporting another person is a noble characteristic, valuing the life of the PLWEI over the carer trespasses the line of the dignity and worth of everyone. Carers providing essential care may be in most need of professional supports to assist with early identification of burnout or abuse. However, when relational boundaries are set in episodic care, the burden is reduced, and reciprocity is higher in the dyad.

These factors contributing to ethical and moral care are woven into a broader social culture of care. This culture considers how care values are applied by family/friend carers on a macro level. Although care is provided one-to-one, which may feel isolating at times, carers are part of a broader community, including thousands of people in Canada who provide care. The
values that make up a culture of care may vary depending on community cultural practices. To help establish social connections between carers, provincial and national care organizations could facilitate groups and support resources to help carers recognize the various forms of information and support resources available to carers.

The next part of the section will discuss how community-based cultural values and practices are relevant to a culture of care. In a general sense, many study participants framed care provision as part of what families/friends do, and care is both situated and embodied within the local environment (Appadurai, 1996). Across ethno-racial groups in Canada, cultural values of care provision as a family-centred tradition are often present (Ayalong, 2004), but there are differences in how care is understood. Carers from Non-Western cultures often share a strong sense of community ties and a desire to reach out to community members (Scharlach et al., 2006). Stack (1993) describes these values as “concern for reciprocity, commitment to kin and community, and belief in the morality of responsibility” (p.110). This reaching beyond the bounds of family ties reflects the community orientation that places value on family and community needs ahead of the self (Santoro et al., 2016). Considering who receives care supports, episodic carers from diverse cultural communities reach out beyond close family circles to include indirect connections that may consist of existing acquaintances of family members/friends or members of the broader community (Pharr, Dodge Francis, Terry, & Clark, 2014).

As seen in the study, the multiple relationships of care are illustrated by common monikers showing the value of the relationship between carer and PLWEI. The use of the terms family/friend or aunty has gained acceptance among cultural groups, including African/Caribbean communities, to connote the intimate relational aspect of a care provider,
especially one who is unpaid (Dysart-Gale, 2007). The labels speak to family relationships, to people who know life details and personal needs, to people who are worthy of respect. These terms also signify the extraordinary roles played by carers (Thornton & Hopp, 2011). Each title sheds light on an aspect of the intimate, emotional, relation-based nature of care; however, none are entirely successful in capturing the breadth of supports, and the emotional depth developed between carer and the PLWEI, or how caring captures the essence of being in a meaningful relationship (Pharr et al., 2014).

Previous research indicates cultural practices may also influence the roles of episodic carers (Dilworth-Anderson, Canty Williams, & Gibson, 2002). Study participants coming from African/Caribbean and South American backgrounds also experienced social pressures to care according to a cultural standard or what has been called a duty of care (Dilworth-Anderson, Williams, & Cooper, 1999). Within African/Caribbean cultures, extended family, which often includes friends and relatives such as aunts, uncles, and cousins, collaborate to meet emerging needs. The bonds forged through these relationships are frequently strong and further the collaborative feeling described by study participants as caring for our own and seen in the study with higher than average response rates from communities of colour (Dysart-Gale, 2007).

In the study, multi-faceted semi-professional care provision, including roles commonly filled by professionals from the community, show intersections in care provision, community-duty, and cultural expectations often experienced by racialized carers. Some carers experience substantial blurring of semi-professional care responsibilities (Sadler & McKeivitt, 2013; Dilworth-Anderson et al., 1999). Carer roles may include psycho-social counselling, medication management, toileting supports, and doing information research. Additional functions may consist of emotional support, financial support, medical assistant, and any other forms of support
relevant to the PLWEI (Ergh, Rapport, Coleman, & Hanks, 2002; Taylor & Quesnel-Vallée, 2016). While any carer may take on these roles, racialized carers from diverse cultural backgrounds may be vulnerable to an increased burden of additional care roles due to community expectations (Mitchell & Knowlton, 2012). This blurring of roles may stem from cultural expectations, a lack of information about existing resources, or feelings of disempowerment within the current health system (Dilworth-Anderson et al., 2005; Scharlach et al., 2006).

For episodic carers, the desire to alleviate and prevent discomfort while supporting family/friends means constant vigilance and response to an otherwise unpredictable illness despite low social value placed on providing care (Friedemann-Sánchez & Griffin, 2011). This may contribute to feelings of isolation in carers of varying cultural backgrounds who may not have access to culturally sensitive outreach or support (Adelman et al., 2014; Donovan, Williams, Stajduhar, Brazil, & Marshall, 2011). The combination of community-level responsibility to provide care and barriers to reaching out for community supports places communities of colour at increased risk of heavy burdens from episodic care provision.

Additionally, newcomers may experience cultural impacts from care provision. Five newcomer carers in the study reported experiencing increased pressures to manage personal, family, and community demands, taking on the roles of healthcare aide, translator, system navigator, and familial support. Recent immigrants bring unique care patterns from their homelands, and many have worked through significant challenges in coming to Canada. Newcomers may also experience a unique set of problems in functioning in a carer role in Canada, including health implications due to uncertainties about navigating the healthcare system or limited access to health supports (Suwal, 2010). Language barriers, lack of adequate income support and affordable housing, and the health status of the carer also impact how care is
provided (Zarit, Pearlin, & Schaie, 2018). Episodic carers, especially from communities of colour, find themselves processing multiple changes simultaneously. These adjustments include navigating the immigration system, learning a new language, and understanding the social welfare system (Guo, 2013; Klassen et al., 2012). Besides, recognition of academic and employment achievement is challenging in Ontario, while structural discrimination in the workplace is biased toward individuals born in Canada or people who identify with Western approaches to work (Ahmed et al., 2016; Edge & Newbold, 2013; Kubota, 2015). Thus, with rising immigration rates comes a growing recognition of the importance of understanding the needs of carers who are also newcomers to Canada (Latulippe et al., 2019).

This discussion on the intersections of episodic care, race, income, immigration status, and culture is timely, sensitive, and increasingly relevant as the complexity of the environments in which people in Ontario provide care increases (Whitehead & Lero, 2014). The study findings and literature review highlight that there is much still to understand about the nature of carer struggles and supportive individually tailored systemic interventions that can alleviate personal struggles and reduce systemic support barriers faced by newcomer and racialized carers.

5.4 Conceptualizing Social Care in Ontario

All people are both carers and care-receivers at the same time (Tronto, 2013). Throughout episodic care, carers navigate intersecting identities, among others, the social identity of friend/family member, and the relational identity of carer. Carer identity often comes quietly, little by little, act by act, until a shift occurs, moving carers from a solely social relationship to one including roles of advocate, manager, supporter, facilitator, or coach. Care is transformative
for both the carer and PLWEI, as resolving the tensions arising from performing care activities initiates changes in how carers understand themselves through their relationships of care.

Care relationships construct how carers and PLWEIs have experienced the past and continue in the present (Gergen, 2009a). Social construction theory opens doors to changing and refining carer identities as circumstances change, and carers evaluate what they receive from the relationship (O’Toole, 2013). As such, family member/friend carers step into relational care with a commitment to the relationship despite the uncertainty about how to proceed. Working through the episodes and activities of care adds strain to the relationship between carer and PLWEI.

Care is hard to do. It requires not only an emotional and ethical sensibility, but the capacity to understand different personal, economic, social and cultural contexts, to read particular responses to acts of care and to draw from diverse sources and types of knowledge to make good judgments with others about the right things to do in situations that may be messy, confused, and changing. (Barnes, 2012, p. 172)

The increasing strain may prompt carers to question whether unpredictable care signifies relational untenability. Often carers choose to continue the relationship, making changes to relationship boundaries to balance the distribution of responsibilities between carer and PLWEI.

Presently, within Canada’s spectrum of care policy, the unrecognized and little-discussed misfit is episodic care. Carers who deliver supports at unpredictable times and for often unforeseen reasons are at the centre of a world of care delivery, doing the work of a carer without the aid of system-based episodic care supports in policy or practice. Carers themselves may not recognize the volume of care they perform as they go about doing what a good family member/friend would do. But definitions can change. To do so, social work research, education, and practice can invite participants to initiate discussions in relevant circles, moving toward
social change. As an applied discipline, social work practice uses a social justice perspective as a lodestar, arguably setting social work apart within the broader research, policy, and practice communities. Each facet of social work is important to the upcoming conversation about a more overall vision of care in Ontario, including episodic care.

The current definitions of public care policy across Canada fail to include episodic care, which effectually erases the work of episodic carers from the range of care provided. Maintaining current public policy definitions of care leaves carers in an “aura of invisibility” in public policy (Bowden, 2008, p.5). Contrarily, the project participants shared a wider array of Episodic Care provision than is publicly acknowledged. Moving beyond this perspective of action-in-isolation toward a democratized approach to care involving carer and PLWEI as influencers of public policy, Joan Tronto (2013) proposes the concept of *caring with* a community-oriented way of considering all involved in care as active participants. Active participation means involvement in the direct activities of episodic care and being involved in citizenship activities that connect what happens within the walls of the home, where much of care is provided, with social policy to facilitate a dialogue involving all who participate in care.

Politicized care interventions move beyond the practices or the *doing* to provide political and structural care supports. Care ethicists have called for a more in-depth exploration of contextualized policy development in Canada and internationally through *situated care*, which is described as,

a relational ontology, which conceptualizes selves as fully relational – existing in and through complex, constitutive webs or relations with others; a focus on attention, responsiveness, and responsibility to the needs of particular others as core substantive moral values; a commitment to addressing moral problems in the historical and spatial
contexts of real, lived experiences; and, finally, a reconceptualization of traditional understandings of the nature of and relationship between the “public” and the “private” spheres (Robinson, 2011, p.131).

Through a broader reconceptualization of the interconnected levels of response that constitute care, within political, normative, economic, and cultural spheres, the relatively hidden presence of episodic care becomes more visible.

Situated care principles involve the pursuit of social justice within the micro experiences of daily care provision and are a form of context-bound social justice (Charmaz, 2014). In the context of episodic care, situated social justice involves individual carers who pursue the needs of PLWEIs against the countervailing social policy, which currently limits access to care resources for episodic carers. Situated social justice in this context also involves attention to the variability of care needs, which require constant vigilance from carers. Lastly, situated social justice is brought into the political sphere by carers who, based on lived personal experiences with episodic care, seek to pursue organizational policy reform within community organizations or as social policy advocates for episodic carers.

Thinking beyond the impacts and rationales for raising a conversation about episodic care, there is a more significant reason, a uniting ethics of care that binds together the unpredictable experience of being human. Western values of consistency and order clash with the daily experience of episodic care, creating a false perspective that predicting or controlling individual or population-level health is possible. The result is a social perception that illness should not occur, a view that denies a normal part of life. The task ahead is to develop a realistic vision of care in Ontario that includes the activities and people involved in episodic care, as well as how their lives are repeatedly impacted during care. A re-visioning of care recognizes the
increasing demands on episodic carers, making care delivery an option within a social system that recognizes and supports the tremendous work of carers. With vision and thoughtful planning, it will be possible to develop a system where care provision shifts away from being a forced choice to an informed decision and “feels not so much that something has been given but rather added to” (Noddings, 2013, p.20). The implications emerging from the findings of this study offer promise for change to a system that has long been separated from the everyday realities of episodic care.

5.5 Study Limitations

There are benefits and repercussions to researching from a cross-illness perspective. For cross-illness episodic care research to have meaning, there must be enough similarities to consider the illness groups sufficiently compatible. In this study, similarities do not refer to the illness origins or the treatment course. Instead, both illnesses show the hallmark trait of an ongoing unpredictable illness course, which makes planning for care difficult and have various bio-psycho-social impacts on the life of the carer. MS, even relapsing-remitting MS, has an eventual downward health trajectory, however, and fewer unpredictable episodes late in the illness course, as challenging as they might be (Bonsaksen, Fagermoen, Lerdal, 2014). Even though there are episodes where there may be a return to wellness, the illness path is different from HIV in that there is an anticipated eventual decline.

Aging with HIV is an emerging area of research; however, as the first cohorts to survive are approaching 35 years of living with the virus. Presently, there remains much to be learned about living long term with the virus, although current research indicates a course of accelerated
aging (Cohen & Torres, 2017; Horvath & Levine, 2015). Thus, there may be an eventual health decline in people living with HIV as new information emerges about the course of the illness (Wing, 2016). The development of new HIV treatments may also influence how the virus impacts the body. Thus, the model presented may be relevant for the period when the illness course of HIV is episodic. With this in mind, the Relational Model of Episodic Care focuses on the period where relapsing/remitting MS and HIV are episodic. When the illness progression becomes increasingly degenerative, other care models may be more useful to represent the care trajectory.

Additionally, the two episodic illness groups under study have differential impacts from social stigma. HIV transmission modes have been a subject of social and moral judgments since the beginning of the epidemic. In Canada, despite years of education on HIV, misinformation persists about the movement of the virus, the susceptibility of becoming infected, and treatment options, which results in stigmatized attitudes and beliefs (Tulloch et al., 2012). Stigma is also connected with the carer, known as stigma-by-association, based on the idea that family/friends travel in similar social circles (Pryor, Reeder, & Monroe, 2012). In contrast, stigma in MS is associated with loss of functional abilities, resultant reductions in productivity, and increased dependence on others. There is a perception that disclosure may result in stigma, making this a form of perceived stigma (Cook, Germano, & Stadler, 2016; Earnshaw, Quinn, & Park, 2012). In MS care, although illness diagnosis is not associated with moral attitudes, stigma is associated with the invisibility and mutability of the illness, possibly resulting in the silencing of MS carers.

Another limitation of the study is the challenge of using a term unfamiliar to many carers and professionals alike, episodic care. Potential participants may have seen the recruitment documents and questioned the applicability of their experiences to the study criteria. This may be
due to the limited way the term carer or caregiver is conceptualized in Canada, by a professional in a contractual paid position, or done in circumstances where health impacts of the person living with the disability are both severe and prolonged. Besides, chronic illness often falls outside of the definition of a permanent disability, such as a spinal cord injury or temporary disability, such as breaking a bone. The idea of an episodic, fluctuating form of disability is still gaining ground within research and community areas of practice. This challenge of awareness and acceptance may have limited the number of responses to the study call. Also, the need for carer intervention may be challenging to recognize as this type of care continues under the radar.

In terms of representation of all involved in a circle of care, the study sheds light on the diversity of different dyadic relationship identities developed by episodic carers. This study did not explore the relationships and relational identities of the people commonly involved in a care circle for someone living with HIV or MS. However, during data gathering, interviews were conducted with two carers for the same PLWEI. To understand the various relationships in episodic care, additional research with members of episodic care circles may help explain how episodic carers work together to support a PLWEI and facilitate carer access to social determinants of health when multiple carers are involved. Despite these limitations, this study contributes to the scarce literature on theoretical and practice frameworks describing episodic care by outlining relation-centred constructs.

5.6 Implications for Research, Policy, and Social Work Practice

Episodic carers face barriers to accessing system resources in a social system where local, provincial, and national policies do not recognize episodic forms of care in public policy.
Additionally, community leaders, advocates, and policymakers are mostly uninformed about the long term impacts of providing episodic care on carers and care circles, thus maintaining the challenges faced by episodic carers below the radar of social intervention. Episodic carers who experience increasing burdens over years of providing care may then search for community supports and find many doors closed.

One of the roles of social work advocates is to create openings, allowing more voices to influence social change. Now is the time to begin a multi-level dialogue on episodic care in Ontario. As such, carers may act alongside researchers, policymakers, and community practitioners to improve the experience of providing episodic care. This section will explore avenues for expanding the episodic care dialogue into the three areas of research, policymaking, and social work practice and education. Moving forward, interdisciplinary dialogue may connect future work in episodic care to allied health and social fields of practice.

5.6.1 Implications for research.

The research community has an essential role in making audible the voices of episodic carers by producing new knowledge to highlight the growing rates and implications of episodic care in Ontario. As a nascent area of research, much remains to be understood about the community-based needs of episodic carers. Several years ago, an Ontario-based scoping review provided a valuable list of resources available to episodic carers (Whitehead & Lero, 2014). Because much of care research has focused on specific illness groups, episodic chronic illness groups stand to benefit from cross-illness research. This approach has a higher likelihood of highlighting common issues, thereby better developing the scope of carer needs.
To coordinate research priorities, it may be useful to develop a research agenda to focus on the social and material aspects of the episodic nature of these illnesses, the resultant impacts on access to social determinants of health, and the practice of episodic care. Research projects focusing on macro and micro perspectives of episodic care can illuminate the range of episodic carer experiences. With the growing recognition of social determinants of health as contributors to the overall quality of carer health, future episodic care research priorities should explore access to housing, employment, income support, education, social aspects of community life, and the local built environment (Hankivsky & Christoffersen, 2008). Quantitative episodic care research may shed light on the numbers of people involved in episodic care and the most pressing barriers to social determinants of health access for carers. In comparison, qualitative research may focus on rich details of the stories of individual care journeys, gendered impacts of episodic care, or understanding episodic care endings to prepare carers for transitions from a care relationship. Lessons can be learned both from studying the experiences of carers themselves and understanding the health and social circumstances of the PLWEI.

Also important are the psychological determinants of health enacted in the daily lives of episodic carers in Canada (Akkuş, 2011). As noted in the study, the emotional impacts of care are some of the most challenging faced by episodic carers. As well, little is known about the roles and experiences of care circles in episodic care. Additional testing of the potential for shifts between the reciprocal care identity and either essential care or care exits would also be useful. Lastly, after exiting care, the transitions of carers may provide a path forward for carers struggling with unduly heavy burdens of episodic care.

As interviews present a point-in-time understanding of the many experiences associated with providing care, carer perspectives may continue to change over time. Funk and Stajduhar
(2009) note that using interviews in qualitative carer research will contain a confounding issue that limits how well carer research is represented, due to the lived experience of the carer. Carers are thus reflecting on their experiences with care provision while simultaneously trying to cope with the emotional side. Their recommendations to use long term approaches to research and observational techniques may help separate what may be coping mechanisms used by carers to continue forward and the relational experiences of PLWEIs.

5.6.2 Implications for policy.

The lack of recognition of episodic care is widespread and poorly understood by the general public, healthcare professionals, policymakers, and community organizations offering supports for carers. One example is the Employment Insurance Caregiving Benefit and Leave program, which recognizes forms of disability for people who are critically ill or injured (Government of Canada, 2019a). Episodic illnesses often fail to meet the threshold standard of critical. Carers are thus ineligible for the income support benefit, despite the ongoing provision of care. For PLWEIs with limited access to income supports, carers, at times, provide various forms of financial assistance, as noted in the study.

Nearly a decade ago, Manitoba became the first province to develop legislation for caregivers, known as the Caregiver Recognition Act, designed to increase awareness and recognition of Manitoba’s family caregivers (Government of Manitoba, 2011). In 2016, the Canadian Caregiver Coalition released a policy brief declaring supports for carers to be a fundamental human right. To increase supports for carers, Nova Scotia implemented a provincial carer benefit for adult carers who provide support to a family member/friend with significant
impacts due to disability or impairment, as determined by a home-based assessment (Province of Nova Scotia, 2018). The benefit includes providing care at more than 20 hours a week or more, a level of impact met by some who provide episodic care. With healthcare fluctuations, however, the ongoing need may vary from week to week. In some cases, carers of PLWEIs might be eligible for this benefit; however, the provision of 20 hours per week or more may be difficult to meet for carers of PLWEIs who experience periods of relative wellness.

In a recent attempt to recognize and legitimize episodic care, the Federal Government, as part of the first national disability act, Bill C-81, the Accessible Canada Act, defines disability as:

any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society (House of Commons, 2019).

The bill received Royal Assent in June 2019 but is still the subject of significant debate within the disability community regarding the perceived reach of the new act. This addition of episodic as part of the definition of disability lends credence to care as having starts and stops; a subsequent step will be to formalize a definition of episodic care. Developing and educating key audiences to an expanded definition of care, including episodic care, will enable more carers to access supports before the strain becomes difficult to bear. Toward this end, initiating public conversations about episodic care may have a legitimating function for recognizing episodic care and may also create discussion space to consider beneficial community supports for carers. The
unrecognized uniqueness of care for PLWEIs with unpredictable fluctuating illness is particularly relevant to audiences, including carers, physicians, CBOs, and the general public.

The 2017 Canadian Survey on Disability (CSD), three questions helped identify the populations in Canada living with an episodic illness (Statistics Canada, 2017b). This survey is the first known public initiative to explore the disabling experience of episodic illness on a national level, as well as the experience of providing episodic care, indicative of increased recognition of the distinct nature of episodic illnesses. Additionally, recent literature has provided information regarding the scope of care in Canada. During 2018, as part of the nationwide General Social Survey (GSS), the federal government conducted a survey entitled “Caregiving and care receiving” (Statistics Canada, 2019b). At the time of this dissertation report, the results of the GSS study were not yet available. As a result, little is understood about the population-level characteristics of episodic carers. Given the lack of recognition of PLWEIs as requiring care, the rates of support may be higher than reported.

At the community-level, service supports for carers are often illness-specific. There are carer resources within several HIV organizations in Toronto, and MS carer resources exist in regional chapters in several areas. Unlike other disability organizations, the approach of the MS Society is bold. When a friend/family member is diagnosed with MS or a suspicion that a diagnosis of MS is forthcoming, the MS Society can be contacted for additional information on the expectations and supports related to living with the chronic illness. When a friend/family member contacts the MS Society, the organizational practice uses the label of carer for the family member/friend, often from the first point of contact (Multiple Sclerosis Society of Canada, 2008; Packenham, 2012). Considering how the label of carer impacts the self-concept of the friend/family member and the nature of the relationship with the person diagnosed with MS,
it may help expand definitions of caring. Community organizations can take a leadership role in reflecting a more expansive carer definition to improve access to supports for episodic carers.

In recent decades, public support for carers in Ontario has declined as the province has sought to make family/friend care the new normal for supporting someone with a chronic illness (Coyte & McKeever, 2016). Regressive policy decisions have increasingly shifted the responsibility for episodic care from the health system to the shoulders of family and friend carers. While some may view this shift to family/friend care as positive, Kleinman (2009) has encouraged perspective in guarding against utopian perspectives of family/friend care. Instead, it is recommended that family/friend care provision be an option and one in which carers are well supported in their role. Ideally, this will translate into better-informed public and private care policy that considers the full impact of care on all life areas and is ultimately more compassionate and humane. Levine (1998) refers to this as the setting of *fair limits* on the sacrifices made by carers (p.172). The responsibilities of care often translate into a significant burden (Adelman et al., 2014), including the risk of burnout (Li et al., 2015).

From an employment perspective, although government and employer-initiated labour policies and practices exist to improve employment opportunities for carers, these often are developed with economic intent designed to avoid legislative penalties levied against organizations that fail to comply with publicly mandated employment equity practices (Bornstein, 2013). Punitive legislation does little to motivate improvements in practice. Unfortunately, the pressure to initiate policies recognizing the unique needs of carers occurs only when an issue is relevant to governments or when labour market shortages are experienced (Varecamp et al., 2009). At the organizational and systemic levels, ideologies may lean toward opportunities that favour the employer (Lysaght, Krupa, & Gregory, 2011), which may leave
carers with reduced choice over career paths and professional development. Responses from employers to these challenges are varied, with many employers waiting until a crisis occurs before considering the unique needs of the employee. Improved opportunities may exist in workplaces with insurance programs that make resources available to workers. Still, insurance access varies from region to region in terms of available resources and their access requirements.

Episodic care policy discussions are in the early stages, but there is growing interest in working toward solutions to benefit all types of family/friend episodic carers. Although social policies exist to improve employment opportunities for people with disabilities, episodic carers often find themselves outside the reach of flexible policy options. Thus, consideration should be given to flexible employment policy that provides carers rights under Duty to Accommodate provisions in provincial and federal legislation. Otherwise, carers may have reduced career path options and professional development, as care requirements create unpredictable employment involvement.

With the growing influence of neoliberalism, individualism, and self-management have become central principles, resulting in carer isolation (Han, 2017). The current Ontario health system supports independence but not interdependence, even though interdependence is associated with improved health outcomes for carers and PLWEIs (Suro & Weisman de Mamani, 2013). Carers need understandable and timely information, better preparation, and guidance in understanding the responsibilities of care and long term decision-making and training for the technical and emotional aspects of care. Carers also need compassionate recognition of their anxiety, challenges, and hard work (Levine, 2004). All these factors point to a need for thoughtful policy translated into programming by all levels of government.
5.6.3 Implications for social work practice and education.

For carers, the early years of episodic care are fraught with questions and uncertainties, with shifts in the health course of the PLWEI and the emerging relationship between the carer and PLWEI, while struggling to navigate the relational journey of episodic care. Faced with increasing pressure to provide healthcare no longer delivered through the formal system, carers become involved in physical and emotional healing (Williams & Crooks, 2008). Family/friend carers become managers and coordinators of care, advocates on behalf of family members and friends, and therapists who provide emotional support, in addition to other semi-professional and supportive roles. Few information resources exist to prepare carers or alleviate carer burden, which is a problem in Ontario and nationally (Black et al., 2010; Taylor & Quesnel-Vallée, 2016).

The primary healthcare team, including physicians, nursing staff, and therapists, are tasked with restoring health, including making diagnoses, medication selection and regimen changes, completing required paperwork to access programs and services, making referrals, and providing information (Marsh, 2018). Social work practitioners, along with healthcare providers, are central to raising awareness for carers, early in the illness course, of the unpredictable path ahead and the likely need for community support (Kodner & Kyriacou, 2003). Social workers can also assist with coordinating supportive resources, primarily where episodic care occurs in a complex environment. Due to unique circumstances, each episodic carer would be best supported by individually tailored supports with a single point of entry to reduce the burden of requesting supports at multiple access points. In the absence of public education and supports, carers may have limited understanding of how to experience respite, information resources, and community
professionals between or during illness periods. Stakeholder education is thus a priority for supporting episodic carers.

In collaboration, researchers and community-based supports can develop accessible information to help recognize relational episodic care, understand the illness trajectory, and make available what community-based and electronic resources exist to support carers. Professional groups that may benefit from episodic care training include physicians, nurses, personal support workers, and staff of disability organizations. Professionals across various health domains are encouraged to become more aware of the pressures faced by episodic carers when interacting with clients. Complementing stakeholder training will be the development of training resources for episodic carers about the shifts in the illness course and expectations during care provision. The broader public will also benefit as episodic care terminology gains legitimacy through association with established organizations in the community.

As system navigators, community innovators, and educators, social work practitioners play a central role in establishing systems to support episodic carers where they live and work. Many carers will benefit from professional counselling supports throughout the journey of providing care, especially when individual carers need it most. For episodic carers who pass through multiple transitions during care, providing anticipatory counselling in advance of illness episodes may help prepare for the unexpected (Collins & Swartz, 2011). Social work practitioners are adept at working with individual client strengths and can support carers with learning care-related skills such as advocacy and time management. Social workers may also assist with the training of healthcare professionals and community leaders to create linkages between carers and community resources.
Early and ongoing carer access to medical information and local support resources is crucial to assist with medical decisions. Allied health professionals can educate carers about their scope of work, which may aid carers in making decisions about resource access. Community organizations can serve as sources of information referrals for carers to reduce the isolation associated with care. In partial response to the commonalities across forms of care, the province of Ontario has been developing a digital information resource hub for carers. The website links carers to resource information, carer-related news information, and community referrals on various topics (Ontario Caregiver Organization, 2018).

For carers who provide supports via a CBO connection, questions arise regarding the responsibility of the organization to ensure continued support to the episodic carer. At a minimum, organizations may want to consider the individual and collective burdens experienced by episodic carers following diagnosis and throughout care provision to minimize burdens placed on carers and care circles. Additional supports, such as transportation assistance and support staff to offer reprieves from care duties, may be useful. Organizations may also consider acknowledgments of gratitude for the efforts made by episodic carers to provide supports, whether that be via volunteer recognition, awards, simple gifts, or additional training.

Opportunities exist to improve the coordination of current supports to reduce systemic redundancies, where multiple services provide similar forms of supports. Reviewing administrative entanglements may lessen the challenges associated with navigating the existing labyrinth of available programs and services (Romanow, 2002). The use of technology to provide additional resources to remote and rural communities can provide an added benefit, although, ultimately, direct and interpersonal forms of support remain the preferred standard. Recognizing the often-long term nature of care delivery and the value of having carer supports in
place, episodic care is part of the present and future of Ontario healthcare. As such, the time has come to bring stakeholders together to plan for improved future opportunities to recognize and value the work of episodic carers.

5.7 Conclusion

This dissertation explored relational impacts of unpredictable episodic care provision in Ontario. For each of us, uncertainty plays a role in our lives. We plan, we prepare, and yet there are elements beyond our control. Episodic care may feel like an emotional rollercoaster given the multiple ways care occurs, which shift over time. The forms of care are non-standard. The health episodes are unpredictable. The environment of care is uncertain. Among all the uncertainty, dedicated long-lasting relationships between carer and PLWEI persist. As episodic carers have shared, these relationships are frequently strained by limited access to resources and a narrow understanding of episodic care itself.

While carers function, arguably nobly, amid challenging circumstances, their burden is increasing. What remains to be developed and implemented is a vision for a more inclusive culture of care – inclusive of gendered care, inclusive of carers who themselves live with illness and disability, and inclusive of carers from the social margins. An alternate vision is possible, focusing more on the individuals involved in care, considering their present and future needs. Together we can build an integrated care-system in an environment that allows carers to live fully and thrive.
5.7.1 Reflexive thoughts.

A journey feels like a fitting metaphor for this dissertation, both as a personal process and descriptor for episodic care. Both are long roads, filled with twists and turns, challenging to envision what the day-to-day experience may be. During the time of data gathering and analysis, I reflected on the voice of the participants in the paper. Were their words reflected? I think the participants gave to the project more than was received, as they gave more than accounts but instead shared deeply personal circumstances that redirected the course of their lives.

Arriving at the model was itself a process of discovery. During the earlier phases of data gathering, the model was primarily descriptive. With the involvement of the dissertation committee, the project advisory committee, and personal reflection, the model transitioned from static labels to a process of carer identity development. For me, the revision speaks to the value of ‘sitting with the data,’ which involves both reflexivity and time, as concurrent, intersecting processes that contribute to insights not gained in any other way. Insights simply cannot be rushed but instead seem to have a timeline of their own.

For me, moving through this writing process, I again connected to my carer role, which I resumed at the very end of the dissertation near the start of the COVID pandemic restrictions in Ontario. This time around, I’ve begun doing things differently, such as reaching out to others around me to share the emotional burden of support, asking more questions, and learning about the health challenges faced by my parents. Although the past several months have been challenging, I now feel even more connected to the participant experiences shared during the interviews. The participants’ stories have come alive in many ways as I move through the
learning curve of illness-specific language, learn how to use homecare technologies, and advocate with the hospital and medical teams for improved care options.

Although this project focused on adult-to-adult care, the relational changes, the shifts and fluctuations that came to redefine who we were as a family in my own care experience connect me to the stories of the participants interviewed. From time to time, I found myself thinking back on my own experiences as I typed a transcript or worked on the writing. Care experiences run deep, as they connect to how we feel and, more broadly, how we understand ourselves. With my parents’ aging, I still consider myself a carer, although one providing care due to current circumstances. As the years have passed, the thoughts and feelings have stayed with me, becoming a part of the person I am now. Participants were often uncertain about their futures, and many expressed the hope that systemic changes would recognize the work they do to improve the circumstances for carers yet to come.

Perhaps one day, we may not need the *episodic* label. This project is envisioned as a conversation starter and less a system to classify types of carers. The intent is to expand how we conceptualize carers, to give voice to the people who provide labour and emotional toil day after day, month after month, and year after year. The definition of who is a carer can be expanded. More resources can then be developed for PLWEIs needing community-based support, thus making episodic care an informed choice for family/friend carers.
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Episodic Caring: Exploring Life Impacts from an Unpredictable Caring Role

Do you provide assistance periodically to a family member/friend/significant other with HIV or MS who is 18 years or older?

Do you live in southern Ontario (Windsor, London, Hamilton, Toronto or surrounding areas)?

Are you at least 18 years of age?

If so, you are invited you to participate in this research study

WHAT IS THE STUDY ABOUT?

Episodic illnesses are chronic illnesses, unpredictable in their length, severity, and occurrence. Many people living with episodic illnesses have one or more people who provide supports with various life activities. Providing this type of assistance is sometimes known as *episodic caring*. Little is understood about the how carers are impacted by unpredictable, episodic caring and what
types of supports might help episodic carers continue to be emotionally and physically well, as well as able to access basic necessities of life.

**WHO IS RUNNING THE STUDY?**

Melissa Popiel, MSW, a PhD candidate at the Faculty of Social Work at Wilfrid Laurier University is conducting this study as part of her dissertation research. If you have any questions or concerns about the research, please feel free to contact Melissa at mpopiel@wlu.ca. Her thesis advisor is Dr. Eliana Suarez who can also be contacted at esuarez@wlu.ca.

**WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this project is to better understand the life and health experiences of people who provide unpredictable episodic caring supports for a family member/friend and live in Southern Ontario.

**WHAT WOULD I HAVE TO DO?**

If you agree to participate in this study, you will be asked to participate in one interview for approximately 90 minutes. Your responses to the interview questions will add to the understanding of the life and health needs of episodic carers.

**WHAT ARE THE RISKS?**

For those participating, questions will be asked of a personal nature which may trigger emotional responses. If this happens, support will be provided to participants which may include: pausing the interview, stopping the interview, and/or a referral to counselling supports. The interview may be paused or stopped without any negative consequences.
WILL I BENEFIT IF I TAKE PART?
Your responses to the interview questions will add to our understanding of how episodic carers are impacted by their caring responsibilities in their daily lives and over time and contribute to the development of a new model of the experience of episodic caring. It is possible that practitioners and organizations who provide supports to episodic carers may improve their practice through your participation in this project.

DO I HAVE TO PARTICIPATE?
Participating in this research is completely up to you – You may freely choose not to participate in this project at any time without any negative consequences including any penalty or loss of benefits of any kind. However, if you withdraw from this research project, all data you have provided will be retained for analysis purposes.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?
If you agree to participate you will be asked to provide your name, and your email address or other contact information to enable us to contact you to arrange an interview. Basic demographic details will also be asked on a questionnaire. All interviews will be audio recorded and transcribed later for analysis purposes.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?
You will receive $30 for participating in this project.
WILL MY RECORDS BE KEPT PRIVATE?

You will be asked to provide a pseudonym that will be used to identify you on transcripts. All of the results will be kept confidential. If you decide to participate, nobody except for the researcher will have access to your information. All electronic data (e.g., audio files, transcripts, and research related documents (e.g., consent forms) will be kept in a password secured computer and in a locked filing cabinet at the Faculty of Social Work.

The results of this study will be presented at conferences and published in the format of reports or journal articles but participants will not be identified in any way.

HAS SOMEONE HAS CHECKED IF THIS PROJECT IS OKAY?

This project has been reviewed and approved by the Wilfrid Laurier University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University (519) 884-1970, extension 4994 or rbasso@wlu.ca (REB tracking number: REB4933).

If you would like to know more about something mentioned above, or information not included here, please contact Melissa Popiel at mpopiel@wlu.ca

Thanks for your interest in the project.
Appendix D  HIV Recruitment Flyer

Research Study Looking for people who support someone with HIV

Who can participate?

- Adults living in south-western Ontario assisting an adult family member/friend/acquaintance/other living with HIV

What Participants Can Expect

- A one-time in-person interview
- A thank you gift of $30

This project has been approved by Wilfrid Laurier University Research Ethics Board - Ethics ID: REB4933.

For additional information please contact: MPopiel@wlu.ca or 416-458-5623 (text or voice mail)
Research Study Looking for people who support someone with HIV or MS

Who can participate?
- Adults living in south-western Ontario assisting an adult family member/friend/acquaintance/other living with HIV or MS

What Participants Can Expect
- A one-time in-person interview
- A thank you gift of $30

This project has been approved by Wilfrid Laurier University Research Ethics Board - Ethics ID: REB14933.

For additional information please contact: MPopiel@wlu.ca or 416-458-5623 (text or voice mail)
Appendix F Participant Informed Consent Statement

WILFRID LAURIER UNIVERSITY FACULTY OF SOCIAL WORK

TITLE: Episodic Caring: Exploring Life Impacts from an Unpredictable Caring Role

INVESTIGATOR:         ADVISOR:

Melissa Popiel, PhD Candidate       Dr. Eliana Suarez, PhD
Faculty of Social Work               Faculty of Social Work
Wilfrid Laurier University          Wilfrid Laurier University
75 University Ave West               75 University Ave West
Waterloo, ON, N2L 3C5                Waterloo, ON, N2L 3C5
Email: mpopiel@wlu.ca                Phone: (519) 884-1970 x. ext.5273
                                     Email: esuarez@wlu.ca

You are invited to participate in a research study. The following document outlines the purposes of the research and the role of participants. This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or
information not included here, please contact the researcher. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

**BACKGROUND**

Episodic illnesses are forms of complex chronic illness that are unpredictable in their length, severity, and occurrence, such as HIV and some forms of MS. Many people living with episodic illnesses have one or more people who provide supports with daily life tasks (cooking, cleaning, etc.), managing health-related circumstances (i.e. scheduling appointments), and/or with providing assistance with health maintenance (i.e. with medications, treatments, etc.). Although these supports may be performed out of duty to a loved one or as simply as something a friend/family member would do, they represent a form of caring also known as episodic caring. This type of caring is under-represented in research and little is known about the various types of supports that might help episodic carers to continue to be emotionally and physically well, as well as able to access basic necessities of life such as employment, housing, and income supports.

**WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this project is to better understand the life and health experiences of adults who provide unpredictable episodic caring supports for an adult (18 years old or older) family member/friend/significant other living with HIV or MS and live in southern Ontario. Approximately 30 people will be participating in the study from around the region.

**WHAT WOULD I HAVE TO DO?**
If you agree to participate in this study, you will be asked to participate in one interview for approximately 90 minutes which will be audio recorded. Later in the study comments on the study findings will be sought from participants who are interested and/or available to provide feedback. Any follow-up conversations will be voluntary.

**WHAT ARE THE RISKS?**

There are minimal risks for participating in this study. Your responses to the interview questions will add to the understanding of the life and health needs of episodic carers. For those participating, questions will be asked of a personal nature which may trigger emotional responses. If this happens, support(s) will be provided to you which may include, pausing the interview, stopping the interview, and/or a referral to free counselling supports. The interview may be paused or stopped without any negative consequences.

**WILL I BENEFIT IF I TAKE PART?**

Your responses to the interview questions will add to our understanding of how episodic carers are impacted by their caring responsibilities in their daily lives and over time as well as contribute to the development of a new model of the experience of episodic caring. It is possible that practitioners, organizations, and/or policymakers who provide supports to episodic carers may improve their practice through your participation in this project.

**DO I HAVE TO PARTICIPATE?**
**Participating in this research is completely up to you** – You may freely choose not to participate in this project at any time without any negative consequences of any kind including any penalty or loss of benefits to which you would be otherwise entitled as an employee in your agency. If you withdraw from this research project all forms and data collected from you will be deleted.

**WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

You will be asked basic demographic details on a brief questionnaire concerning your gender, age, ethnicity, years of group work experience, and education. All interviews will be audio recorded and later transcribed for analysis purposes.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will receive $30 for participating in this project.

By law, we are required to inform you that any funds earned through participating in research studies are to be reported to the Canada Revenue Agency, if applicable.

**WILL MY RECORDS BE KEPT PRIVATE?**

You will be asked to provide a pseudonym that will be used to identify you on transcripts. All of the results will be confidential unless disclosure is required by law or applicable ethical codes.

All data (e.g., audiotapes, questionnaires, transcripts, datasheets) and research related documents (e.g., consent forms) will be kept secured electronically and in hard copy.

An advisory committee will guide the process and dissemination of this research project. But if you decide to participate, nobody except for the researcher and her thesis advisor will have
access to your completed questionnaires, interview/focus/support group tapes, and transcripts.

The results of this study may be presented at scholarly conferences and published in journals. All results contained in any presentations and publications will be anonymous; no individual will be identified in any of the write-ups. All responses to the questionnaires will be reported in aggregate form only, however, some of the responses and comments shared with the researchers may be reported to illustrate specific themes. However, your identity will not be disclosed, and all details that may potentially identify you will be excluded from any published statements.

**CONTACT INFORMATION**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Melissa Popiel, at 75 University Ave West, Waterloo, ON, N2L 3C5 or email: mpopiel@wlu.ca. Alternatively, Dr. Eliana Suarez, the advisor to this project may be contacted at 120 Duke Street West Kitchener, Ontario, ON, N2H 3W8 or Phone: (519) 884-1970 x. ext.5273 or email: esuarez@wlu.ca

This project has been reviewed and approved by the University Research Ethics Board (REB #4933). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may also contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 4994 or rbasso@wlu.ca
SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. If you have further questions concerning matters related to this research, please contact: Melissa Popiel at mpopiel@wlu.ca

Participant’s Name ____________________________ Signature and Date ____________________________

Investigator’s Name ____________________________ Signature and Date ____________________________

Witness’ Name ____________________________ Signature and Date ____________________________

A signed copy of this consent form has been given to you to keep for your records and reference.
Appendix G  Participant Demographics Questionnaire

First Name & Last Name Initial (e.g., Sean S.) ____________________ Date__________

Responses to the following questions are voluntary. Please select a response that best fits you and your life circumstances.

1. Participant Gender (circle):  Male    Female    Trans    Non-Binary    Other

2. Number of years supporting family member/friend/significant other with an episodic illness:_____


4. Are you presently a student (either full or part-time)?    Yes    No

5. Employment Environment (check most relevant):
   _____ Non-profit agency    _____ Government agency    _____ Agricultural
   _____ Education    _____ Construction    _____ Manufacturing    _____ Finance
   _____ Service Sector    _____ Health care    _____ Professional/scientific/IT
6. Type of community where you live (rural, town, city, large urban centre):_________________

7. Participant Age Group: (circle one):

18-24  25-34  35-44  45-54  55-64  65+

1  2  3  4  5  6

8. Relationship Status (circle one):

Single  Widow/Widower  Divorced  Separated  Married/Common Law

1  2  3  4  5

9. Participant Religious Observance (check primary):

_____ Aboriginal Spirituality    _____ Buddhist    _____ Christian

_____ Jewish    _____ Hindu    _____ Muslim    _____ Sikh

_____ None (Atheist)    _____ Other (Please describe) ____________________
10. Participant Education (select one):

_____ Less than high school (no certificate, diploma or degree)
_____ High school certificate or equivalent
_____ Apprenticeship or trades certificate or diploma
_____ College, CEGEP or other non-university certificate or diploma
_____ University certificate or diploma below bachelor level
_____ Bachelor's degree
_____ Master's degree
_____ Doctorate

11. How do you best describe your ethno-cultural identity (e.g. South Asian, East European, French Canadian, etc.)? __________________________________________________________________________

12. Income

Personal Income (000’s)  (circle one):
< 20  20-30  30-40  40-50  50-60  60-70  70-80  80-90 >90
1   2   3   4   5   6   7   8   9

13. Abilities

Do you experience a mental or physical challenge (disability)? (circle) Yes No
If so, please specify__________________________________________________________
14. Sexual Orientation *(select one primary)*:

- Gay  
- Transsexual  
- Bisexual  
- Heterosexual  
- Questioning  
- Lesbian  
- Other

15. Citizenship and Immigration status *(Select one)*:

- Canadian citizen  
- Landed Immigrant  
- Refugee  
- Working Permit  
- Student Visa  
- Other

16. Years in Canada

- Canadian born  
- Newcomer (less than 5 years)  
- 5-10 years  
- More than 10 years

17. Please think about a pseudonym (fictitious name) to be used to identify your comments on all transcripts.

Pseudonym for transcripts: ________________________
Last three digits on your postal code: ____________

18. Are you interested in being contacted for your opinion on how the results of this study are analyzed? (Circle) Yes / No

If yes, please provide the following:

Contact Name: ______________________

Primary phone number: ____________________

Or Email address (please print clearly): ____________________
Appendix H  Qualitative Interview Guide for Participants

Participants will be invited to respond based on individual interpretations of word meanings, integrating personal context and lived experiences. Prompts, as outlined below, will be used as appropriate.

The term episodic carer will be used. An episodic carer is someone who provides additional supports unpredictably to a family member/friend who is living with an episodic illness.

Emergent Research Question

What are the relational impacts of Episodic Care on HIV and MS carers?

Interview Questions

Related to the episodic nature of caring

1. How might you describe your experience with providing episodic supports to your family member/friend with an episodic illness? (Probe: for life experiences/examples/situations, with an emphasis on the unpredictable nature of the care)

2. What does ‘episodic caring’ mean to you?

3. In what ways do episodes of illness and wellness impact on how you provide supports?

4. What types of caring supports do you provide? Have these supports changed over time?
   If so, in what ways? (Probe: for types of temporal activities of daily life – housekeeping/cooking/bathing, managerial tasks, emotional assistance, and health-related supports?)

5. Are there others who provide assistance to your family member/friend? What types of supports do they provide? How were the supports determined between you and the other(s) person?
Related to Personal Impacts

6. As a result of providing unpredictable supports, has your life been impacted? If yes, in what ways has your life been impacted most?

7. In what ways is your life different since you’ve been providing support compared with what life was like before?

8. Have you experienced losses as a result of the assistance you’ve given? Have you experienced any improvements in your quality of life?

9. During the time that you’ve been providing supports, have your caring responsibilities impacted on any of the following, such as your:
   - housing
   - job
   - access to education
   - income
   - physical health
   - emotional wellness
   - social supports

10. Have there been any broader social factors that have influenced how you provide supports (probe: political influences, economic changes, social trends)? If yes, can you describe in what ways you’ve been influenced?

11. What types of supports do you think might benefit you as an episodic carer? From the community? From policy makers?
12. What would you like policymakers to know about how episodic caring impacts on the lives of family/friend carers?

Additional questions related to self-perception of the caring role

Note: The following questions will be asked where additional explanation is helpful and to understand the relationship between the carer and the person living with HIV/MS, as well as the changes over time in the self-concept of the carer

13. How do you understand your role/s as an episodic carer?

14. What terms would you use to describe the various tasks and activities that you do?

15. To what degree do you feel responsible for the well-being of your family member/friend?

16. What do you do to help manage the unpredictable aspects of episodic caring?

17. What boundaries/limitations currently exist in your caring relationship? Are there any boundaries/limitations you would like to change?

18. Do you anticipate continuing to provide care/assistance in the future? If so, what do you think the types of support you provide may look like in the future?
Appendix I  Episodic Caring Dissertation Codebook

**Themes**

<table>
<thead>
<tr>
<th>Forms of Episodic Care:</th>
<th>Ways of caring in an episodic context</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Single dyad care</td>
<td>Approach to care network</td>
</tr>
<tr>
<td>• Collective care</td>
<td>Reciprocity in care network</td>
</tr>
<tr>
<td>• Exiting care</td>
<td>Types of supports provided</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Redefining the care relationship</th>
<th>On roles in episodic caring</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Impact of illness episodes on carer</td>
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<tr>
<td></td>
<td>Nature of caring relationship</td>
</tr>
<tr>
<td></td>
<td>Care timeline</td>
</tr>
<tr>
<td></td>
<td>Emotional impacts on carer</td>
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<tr>
<td></td>
<td>Navigating socio-relational impacts</td>
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<tr>
<td></td>
<td>Relational aspects to care</td>
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<table>
<thead>
<tr>
<th>Navigating Unpredictability</th>
<th>Approach to episodic nature of care</th>
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<tbody>
<tr>
<td></td>
<td>Types of supports accessed by carers</td>
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<tr>
<td></td>
<td>Experiencing the episodic nature of the illness</td>
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<tr>
<td></td>
<td>Shifts in care provision over time</td>
</tr>
<tr>
<td></td>
<td>Psychological impacts</td>
</tr>
</tbody>
</table>

**Families, Groups, and Codes**
Legends:

- **Yellow** – Coded 10 – 19 times
- **Green** – Coded 20 – 39 times
- **Red** – Coded > 40 times

Families in **bold**

Subgroups *italicized*

Codes in plain text

- based on number of codes to look for prominent themes, although outliers not ignored

**Defining Episodic Caring**

- [Approach to episodic nature of care](#)
- [Carer definition of episodic caring](#)

Carer insights into episodic caring term

Recognizing illness

**Types of Supports Accessed by Carers**

- [Access to medical supports](#)
- [Accessing spiritual supports](#)

Connections between social supports and wellness

Coping strategies

Experience of community supports

Forms of self-care
UNPREDICTABLE PATHS INTO CARE

Healthy diet as care

Supports accessed by carers

Sense of community as important

Support through long-term care

Use of mental strategies to cope

Use of systemic supports

Ways of staying connected

**Experiencing the Episodic Nature of the Illness**

Care timeline

Carer dealing with uncertainty

Challenge of providing care

Complexity of care needs

Confusion of navigating system

Distance as a challenge

Episodic nature of illness

Episodic illness as unfair

Experiencing losses

Frequency of care

Intersections of MS and other health issues

Making sense of changes

Medication interactions

Navigating episode of illness
Progression of illness

Stabilization of illness

Variation in support needs

Ways of Caring in an Episodic Context

Approach to network care

Boundary testing in network care

Care as meeting basic needs

Carer as primary carer

Caring for others as expression of gratitude

Caring in a network

Empathy as strategy

Ensuring a safe environment

Exercising faith in process

First nations approach

Influenced by others to care

Involvement of multiple carers

Making decisions about who receives care

Manipulation in network care

Non-primary support

Other members of care circle

Personal story as point of connection in network care
Provision of care to multiple people over time
Range of caring experiences

Reciprocity in network care
Responsibilities of primary carer
Trust as factor in network care provision
Types of supports provided
Volunteerism in network caring
Willingness to provide additional supports

On Roles in Episodic Caring

Roles in the context of HIV

Roles in the context of MS

Blurred lines of professional and personal care

Bringing aspects of self into caring
Caring as personal calling
Creating new priorities
Differences between primary and non-primary care
Focusing on meeting needs of the other
Involvement in social causes
Looking to change patterns of care
Modelling good practice
Obtaining/acting on power of attorney
Openness to additional caring opportunities
Preferred term to be called

Presenting a social face to community

**Role of managing care**

Viewing self in other’s shoes

---

**Shifts in Care Provision Over Time**

Anticipating future needs

**Attitude toward care provision**

Challenge of instability of care

Dividing activities of daily living

Escalation in care needs

**Limitations to supports provided**

Looking backwards to understand

Negotiating care supports

Normalizing care

Noticing patterns in the episodes

**Placing boundaries on supports provided**

Pre-diagnostic uncertainty

**Preparation to care**

Preparing to access supports

Reason for stopping care

**Response to diagnosis**

Searching for treatment options
Impact of Illness Episodes on Carer

Altered future plans

Benefits and repercussions to caring

Caring at a personal cost

Changes to care recipient

Communication with systemic supports as barrier

Comparing with others

Dealing with cultural impacts

Dealing with life threatening situation

Dealing with loss of control

Education impacts

Emotional aspects to care

Emotional impacts on carer:

Emotional impacts of living with episodic illness

Employment impacts

Fear of stigma

Feeling mistrusted by system

Feeling supported in making decisions

Flexible nature of employment

Financial impacts

Financial resources to access additional supports

Growth through providing support
Grieving what could have been
Humanizing care
Humour as empathic connection
Illness puts life into perspective
Impacts due to stigma
Limited impacts from caring
Looking for meaning in care
Maintaining positivism
Maintaining sense of normalcy
Making scheduling adjustments
Mixed feelings about caring
**Navigating socio-relational impacts**
Not wanting to be a burden to others
**Personal benefits from caring**
Personal instability
Points of frustration for carer
Potential for burnout
Preparing for worst case scenario
**Psychological impacts**
Silencing carer
Social impacts
**Stress impacts**
Systemic impacts
Time as a factor in meaningful care

Trauma of caring

Traumatic experiences with care

Types of care challenges

Types of mental health impacts

Types of physical impacts

Unmet life expectations

Nature of Caring Relationship

Changes due to care provision

Desire for expressed gratitude

Fear of loss of relationship

Network care as relational

Relational aspects to care

Relational impacts

Relational improvements

Repeated relationship concerns

Working through relational impacts

Caring from a Systems Perspective

Desire for additional supports

Advocating for care recipient
Desire for additional supports

Disappointments accessing personal care supports

Maintaining structural inequity

*Initiating Change within the Community*

Strategies to accessing care supports

Support of care allies

*Proposed Suggestions for Systemic Improvements*

Advice for policy makers

Suggestions for carers

*Suggestions for systemic improvements*
References


*Guidelines for prevention and treatment opportunistic infections in HIV-infected adults and adolescents.* Retrieved from

https://www.cdc.gov/mmwr/preview/mmwrhtml/rr58e324a1.htm/rr5516a1.htm


doi:10.1016/j.jaging.2005.08.001


doi:10.1016/j.jpubeco.2011.09.001


https://doi.org/10.1177/0164027514549258


SAGE.


Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE.


https://doi.org/10.1177/0886109911405485


http://dx.doi.org/10.1037/h0090598


general population. *Clinical Infectious Diseases*, *53*(11), 1120-1126.

https://doi.org/10.1093/cid/cir627


https://doi.org/10.1177/1352458517690270


Ho, J. W., Kuluski, K., & Im, J. (2017). “It's a fight to get anything you need”—Accessing care in the community from the perspectives of people with multimorbidity. *Health Expectations, 20*(6), 1311-1319.


Ironson, G. (2007). Altruism and health in HIV. In S. G. Post (Ed.), *Altruism and health: Perspectives from empirical research* (pp. 70-81). Oxford University Press.


[https://doi.org/10.1093/cid/ciu701](https://doi.org/10.1093/cid/ciu701)


Shier, G., Ginsburg, M., Howell, J., Volland, P., & Golden, R. (2013). Strong social support services, such as transportation and help for caregivers, can lead to lower health care use and costs. *Health Affairs, 32*(3), 544-551.


https://doi.org/10.1016/j.jana.2017.05.006


http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.130.2579&rep=rep1&type=pdf


