Who is on the Team? Exploring a Person-Centred Care Approach on an Interdisciplinary Healthcare Team, from the Healthcare Provider’s Perspective.

Bianca Fucile, BSc

Submitted in fulfillment of the requirements for the degree:
Master of Arts in Applied Health Science
(Community Health)

Supervisor: Dr. Madelyn Law (PhD)

Faculty of Applied Health Sciences, Brock University
St. Catharines, Ontario

Bianca Fucile © June 2019
Abstract

The purpose of this study was to gain an understanding from the perspective of healthcare providers how person-centre care ideologies are translated into day-to-day practice at an oncology center. This was a single case study, conducted at a local Oncology Center. The study included 15 interviews with healthcare providers, the analysis of 15 documents, and the keeping of a reflexive research journal. Four themes and ten sub-themes were found to represent the experiences of healthcare providers: (1) Educating with Empathy (2) Informed Personal Advocate, (3) Being the “Rock”, and (4) Progressing as a Team. This study demonstrates the roles of healthcare providers, patients and caregivers on a healthcare team committed to delivering person-centred care. It also introduces a new kind of team, a person-centred care team along with complimentary guiding principles to inform the practices of healthcare providers. This study contributes to the shift in the culture of care in oncology, where patients and caregivers are welcomed onto their healthcare team.
Acknowledgements

I would first like to thank my thesis supervisor Dr. Madelyn Law. Your support, knowledge and encouragement has been invaluable to me throughout my years at Brock University. In my third year of undergraduate studies, Dr. Law first introduced me to research and it was from that point on that I become passionate about person-centred care and healthcare teams. From this initial experience, it felt natural to continue working with Dr. Law and it was an exciting transition into a Masters program. You have demonstrated your dedication as a researcher, mentor, and teacher throughout the completion of my thesis, I could not be more grateful!

I would like to thank my committee members Dr. Colleen Whyte, Dr. Irene Podolak and Dr. Joe Norris for their guidance throughout my Master’s degree. Your expertise in research and your willingness to guide me through this process was extremely helpful and I am truly appreciative. I have learned so much from all of your thoughtful and constructive feedback, it not only enhanced my research skills but elevated my final thesis document.

Mom, Dad and Marty, thank you for your unconditional love and support during this time and always! Having three teachers as parents has taught me that learning is a life long process and to never shy away from a challenge. Thank you for instilling in me to work hard, stay humble and be kind.

I would like to thank Andrew for being my supporter and editor! You continually provided me with words of encouragement and cheered me on along the way. You also offered your keen eye for improper sentence structure and grammatical errors, very grateful for this and I am sure my committee was too.
Thank you to my Brock colleagues, Melanie, Kaitlyn, Tia and Harish. You provided me with the community and the laughter that I needed during this process. I cherish the times we had together in the graduate office. Congrats to all of us, because we did it!

Dr. Pietrangeli, thank you for your open door policy and sage advice. There were many times that I leaned on you and without fail you were there to extend a listening ear and helpful hand.

To my friends, Phoebe, Jessica, Dalton, Charlotte, Cassandra, and Robbie, we have all experienced many transitions and milestones together. I am very lucky to have such a supportive network of friends. Thank you for sharing in my challenges and successes!

I would like to acknowledge the financial support I received from the Ontario Graduate Scholarship and Brock University’s internal graduate scholarships.

Lastly, I would like to thank my participants, without them I would not have been able to achieve what I have. I truly appreciate their willingness to participate and the trust they put in me to tell their stories!

Thank you!
# Table of Contents

## Contents

Abstract ................................................................................................................................. ii
Acknowledgements ............................................................................................................... iii
Table of Contents .................................................................................................................. v
List of Table and Figures ...................................................................................................... viii

- Foundational Practices ..................................................................................................... 1
- Current Healthcare Context .............................................................................................. 3
- Levels of the Healthcare System ...................................................................................... 4
  - Micro ................................................................................................................................. 4
  - Meso ................................................................................................................................. 4
  - Macro ................................................................................................................................ 5
- Significance ......................................................................................................................... 5
- Document Overview .......................................................................................................... 7

Chapter 2: Literature Review ............................................................................................. 9
- Teams ................................................................................................................................... 9
  - Teams and Groups in Oncology ................................................................................... 11
  - Team-Based Care ......................................................................................................... 12
  - Team-Based Care in Oncology .................................................................................... 15
- Patient-Centred Care ........................................................................................................ 21
- Person-Centred Care in Oncology ................................................................................. 24
- Patient’s Perspective ......................................................................................................... 26
- Healthcare Providers Perspective .................................................................................... 28
- Making Patients Team Members ...................................................................................... 29
  - Shared Decision Making ............................................................................................... 29
  - Patient-Centred Interdisciplinary Teams ..................................................................... 30
  - Patient-Centred Collaborative Care ............................................................................. 31
- Overview of Literature ....................................................................................................... 31
- Gap in the Literature ......................................................................................................... 33
- Research Purpose and Questions ..................................................................................... 33

Chapter 3: Research Design ............................................................................................... 35
Positionality Statement ................................................................. 35
Qualitative Inquiry ........................................................................... 37
Methodology .................................................................................... 37
Types of Case Studies ....................................................................... 38
Single Case Study Design ............................................................... 38
Research Site ................................................................................... 41
Participants ...................................................................................... 42
Recruitment ..................................................................................... 42
  Individual Interviews ..................................................................... 45
  Document Analysis ...................................................................... 48
  Reflexive Journals ...................................................................... 49
Data Analysis .................................................................................. 51
Trustworthiness .............................................................................. 55
  Credibility ................................................................................... 56
  Transferability ............................................................................. 57
  Dependability ............................................................................. 58
  Confirmability ............................................................................ 59
Ethical Considerations ................................................................. 60
  Research Ethics Board ................................................................. 60
  Informed Consent ....................................................................... 61
  Confidentiality ............................................................................ 61
Chapter 4 – Findings ...................................................................... 63
Case Description – The Context ..................................................... 63
Theme 1.0: Educating with Empathy .............................................. 65
  Sub-Theme 1.1: Forming a Caring Relationship ......................... 66
  Sub-Theme 1.2: Supporting without Judging ............................ 69
Theme 2.0: Informed Personal Advocates ...................................... 71
  Sub-Theme 2.1: Identifying your Goals of Care ....................... 72
  Sub-Theme 2.2: Showing Up, Speaking Up, and Making a Decision . 74
Theme 3.0: Being the “Rock” .......................................................... 77
  Sub-Theme 3.1: Keeping the Patient on Track ......................... 78
  Sub-Theme 3.2: Providing the Inside Scoop ............................ 80
List of Table and Figures

Tables
Table 1: Different Types of Teams in Healthcare ......................................................12
Table 2: Definitions of Patient-Centred Care and Person-Centred Care ..................19
Table 3: Single Case Study and Multiple Case Definitions ......................................37
Table 4: Components of Case Study Research Designs .................................................39
Table 5: Participant Eligibility Criteria and Rationale for Participant Selection ..........43
Table 6: Guiding Principles for Progressing as a Team .............................................100

Figures
Figure 1: Diagram of Four-Level Health Care system ............................................3
Figure 2: Modified from Schwarz, Neuderth, & Gutenbrunner (2015). Continuum of team-based care models .............................................................12
Figure 3: Visual Representation of the Comparison of Patient-Centred Care and Person-Centred Care *Picker's 8 Principles and Cancer Care Ontario* ....................20
Figure 4: Data Analysis – Open Coding and Categorizing ........................................55
Figure 5: Person-Centred Care Team Makeup.........................................................96
Chapter 1: Introduction

Canada is facing a cancer crisis (Ahmed & Shahid, 2012; Faller, 2014; Canadian Cancer Society, 2005). Cancer is the leading cause of death in Canada with more people each year receiving a cancer diagnosis (CCS, 2017). With the yearly increase of risk factors causing cancer, such as outdoor air pollution, UV radiation, body weight, diet etc., it has been documented that one in four people will die from cancer, creating a rising public health concern. Prevention and protection techniques, such as screening, early diagnosis, exercise, and a healthy diet, are often cited as “lifesaving” practices within the healthcare system. The most recent statistic from the Canadian Cancer Society (2017) suggests that one out of every two people will receive a cancer diagnosis in their lifetime. Therefore, supports are required for cancer patients and their caregivers (CCS, 2017) to ensure that patients are receiving the care they want and need, as cancer is now being considered a long term, life altering experience (Naughton et al., 2012).

Foundational Practices

There are two models of care that have an integral part in servicing patients and family caregivers’ unique needs and wants, team-based care and person-centred care. Both models are considered foundational practices in oncology care (Azar et al., 2017; Bilodeau, Dubois & Pepin, 2015; Canadian Cancer Society, 2017; Cancer Care Ontario, 2017; Gagliardi, Dobrow & Wright, 2011; Lederman et al., 2012; McComb & Hebdon, 2013; Tremblay et al., 2014; Wright et al., 2009).

The Canadian Cancer Society states that a patient’s healthcare team can include over 30-healthcare providers, such as a dietitian, medical oncologist, and occupational
therapist, all of whom have their own specific roles, supports, and strategies for treating the patient. With the complex and long-term nature of cancer (Naughton & Weaver, 2014), healthcare providers are expected to collaborate with other healthcare professionals, creating a healthcare team (Azar et al., Gagliardi, Dobrow & Wright, 2011; 2017; Tremblay et al., 2014; Wright et al., 2009).

The purpose of forming a healthcare team that includes multiple healthcare providers is to effectively coordinate the patient’s care. Under a person-centred approach, healthcare teams should not only be collaborating with other healthcare providers, but also with the patient and their caregiver, as they are considered the primary focus, guiding the decision-making process based on their needs, wants, and preferences (Bilodeau, Dubois & Pepin, 2015; Cancer Care Ontario, 2017; Coulter & Dunn, 2002; Dawood, 2005). This is showcased by the CCS (2017), as it is made clear that “you (the patient) are the most important person on your healthcare team.”

The Institute of Medicine (2001) stated that teams of healthcare providers are often not as patient/person-centred as they could be. There are still questions that remain about the operationalization of this practice. For instance, are patients and their caregivers considered a part of their healthcare team, as active team members? Currently, no collaborative model exists within oncology (Gagliardi, Dobrow & Wright, 2011; Vogel & Hall, 2016), as there is a lack of agreement on who is considered a team member (Lederman et al., 2016; McComb & Hebdon, 2013). Some consider the patients to be team members and others refer to team-based care as encompassing only healthcare providers (Coniglio, 2013; Lederman et al., 2016; McComb & Hebdon, 2013; Mitchell et al., 2012).
Figure 1: Diagram of a four-level health care system.

Current Healthcare Context

With the increasing priority of framing care decisions around the needs, wants, and values of patients and caregivers, it has been recommended that healthcare providers take the next step and give patients and their caregivers a role to play on the healthcare team (Ontario Ministry of Health and Long-Term Care, 2015) by integrating them as active team members (Lederman et al., 2016; Martin & Finn, 2011; Mitchell et al., 2012). Recently, there has been a growing dialogue within the oncology literature, suggesting that if patients are not considered team members, then healthcare providers are not actively engaging in a patient-centred approach, and as a result, are not meeting the needs, wants, and preferences of the patients (Lazure et al., 2014; Lederman et al., 2016; Mitchell et al., 2012). This call to action has been seen at all levels of the healthcare system, targeting the practices of healthcare providers. It is the
healthcare provider’s role to include the patient on the team, as they are considered the gatekeepers and authority of team-based care and person-centred care (Bilodeau, Dubois & Pepin, 2015; Lazure et al., 2014).

**Levels of the Healthcare System**

At each level of the healthcare system, the integration of patients and caregivers as team members has been suggested and encouraged (Martin & Finn, 2011) through advocacy, policy and action. The healthcare system is divided into three levels; Micro, Meso, and Macro (Tremblay et al., 2014; Martin & Finn, 2011). This will be discussed below coupled with examples from the literature and current practices.

**Micro**

At the Micro-Level which represents front line care providers, there is a new role titled, the “patient advocate”. It has emerged to help facilitate person-centred care (CCS, 2017; Lederman et al., 2016). A Patient Advocate, according to CCS (2017) is a healthcare provider who acts as the liaison between the patient and their healthcare team. Recently, a call to action was made by patient advocates to determine the role of the patient and their family caregiver (Lederman et al., 2016) (See below for discussion on the differentiation of patient and person-centred care). This is further supported by patients as their desire is to be considered a team member, being actively engaged through the cancer journey (Bilodeau, Dubious & Pepin, 2015)

**Meso**

At the Meso-Level, which represents local action, organizations, and infrastructures, the Local Health Integration Network (LHIN) has enacted the Patient’s First Act in 2016, which highlights the political agenda with regards to the engagement
of patients and caregivers. It is the desire of healthcare policy makers to reduce the barriers that exist between users and providers of the healthcare system (Martin & Finn, 2011). With this act taking effect in 2016, it demonstrates a clear picture that the intention is to move towards a more fluid healthcare system, where patients and caregivers are not merely treated as consultants; rather they are considered an integral part of the healthcare team. It also aligns with the foundational practice of person-centred care within oncology services, as it is recommended that healthcare providers attempt to remove the “illness” lens that is often used to view a patient and treat them as a person.

**Macro**

At the Macro-Level, the Canadian Medical Association states that our current operation of healthcare is not meeting the needs of patients and caregivers, due to the patient and caregiver’s desire for individual based care and acceptance as a team member (Bilodeau, Pepin & Dubious, 2015). One portion of their framework to revitalize healthcare services is to “build a culture of patient-centred care.” It is recommended that this can be accomplished through the creation of a Patient Charter. Within this charter, the act of decision making is mediated by both patients and providers, prompting the integration of patients and caregivers as active team members.

**Significance**

In summary, advocates within the healthcare system are recommending the collaborative efforts between healthcare providers, patients and caregivers; however, what is seen throughout the literature is a lack of distinction of what person-centred care means in terms of engagement, involvement, and collaboration between healthcare
providers, patients and caregivers (Calisi et al., 2016). Healthcare providers are encouraged to engage, involve, collaborate, consult, communicate, empower and partner with patients (Health Canada, 2017). Yet, it is still unknown whether this translates to patients and caregivers being considered a part of the healthcare team, as an equal team member. For this reason, a model for interdisciplinary teamwork has yet to be defined within oncology services.

With the lack of direction on team-based care in oncology coupled with the reality of the increasing importance of person-centred care, there needs to be a definitive role of the patient and their caregiver throughout the cancer continuum. The intent for this study is to comprehensively define the role of the patient on an oncology healthcare team from the healthcare provider’s perspective. Currently, there is a disconnect when it comes to the concept of being at the center of care, in comparison to being considered a team member. A confusing landscape with multiple terms of reference and a lack of knowledge on how to engage, partner and collaborate with patients, healthcare providers are left with unmet expectations and dissatisfied patients.

This research is very timely as the Ministry of Health and Long Term Care published the Patient First Act in 2016 that was intended to strengthen patient engagement and patient-centred care within the healthcare system. Within the Patient First Act, it is outlined that patients and caregivers can no longer be simply led by their healthcare providers, rather their voices need to be heard. As well, from an international perspective, the World Health Organization has created a framework for people-centred healthcare services. Sharing similar guiding practices and foundational principles of person-centred and patient-centred care, this framework was created to empower and
engage people and communities, strengthen governance and accountability, reorient the model of care, coordinate services within and across sectors, and create an enabling environment. The healthcare system from a local and global perspective have paralleling agendas to move care in the direction of a more patient-centred and person-centred system, where shared clinical decision making, team-based care, and active participation are the norm. The bottom line as it currently stands, is that the patient’s role is still unknown. With the mounting evidence that suggests, recommends, and states that patients and caregivers need to be engaged in a way that creates a team-based relationship, we have failed thus far to operationalize this into a tangible and actionable practice.

**Document Overview**

The following chapter will provide an overview of the literature pertaining to team-based care, patient-centred care and person-centred care within the healthcare system and specifically oncology care, along with highlighting the perspectives of healthcare users and providers. In the process of reviewing the literature, the need for a distinction between contrasting terms, such as multidisciplinary and interdisciplinary teams and patient-centred care and person-centred care, became apparent. These terms were often used interchangeably; however, have different meanings and were intended to be practiced differently. As you will see, I provide an overview of each term and their adoption in the healthcare system. For the purposes of this study I have chosen to base my research study on the exploration of interdisciplinary teams and person-centred care. The reason for this decision was due to their relevancy within oncology literature, and the alignment to my research site.
In Chapter 3, the research design for the current study is described, followed by Chapter 4 outlining the findings and key themes. This leads into Chapter 5 where two figures are presented, illustrating the findings of this study along with demonstrating how the findings align and contrast the current landscape of literature. Chapter 6 then provides an overview of the key take away messages and implications of this study.
Chapter 2: Literature Review

Team-based care and person-centred care were both enacted for the same reason; to increase the quality of care patients were receiving in the healthcare system (Tremblay et al., 2014; Calisi et al., 2016). With the implementation of the team model and through involving patients and caregivers in the care process, team-based care and person-centred care are considered integral elements of treating patients with respect, empathy and ensuring they have a positive patient experience (Azar et al., 2017; Bilodeau, Dubois & Pepin, 2015; CCS, 2017; CCO, 2017; Gagliardi, Dobrow & Wright, 2011; Lederman et al., 2012; McComb & Hebdon, 2013; Tremblay et al., 2014; Wright et al., 2009). One of the unique aspects of oncology care is the breadth of healthcare providers working to treat a single patient. With the team model approach, care is coordinated and collaborative to meet the patient’s needs, fulfilling the aim of person-centred care (Page et al., 2016).

The current chapter will provide an overview of team-based care, patient-centered care, and person-centred care literature in both the healthcare system and oncology care. Furthermore, this chapter highlights the gaps within the literature, the research questions along with the aim of this research study.

Teams

A team can be described as, “a small number of people with complementary skills who are committed to a common purpose, set of performance goals, and approach for which they hold themselves mutually accountable” (Katzenbach & Smith, 1993, p. 112). The main distinguishing factor for identifying a group of people as a team
is the operationalization of a shared goal that is only achieved through interdependent practices (Armstead et al., 2016; Taplin et al., 2015; Weiss, Tilin, Morgan, 2014).

A group is defined as “a number of individuals assembled together or having some unifying relationship” (Merriam Webster, 2017). The origin of this word does not reflect a formalized intention for the collection of people working together (Armstead et al., 2016; Taplin et al., 2015; Weiss, Tilin, Morgan, 2014). Rather, the nature of a group is perceived to be short term and led by a single person (Armstead et al., 2016). Within the healthcare system, group and team are the two terms used most often to describe two or more healthcare providers collaborating and collectively making care decisions for a single patient (Armstead et al., 2016; Taplin et al., 2015; Weiss, Tilin, Morgan, 2014). It has been questioned within the literature whether a self-identified team is truly that or is their working dynamic indicative of a group. According to Armstead et al., (2016), “all teams are groups, however not all groups are teams (p. 179).” It is evident by this statement and supported by the literature that a healthcare team is perceived as a higher-ranking group. As Weiss, Tilin and Morgan (2013) explained, groups are a collection of people who share a commonality, rather teams are a group of people working together to achieve a common goal.

A healthcare group and a healthcare team both strive to help and support the patient, by relieving them of their disease, infection or pain; however, what distinguishes the two lies in the level of collaborative efforts and their interdependent nature (Armstead et al., 2016; Taplin et al., 2015). Members of a group often work independently; conversely members of a team rely on the decisions made by others to achieve the shared goal (Katzenbauch & Smith, 1993).
Teams and Groups in Oncology

Within cancer care, one of the tenets is person-centred care, which requires healthcare providers to involve and engage the patients and their caregivers in all care decisions (Calisi et al., 2016; CCO, 2017). This model of care has influenced the structure of healthcare providers and has led to the introduction of the term “team” within cancer services, as opposed to group because of the intended collaboration among patients and caregivers (Armstead et al., 2016). It is also supported because of the frequent referral process that occurs in cancer care. As stated previously, there are 30 different healthcare providers that can support and help patients. Some healthcare providers are strictly referral based by another healthcare provider. This speaks to the interdependent and interdisciplinary nature of cancer care (CCO, 2017; CCS, 2017); however, the concept of time can confuse the distinction between teams and groups. A long-term commitment is an indicative of the formation of a team, rather than groups’ work together only on short term projects (Weiss, Tilin & Morgan, 2014). Healthcare teams addressing cancer care can be perceived as short term, as healthcare providers come together to treat a single patient for a period. More recently, cancer is being considered a long-term illness (Naughton & Weaver, 2014). The time of treatment may vary, a person with cancer is forever changed because of their experience, and therefore, remission, check-ups, and screening continue to be an integral part of their life even after they transition into remission.

In summary, within the healthcare system and oncology care, the term group is rarely used. Furthermore, the long-term nature of cancer, coupled with the collaborative
efforts and the diversity of healthcare providers, “group” does not fully encompass the depths of this composition.

**Team-Based Care**

Team-based care can be defined as, “...the provision of health services to individuals, families, and/or their communities by at least two health providers who work **collaboratively** with patients and their caregivers—to the extent preferred by each patient—to accomplish shared goals within and across settings to achieve coordinated, high-quality care” (National Academy of Medicine). Team-based care includes five main principles; shared goals, clear roles, mutual trust, effective communication, and measurable processes and outcomes (Mitchell et al., 2012). The formation of a healthcare team has become embedded into the fabric of the healthcare system and is considered a foundational practice for high quality care delivery (Batorowicz & Shepherd, 2008; CHSRF, 2006; Hylin, Mattiasson & Ponzer, 2007;), as it has been shown to deliver safe, cost effective and patient-centered care (Armstead et al., 2016). As previously defined, teams are a collection of people who work interdependently. All teams in the healthcare setting are considered interprofessional, meaning that a single team is made of several healthcare providers, with different roles and specialities (Azar et al., 2017; Thylefors et al., 2005; Tremblay et al., 2010). Therefore, the makeup of a team often looks different compared to others. In the literature, there are three distinct forms of healthcare teams; multidisciplinary, transdisciplinary, and interdisciplinary. Each type of team varies in their level of interdependency and integration (Batorowicz & Shepherd, 2008; Parsons et al., 2016; Thylefors et al., 2005). Table 1 presents the different definitions in the literature of team-based care.
### Table 1: Different Types of Teams in Healthcare

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transdisciplinary</td>
<td>A healthcare team that is interprofessionally populated but driven by shared responsibilities.</td>
<td>Reilly, 2001; Thylefors et al., 2005, as cited in Batorowicz &amp; Shepherd, 2008; Parsons et al., 2016; Dyer 2003</td>
</tr>
<tr>
<td>Multidisciplinary</td>
<td>An interprofessional collection of healthcare providers that have their own individual tasks, completed independently and then shared with the larger team to help and treat the patient.</td>
<td>Batorowicz &amp; Shepherd, 2008; Parsons et al., 2016; Dyer 2003</td>
</tr>
<tr>
<td>Interdisciplinary</td>
<td>A team comprised of individual healthcare providers, each having their own role on the team along with tasks and responsibilities based on their expertise.</td>
<td>Beukelman &amp; Mirenda, 2005, as cited in Batorowicz &amp; Shepherd, 2008; Dyer, 2003</td>
</tr>
</tbody>
</table>

**Figure 2**: Modified from Schwarz, Neuderth, & Gutenbrunner (2015). Continuum of team-based care models.

In healthcare, there are three main models that lie on a continuum of collaboration and interdependence; multidisciplinary, interdisciplinary, and transdisciplinary. In reference to Figure 2, all teams are interprofessionally populated, meaning a single team is made up of different healthcare professional roles. All the teams have shared goals and are focused on the patient. Multidisciplinary teams have the least amount of
collaboration and interdependence, and as you move to the right, transdisciplinary has the most, where their roles and responsibilities become intertwined and all team members can conduct each other’s work. Whereas, multidisciplinary and interdisciplinary teams have defined roles and individual responsibilities.

Within the literature, there was no mention of the patient in a team member capacity with transdisciplinary teams. This type of team is not often found within the healthcare system, as each healthcare provider has had extensive training to perform very specific procedures, tests, and assessments, that another healthcare provider could not.

The formation of multidisciplinary teams is mandated in the United Kingdom, under their “no decision about me, without me” policy (Coulter & Collins, 2011); however, it is suggested that multidisciplinary teams are formed in the United States and have relevancy in Canada (Sublett, 2014). Within the multidisciplinary team literature, research has been conducted to assess the proximity of the patient to their healthcare team and more specifically the presence of patients at multidisciplinary team meetings (Taylor, Finnegan-John & Green, 2014). It was found that patients were not included in conversations and though healthcare providers may consult patients on decisions made, they were not given opportunities to be active team members (Taylor, Finnegan-John & Green, 2014).

For interdisciplinary teams, there was a term in the oncology literature that described healthcare teams that coordinated their care around the patient’s wants, needs, and values, which was identified as patient-centred interdisciplinary teams (Bilodeau, Dubois & Pepin, 2015). This type of team was introduced due to the
importance of patient-centred care within the healthcare system, the emergence of person-centred care within oncology services and the increasing prevalence of healthcare teams (Bilodeau, Dubious & Pepin, 2015; Institute of Medicine, 2001; McComb & Hebdon, 2013). Though, we are still left to wonder the role of the patient and caregiver (Bilodeau, Dubois & Pepin, 2015; McComb & Hebdon, 2013).

Overall, the transdisciplinary, interdisciplinary or multidisciplinary literature failed to acknowledge the patient or caregiver as team members or define their role among the healthcare providers. Rather it was assumed that the efforts made by the healthcare teams were performed for the patient, not with the patient. Therefore, what is practiced by healthcare providers does not necessarily reflect what is mandated or recommended. The Canadian Health Services Research Foundation conducted an extensive literature review on the nature of teams within the healthcare system, and tackled concepts such as collaboration and the current “team” policies. One aspect that became apparent was their statement about patients and their caregivers being important team members. The barrier to this team model was the lack of knowledge on how to be a team member from the patient and caregiver perspective (CHSR, 2006). Through my research, I would like to address this gap, by comprehensively defining the role of the patient and caregiver, from the healthcare provider’s perspective. By doing so, the first step in operationalization of patients and family caregivers as team members can be made.

Team-Based Care in Oncology

Cancer is unlike any other disease, as it is often defined as complex (Bilodeau, Dubois, Pepin, 2015; Hylin, Mattiasson & Ponzer, 2007; McComb & Hebdon, 2013;
Parson et al., 2016; Vogel & Hall, 2016), but why is that? Cancer is referred to as a journey or a continuum, speaking to its long-term nature (Naughton et al., 2011), with the potential for sporadic remission or recurrences. Due to this, it has been suggested there is a need for multiple healthcare providers to support a single patient, (CCO, 2017; CCS, 2017; Institute of Medicine, as stated in Parsons et al., 2016; Tremblay et al., 2017).

Team-based care continues to be at the forefront of importance, as its practice has been documented to achieve better quality of care, better value, better patient experience, and more satisfied physicians (Bodenheimer & Sinsky, 2014; Kosty, Hanley, Chollette, Bruinooge & Taplin, 2016); however the makeup of the healthcare team has yet to be defined (Bilodeau, Dobrow, Pepin, 2015; Gagliardi, Dobrow, Wright, 2011;). The literature has depicted the oncology team as a healthcare professional driven membership (Azar et al., 2017; Tremblay et al., 2014; Vogel & Hall, 2016). Conversely, new research has emerged illuminating the need for patients and caregivers to be considered team members (McComb & Hebdon, 2013; Lederman et al., 2016; Taplin et al., 2015). This sentiment has been reiterated by organizations like the Canadian Cancer Society and Cancer Care Ontario, advocating for patients and caregivers to feel as though they have a voice among the healthcare providers.

More recently, the idea of partnerships and collaboration (originally defined in the patient-centred and person-centred care literature), has been applied to the team-based care literature within oncology services. According to Coniglio (2013), “a healthcare team is a mutually agreed on relationship between a patient and a provider” (pg. 99). McComb et al., (2012) agrees, indicating that a healthcare team includes a physician, a
nurse, and a patient. This is further reflected in the idea that the coordination of care should be a mutual decision made by the patient, caregiver and healthcare provider (Taplin et al., 2015, as stated in Page et al., 2016). Recent literature has echoed this concept by identifying the term patient-centred inter-professional teams (Bilodeau, Dobrow, Pepin, 2015; McComb & Hebdon, 2013). This along with shared decision making, are steps to conceptualizing patients as team members and this is what my research will build upon.

For these reasons, multidisciplinary (Borras et al., 2013; Coniglio, 2013; Gagliardi, Dobrow & Wright, 2011; Lamb et al., 2014; Lanham et al., 2009; Lederman et al., 2016; McComb & Hebdon, 2013; Parsons et al., 2016) and interdisciplinary (Bilodeau, Dubois, & Pepin, 2015; Fadol et al., 2015; Page et al., 2016; Rose & Yates, 2015, as cited in Calisi et al., 2016; Tremblay et al., 2014; Tremblay et al., 2017) teams are considered a crucial element of oncology services.

These two terms are often used synonymously; for example, a literature review was conducted in 2006 by the University of Toronto that attempted to uncover team effectiveness within a healthcare setting. For this literature review, the authors used key terms and created a search strategy using multidisciplinary and interdisciplinary teams interchangeably (Gunson & Hart, 2015). In addition, another study titled, “Economic Soundness and Interdisciplinary Teamwork in the UK: Is It Financially Sound?”, referred to healthcare teams as multidisciplinary throughout the article (Lemieux-Charles & McGuire, 2006).

These examples speak to the inconsistencies with these terms, without acknowledging clear differences and distinctions. For the purposes of my study, I align
my research with the structure of an interdisciplinary team. I do this because my research will take place at a local Oncology Center and the staff have identified themselves as an interdisciplinary team. As I will be exploring the inner workings of the healthcare environment, the healthcare providers and their practices, I must acknowledge their perspective, and use that lens in my research.

In comparison to other types of healthcare teams, interdisciplinary teams require consensus from all team members, making it an exemplary framework for true partnerships to be formed, in accordance with the definition by the Health Canada Public Involvement Continuum and the principles of person-centred care. As well, according to Tremblay et al., (2017) interdisciplinary teamwork was associated with positive experiences regarding patient-provider communication. Building off these initial findings, an interdisciplinary team framework could facilitate the integration of patients and caregivers on the healthcare team, as patients should be considered equal in their ability to influence a care decision (Calisi et al., 2016; Tremblay et al., 2017). Finally, it has been stated that interdisciplinary teams in oncology services is necessary to meet the needs of the patients (Bilodeau, Dubois, & Pepin, 2015; Fadol et al., 2015; Page et al., 2016; Rose & Yates, 2015, as cited in Calisi et al., 2016; Tremblay et al., 2014), as patients should be treated and supported by a diverse collection of healthcare professionals. The literature is stating that healthcare providers need to be patient focused by involving them in the care process, but they are not explicitly considered team members.

Patients are the experts of themselves, they know how they feel. If the team requires skilled experts that add to the diversity of the team, they need the patient
(Coutler & Collins, 2011). I will be exploring this concept under a person-centered model of care, as it remains unclear whether engaging, partnering and collaborating with the patient equates to the formation of a team. The reason for highlighting this unique perspective is, as mentioned previously, healthcare providers are considered the gatekeepers of the team. Additionally, an emphasis in the literature is put on the patient’s perspective, identifying barriers and challenges (Coutler & Collins, 2011; Tariman et al., 2010), leaving room for assumptions and expectations to grow from healthcare providers. Recommendations on how to improve team-based care are directed towards the practices of healthcare providers, such as enhancing the practice of shared decision making, and integrating patients into the healthcare team (Tariman et al., 2010). Despite this target audience, we have yet to ask the healthcare providers what they need to create this harmonious partnership where each member plays an active role and contributes to achieving the shared goal.

With the interchangeable nature of patient-centred care and person-centred care, please refer to Table 2 for distinct definitions of each.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Source</th>
</tr>
</thead>
</table>
| **Patient-Centred Care**    | Ensuring that healthcare provider’s tailor a patient’s care to their needs, wants, values and preferences.  
Patients are at the center of their care and the healthcare system revolves around their needs. It involves listening to patients and families. It means that patients are working with their healthcare providers.  
An approach that integrates the patient perspective and preferences while involving the patient in decision making and self-care.  
Knowing the patient as a person while accurately diagnosing his or her illness.  
Involves enabling patient responsibility for health care by promoting patient involvement and individualization of patient care.                                                                                                                                                         | Institute of Medicine, 2001; Agency for Healthcare Research and Quality  
Canadian Interprofessional Health Collaborative, 2009  
Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993  
Epstein, 2000  
Robinson, 2008                                                                                                                                                                                                 |
| **Person-Centred Care**     | Providing a level of care that actively engages the patient, ensuring the patient’s needs, wants, values, and preferences are being met with the intention to partner with the patient for the patient and healthcare provider to make care decisions together.  
People using health and social services as equal partners in planning, developing, and monitoring care to make sure it meets their needs.  
From the nurse’s perspective, it’s a strong interest in the patient’s own experience of health, illness, injury or need. It is about knowing the patient as an individual, respecting the individual’s values, preferences, and needs. Fostering trusting caregiving relationships and involving the person’s family and friends.  
Care that is personalized, coordinated, and enabling. Treating the person with dignity, compassion, and respect.  
An approach to planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families, which results in better health outcomes. | Cancer Care Ontario, 2015  
Health Innovation Network; Royal College of Nursing, 2016  
Draper & Tetley, 2013; Arakelian et al., 2017  
The Health Foundation, 2014  
Institute for Patient and Family Centred Care, 2014 |
When comparing patient-centred care and person-centred care, from the depiction of Picker’s 8 Principles of Patient-Centred Care and Cancer Care Ontario’s Person-Centred Care guidelines, it is clear that both have similar philosophies providing care to the patient and their family caregiver that addresses and targets their needs, wants, values, and preferences (Dawood, 2005; Calisi et al., 2016; CCO, 2017; CCS, 2017). What distinguishes the two is, if you refer to Figure 3, there are elements of person-centred care and patient-centred care that are not shared, such as, seeing the patient as a person first and the commitment to advocating for active participation from the patients, to build a partnership between them and the healthcare provider.

**Patient-Centred Care**

Patient-centred care has become a top priority within the healthcare system (Epstein et al., 2010; Institute of Medicine, 2001). Before the concept of patient-centred care was introduced, healthcare providers followed a biomedical model of care, which focused strictly on treating the disease rather than the person (Dawood, 2005). It was in 1957 when Balint presented the idea of delivering quality care that fits the needs, values, and preferences of patients. It was originally designed to address the well-being
of patients within the healthcare system, as it introduced a more holistic approach to care, promoting partnerships between patients and their care team (Dawood, 2005; Gluyas, 2015). It has since been defined to encompass many aspects of care, such as empowering patients, building relationships, fostering partnerships, and framing decisions around patient’s wants and needs (Dawood, 2005; Gluyas, 2015). It has become a foundational principle within the healthcare system, as the Institute of Medicine in 1999, released 6 domains of healthcare, and deemed them “must haves”; healthcare must be safe, effective, **patient-centred**, timely, efficient, and equitable. Therefore, many healthcare organizations, clinics, and healthcare centers brand themselves as patient-centred; however often their care delivery does not align with the cornerstones of patient-centred care, and as a result, patients become lost within the system (Kreindler, 2015; McInnes, 2010).

A patient is defined as a person suffering from a disease or illness, who is **receiving** medical care (Merriam Webster, 2017). The language used in this definition speaks to the one-sided nature of the healthcare system, where patients are essentially seen and treated as holders of a disease (Dawood, 2005). Based on the definition of patient-centred care, treatment should meet the needs of patients, while also valuing their preferences (Institute of Medicine, 2001); however, it appears that the healthcare system perceives patients as consultants of care, rather than team members (Bilodeau, Dubois & Pepin, 2015; Kreindler, 2015; McInnes, 2010). It has been well documented that healthcare providers present their care as patient-centred, they listen, attempt to communicate, but ultimately make the decision on what they feel is best (Bilodeau, Dubois & Pepin, 2015; Kreindler, 2015; McInnes, 2010).
One of the core values of patient-centred care is patient participation and involvement, which lies on a spectrum of collaboration (Kitson et al., 2012). According to Health Canada, this continuum includes level 1, communication, level 2, listening, level 3, consulting, level 4 engage, and level 5, partnering (Appendix A). As you move along the continuum, it is clear the collaborative and interdependent practices are fluctuating. Based on the definition by the Institute of Medicine, patient-centred care would align with levels 1 to 3; however there has yet to be a clear distinction of where patient-centred care lies on this continuum. Currently, within the patient-centred care literature, healthcare providers should be engaging and partnering with patients. Therefore, there is a lack of consistency whether healthcare providers simply communicate and listen or they discuss, engage and partner with patients and caregivers (Dawood, 2005; Coutler, 2002, Frampton & Charmel, 2009). Along with the level of engagement that exists among healthcare providers and patients is the nature of the patient-provider relationship.

Patient-centred care is not a new concept; rather it has been well documented that the implementation of this model has increased patient satisfaction and produced better patient outcomes (Dawood, 2005; Ekman et al., 2011). Creating a patient-centred healthcare model has been studied in several healthcare settings, such as primary care, treatment for dementia patients, rehabilitation, and oncology services. Often what gets lost is the actual practice and operationalization of patient-centred care. Patient-centred care has taken on many definitions throughout the years, it has been referred to as client centred care, person-centred care, patient experience, patient’s first, and patient focused (Edvardsson, 2015). Each definition has their own connotation and context;
however, the connective tissue is the idea that patients and caregivers should be active participants among the healthcare team. Within oncology services, person-centered care is most often used (Calisi et al., 2016; Cancer Care Ontario, 2017).

**Person-Centred Care in Oncology**

A variation in the model of patient-centred care has been supported by cancer-based organizations such as Cancer Care Ontario, referred to as person-centred care (Cancer Care Ontario, 2017; Calisi et al., 2016; Parsons et al., 2016; Kullberg et al., 2017). The use of this new term is an evolution from patient-centred care. This transition may seem like a simple word change, it is a significant transformation that provides a new meaning to labeling someone as a “patient” (CQCO, 2017).

Under the person-centred care philosophy, patients have a voice and are more active members of their care team (Cancer Care Ontario, 2017; Ekman et al., 2011). This definition encompasses the original intention of patient-centred care, allowing the thoughts, opinions, and feelings of patients to be expressed while treating them as a holistic being rather than as a disease (Coutler, 2002; Dawood, 2005; Institute of Medicine, 2001). What separates it from its origins is removing the label of “patient”. This allows healthcare providers to see the person as they are, which enables them to have a better understanding of their wants, needs, and values. This is extremely important for cancer patients as it was suggested by Thorne et al. (2005) that forming a human connection during the cancer journey could be considered a “universal ingredient” to quality care (p. 890).

The word “person” encompasses more than just the patient, rather it includes the engagement of caregivers. A caregiver for a cancer patient is an integral part of the
healthcare team (Catlin, Ford & Maloney, 2016; Jacobsen et al., 2015; McComb & Hebdon, 2013). The impact of a diagnosis of cancer is not isolated to the patient, rather it extends beyond this and affects family and friends (Catlin, Ford & Maloney, 2016; Jacobsen et al., 2015). Furthermore, caregivers act as pillars of support for the patient, providing emotional, physical, spiritual and often financial care (Catlin, Ford & Maloney, 2016).

It has now been recognized that the quality of a patient’s care is being determined by a person-centred care approach (Brooker, 2003). The reason being is there is an emphasis put on the partnership between patients and healthcare providers (Ekman et al., 2011). The patient-centred care literature places value still on the healthcare provider. The language used implies that healthcare providers are gaining the knowledge of the patient and then subsequently making decisions for them, with their needs and preferences in mind (Kullberg et al., 2017). Therefore, the authority and control is still in the healthcare provider’s hands. With person-centred care, partnerships are intended to be formed, which details a more collaborative relationship, hinting at a team dynamic. Within oncology services, the diversity of a healthcare team is valued, and is recognized as an element of achieving person-centred care (Parsons et al., 2016). To this end, the integration of patients and caregivers would align with the need for diversity and allow for healthcare provider’s to truly be achieving the core elements of person-centred care. This unfortunately does not currently reflect an oncology healthcare team’s composition (Calisi et al., 2016), which prompts the question, are healthcare teams truly practicing person-centred care, if the patients and family caregivers are not considered team members?
If patient-centred care and person-centred care are set as priorities and standards within oncology care and the healthcare system at large, a triple aim perspective needs to be assessed (Kreindler, 2015). Meaning that we need to understand the thoughts and opinions of this matter from healthcare providers, patients, caregivers and, policy makers. The patient-centred care and person-centred care literature has highlighted the patient’s perception of patient-centred care delivery, patient’s unmet needs, along with how patients and caregivers understand person-centred care (Calisi et al., 2016; Ford et al. 1997; Harrison et al. 2009; Lis et al. 2009, as cited in Zucca). What has yet to be assessed is the healthcare provider’s perspective on the delivery of person-centred care and the formation of partnerships with patients and caregivers.

**Patient’s Perspective**

It has been well documented that patients want to be informed, discuss their treatment options, and to be valued by their healthcare team (Kvale & Bondevik, 2008; Tariman et al., 2010). A literature review detailing the preferences of participation by patients identified that patient’s preferences were not being met in terms of the level of involvement on their healthcare team; the majority were less involved than they wanted (Tariam et al., 2010). From the patient’s perspective, they have the same goals as the healthcare providers and as a patient are actively fighting against their disease. Additionally, a diagnosis of cancer is not isolated to the oncology unit, it affects the patient and impacts their close family and friends (Jacobsen et al., 2015; Lederman et al., 2016; McComb & Hebdon, 2013). It has been suggested that healthcare providers should allow patients to take a more active role in the process of shared decision
making (Tariam et al., 2010), as conversely, patients do not feel as though they are actively contributing to their inter-professional team (Bilodeau, Dubois & Pepin, 2015; Lazure et al., 2014; Lederman et al., 2016; Martin & Finn, 2011).

So far, from the patient’s viewpoint, there is a lack of acknowledgment of their unique position along with their caregiver. Patients and caregivers do not have a clear and defined role, and patients have reported that they often feel inferior to the healthcare provider (Bilodeau, Dubois & Pepin, 2015; Martin & Finn, 2011; Thorne et al., 2005). With that being said, we must acknowledge that not all patients and caregivers share the same viewpoint and perspective on this matter. Some patients do not want the responsibility of making their final care decision (Tariiman et al., 2010; Brom et al., 2014). According to Brom et al., (2014), some patient’s would like to take an active role in their care; however, depending on the patient’s knowledge of their disease and comfortability making decisions, other patients would rather defer to their physician.

With the diverse collection of roles on an interdisciplinary team, each member has their own distinct role (Lamb et al., 2014; Parsons et al., 2016). Oncology care does not follow a transdisciplinary team model, where roles begin to intermix. In oncology care, they stress the need for diversity on the healthcare team, creating a unique collection of experts (Parsons et al., 2016). Healthcare providers are considered the leaders and “experts” on cancer knowledge and process (Frerichs et al., 2016); however, patients are the authority on their own wants, personal values, preferences, and needs (Coutler & Collins, 2008). The kind of information that patients offer is considered necessary for the effective delivery of person-centred care.
Healthcare Providers Perspective

The limited studies that are available highlighting the healthcare provider’s perspective have outlined difficulties attempting to involve the patient and caregiver throughout the care process (Martin & Finn, 2011; Lazure et al., 2014). They report several barriers to care, such as failing to find a shared language to communicate effectively and lacking the confidence to provide emotional support (Bilodeau, Dubois & Pepin, 2015; Lazure et al., 2014). The barriers and challenges of communicating with the patient and the delivery of patient and person-centred care has been well documented from the healthcare provider’s perspective (Bilodeau, Dubois & Pepin, 2015; Kitson et al., 2012; Lazure et al., 2014). What has yet to be studied is the healthcare provider’s perspective on their needs and wants from the patient to define their role on the healthcare team.

The patient-physician relationship is extremely complex, often healthcare providers feel they are the leaders of the team, whether that was their intention or not. With the rise of patient engagement and the current focus on delivering care that is tailored to the patient’s wants, needs, and values, there is an equal responsibility for active engagement from the patients (Jenerette & Mayer, 2016). On the other side of creating a close patient-provider relationship desired by patients, is the reality of professional boundaries. This was indicated by a personal story told by a nurse that became too close to her cancer patient undergoing multiple rounds of treatment (Armstrong, 1996). Finding a balance between professional protocol and empathy for the patient is a challenge healthcare provider’s encounter. It has been suggested that delivering patient-centred care, along with avoiding conflicts of interest, are the key
practices of fostering a good patient-provider relationship. Through the application of my research questions, I will shine a light on the nature of the patient-provider relationship from the healthcare provider's perspective (Goold & Lipkin, 1999). Healthcare providers are expected to facilitate person-centred care and are encouraged to integrate patients and caregivers as team members (Lazure et al., 2014; Lederman et al., 2016; Mitchell et al., 2012), unfortunately, their viewpoint regarding implementation has never been addressed.

**Making Patients Team Members**

The conceptualization of patients and family caregivers as active team members among their healthcare team has been recognized through the practices of shared decision making, patient-centred interdisciplinary teams and patient-centred collaborative care; however, currently there is no blueprint for healthcare providers, patients, and caregivers to work together as a team (Schottenfeld et al., 2016). With each attempt comes the failure to operationalize this practice and clearly define the role of the patient and their caregiver.

**Shared Decision Making**

The patient and family caregivers are an integral element to the decision-making practice of a healthcare team. With the use of Shared Decision Making (SDM), a desired state of collaboration between patients and healthcare providers is achieved (Coutler & Collins, 2011). SDM is considered an integral element of patient/person-centred care (NLC, 2013), as it allows the patient to have a voice, provide input on the decision that is made, and be considered an equal team member as the expert of themselves, aligning with the practices of person-centred care (Calisi et al., 2016;
Coutler & Collins, 2011). SDM is an ideal state to achieve team effectiveness and satisfy patients. Conversely, healthcare providers believe the extent of SDM is providing enough information to the patient for them to make an informed decision (Frerichs et al., 2016; Hoffman et al., 2014). Underscoring this perspective of SDM, was the perception that the healthcare providers are the leaders, leading patients during the cancer journey. Healthcare providers value SDM and their intention is to create an atmosphere where patients are able to voice their wants and needs; however, what has been seen is that patients and caregivers are treated more as consultants, rather than decision makers (Bilodeau, Dubois & Pepin, 2015; Frerichs et al., 2016; Kreindler, 2015; McInnes, 2010).

**Patient-Centred Interdisciplinary Teams**

As discussed above, patient-centred interdisciplinary teams describe an oncology team that has attempted to merge the practices of patient-centred care with the formation of an interdisciplinary team. According to Bilodeau, Dubois and Pepin, (2015) there is a need for training, interventions and clear guidelines for the implementation of patient-centred interdisciplinary practices, as misunderstandings and confusion are found from the patient and healthcare provider’s perspective. Without a defined role for the patient and caregiver, healthcare providers feel they are meeting the expectations of patient-centred care; however, patients report they “were never invited to be a part of the interprofessional team” (p.111). Paralleling this feeling, the patients are left to wonder if they are part of the team, without clear expectations, there are misconceptions of the true membership of a team.
Patient-Centred Collaborative Care

Ensuring care is meeting the needs, wants and values of patients and caregivers, comes with the responsibility of healthcare providers to foster a relationship that enables this practice. The relationship between the healthcare providers and the patient is the cornerstone of person-centred care, as this practice requires them to become partners in the care process. The Canadian Medical Association has advocated for collaborative and interdisciplinary care during any healthcare situation, as they state that true patient-centred care “makes the patient and caregiver an integral part of the care team.” According to Vogel and Hall (2016) cancer care falls along a continuum of varying levels of engagement, interaction, interdependency and recognition. Currently, it is proposed that work needs to be done to shift oncology teams to work collaboratively with patients (Vogel & Hall, 2016). Roles and responsibilities are defined for the healthcare provider, yet the patient still does not know what is needed from them in order to assist their healthcare provider as a mutually contributing team member (CMA, 2007).

Overview of Literature

To gain access to the breadth of literature that exists on my topic, I used several search engines such as Brock University Library, Supersearch, Research Gate, Google Scholar, the Journal of Oncology Practice, and the Journal of Interprofessional Care. My search strategy included a wide range of key terms to provide a comprehensive understanding of my topic, such as patient-centred care, person-centred care, oncology, cancer, team, healthcare team, patient, and caregiver. This led to a variety of academic journals and articles including qualitative and quantitative based research, along with
letters to the editor, editorials, and commentaries. Several of the binding articles encompassing the “call to action” for team-based care and person-centred care to be researched came from editorial’s and commentaries in the Journal of Oncology Research. Patient Advocates, policy makers, and researchers used a critical lens on the current state of oncology services and expressed the need for a true collaborative model. Coupled with these types of literature were several qualitative based studies. With the nature of this research, assessing and reporting on the patient’s experience, it is rare to find a quantitative research study, as numbers and metrics cannot fully capture the depth and complexity of a patient’s journey. This was the basis for my decision to collect data qualitatively.

One part of the literature that needs to be mediated is the inconsistency with the use of critical terminology. In my literature review I have summarized the main points on healthcare teams and patient-centred practices. However, the interchangeable nature of interdisciplinary and multidisciplinary teams along with patient-centred care and person-centred care, demonstrates an extreme lack of continuity. Along with my research purpose, I aim to facilitate discussions about these key terms with my participants to depict a clear picture of the nature of care within oncology services. I will be probing healthcare providers to provide their perspective on the distinction of person-centred care as the intention to treat the whole-person rather than seeing them as a holder of a disease. I will also ask them to provide their experience working on a team and describing the nature of their interactions and dependency on one another. With this prominent limitation within the literature, I have chosen to base my research study on the exploration of interdisciplinary teams and person-centred care. The reason for this
decision was due to their relevancy within oncology literature, and the alignment to my
population.

**Gap in the Literature**

Collaboration is mandated under the person-centred approach and it is the desire
of the patient and caregiver to be considered team members (Jacobsen et al., 2015).
Despite this reality, there are several gaps within the literature pertaining to patient-
centred care, person-centred care and how they influence the nature of the patient-
provider relationship. It has been suggested that within oncology services, patients and
caregivers should be considered team members (Lederman et al., 2016; McComb &
Hebdon, 2013); however, to date the operationalization of this concept has not been
explored. Additionally, no literature has demonstrated the perspective of the healthcare
providers, identifying what they need in terms of expertise, education, skills, practice
changes or implementation resources to integrate patients and caregivers as team
members (Coniglio, 2013; Gagliardi, Dobrow, & Wright, 2011; Lederman et al., 2016).

**Research Purpose and Questions**

I would like to demonstrate the connection between the team-based care
literature and the person-centred care literature, providing insight into the feasibility of
patients and caregivers as active team members. Therefore, the **purpose** of this study,
from the perspective of healthcare providers, is to understand how person-centre care
ideologies are translated into day-to-day practice at an oncology center. The following
two **questions** will be guiding my exploration of my research, (1) How do healthcare
providers at an oncology center perceive the role of all team members, patients,
caregivers, and healthcare providers on a person-centred care team? (2) How can
healthcare providers, patients, and caregivers work together to form a person centred care team?

This topic has been highlighted as a concern by several editorials, literature reviews, and research studies, demonstrating the need for clarity on this issue (Coniglio, 2013; Gagliardi, Dobrow & Wright, 2011; Jacobsen et al., 2015; Lederman et al., 2016; McComb & Hebdon, 2013; Tremblay et al., 2014; Vogel & Hall, 2016). Beyond the recommendations made by previous literature, the sheer importance of this study is driven by the well-being of future cancer patients and their caregivers. With the hopes of taking the first step in operationalizing patients and caregivers as team members.
Chapter 3: Research Design

The current chapter outlines the research design for the current study. The methodology, research site, data collection methods, data analysis, and trustworthy strategies are described.

Positionality Statement

My position in this research study aligns with an interpretive paradigm. Based on this perspective, I believe that my role as a researcher is to co-construct meaning with my participants (Glense, 2015; Jones, Torres & Arminio, 2014). My theoretical perspective and my understanding of how knowledge is created enables my voice, coupled with that of my participants, to be conveyed through my findings (Glense, 2015; Jones, Torres & Arminio, 2014). The themes of my research did not emerge or appear from the data; rather I became an active participant in constructing the findings and assigning meaning through the lens of my participants. Before beginning my research, I needed to have a deep understanding of my values, biases, assumptions, personal interests and connections to my research and my participants (Thomas & Magilvy, 2011).

At conception, my research focused on the relationships that are built between patients, caregivers, and healthcare providers. From there, it has transformed into understanding the intersection of team-based care and person-centred care. The desire to research the dynamic between patients, caregivers, and healthcare providers comes from my passion for health education, health advocacy, and teamwork. Both of my parents are teachers and growing up I was exposed to several conversations about education, information, and collaboration. With my interest in biology and math, a
degree in health science seemed fitting. During my undergraduate degree, I was drawn
to research projects that highlighted education within a health setting; this is how I
started a quality improvement project at a local oncology center. At this center, I heard
stories from former patients and caregivers about their experiences, some positive and
some negative. Patients with positive stories felt that their healthcare providers worked
with them, incorporating them into the decision-making process. Conversely, negative
experiences usually left patients feeling that their healthcare providers ignored their
thoughts, feelings, and opinions.

My assumptions and biases grew from there. I thought: (1) patients and
caregivers are currently not considered members of their own healthcare team, (2)
patients and caregivers want to be considered team members, (3) healthcare providers
do not believe that patients and caregivers can be equal team members, (4) healthcare
providers perceive the healthcare team as including just other healthcare providers, and
(5) healthcare providers intend to deliver person-centred care but revert to professional
centred care when serious decisions need to be made. I believe that without the
acknowledgment of patients and caregivers as team members, healthcare providers are
not following a person-centred care model. I believe that if patients and caregivers want
to be team members, they must be actively engaged with healthcare providers and
embrace a transparent relationship. Healthcare providers may not be meeting all of the
patient’s needs, but it is equally as important for patients and caregivers to understand
the viewpoints of the healthcare providers.

It may seem unusual that I am not studying the perspective of patients and
caregivers since I consider myself to be a self-proclaimed “patient advocate.”
Nevertheless, from my experience, healthcare providers are the leaders mandated to deliver person-centred care, meaning they are instructed to actively engage with patients, by understanding their wants, needs, values and priorities to then choose the best course of action for their care. Regrettably, they also seem to be silenced in the literature when discussing the conceptualization and operationalization of these processes. For these reasons, I felt compelled to highlight the healthcare provider’s opinions, thoughts, and feelings on this topic. I am interested in gaining their perspective on the intersection of team-based care and person-centred care and the feasibility of patients and family caregivers as active team members.

Qualitative Inquiry

Qualitative research explores human experience in relation to an individual’s perspective and interpretation of their own reality (Creswell, 2013; Yin, 2009). My perspective on research aligns with the belief that experiences are interpreted and “truth” is personally and socially constructed, demonstrating the strong relationship between people and their environment (Glense, 2015; Schwandt, 2007). Therefore, my epistemological perspective aligns with interpretivist paradigm (Creswell, 2013; Glense, 2015; Schwandt, 2007). My belief on how knowledge is created built the foundation for my research project and provided me guidance on decisions regarding my methodology, data collection, data analysis and data representation (Glense, 2015; Jones, Torres & Arminio, 2014).

Methodology

A case study approach has been recognized as a methodology that seeks to understand people as individuals and how they attach meaning to their real-life context.
(Baxter & Jack, 2008; Creswell, 2013; Holloway & Wheeler, 2002; Johnson & Parry, 2015; Yin, 2003, 2009, 2012). It provides a set of practices that enables the researcher to gain an in-depth understanding of the relationship between the phenomenon and the lived environment (Yin, 2003, 2009, 2012). Each methodology has guiding principles that ensure the alignment and congruence of a research study, indicating quality and trustworthy findings (Johnson & Parry, 2015). Wanting to know the “How” rather than that “What” with regards to healthcare provider’s perspective on role clarification and team assembly in oncology care, along with emphasizing their work environment led me to choosing a case study methodology.

Types of Case Studies

There are two distinct categories of a case study design, single case study, and multiple case study. Once I decided that case study was an appropriate methodology, my next step was to decide if I was going to study a single system or multiple systems. This decision was pivotal, as it guided the methods of data collection and the data analysis process (Glense, 2015; Johnson & Parry, 2015; Yin, 2009, 2013).

<table>
<thead>
<tr>
<th>Table 3: Single Case Study and Multiple Case Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Single Case Study (Robert Yin)</strong></td>
</tr>
<tr>
<td><strong>Aim of the Research:</strong></td>
</tr>
<tr>
<td>To understand the relationship between a phenomenon and a single system, exploring specifically how that phenomenon is experienced within the context of the researched environment.</td>
</tr>
</tbody>
</table>

**Single Case Study Design**

Following the formulation of my research questions and reflection on the true purpose of this research, I aligned my study with Robert Yin's perspective on a single
case study approach. This single case study design was used to explore the operationalization of patients and family caregivers as active team members on their interdisciplinary care team.

There are 5 components that Yin (2009) proposed are essential to conduct sound and trustworthy case study research (viewed in Table 4).

When conducting a single case study, the first step is defining the case (Yin, 2003, 2009, 2013). In this research, the case can be defined as the experiences of healthcare providers working in an oncology center, fulfilling their role on the “patient’s team”. The case was bounded by location: a local oncology center; healthcare provider role: Physician, Nurse, Staff/Provider/Other Team Member; level of experience: healthcare providers with more than 18 months’ experience, and patient-provider relationship: healthcare providers who have regular and consistent interactions with the patient at this oncology center. Regular and consistent interactions was defined by the use of the Patient and Family Education Binder. This educational resource listed the healthcare providers that patients could interact with during their care. The use of this resource as a guide, ensured that participants had experience being a part of patient’s oncology journey.

What distinguishes a case study from other methodologies is the exploration of three interacting and dependent elements; the phenomenon, the participants, and the real-life context (Yin, 2003, 2009, 2013). The reason I wanted to understand the participant’s environment was due to the strong emphasis in the literature on context and culture of care in the delivery of team-based care (McComb & Hebdon, 2013; Vogel & Hall, 2016). The working environment is seen as an influential factor on the action of
healthcare providers. Therefore, in order to understand the inner workings of an oncology center and the day-to-day practices of healthcare providers, the phenomenon and participants must be grounded in their working environment.

Table 4: Components of Case Study Research Designs

<table>
<thead>
<tr>
<th>Case Study Components</th>
<th>My Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Study’s Questions</td>
<td>The nature of my study’s research questions do not simply ask “What”, but rather dives deeper into the inner workings of the oncology center, by prompting my participants to answer the “How”.</td>
</tr>
<tr>
<td>It’s Propositions</td>
<td>My positionality statement coupled with my researcher reflexive journals identifies my propositions and led me to relevant evidence to support the exploration of my research purpose</td>
</tr>
<tr>
<td>Its Unit(s) of Analysis</td>
<td>A “case” can take many forms, in this study the case was bound by 4 components, location, level of experience, healthcare provider role, and provider-patient relationship.</td>
</tr>
<tr>
<td>The logic linking the data to the propositions</td>
<td>The final two components of a case study are complimentary to the data analysis process. At the design phase of the research, I foreshadowed my data analysis strategies. To this end, I considered my sample size based on qualitative research guidelines and previous research and I ensured I embedded trustworthy strategies throughout my research process.</td>
</tr>
<tr>
<td>The criteria for interpreting findings</td>
<td></td>
</tr>
</tbody>
</table>

The decision to conduct a single case study was also due to the variations of "person-centred care." The evolution of healthcare sparked differing beliefs on what term should define care that is focused on delivering care that meets patients wants, needs, values, and preferences. Currently there is patient-centre care, person-centred
care, people-centred care, family-centred care, client-centered care, patient experience, and patient focused (Canadian Cancer Society, 2017; Cancer Care Ontario, 2017, Dawood, 2005; The Beryl Institute, 2017, World Health Organization, 2015). With the inconsistent definitions and interchangeable nature of these terms, I believed that an appropriate starting point to fill a gap in the literature would be to look at a single system and explore the use of care delivery terminology. Future research in this field could use this study to explore further the differentiation of oncology care language across several systems.

**Research Site**

With the research purpose and research questions in mind, I took a purposeful sampling approach to choose an oncology center to conduct this research study. The two components that were needed to reflect the purpose of this study were (1) an oncology center that had an interdisciplinary and interprofessional team of healthcare providers, and (2) an oncology center that took a person-centred care approach to care delivery. A local oncology center was chosen based on these two criteria. This local oncology center considers itself to be “Patient Focused” and has built their culture of care around delivering patient-centred care by an interdisciplinary team. With a critical lens, I assessed the nature of their care delivery and attempted to identify the congruence and possible incongruences in relation to my research questions and purpose. This location was chosen based on (1) the oncology center’s team-based care approach and (2) their patient focused mandate (Calisi et al., 2016).
Participants

My choice to study only healthcare providers was prompted by the gap in the literature on their perspective on integrating patients onto the healthcare team (Gagliardi, Dobrow, & Wright, 2011; Martin & Finn, 2011; McComb & Hebden, 2013). Healthcare providers oversee the delivery of patient care, and they are considered the communicators and the coordinators of care between professionals, patients, and family caregivers (Bilodeau, Dubois & Pepin, 2015; Lazure et al., 2014). Part of conducting a literature review is critically assessing what has been done and highlighting what hasn’t. Based on what I found in this field of literature, it was important for me to illuminate healthcare provider’s perceptions and readiness for having patients and caregivers considered a part of the team, together with identifying how this model of care can be operationalized.

Recruitment

I recruited participants through established relationships I have with the Director of Oncology Development and other healthcare providers at this local oncology center. I first met with the Director of Oncology Development, the Staff Educator, and the Patient Experience Specialist, whom showed interest in my research. Following this initial meeting and after receiving ethics approval from both Brock University and the oncology center’s designated REB board, I then used a purposeful sampling strategy to recruit participants (Jones, Torres & Arminio, 2014). My chosen methodology emphasizes the need to define a case within a bounded system (Yin, 2003, 2009, 2013), therefore, purposeful sampling allowed me to recruit participants who could provide a rich
description of their experiences, aiming to answer my research questions (Jones, Torres & Arminio, 2014).

The Director of Oncology Development sent out my letter of invitation and recruitment email to all healthcare providers at the oncology center, (See Appendix B). If staff were interested in participating, they emailed me directly, keeping their identity to any other hospital staff at the oncology center confidential. Once participants demonstrated interest in the study, an email was sent to them outlining the purpose of the study and asking them three questions, identifying the inclusion and exclusion criteria, (See Table 5). To ensure voluntary participation and clear expectations of the study, participants were asked to read through the informed consent document (See Appendix C), and choose whether they wanted to participant.

In qualitative research, there is no set number of participants needed (Yin, 2009), rather the goal is to provide a rigorous perspective of each participants’ experiences. One of the benchmarks I used to ensure rigor and trustworthiness during my recruitment, was saturation (Glaser & Strauss, 1967). Saturation is a strategy used in qualitative research to estimate the number of participants needed to collect a well-rounded and complete perspective of your participants. Traditionally, saturation is perceived to be the point in the research process when no “new” information, experiences, or opinions are being identified by participants. Based on previous literature (Bilodeau, Dubois & Pepin, 2015), I aimed to recruit 10 – 15 participants. I was able to conduct interviews with 15 participants and collected 15 documents from the oncology center. Towards the end of data collection, saturation had been reached, as similar words, phrases, and stories were being reiterated by different participants.
Table 5: Participant Eligibility Criteria and Rationale for Participant Selection

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Provider</td>
<td>Meeting the needs of the research purpose and questions</td>
</tr>
<tr>
<td>Full-time employee at oncology center</td>
<td>Having an understanding of the cancer process and possessing the ability and opportunity to interact with patients on a regular basis.</td>
</tr>
<tr>
<td>Employee at oncology center for at least 18 months</td>
<td>This specified period was used as a benchmark for knowledge of the oncology center, i.e. the inner workings, the protocols, the staff, and the resources available.</td>
</tr>
</tbody>
</table>

During the recruitment process, three part-time staff members became interested in the project and offered a unique perspective to the delivery of person-centred care and team-based care. Two potential participants would be defined as “part time” at the oncology center, but full time employees of the Hospital, and one potential participant would be considered “part time” both at the oncology center and within the Hospital. Considering my recruitment criteria, research purpose, research questions and my overall intention for the study and with the approval of my thesis supervisor, it was decided to include the three part-time staff. In the scope of practice, these potential participants and their role on the oncology team provided a perspective rounding out the team-based care aspect of person-centred care. Furthermore, through document analysis, the three roles identified as part-time were either listed in the Patient and Family Education Binder as part of the interprofessional team or were included in the collection of documents from the patient library.
Data Collection and Procedures

The data collection period lasted two months, September 2018 – October 2018, during which I employed three forms of data collection. When using a case study methodology, one of the main guiding principles is the use of multiple sources of data (Baxter & Johnson, 2008; Yin, 2003, 2009, 2013). In this study, individual semi-structured interviews with participants were conducted, along with document analysis and reflexive journals. These forms of data collection were used in order to gain a comprehensive understanding of the phenomenon being studied and the context of which it occurs (Yin, 2009). My primary source of data collection was semi-structured interviews, which were conducted with the healthcare providers of the local oncology center. I used document analysis and my reflexive journal as secondary sources of data collection. Document analysis was used to gain knowledge on the context, environment, and culture of care and the reflexive journal was used to acknowledge my biases throughout the research process and further my analysis of transcripts and documents. These three data sources provided opportunities to solidify my findings with paralleling themes and identification of future research opportunities (Yin, 2009). The use of these three data collection methods created an in-depth and comparative data analysis process yielding multi-dimensional and trustworthy findings.

Individual Interviews

A foundational practice in qualitative research is the use of interviews as a data collection method, especially when conducting a case study (Yin, 2009, 2013). According to Yin (2009), interviews are one of the most important sources of information for reaching the aim and purpose of the research study. Given the guidelines of a single
case study, and considering the nature of my interpretive paradigm, I am aware that my questions, prompts, and probes were subject to change (Yin, 2003, 2013). My participants spanned across several health professions, all with varying levels of patient and caregiver interactions. Therefore, during each interview, I used a semi-structured interview guide along with my judgment and interpretive research lens to facilitate an appropriate conversation based on the nature of each healthcare provider.

Individual interviews were conducted with healthcare providers at the local oncology center, following a semi-structured interview guide (See Appendix D). The questions included in the interview guide were designed for two purposes: (1) to gather background information on care delivery in oncology services, and (2) answer my two research questions, underlying my research purpose, (See Appendix E) (Gill et al., 2008; Yin. 2009).

I chose to conduct semi-structured interviews as oppose to structured interviews, as I felt they provided me with the freedom to ignite a discussion on care delivery practices. Semi-structured interviews are “loose” in nature and open ended, conversely, structured interviews are considered standardized and rigid (Britton, 1995). My goal was to gather information on each participant’s personal work experiences and opinions, rather than searching for pre-determined “right” and “wrong” answers. Therefore the choice to conduct semi-structured interviews was based on the associated flexibility with this data collection practice (Britton, 1995; Yin, 2009, 2013). Though semi-structured interviews are open ended, there is structure embedded in this type of interview. Semi-structured interviews provide the researcher the ability to define the purpose of the interview with predetermined questions and allows them space to diverge the
conversation to delve deeper, while at the same time allowing the participants to recall their experiences in a manner they feel most meaningful (Britten, 1995, 2006; Gill et al., 2008). With the use of guiding questions, prompts to explain answers further and probes to gain a deeper understanding, the interviews allowed for extensive data collection (Yin, 2009).

The background section of the interview guide started the conversation with the intention to explore terminology used within oncology services and healthcare at large. The first question that was asked connected the participant to their own thoughts, opinions, and experiences with person centered care, “What is your personal definition of person centred care?” At the beginning and throughout the interview, some participants used other terms alternatively to person-centred care, such as patient-centred care or patient experience. From there, those terms were explored to understand their meaning and association/affiliation with person-centred care. This laid the foundation for a discussion on terminology, the connotation of the words that are used and how that ultimately relates to and determines who is on the “healthcare team.”

Following the background section, participants were asked specific questions on how person-centred care equates to team-based care and the membership of patients on the healthcare team. Participants were asked, “What do you perceive as the role of the patient, family caregiver and what do you see your role as healthcare provider?” They were also prompted on the challenges and enablers they see to integrating the patient and family onto the healthcare team.

Fifteen participants (13 females; 2 males) who are considered healthcare providers at the local oncology center and hospital at large were interviewed.
Participants included 5 physicians, 6 nurses, 4 providers/staff/other team members. This sample represents the diversity of roles at the oncology center highlighting multiple perspectives, which yielded a well-rounded and holistic picture of cancer care delivery. The interviews were conducted in a place and at a time that was most convenient for the participant. Most often the interviews took place in a private meeting space, as the main goal was to ensure that participants were comfortable during the interview process. The interviews were audio recorded and subsequently transcribed verbatim (Yin, 2013). Following each interview, initial thoughts and reflections about the interview were recorded. This was used as a reference during analysis.

**Document Analysis**

One of my secondary sources of data collection that I utilized was document analysis. This form of data collection examines written materials as they are presented in the researched environment (Krippendorff, 2004). This method can be perceived as static; however, my role as the researcher is to interpret and obtain meaning from these written documents in relation to the people who read them and the context they exist within (Krippendorff, 2004; Yin, 2003, 2013).

In a case study, this form of data collection is often used for triangulation (Yin, 2009) and the solidification of main themes and findings. Document analysis was used for three other important purposes: (1) as a gateway to understand how the culture and environment was shaped by the information, materials, and resources provided to patients and caregivers; (2) as a tool to understand the representation of the local oncology center as a “Patient Focused” and patient-centred oncology system, and (3) as comparative data with my interviews and reflexive journal data to demonstrate
contrast or alignment of themes and findings (Yin, 2003, 2009, 2013). In order for the reader to feel confident that the findings presented are the findings representative of the participant’s perspective, it was vital to use the documents to ground the individual interview data and reflexive journal.

In this research project, the oncology center documents that were analyzed included, a Patient Education Binder, Supportive Care Pamphlets, an oncology clinic Self-Reporting History Questionnaire, Treatment Information Handout, Oncology Orientation Manual, and the Oncology Orientation Education Presentation. These documents were collected from the patient library, my participants, the lead staff educator, and the lead nurse educator.

For data collection and data analysis purposes, a document analysis tool was employed (Appendix F). This tool provided a guide to identify the type of document, the purpose of the document and the audience (Bowen, 2009). It also aided in assessing and summarizing the contents of the document, interpreting the meaning, and determining the significance, the importance, and the relevancy of the document to this research study (Bowen, 2009; Miles & Huberman, 1994). The data were collected through document analysis were used to ground the purpose of this research in the oncology center where my participants work.

**Reflexive Journals**

The inclusion of my reflexive journal as a data collection tool parallels my interpretive paradigm (Ortlipp, 2008) and aligns with my chosen methodology (Yin, 2013). Using semi-structured interviews, I gained the perspective of my participants and document analysis framed the phenomenon within the context of the care environment.
My reflexive journal was then used to document my interpretations of both sources of data. Aligning with my interpretive paradigm, I believe that I am an active participant in the research process, as the “research instrument” (Janesick, 1999, p. 506). Therefore, my values, experiences, and assumptions were used as a continuous touch point to hold myself accountable for my interpretations, ensuring that they were rooted in my participants’ experiences and not my own (Ortlipp, 2008; Janesick, 1999).

I used reflexive journal to document my experiences, interpretations, and thoughts about what I saw, heard, and felt throughout the research process (Janesick, 1999). Following the completion of each document analysis form and individual interview, I wrote down my initial reflections on the content I read and the experience I had during the interview. The journals initiated my own interpretations of what I was hearing, seeing, and feeling.

I continued keeping reflexive journals during data analysis. This would be considered memo writing. This was woven throughout each step of data analysis. This form of data analysis originated from grounded theory and now has been accepted among several methodologies (Glense, 2015; Jones, Torres & Arminio, 2014; Yin, 2013). Memo writing is a form of reflexivity (Glense, 2015), correlating with my interpretive paradigm and is readily employed in case study research (Yin, 2013). Following the completion of each transcription, I wrote down my overall impressions and notes for improvements for the next interview. Throughout the analysis process I kept track of my interpretations, acknowledging any biases or assumptions I was making. I continuously asked myself questions, such as: What are my assumptions?; What is the recurring theme?; What is the purpose of this question?; How do these transcripts and
documents relate to my research purpose and questions?; What do I notice about this situation?; How is it different and how is it similar?, and How do my previous experiences as a volunteer at this local oncology center affect my interpretations?

As part of my analysis process, I did engage in a member checking process with my participants; however, reflexive journaling can also be considered a form of member checking for the researcher (Janesick, 1999). It gave me an opportunity to stay close to the data throughout the process. If I was not spending time conducting an interview or reviewing documents, I was recording my thoughts about the data collection and research process. I then used these initial interpretations to form my data analysis process.

**Data Analysis**

When I began the analysis process, I adopted the mindset of "working from the ground up," proposed by Yin (2013, p.196). This outlook enabled me to use my interpretive research lens to identify prominent patterns and themes (Yin, 2003, 2013). Rather than themes emerging from the data collected, this perspective allowed me, as the researcher, to clearly notice recurring patterns from all my data sources and the space to interpret significant meaning (Yin, 2009, 2013).

The first phase of data analysis was the organization of data collected (Yin, 2009, 2012). This meant the oncology center documents were summarized using the document analysis tool (See Appendix F), my researcher reflexive journals were gathered and summarized, and finally, my individual interviews were transcribed (Yin, 2009, 2012). As the researcher, I transcribed every interview conducted. There were several advantages to transcribing the interviews myself, one in particular was being
able to stay close to the data throughout the research process. Transcription occurred following the completion of each interview. This helped me to become familiar with the data early in the data collection and analysis process, allowing me to recognize “patterns of experience.” It also aided in making an evidence-informed call on data saturation (Aronson, 1995; Yin, 2009;).

An important step in the analysis phase is to “Notice Things” (Seidel, 1998); this is the process of identifying any observations the researcher has, gathering important documents, and recording any thoughts or feelings about the data. As I read through the transcripts and document analysis forms several times, I kept my researcher reflexive journal close by to record initial thoughts (Creswell, 2012; Seidel, 1998). Some initial thoughts that I wrote down included, “I have never heard the term ‘goals’ before to describe person-centred care, make note of this” and “throughout most interviews, participants are using ‘person-centred’ and ‘patient-centred’ interchangeably; do they perceive them to be different?”

The document, interview and reflexive journal data were analyzed using two data analysis strategies, thematic analysis and constant comparative analysis (Bowen, 2009; Fram, 2013; Glaser 1965; Glense, 2015). Thematic analysis provided a process to interpret the data and translate those interpretations into codes, patterns, categories and themes (Boyatzis, 1998). Constant comparative analysis was employed to notice the similarities and differences between the data, and to deepen the analysis process (Glaser, 1965). It is important to find themes that encompass the experiences of the participants and ultimately answer the identified research questions, but trustworthy research is carried out by a researcher who acknowledges all the sources of data and
their unique contributions to the findings. Part of the data analysis process is to include the findings that question and challenge the popular narrative (Yin, 2009); both analysis strategies were necessary for the final constructions of themes. Thematic analysis helped to tell the story of the phenomenon studied (Boyatzis, 1998), while constant comparative analysis helped to identify areas within the data where there were verging and converging interpretations (Glaser, 1965).

Following the initial phases of analysis, I began an open coding process (Patton, 2002). In my data analysis process, open coding included reading the transcripts line by line and assigning a word or phrase, known as a code, to sentences, paragraphs, or blocks of data (Aronson, 1995; Boyatzis, 1998). Chunking the data, capturing the meaning, and translating it into codes can take two forms, in-vivo codes or constructed codes (Aronson, 1995). Codes that are chosen based on the words and/or phrases participants used are considered in-vivo. Whereas, constructed codes are owned by the researcher, requiring the interpretation of the participant’s words.

My open coding process included both naming strategies, in-vivo and constructed codes, and included three iterations of open coding (Aronson, 1995). Documents analysis and the reflexive journals were considered supplementary data and were used as supportive data to the semi-structured interviews (Bowen, 2009). Therefore, transcripts were coded first, then following the 3 cycles of code refinement, codes identified in the transcripts were then used to analyze the document analysis forms and reflexive journal (Bowen, 2009). During this stage, transcripts, document analysis forms, and the reflexive journal were compared with transcripts to identify any similarities and differences.
Following the open coding process, codes were transferred to sticky notes (See Figure 3) (Patton, 1990). For the three categories of participants, physician, nurse, and provider/staff/other team member, a different coloured sticky note was used. This was an intentional decision to ensure that the patterns and the themes would be representative of all participants. The grouping of the data continued to identify similarities and differences in the codes. Originally 300 unique codes were identified and these were subsequently grouped into 47 categories. These patterns within the data were then further collapsed through continuous comparison, into themes. There were 8 prominent themes identified which were then critically analyzed to examine the larger connections between the themes, revealing the state of their interrelationship.

![Figure 3: Data Analysis – Coding and Categorizing](image)

After I had my themes and sub-themes, I started the process of data representation, which included paring quotes and writing thick descriptions for each theme and sub-theme. Not only does this establish trustworthiness, but also allows the reader to gain an in-depth understanding of the phenomenon studied. During this process, there were several variations of the themes created, as the quotes caused the researcher to continue to question the appropriateness of theme. I asked myself, “does this theme represent the experiences of my participants?” Through data triangulation,
member checking (by participants), theme-quote pairing and advisory committee feedback, four overarching themes, and ten sub-themes were finalized.

**Trustworthiness**

The trustworthiness of a qualitative research study is the barometer used to ensure that quality research has been conducted (Jones, Torres & Armino, 2014). A criticism of qualitative inquiry is the perceived lack of structure and validity that is demonstrated through the methods of data collection and data analysis (Kvale, 1994). Qualitative research is based on human experience and is grounded in personal interpretation. The notion of a single truth or a “right” answer is not recognized in a qualitative study; however, it is imperative that qualitative research demonstrates trustworthiness in the representation of findings (Nowell et al., 2017).

The data that I collected through interviews, document analysis, and my personal reflexive journals has been interpreted and made meaningful through the lens of my research purpose and questions (Glense, 2015). The importance of trustworthiness of qualitative research can be equated to the accuracy, validity, and reliability of a quantitative study, all aiming to solidify confidence in the reader that the findings represent participant truth (Jones, Torres & Arminio, 2014; Shenton, 2004). The nature of a qualitative research process embodies several potential interpretations and experiences that could be highlighted in a single data collection method. Therefore, I must be conscious of asking myself the question, “How can I know that my interpretation is the ‘right’ choice?” (Hollway & Jefferson, 2000). There are four key components to establishing trustworthiness and demonstrating that a researcher has
conducted a rigorous qualitative study; credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

**Credibility**

By demonstrating credibility, the reader can trust that the depiction of findings does not represent a singular perspective created by the researcher; rather it is a harmonious blend of the researcher and the participants (Jones, Torres & Arminio, 2014; Patton, 199; Yin, 2009, 2013). This was accomplished through: data triangulation and member checking.


Member checking is a trustworthy strategy that is used to gain feedback from participants following the completion of individual interviews (Patton, 2002). My member checking process consisted of presenting my preliminary findings, including my 4 overarching categories, 8 themes and a description of each theme to my participants. Participants were asked for their feedback on the representation of their experiences in
the themes presented (Creswell & Miller, 2000). I utilized this strategy of credibility to further my data collection process and use the interpretations of the findings to continue the co-construction of meaning (Carlson, 2010; Lather, 2003). Participants were informed that the themes were subject to change based on further feedback from my thesis committee and supervisor, but the final results would be representative of the themes that were sent. All fifteen participants were contacted, and three participants provided positive feedback. If participants chose not to provide feedback it was understood that they did not feel it necessary to provide any feedback.

**Transferability**

The ability of qualitative research to be transferable aligns with the assessment of external validity in quantitative studies (Curtin & Fossey, 2007). Demonstrating transferability of one’s study and findings prompts the researcher to ask themselves: “Who can benefit from my research?”, “Who can relate to my research findings?”, and “Can my research be applied to other contexts?” (Yin, 2009). In the current research study strategies to ensure transferability of the research findings include: diversity of population sample, and content of interviews (Krefting, 1991; Curtin & Fossey, 2007). In this study, three categories of healthcare provider roles were included, Physicians, Nurses, and Providers/Staff/Other Team Members. Originally, the third category was thought to be called Supportive Care or Allied Health Professionals. This was modified based on the recommendation from my contacts at the oncology center and my thesis supervisor and committee members. Providers/Staff/Other Term Members is a more inclusive term that incorporated non-medical professionals, which identified three of my participants. This furthered the reach and applicability of this research. My diverse
sample is representative of Cancer Care Ontario’s distinction of Healthcare Team members; thus, the results can be transferable to additional oncology centers (CCO, 2018).

The makeup of the semi-structured interview guide, as mentioned previously contained two parts, (1) background information (2) specific questions framed around the research purpose and questions. It was important, due to the variety of terms used in oncology care, to have a conversation about the use of person-centred care, patient-centred care and client centred care. The content of my interviews spanned several well-known concepts in oncology care and healthcare at large. The individual interviews included discussions about person-centred care, team-based care, challenges and enablers of quality care, and strategies for engagement of patients and family caregivers. These are concepts that are unique to cancer care; however they are not exclusive. Therefore, these results could be generalizable to other oncology centers and/or hospitals (Yin, 2009).

**Dependability**

Dependability is seen as the reliability of one’s study. In quantitative research, it is when the “right answer” can be achieved following several iterations of the study. This builds trust that the researcher has conducted the study correctly. In qualitative research, the researcher is heavily involved in the interpretation of the findings, which casts doubt on the ability of the findings to be replicable (Kvale, 1994). Dependability describes a notion that if another researcher were to follow a similar process as the primary researcher, there would be congruence in their interpretations and representation of the data (Thomas & Magilvy, 2011; Yin, 2009). Therefore, the
dependability criteria are based on the inclusion of rigorous methods for data collection, data analysis, and data representation.

The dependability of my study can be judged on the basis of the utilization of multiple sources of data, two data analysis strategies and rigorous methods of data analysis, member checking with participants, and thesis committee consultation (Creswell, 2013; Yin, 2003, 2009, 2013). In addition to using direct quotes and thick descriptions in my findings (Carlson, 2010; Sparkes & Smith, 2014). Verbatim quotes and thick descriptions further demonstrate dependability, ensuring that my interpretation of the data has not falsified or manipulated my participants’ experiences and/or opinions.

To further demonstrate the dependability of my findings, my thesis supervisor was involved in constructing themes and assigning meaning to the themes. We met every week to discuss the study’s progress. By keeping an audit trail of the research process, she was able to embed herself in the findings and determined that the representation of my findings was dependable, as similar themes and patterns of experience were identified from her research stance and perspective (Thomas & Magilvy, 2011).

**Confirmability**

Confirmability as a trustworthy strategy is an all-encompassing criterion that requires a research study to be credible, transferable and dependable. The collective assessment of these three components, builds the foundation of confirmability. To achieve the stamp of confirmability, the practice of reflexivity and keeping an audit trail are often cited as two necessary strategies (Shenton, 2004; Thomas & Magilvy, 2011).
Reflexivity was a large part of my research study and was used to further data collection and analysis. I was critical of my stance throughout the entire research process and kept detailed notes of my thoughts, feelings and assumptions. My researcher reflexive journals became a vital portion of my data analysis process as it helped to shape the final themes and grounded the results in my participants’ experiences and this oncology center’s culture of care (Shenton, 2004; Thomas & Magilvy, 2011; Yin, 2009). In my research journals, I also documented my methodological process and reflected on my data analysis procedures, critiquing each step (Shenton, 2004; Thomas & Magilvy, 2011; Yin 2009). By keeping an audit trail, it helped to justify the choices that were being made and communicate the details of the research process (Thomas & Magilvy, 2011).

**Ethical Considerations**

Ethical considerations are a vital piece of qualitative research as there is always risk involved with a study involving humans (Richards & Schwartz, 2002). To alleviate and minimize any potential risks or harm to my participants I: (1) received ethics clearance from two Research Ethics' Boards; (2) included an informed consent document that was required to be read and signed by my participants, and (3) took several steps to secure the confidentiality of my participants.

**Research Ethics Board**

One of the main guiding principles of research is to “*do not harm.*” As a qualitative researcher, this concept may seem strange as there is no perceived physical strain to interviews, focus groups, document analysis or other qualitative-specific data collection methods; however, the risks involved in qualitative research include delving
deeper into personal experiences and opinions, which can cause undue psychological, social, or emotional harm. A necessary step to ensure that researchers are limiting the risk of participants is to seek approval from a research ethics board (Guillemin & Gillam, 2004; Yin, 2009). The current study received ethics clearance from the Brock University Ethics Board [17-167] (Appendix G) and the Hamilton Integrated Research Ethics Board [File] (Appendix H).

**Informed Consent**

In the current study, participants were recruited through a letter of invitation (Appendix B). The letter of invitation outlined the intention of the study, the research purpose, and questions. It also outlined the perceived risks, benefits, and plans for the potential findings. Once the participant expressed interest in the study, at the time of the interview, participants were provided with the consent form. They were given time to read it and then asked to sign it if they still agreed to participate. Following this, participants were asked if they had any questions and were later provided a copy of their consent form (Yin, 2009).

**Confidentiality**

Due to the inherent risks associated with qualitative research, it is especially important to protect the privacy and confidentiality of participants. Steps that were taken to ensure confidentiality were: (1) limiting identifying information; (2) categorizing job titles, and (3) limiting access to raw data. The only identifier which was collected was the participant’s job title. The participant’s job title was further categorized into Physician, Nurse, and Provider/Staff/Other Team Member. These categories were used to further aggregate the data and remove any identifying job title. Supportive care,
clerical staff, and any other non-medical staff members working at this oncology center were encompassed under Provider/Staff/ and Other Team Members. Additionally, I spoke with Physicians and Nurses who specialized in Chemotherapy or Radiation, and neither of these identifiers were included. It was important to collect a diverse sample; therefore, the steps were taken in order to collect this information but also protect the confidentiality of the participants. Names and job titles of participants were separated in the storage of the data, and only the primary researcher knew the connection between the two. All quotes that were used in the findings were associated with the job titles previously identified. As well, any information discussed during the interview that would identify a participant was deleted from the transcript. There was limited access to the raw data, including only the primary researcher and the thesis supervisor. The audio files were stored on a password protected computer and any hard copies of data were stored in a secure filing cabinet in the investigators research office. The audio files will be deleted at the completion of the study and there were no hard copies made of the transcripts.
Chapter 4 – Findings

The following findings section is represented in two parts. The first is the case description, which provides an overview of the context of the oncology center in which this research study was conducted. The second section presents the overarching themes and complimentary sub-themes with verbatim quotes. Four key themes were found through the individual interviews, document analysis and reflexive journal. The themes and subsequent sub-themes highlight this oncology center’s perspective on the role of the patient, the caregivers, and the healthcare providers and how collectively they all contribute to forming a person-centred care team. In this chapter, each theme and sub-theme is described in detail with associated quotes to tell the story of healthcare providers’ daily experiences engaging patients and caregivers, and delivering team-based care and person-centred care.

Case Description – The Context

In 2015, Cancer Care Ontario in partnership with Program in Evidence Based Care, published a Person-Centred Care Guideline. The objective of this document was to “establish a standardized set of recommendations for providing person-centred care in the delivery of adult oncology services in Ontario.” This document made it clear that person and patient-centred care were two distinct forms of a similar care process, but that person-centred care had a subtle but important difference. The need for the change from patient to person was prompted by the idea that patients should be treated as people first, as their disease affects every aspect of their life. Rather than being a cancer patient, the language allows for healthcare providers to see patients as a person with cancer. The guidelines identified in this report provided a unique set of strategies
and practices that can be adopted by local oncology centers to take a person-centred care approach. Building off of this, the present study wanted to gain a better understanding on how guidelines and practices like these are translated into action.

In order to gain a better understanding of the inner workings of the chosen oncology center, interviews were conducted with healthcare providers. Nurses, Physicians, Providers/Staff/Other Team Members encompassed all participant interviews. Nurses and Physicians were compromised of those who worked in the chemotherapy, along with the radiation department. Providers/Staff/Other Team Members were not uniquely identified by their job title to protect confidentiality; however aid in their role by helping patients physically, emotionally and/or mentally.

The Oncology Center explored in this research project does not identify as a person-centred care Oncology Center. They do in fact on their website note that they deliver patient-centred care and are “focused on the patient”. In order to focus on the patient, this oncology center has assembled a Patient and Family Advisory Council to act as consultants in order for the staff to provide the best patient experience possible. As stated previously, participants were asked to provide their personal definition of person-centred care and responses to this question varied. Participants were asked for their own interpretation of this term, because it was important to highlight the working definition of person-centred care, rather than the textbook answer. Based on participant’s answers, an underlying core concept was evident, which was person-centred care is about focusing on each patient’s priorities. To this end, even though this Oncology Center does not specifically identify as delivering person-centred care, their mindset and practices reflect the core tenants of this care model.
Both governing bodies of cancer care, Cancer Care Ontario and the Canadian Cancer Society, have identified that person-centred care is a priority in oncology care. Along with Cancer Care Ontario’s guiding document of person-centred care practice, the Canadian Cancer Society, has stated that patients are the most important member of their healthcare team. This guided the conversation with participants, as they were explicitly asked if patients were considered a part of their team. The majority of participants agreed that patients were a part of the team, in fact many stated that they were the most important member of the healthcare team. Other participants explained that they saw patients as the middle of the team; however did not like the use of the word team, as it denoted the need for medical expertise.

In this chapter, the patient, caregiver, and healthcare provider roles will be outlined, from the perspective of the healthcare providers, along with answering how all team members can work together to form a person-centred care team. Patients are defined as those with the cancer diagnosis. Caregivers are defined as either a family member or a friend who accompanies the patient in their cancer journey, offers support but does not act as a medical professional. Finally, healthcare providers are known as the medical professionals with expertise in oncology care who diagnosis, treat, and support the patient in their cancer journey.

**Theme 1.0: Educating with Empathy**

*Educating with Empathy* describes the healthcare provider’s perceived main role on a person-centred care team. In the positionality statement and initial entries into the reflexive journals, the perspective taken was that healthcare providers were considered the “leaders” of the team. This created the illusion that healthcare providers were
providing options to the patient but ultimately the decision was made by the Physician, yet during the individual interviews, it became apparent that these healthcare providers perceive the patient to be the decision-maker.

All participants, Physicians, Nurses, and Providers/Staff/Other Team Members agreed that a large part of their role is education and “providing [patients] with knowledge.” Within this Oncology Center, educational resources such as the Patient and Family Education Binder, Systemic Therapy Education Class, and Orientation Manual are all geared towards providing patients with the information they need. When a Nurse was asked what their personal definition of person-centred care was, she stated that it is “when that patient is truly informed of their situation.”

What distinguishes healthcare providers educating patients on a traditional medical team and person-centred care team is the addition of “personal touches”. Within this theme there are two underlying sub-themes, demonstrating how healthcare providers translate their medical expertise into the empathetic and compassionate delivering of information and knowledge: (1) **Building a Relationship**, and (2) **Supporting without Judging**.

**Sub-Theme 1.1: Forming a Caring Relationship**

A core value of person-centred care is seeing and treating the patient as a person. **Forming a Caring Relationship** highlights how healthcare providers achieve an integral element of person-centred care, which is knowing the patient as an individual. A Nurse explained that when a healthcare provider first meets a patient, their “number 1” task is, “trying to get to know the patient.”
It is the responsibility of healthcare providers to care for a patient, by educating them on their diagnosis, providing treatment and helping them manage their symptoms. When a healthcare provider was asked what they perceive their role on the team is, they answered: “First and foremost, I do think of myself as an educator. I do think obviously; my expertise is in the medical side of things.” In addition to this, all the healthcare providers acknowledged another side of care and demonstrated an interest in trying to understand “who [the patient is] as a person.” What was illuminated in the interviews with participants was the presence of a deeper meaning to the patient-caregiver-healthcare provider relationship, and that is a true interest is caring for the patient and connecting with them and their caregiver. A Physician stated that when they first meet a patient they usually ask, “tell me who you are, who are you as a person?” By knowing this information, it helps the healthcare providers “[know] the words to use that are meaningful to that patient.” It becomes vital, if person-centred care is to be delivered, for healthcare providers to bond with the patient. A Physician explained:

I want my patients to think that I see them more than just a diagnosis that I value what they want, and I am not just trying to push my treatment. I am really trying to build a relationship where I can help them make decisions.

This highlights the true distinction between a traditional healthcare team and a person-centred care team. One of the first ways healthcare providers attempt to gather information about the patient is through the “self-reporting history.” The self-reporting history is a 4-page document completed by the patient at their first visit. This is a tool that gathers rich information about the patient, including personal characteristics such as marital status, preferred language, power of attorney, and religion, along with the patient’s medical, nutritional and pain history. It even touches on some of the emotional
aspects of a cancer diagnosis by explicitly asking, “How much does your health problem change the way you feel about yourself and your body?” This tool is designed to highlight the priorities of the patient, and helps the healthcare providers decipher what “[the patient] wants and what they need.” This information is then used to design a treatment plan that is best suited for the patient.

Along with using the self-reporting history, healthcare providers also “just ask the patient” what is important to them. With multiple visits including diagnosis, orientation, treatment, and screening, patients spend extended periods of time with their healthcare providers of the oncology center. Contrary to some of the negative perceptions of an oncology center, a Nurse explained that this Oncology Center is very “light hearted” and there is a lot of “joking” that goes on with patients. The long-term nature of cancer care enables the bonding of patients, caregivers, and healthcare providers. A Provider/Staff/Other Team Member explained that there is a “family spirit” that is created in the chemotherapy treatment area:

[We] get to know this patient because they come for a long [time]. It’s not like they are in and out, and have a broken leg, heal and then they never see them again.

On the flip side, with such a large emphasis put on getting to know the patient, Physicians specifically, highlighted the importance of “trying to tell [patients] a little bit about [themselves].” Another Physician echoes this sentiment by explaining that the relationship with the patient is “a two-way street”, and “there has to be an element of trust.” On a person-centred care team, patients are active team members, not just receiving information but processing that information and contributing. During an individual interview with a Physician, they expressed that something they would like to
do, to enhance their person-centred approach, is to open-up to the patient about who they are:

Initially I thought about giving [the patient] a letter as an introduction because I think in medical school we are taught not to show who we are. But a lot of my patients when I see them in follow up, come to appreciate that they know I have a daughter. It’s something that they want to connect with me. The connection I realize is important, for it to be both ways, because then they realize that I am not at a different level, I am just at the same level, I am just another person who is involved in their care. Versus here I am the doctor… It has to be a lateral, they have to view you as a human.

*Forming a Caring Relationship,* not only helps the patient’s overall experience and aids in the team dynamic, but can leave a lasting positive impression on the person. A Nurse recalled that one of their patients, at the end of their treatment, said to them, “*I don’t really want to see you guys again here, but I am going to miss you guys.*”

**Sub-Theme 1.2: Supporting without Judging**

*Supporting without Judging* describes the mindset and attitude healthcare providers have throughout the entire cancer care process. This theme, at its core, represents healthcare providers “*respecting what the patient wants and what they don’t want*”. Healthcare providers perceive themselves as the educators and patients as the decision makers. Therefore, patients could make decisions that their healthcare team doesn’t agree with or recommend; however, healthcare providers stated that they try to continue supporting the patient even if their care takes a turn they weren’t anticipating. A Provider/Staff/Other Team Member demonstrates this through their relationship with a patient:

One of the big things, and this isn’t something that is tangible, [but] one of the big things that I always try to make sure I do is maintain a rapport with the patient, no matter what. It could be a patient… doing all these crazy
things that you think oh boy, but to me it’s still important to maintain that relationship and that rapport and convey a persona of understanding and empathy.

Giving the patients the power to make their own decisions, knowing that they could make decisions that are “detrimental to their care”, is cited as a challenge for healthcare providers as there is true concern for the patient’s health. A Nurse explained that the reality is that some patients refuse treatment, and even though “they believe [the patient] should do treatment [because] it would help them live”, healthcare providers respect the decisions of their patients. Another Nurse provided an example:

Some young women who have breast cancer don’t want to be treated and [I] know they have [a] good chance of being cured but they don’t want [treatment] and [I] know that is likely the thing that will take their life. It is very challenging but you have to respect it, because not everyone wants to do treatment and that is their right that is part of their person-centred care. That is their decision so they are ultimately the ones that are making the decision.

It is important to note, during these challenging times of disagreement in care, healthcare providers do not “judge”. For example, part of the self-reporting history is a question asking, “Are you using or thinking about using any other types of alternative or complimentary therapies? E.g. herbal, vitamin, therapeutic touch, Essiac etc.” It was explained that if “patients would rather follow a naturopathic route, than take traditional treatment… the oncologist will support that.” One of the enablers of care that a Provider/Staff/Other Team Member cited is “letting [the patient] know they are being listened to and [we are] not judging them or their choices.” A Nurse further explains this:

Sometimes patients choose the route that we think they should choose, they might, some people choose to go to Mexico and have different things and it’s not what we would choose for them but we have to always remember. Especially as nurses that we have to advocate for patients, to
do what they think is best for them and that there is no better example, that they are at the helm of the team. Because if they decided no more chemo, or if they decide no more treatment or if they decide they are going to go to Boston for this, even though it is experimental. We are still behind them and we help get them there.

As discussed previously, healthcare providers perceive patients as the decision makers and the center of their oncology team. With that, it was also acknowledged that some patients defer to their healthcare provider for advice, opinions, and recommendations. It was mentioned that patients can sometimes express to their healthcare provider, “just tell me what I have to do.” Even though it is not what the healthcare provider perceives as the patient’s responsibility a Physician explains:

You have to remember as well, often times, patients will defer completely to their care team, ‘you’re the expert, you know what you’re doing, you tell me what you advise and I’ll do it.’ And sometimes that is respecting what they want as well.

Supporting without Judging demonstrates that whether patients choose to take on the full capacity of their role or they choose a different course of action, they are still considered a part of the team. It was explained by a Nurse that even if patients defer to their medical community, “in it of itself is a decision”.

Theme 2.0: Informed Personal Advocates

Informed Personal Advocates demonstrates the healthcare provider’s perceived role of the patient on a person-centred care team. A foundational principle of person-centred care is actively engaging and partnering with the patient, which according to these participants is equated to being a member on the healthcare team. This concept is clearly demonstrated in the Patient and Family Education Binder, where it encourages patients to “Take an ACTIVE role in your care.” It explicitly states, “you [the
patient] are the expert of you.” To this end, patients and caregivers contribute valuable information and knowledge to the healthcare team.

Traditionally, any graphic depicting person and/or patient-centred care, puts the patient in the middle with their healthcare team surrounding them. This is how the healthcare providers at this Oncology Center see it. According to healthcare providers, when the patient is in the center, “they hold the most power.” When healthcare providers were asked about the role of the patient on the healthcare team, it was reiterated by several participants that patients must be informed to make decisions and they must advocate for themselves to get what they want and need out of their care. Within this theme there are two sub-themes, demonstrating how patients take on their own role of being an Informed Personal Advocate and how they actively contribute to their healthcare team: (1) Identifying your Goals of Care, and (2) Showing Up, Speaking Up, and Making a Decision.

**Sub-Theme 2.1: Identifying your Goals of Care**

The traditional definitions of person-centred care and patient-centred care identify the patient’s needs, wants, values, and priorities as necessary pieces of the care puzzle. By gathering this information, healthcare providers are able to tailor the care for each patient and participants interpreted this as having the patient, Identify their Goals of Care. The wording of this was something that I took note of in my reflexive journals and was a phrase that continued to surface in other interviews. It was apparent that learning a patient’s goals of care is a practice that is embedded in this Oncology Centers culture of care. By defining “what patients are hoping to accomplish” healthcare providers learn what is “important to them”. A Physician explained that there are often
two categories, “patients are [either] curative intent, and… [then there] stage 4 patients, where quality of life is more important.” Healthcare providers perceive a responsibility of the patient to “articulate their goals of care” and as healthcare providers, efforts are put forth to accommodate, modify and plan around a patient’s goals. A Nurse identifies how patients can express their goals of care:

A patient coming to the cancer center with the expectation that their cancer will be cured and go away, based on treatment, is an example of a patient’s goal of care. Their goal may be to understand that their cancer isn’t curative, their goal is to have minimal pain or any kind of suffering along the way. Their goal may be that they want no cancer treatment that they only want comfort measures and they don’t want to be in the hospital. It is their goal in terms of their reason they are coming to the cancer center seeking care. When you ask the patients what their goal of care is, it helps patients to search within themselves what it is that they want, but it also helps healthcare providers to clarify what the patient’s interpretation is.

Clearly illustrated in this quote, a patient’s goals of care extend beyond diagnosis, treatment or symptoms and gets to the core of the person. What this theme helps to illuminate is the quality of life measures and sometimes palliative intents of patients. It was stated that most patients “just want the best and most aggressive treatment to be able to survive”; however, not all patients want that. A Nurse clarifies that letting the patient “direct their own care”, especially with palliative care “add years to their life.”

During the cancer journey, healthcare providers ask patients to communicate what they want and what they need to feel better. Having a patient verbalize what they hope to get out of their cancer journey, allows for the entire team to get on the same page. Every patient is different; therefore, their goals of care could be different. For example, some patients want comfort measures and as a Nurse put it, some patients
want to fight until “the bitter end.” A Provider/Staff/ Other Team Member provided an instance of this:

I sat in with a gentleman, he was diagnosed, he was basically stage four lung cancer, and he was going to die, and they told him statistically his chances were 1 year or maybe a year and a half and they aren't good. And he said 'I don't want to hear, he told them I don't want to hear that, I need hope, I want you to zap me, and I want you to give me all the medication, heavy duty, I am a strong guy and I can take it, and I want you to give me all the things that you can because I need to live.' Because he had a goal to get to Africa, to feed these kids which he had done for a number of years before. And [he said] 'I have to go, so do whatever you need to do because I'm going.'

Demonstrated in this quote is a patient identifying a personal goal of theirs and asking for treatment to be tailored around that. Healthcare providers acknowledge that often a patient’s life will freeze for a moment following a cancer diagnosis, and during the time of treatment. Due to that, it is important to the healthcare providers that patients have a “semblance of their real life.” By having patients Identify their Goals of Care, this can be possible. Effort is put forth by healthcare providers to plan appointments around the patient’s schedule and “respect their timeframe, so they can live as normal as possible.” Whatever the patient’s goals might be, healthcare providers work with them so they can be achieved.

**Sub-Theme 2.2: Showing Up, Speaking Up, and Making a Decision**

*Showing Up, Speaking Up, and Making a Decision* encompasses what healthcare providers believe to be the patient’s ultimate role on the team. This theme came to light first as noted in the reflexive journal, critiquing the use of the word role. The word “role” used in the interview guide and it was illuminated in the individual interviews and document analysis that their role was equated to “patient
responsibilities”. It became clear that patients play a role on the team but healthcare providers also require patients to have certain responsibilities when working with their healthcare team. One of the responsibilities would include *Showing Up*. Once a treatment plan has been collaboratively decided on, healthcare providers require patients to “come when they are supposed to come” and “follow the treatment plan.”

Another aspect of being on the team is *Speaking Up* and communicating with the team. As the patient resides in the middle with the healthcare providers circling around them, it is vital that the patient be “open with [their healthcare providers] and honest”. Part of the patient’s responsibility is to “report the way they feel” and be “upfront” with their healthcare team. Included in the document analysis process was several educational resources that outline possible side effects, expected symptoms, and “in case of emergency” numbers, steps, and directions. Healthcare providers stated that they communicate with the patient that, “if you are feeling sick, you are not bothering us.” A Provider/Staff/Other Team Member recalled reasoning with a patient and explaining there are several options:

- If that is not going to work, then say, ‘the plan you gave I don’t think I can do that because of this’, communicating, being honest and [then] following through if you say you want to do it.

The interpretation of this theme, came from the language that has circled around person/patient-centred care, specifically advocacy and the phrase “advocating for yourself”. Patients are continuously asked to advocate for themselves and when a Physician stated that a patient should advocate for themselves, I wrote in my reflexive journal, “*what does it mean to advocate for yourself?*” Following up with other healthcare providers and reviewing the Patient and Family Education Binder and Patient
Orientation slide deck, the way it has been interpreted by the healthcare providers is through *Speaking Up*. A Nurse explained:

They have to advocate for themselves, which is a big one, because again most people think, ‘what the doctor says is their god, nobody else can say anything’. That patient will say, ‘well if I say something they don’t like’, too bad I’ll say, this is you, it’s not them, it’s you. You tell them, you are not going to upset the doctor. Things like that.

Demonstrated through this quote, is the need for patients to express how they feel. By *Showing Up* and *Speaking Up*, patients are taking the steps to actively engage their team. In addition to this, *Making a Decision* is perceived as one of the most impactful roles a patient can take on, that is as the decision maker. Traditionally, it has been perceived that healthcare providers, specifically Physicians are in charge, therefore they create the treatment plan, make all the decisions, and tell the patient what they are going to do. This was a concept that was documented in the reflexive journals, stating, “*healthcare providers are the leaders and the ones making the decisions.*” This was absolutely refuted by healthcare providers, as a Nurse stated “*No, in here the patient makes the decision*”. With other healthcare providers collectively agreeing that “*ultimately it should be the patient making the decision*” The healthcare providers shined a light on this concept and the reality became that the decision-making power lies in the patient’s hands. A Provider/Staff/Other Team Member explained the reasoning behind this perspective:

If they are left out of the critical decision making process, they often end up receiving care that isn’t in their best interest from their own perspective. They need to be able to say yes or no to whatever, they need to understand whatever care it is that they are getting, they need informed consent, they need all of those things and if they are not getting that, that isn’t good care, that isn’t exceptional care.
From the healthcare provider’s perspective, it is up to the patient to make the final decision about the course of action. During an interview with a Physician, they revealed they “don’t necessarily view [themselves] as the sole or the most important person [on the team].” Further explaining that their title comes with an associated expectation of leadership, but based on every case, this does not always run true. The patient being in the middle, means they radiate out what they want, need and their course of action, and the healthcare providers follow. By patients Identifying Their Goals of Care and then subsequently Showing Up, Speaking Up, and Making a Decision, healthcare providers feel they are able to actively engage and work together with patients.

**Theme 3.0: Being the “Rock”**

The identification of this theme is a true acknowledgment of the contribution of caregivers. *Being “The Rock”* is the perceived role of the caregiver from the healthcare provider’s perspective. Healthcare providers see the caregiver’s involvement on the healthcare team as an “asset to the team” and “encourage their patients to bring family members” with them to appointments.

While discussing the distinction between patient and person-centred care, it was identified that many healthcare providers prefer the use of person-centred care. One of the reasons being is the use of the word person acts as an inclusive term. A Provider/Staff/Other Team Member explained, “the family and caregivers are part of that team and they are not the patient.” The importance of the caregiver was evident in my reflexive researcher journals. During an interview, I made note of a participant who became emotional speaking about caregivers. This participant explained that
sometimes family members will come and visit the cancer center after their loved one had passed away to mark the final milestone of their cancer journey. Through this story, it became apparent that a person-centred care approach actively engages and partners with not only the patient, but the family too. This theme was also demonstrated in the documents that were analyzed. The Patient and Family Education Binder is an educational resource given to patients at the beginning of their cancer journey. It is clearly addressed to the patients and caregivers and to this end, it acts as a resource for both audiences; however, there were no resources exclusively targeted or tailored for the caregivers.

The consensus was made among healthcare provides that caregivers have an important role on the team and they provide information to the team that impacts the care that is delivered. Within this theme there are two underlying sub-themes, demonstrating how caregivers support and service both the patient and the healthcare providers to deliver care that is best suited for the patient: (1) *Keeping the Patient on Track*, and (2) *Providing the Inside Scoop*.

**Sub-Theme 3.1: Keeping the Patient on Track**

*Keeping the Patient on Track* describes the healthcare provider’s perspective on part of role of the caregiver. If caregivers are involved in the patient’s journey, there is an expectation that they are supporting the patient in any way they can, whether that be “physically, emotionally, socially, [and] financially”. To this end, healthcare providers believe a caregiver’s purpose is “being there for the patient for whatever they need.” When participants were asked how they see the caregiver fitting among the healthcare team, a healthcare provider explained that they are “right there on the team in the
circle." Another healthcare provider shared the same sentiment stating, "I think they are just as valuable as the patient." A Physician articulates this:

I do see them as a part of the healthcare team, I think that is thing that is underestimated. When you have a patient with cancer, it not only affects that person it affects their entire family. You see cancer as a crab or a spider, it branches out and affects everyone. They don’t know what is going to happen to that person, so it affects them emotionally, personally and spiritually... And I enjoy doing oncology because I get to meet their family members, because they often come with multiple people.

Healthcare providers outlined practical tasks that caregivers will often do to support the patient, such as, "helping patient’s get to their appointments”, “accompanying [the patient]”, “[continuing] to listen when the person can’t listen anymore” and “clarifying things.” This theme speaks to the ability of the caregiver to collect information, and provide a level of coordination and order in the patient’s life.

Often a cancer diagnosis and treatment can cause chaos for the patient and the caregiver helps to “just take the chaos out of their life.” A Provider/Staff/Other Team Member explained:

Part of it is to keep the patient’s life a bit organized or manageable, to be the sounding board, to respond to what the patient needs. To not give them any grief, and not to give them anymore to worry about it, because they are mad or whatever... I think, it’s great if they come in and dictate what the doctors says because someone is writing stuff down so when they get home, they got it.

Caregivers have the ability to alleviate some of the stress the patient feels; healthcare providers identified that this assists them with treating the patient, but they also cited that helps the patient “focus on getting well.” In addition, healthcare providers illuminated the reality that patients will sometimes lean on their family member when decisions need to be made. As stated previously healthcare providers put the role of the
decision maker onto the patient; however, part of person-centred care is designing the care around the engagement level of the patient and what the patient wants. Healthcare providers recognize that the caregiver’s opinion and perspective is often appreciated and respected by the patient. That is why a Nurse explains that:

[Caregivers] need to know the process, they often can, if a patient let’s say doesn’t know what to do, they will turn to their caregiver and say, ‘what do you think I should do?’

This quote illustrates the close relationship between patients and caregivers and the trust that exists. Part of the caregivers job is to “keep an eye on the patient.” A Provider/Staff/Other Team Member explains it has “holding the patients hand” and reassuring them that “I’ve got it, we are good.” There is a sense of relief that the caregivers can provide the patient because of the deep and familiar connection they already share. Keeping the Patient on Track encompasses the completion of logistical tasks by caregivers, but it also speaks to the reassurance and emotional comfort that caregivers provide to the patient.

**Sub-Theme 3.2: Providing the Inside Scoop**

In addition to healthcare providers relying on caregivers to Keep the Patient on Track, healthcare providers also seek the perspective of caregivers. It is believed by healthcare providers that caregivers can Provide the Inside Scoop on the patient. Taking a person-centred care approach is perceived to be different by each healthcare provider. Some believe it to be when the patient is “fully informed”, others believe it’s giving patients “time to digest” information, and another healthcare provider interpreted it as, “putting the dignity of the person first.” The underlying theme to a person-centred care approach is working with the patient to identify their priorities. To this end, as
mentioned earlier, healthcare providers must build a relationship with their patient to
learn what those priorities are. It was acknowledged by a Physician that by speaking to
the family, they are “giving a better idea of who and what that person is like”. A Nurse
shares a similar sentiment:

[The patient’s] loved one has given me information that I maybe didn’t have before and that patient isn’t really capable of giving it to me. Like [my patient] didn’t say, ‘I’m really having trouble with my memory right now can you write it down to me, he didn’t say that to me’… [But] his wife has told us that he has some memory issues. So, if [family members] are involved we find it easier to make sure that things don’t get missed or forgotten because they have given us pointers on the patient’s status.

This clearly demonstrates that healthcare providers are appreciative of the
information they receive from caregivers. Healthcare providers do spend extended
periods of time with the patient and form a relationship with them; however, healthcare
providers admit they “don’t know them as well as their family.” When a Nurse was asked
what they perceived as the role of the caregiver, they provided an example:

We have patients who are so sweet and lovely and say I don’t want to bother you, and their spouse will come in and say ‘this is what is going on’. We then have to address the patient and say, this is what I am hearing, how are you feeling what can I do for you?

While healthcare providers are trying to gather personal information about the
patient, caregivers can assist with this. Often caregivers will provide “better or another,
[or] more information” than the patient. Healthcare providers recognize that with a
cancer diagnosis, there is associated fear and anxiety. Therefore, they will sometimes
opt to turn to the caregiver for “extra information.” Healthcare providers explained that
caregivers offer “insight” as to how the patient is coping with the process and how they
are feeling and dealing with it. At this Oncology Center, person/patient-centred care is a
priority, therefore healthcare providers “look at those elements as well.” Healthcare providers did say that patients may refer to caregivers as an “annoying friend” who “rats them out”, but the from healthcare provider's perspective, they value and use that information, as it “helps [to] formulate the [care] plan” A Provider/Staff/Other Team Member stated:

The patient will be like, ‘oh my appetite is fine’, and caregiver says, ‘you know what, it is not good, because you push your food around on your plate, you use to eat 2 plates and now you eat half a plate’. So, they give you a different perspective and they give you information.

Not only do caregivers *Keep the Patient on Track* by coming with them to appointments and offering their support, but they also *Provide the Inside Scoop* when healthcare providers are not privy to certain pieces of information.

**Theme 4.0: Progressing as a Team**

Each person considered to be on the healthcare team was introduced and their associated role was defined, but how does the collective team use each person’s expertise, information, and knowledge to work together to provide the best care for the patient? *Progressing as a Team* describes the necessary conditions and principles needed to form a person-centred care team.

It has long been assumed that the “healthcare team” is made up of professionals with the medical knowledge and skill to diagnosis, treat, and care for the patients. Interestingly, when the question was posed, “*do you consider patients and family members to be a part of the team?*”, participants were extremely adamant that patients and their family members were considered team members. Most healthcare providers even identified that the patient is the most important team member, further explaining that they are “*the key to being a healthcare team*” and “*they are the captain of the ship*.”
Healthcare providers considered their fellow colleagues, patients and caregivers all as “partners” of care.

There are four underpinning sub-themes demonstrating the cultural practices, philosophy and necessary elements of a person-centred care team. With these principles in place the foundation is set for patients, caregivers and healthcare providers to work together to translate theory into action. The sub-themes include: (1) Establishing the Team Makeup, (2) Nurturing the Relationship, (3) Creating an Open Space for Dialogue, and (4) Ensuring the Cancer is Part of Their Life but not Their Whole Life.

**Sub-Theme 4.1: Establishing the Team Makeup**

When patients open the Patient and Family Education Binder, one of the first things they will read is, “Your Interprofessional team is made up of providers from various professions available to help you through your cancer journey.” This statement proposes two things, (1) the healthcare team is made up of “medical professionals” and (2) the choice of who is on the team is up to the patient. The word “available” denotes that those professionals are accessible to the patient if they choose. Establishing the Team Makeup illuminates the concept that in oncology care a generic prescription for a healthcare team does not exist. Part of person-centred care is tailoring the care to meet the patients’ wants and needs. Healthcare providers recognize each patient is unique and a patient could “talk to someone beside [them] in a waiting room and their treatment options are completely different.” To this end, what patient’s need out of a healthcare team will vary. In the absence of a cookie cutter team, is the presence of team options and the assembly of a team that “acknowledges all the different facets of healthcare.” A
Nurse demonstrates that the effects of cancer are not isolated to physical symptoms and how that is acknowledged in the team’s makeup:

It is not just the cancer itself or the body, or the symptoms caused by the symptoms. That is just skating the surface. We need to make that better to help everything else. Everything is interconnected. But it is not only that, it’s the emotional portion too. There are so many factors and no two persons are the same because some people don’t have financial systems at work, if they are off sick, and they may have been the primary caregiver. And now they have no income coming in to support their family, so that is stress itself. It’s difficult. So, there are so many different factors, and then you have patients who are completely covered and that alleviates part of it but maybe they have a daughter or mother who is sick or other things going on. There is always something, you just try to focus in and listen.

Illustrated in this quote is the unique nature of an oncology team. This participant depicts the involvement of different team members based on two individual patients, demonstrating malleability. From the interviews with all participants, it became apparent that there are three constants on the oncology team, the patient, the physician and the nurses. Patients are placed in the center of the team, as the nucleus, to denote the reason for the team’s assembly. Once the circle of care extends outwards to allied health professionals, supportive care, staff, and other team members, it becomes more and more flexible in nature. It is believed at this Oncology Center that “one person can’t do it all” and that person-centred care is not the role of any single profession, rather it should be the approach of all team members. Healthcare providers at this Oncology Center encourage the patient to access as many resources and/or healthcare providers as they see fit. A Nurse demonstrated this by stating “[patients] might talk to 6 different people about it and 1 person says something and it really sticks with them and that
made all the difference.” A Provider/Staff/Other Team Member demonstrated this as well and describes:

There [are] sometimes not a rhythm or reason who patients choose to engage with or not. I have one person who didn’t want to see [the] palliative care physician, the patient is palliative… but she [is] very happy to see me. It’s just we talk about things and we even talk about her cancer and the way she feels, and all these things she has to go through… And sometimes the next person just wants to see the social worker. And the next person is very concerned about their diet, and some want to get involved with all of it.

Before the Nurse or Physician gains a better understanding of who that patient is and who they are as a person, it is unclear who will interact with the patient, who will provide care to the patient, and who will be on the team. To this end, based on who the patient is as a person, a number of challenges can arise, needing further assistance. This Oncology Center has approximately 30 different healthcare provider roles. These roles encompass a range of professions offering help with physical symptoms to emotional and spiritual symptoms and/or financial side effects. Part of Establishing the Teams Makeup is taking a person-centred care approach by identifying the right people to help the patient. For example, the caregiver role is important and healthcare providers consider caregivers to be assets to the team; however they are also not a guarantee team member, as a Nurse stated, “sometimes they don’t want their family involved.” The power lies in the patient’s hands as the center of the team to choose who they feel most comfortable working, interacting, and collaborating with.

**Sub-Theme 4.2: Nurturing the Relationship**

An element that distinguishes a person-centred care team from a traditional healthcare team is the interest that healthcare providers show in Forming a Relationship
with their patients, and their patient’s caregiver. A Nurse expressed this by stating, “You are building that relationship from the minute you meet [the patient]”. For a successful relationship to be formed, collectively, healthcare providers, patients, and caregivers must build trust amongst the team, have respect for each other, enable open communication and display empathy. Once the foundation has been laid for a patient-caregiver-healthcare provider relationship, it must continue to thrive through the entire cancer journey. Nurturing the Relationship points to a continuous need for the team, to “always checking in” with each other and have the time necessary to consistently build on the established relationship. When asked, what are some core strategies that have been integrated into your practice to ensure that you are delivering person centred care, a Nurse answered:

[Asking] the patient, what is your understanding, asking questions such as, what is your understanding of your situation, what your goals? What are the things that frighten you, what are the things that you want to see from us as healthcare providers? I think it is also including the family, in terms of their perceptions, capabilities. It is always clarifying at each step of the journey.

With continuing to foster a working relationship with the patient and their caregiver, a challenge that many healthcare providers expressed was the lack of time that is allotted to meet with the patient. A Provider/Staff/Other Team Member had mentioned that there are improvements that could be made but the reality they face is lack of “space or time” to spend with the patient. A Nurse expressed that they are often “pressed for time” during the initial visit:

Many times, when I am seeing a patient they have been told they have cancer, a lot of times it’s incurable, and I walk in and I have half an hour to build a bond, where they can trust me in helping me make a decision that is right for them.
Another Nurse echoed this but expressing that they give patients their “undivided attention”; however, the reality is, in the back of their mind, “there are 6 people waiting in the waiting room.” Healthcare providers explained that “the bottom line [is], we just run out of time, and we dumb it down to the very basic things that we need to accomplish in this visit.” Person-centred care is about building that relationship with patients and fostering it over time, unfortunately, without the proper amount of allotted time this cannot be done.

Along with simply having time with the patient, there is the need to instill trust amongst the team. Patients, healthcare providers, and caregivers all need to trust that each person is doing their best to help the patient and putting the patient’s wants, needs, values and priorities first. It was expressed by healthcare providers that they can sometimes feel skepticism from the patients in the form of distrust. A Physician explained:

From the patient perspective too, they may have had experiences with the healthcare system that were not positive and where they have learned not to share and not to feel comfortable.

*Nurturing the Relationship* is not a single step that can be taken, rather it is a constant process that is thread throughout the patient’s cancer journey. It requires healthcare providers, patients and caregivers to take the time to build trust amongst the team, openly communicate, be honest and come from a place of empathy and understanding.

**Sub-Theme 4.3: Creating an Open Space for Dialogue**

When healthcare providers were asked about some of the enablers of delivering person-centred care, it was reiterated that openly communicating, being honest, and
building trust amongst the team sets the foundation of a person-centred care team. Creating an Open Space for Dialogue describes the collective efforts by patients, caregivers and healthcare providers to promote an environment where each person’s voice, opinion, and perspective is listened to and validated. This theme is clearly demonstrated in the Oncology Center’s Orientation Manual, as it states that the healthcare team, “employs collaborative practices to provide optimal care in an open, inclusive and supportive way.” The language used in the mission and vision of this Oncology Center expresses the nature of their team dynamic and hints at the level of involvement of the patient and caregiver. Using the words “open”, “collaborative” and “inclusive” indicates that patients are not merely consults of care, rather active partners. As active partners, healthcare providers accept the feedback from patients, caregivers and their colleagues. A Physician demonstrates this by explaining:

I think listening all [team] members, whether it is family or support workers, of course the patient, and the nurse. They come out and say, this patient is thinking this when you say that. You have to open to that kind of feedback and that input. And to learning from all of those pieces of information. That is probably the most important strategy.

Patients need to feel that they can express their wants, needs, and desires to their healthcare team in a “non-judgmental environment”. A Provider/Staff/Other Team Member stated that other healthcare providers are “extremely open to being asked the same question numerous times… [to] make it about the patient.” Similarly, healthcare providers need to feel they can communicate with patients about their reality of the cancer diagnosis and treatment options. A Nurse explained that they need, “an openness on [the patient’s] part to listen to what the team has to say, if what they want is not available.” Finally, caregivers need to be welcomed to share the information they
have on the patient to round out the team dynamic. The underlying core value here, expressed by a Nurse is “communication.” A Physician shared this sentiment and explained that they want patients to feel empowered:

To say, I don’t understand, or to feel comfortable asking questions. Even to feel comfortable to question us, we might have a recommendation that they don’t agree with. I would still hate for a patient to bite their tongue and to be afraid to advocate for themselves because they are nervous about the potential implications on their care. Just making sure they maintain those lines of communication with us, and letting us if they don’t understand, or if they feel things are going into a direction that they don’t want.

This clearly demonstrates that a desire of healthcare providers is for patients to be “open and honest with their primary care team.” A Nurse explains that this initiates a foundation of trust amongst the team, because “[patients] keep things from the primary care team, then there is an opportunity for problems to arise.” In the Patient and Family Education Binder, patients and caregivers are encouraged to Ask, Talk and Listen to their cancer care team. Healthcare providers want to know what the patient is feeling and equally they want the patient to receive the information they are being given. Creating an Open Space for Dialogue relies on all team members being open, honest, and “embracing the belief systems” of the patients. As a Nurse stated, “I think how we expect patients [and caregivers] to be open minded, [and] we are as well.” This theme helps to promote an environment where each person can express their perspective.

**Sub-Theme 4.4: Ensuring the Cancer is Part of Their Life but not Their Whole Life**

The change in language from patient-centred care to person-centred care was prompted by the notion that patients are people first, and should be treated as such. A
Provider/Staff/Other Team Member described it as, “the way you talk to [the patient] is not as a body that has cancer but as a person.” By shifting the focus from the disease to the person, care is designed to treat the full spectrum of the patient’s needs. A Nurse stated that they collect information on “everything from their financial needs, to their psychological needs”. By having this information, supports can be provided to aid in the patient’s physical healing, as well as emotional, mental, spiritual, and financial recovery.

*Ensuring the Cancer is Part of Their Life but not Their Whole Life* highlights the philosophy and mindset of a person-centred care team. It speaks to the willingness of healthcare providers to “acknowledge the wishes [of their patients]” and accommodate based on the patient’s priorities. A Physician provided an example:

> I had a patient with prostate cancer, I gave the usual recommendations, and that patient was a farmer and for him the main thing that was concern was whether he was going to getting his planting, because it was done in the spring time. That is really what made a difference, so because of that, I modified the treatments so that I could safely delay him and so it was personalized to him because of the interest. That way I think he was able to get through treatment better, I think the experience would have been vastly different, in terms of having that stress of knowing that he might not be able to get what he needs to get done.

This clearly demonstrates how this Physician appreciated the patient’s situation and took into consideration the person’s state of mind. By doing so, the Physician tailored the patient’s care to the person’s priorities. Through *Building a Relationship* with the patient and having patients *Identify Their Goals of Care*, healthcare providers can modify treatment plans to fit the schedule and desires of the person. Cancer can take over a person’s life but through a person-centred care team, normalcy can try to be restored. Healthcare providers see themselves as educators; however, another part of the healthcare provider’s role is to modify treatment, if necessary, to ensure that the
treatment is “bearable” for the person. This sentiment was echoed by a Physician who explained:

Sometimes as physicians we are very keen on, we see disease, this is the treatment, and this is what gets you into remission. Sometimes those treatments can be aggressive or onerous, they might not be toxic but it would require the patient to come into the hospital once a week for an injection. That may not necessarily be within their goals of care because of travel or it may just be too much for them, even though it is not toxic.

Every cancer patient’s prognosis differs, some cancers are curable and some are not. Transitioning into remission indicates that a person’s cancer has been managed and can no longer be physically detected. It was the Providers/Staff/ and Other Team Members that illuminated the notion of cancer identity and post-cancer identity. It was explained that “it is important to still feel like a person, [because] you lose a lot of identity when you are going through something like cancer. A Providers/Staff/ and Other Team expressed that sometimes patients can feel they “[have] cancer stamped onto their head”, even though they don’t have cancer anymore. The modifications that healthcare providers make to fit into the lives of the person while they are a patient, can make a huge difference. This is expressed by another Provider/Staff/Other Team Member who recalled a former patient’s transition:

Those little things make a really big difference, I had someone who use to play guitar and between her neuropathy and her radiation treatments, could not hold the guitar or play guitar anymore and she played guitar all the time, so I am thinking of it from that side. I knew someone who loved to do puzzles and she can’t do puzzles anymore, so I think hobbies is really what identifies us. If something was taken away from you maybe you wouldn’t feel like who you are anymore.

The emphasis put on treating a patient like a person, Ensuring the Cancer is Part of Their Life but not Their Whole Life helps to remove the focus from diagnosis,
treatment and cancer and adopt a mindset that resists cancer overshadowing a person’s life and halting their wishes, desires, and priorities.
Chapter 5 – Discussion

The purpose of this research project was to understand, from the healthcare provider’s perspective, how person-centred care ideologies are translated into the day-to-day practices at an oncology centre. Specifically, looking at how healthcare providers, patients, and caregivers work together to form a person-centred care team and what kind of role each person plays on the team. Healthcare providers actively partnering with patients in their care is not a new concept. It has been referenced in cancer-based organizations such as the Canadian Cancer Society, stating that patients are the most important member of the healthcare team. As well, Cancer Care Ontario recently created a guiding document that offered recommendations for providing person-centred care for oncology centers in Ontario (Biddy et al., 2015).

Both team-based care and person-centred care have been referenced in the literature as having positive impacts on patient outcomes and patient experience (Chollette, Bruinooge & Taplin, 2016; Dawood, 2005; Ekman et al., 2011; Kosty, Hanley, Bodenheimer & Sinsky, 2014). What has yet to be explored in the literature is: (1) are healthcare providers using a person-centred care approach on their interdisciplinary team, (2) how do interdisciplinary teams deliver person-centred care in a way that actively engages and partners with the patient and their caregiver and (3) do patients and caregivers have their own role on the team? The novel concept discussed in this study is the formation of a person-centred care team, where healthcare providers, patients, and caregivers work together to deliver the most personalized and best care for the patient.
The perspective of healthcare providers was explored, and Physicians, Nurses and Providers/Staff/Other Team Members outlined expectations, roles and responsibilities for themselves on a person-centred care team, along with patients and caregivers. They also provided examples and experiences that highlighted the necessary components for the assembly of a person-centred care team. In this case study, the Oncology Centre where the research was conducted identifies themselves as taking a patient focused and patient-centred approach on an interdisciplinary and inter-professional team.

Patient-centred care and person-centred care were familiar terms amongst the healthcare providers at this Oncology Center. Some healthcare providers stated that both terms resonate with them and that at the core of their concern is the priorities, wants, needs and values of the patient. Conversely, other healthcare providers made a choice as to which term they preferred, and some found that person-centred care was more inclusive and spoke to the ideals of the cancer center. Exploring the formation of a person-centred care team, the name symbolizes the priority of the team and that is the person. With this kind of team, a balance is derived between treating the patient and their cancer and treating the person and the different dimensions of their care. Though this Oncology Center does not identify as delivering person-centred care, their experiences, mindset, and daily practices parallel the ideals of person-centred care. Therefore, the term, person-centred care will be used throughout the discussion.

Overall, the findings from this study are in alignment with the person-centred care and team-based care literature. Many of the participants spoke about the core values and tenants of person-centred care and provided examples and experiences that
demonstrated these tenants. These include: tailoring the care to meet the needs of the patient, letting the patient actively engage in their care, knowing the patient as an individual, having respect for the patient, and ensuring there is continuity in the delivery of care (Cancer Care Ontario, 2015). Furthermore, the findings in this study support the current literature on person-centred care delivery and underpins the conceptualization of involving and integrating patients and caregivers onto the healthcare team (Lederman et al., 2016; Martin et al., 2015).

Much of the literature focuses on the aspects of person-centred care and reiterates three main concepts: (1) patients should be the focus of care; (2) the patient and their caregiver should be involved in the decision making process; and (3) healthcare providers should use a shared decision making model (Berman et al., 2016; Calisi et al., 2016; Lederman et al., 2015). If healthcare providers were truly delivering person-centred care, patients and caregivers would be considered team members (Lederman et al., 2015). To this end, the current study highlights the importance of translating cancer care ideologies into daily practices in order to provide the best care for patients. It also takes a healthcare provider perspective as they are considered the gatekeepers of the team, and are the ones encouraged and expected to deliver person-centred care.

This chapter will outline the roles of all team members on a person-centred care team, patients, caregivers and healthcare providers. It will present two diagrams, the first illustrates the team makeup and dynamic demonstrating the roles of each team member along with their interconnected relationship. This chapter will also explain how all team members work together to progress as a person-centred care team and will
demonstrate key guiding principles to forming a person-centred care team. Following these two diagrams will be a critical analysis and comparison of the current findings and the literature.

**Perceived Roles of Healthcare Providers, Patients and Caregivers on a Person-Centred Care team**

Figure 4 provides a visual representation of a person-centred care team. The figure depicts the interactive and dynamic relationships between patients, caregivers and healthcare providers, while also demonstrating the roles of each team member and directional flow of information.

In the center of the diagram is the patient and their role as an “Informed Personal Advocate”. Healthcare providers described the patient’s placement in the center as the core of the team and the reason for their assembly. By placing patients in the middle of the circle of care, they are used as a touch point for all decisions that are made. In order to fulfill this role, patients are expected to listen to the information provided by their healthcare provider; nevertheless, communication is a “two-way street”, as patients are also expected to share their needs, wants, priorities and goals with their healthcare team. By having patients act as their own advocate, part of their responsibility is to speak up, ask questions and communicate with their team. Healthcare providers expressed that they want patients to articulate what they want, as each layer of the team is influenced and shaped by their ability to communicate openly and honestly. Without the patient, the team would be missing a vital component as healthcare providers described patients as decision makers, leaders, and the captain of the team.
Circling directly around the patient is the caregiver role described as “Being the Rock”. It was reiterated by many healthcare providers that the caregiver is a vital part of the healthcare team. Though it was evident that caregivers were on the team, there were inconsistencies in terms of where they are placed in the circle of care. Some participants explained that they saw caregivers in the center with the patient; however participant’s stories did not reflect this placement. Rather healthcare provider’s experiences described a dual role that caregivers possess, often being the “go-
between”, connecting patients and healthcare providers. Healthcare providers feel that caregivers provide a foundation of love, support, and structure for the patient, and equally communicate information with them about the patient’s emotional and physical state. Healthcare providers explained that caregivers contribute a new voice to the team, as they have history with the patient and are seen as advocates, care-providers, supporters and communicators.

Surrounding both the patient and caregiver are the healthcare providers, including the Physicians, Nurses, and Providers/Staff/Other Team Members assuming their role to “Educate with Empathy”. Healthcare providers have many roles, when asked, participants described themselves first as educators; however, when recalling stories of accommodating patient’s wants and modifying for patient’s needs, it was apparent that healthcare providers took an empathetic approach to all aspects of care delivery. To this end, healthcare providers demonstrated their value of patients and caregivers’ participation on the team. This prompted the bi-directional and tri-directional arrows in the diagram, representing the collective efforts of healthcare providers, patients and caregivers. Healthcare providers surrounding the caregiver and patient is not meant to symbolize a patriarchal system, rather, it illustrates their patient-focused agenda. Healthcare providers have deemed patients the decision makers and by doing so, they have committed to getting to know the patient and respecting the patient’s decisions. Demonstrated in the findings was the balance healthcare providers create in their work between educating patients and providing options, while also displaying empathy and flexibility.
On a person-centred care team, knowledge, relationships and information is a tri-directional process, as patients, caregivers and healthcare providers are all equally contributing to a person-centred care team. The configuration of the care model, and associated roles and responsibilities, demonstrates three things: (1) patients and caregivers are team members of the healthcare team; (2) patients are in the middle but this placement does not depict the passive acceptance of care; and (3) each team member’s role and responsibilities feed into the team dynamic.

**How Healthcare Providers, Patients, and Caregivers work together to form a Person-Centre Care Team**

Table 6 demonstrates the translation of person-centred care ideologies for a team-based care approach, by outlining the processes, mindset, and environment that fosters and develops a person-centred care team. Along with considering the patient and caregiver as team members and purposefully placing them in the circle of care, the team itself must work together purposefully to deliver care based on the needs, wants, values and priorities of the patient. This table outlines the guiding principles of a person-centred care team and acts as an operational tool for oncology teams choosing to transform their practices to form a person-centred care team. Collectively, healthcare providers, patients, and caregivers must let the patient define who the right team members are, build and maintain a trusting bond, enable a non-judgmental environment and shift the focus from disease to person.

A common theme in team effectiveness models and team principles is having defined roles (Charles & McGuire, 2016; Mitchell et al., 2012; Nancarrow et al., 2013). It is essential to have role clarity and association (Mitchell et al., 2012; Nancarrow et al., 2013), as each member needs to understand their placement on the team, and equally
as important, have an understanding of how their individual role impacts the team (Nancarrow et al., 2013). The care model above illustrates the roles and responsibilities of each team member on a person-centred care team, including the patient, caregiver, and healthcare provider.

Currently, much of the team literature does not explicitly identify the healthcare team makeup (Gagliardi, Dobrow & Wright, 2011), while the oncology team literature leaves patient and caregivers out when describing a healthcare team (Azar et al., 2017; Tremblay et al., 2014; Vogel & Hall, 2016). Several calls to action have been made to re-conceptualize the circle of care and have patients and caregivers included as team members (CCS, 2018; CCO, 2019; McComb & Hebdon, 2013; Lederman et al., 2016; Taplin et al., 2015). This study has answered that call to action by defining the role of the patient and caregiver, explaining the contributions of patients and caregivers, and demonstrating how healthcare providers, patients, and caregivers can work together to form a person-centred care team.
<table>
<thead>
<tr>
<th>Sub-Themes:</th>
<th>Guiding Principles:</th>
</tr>
</thead>
</table>
| **Establishing the Team Makeup** | *Gathering the “Right” People*  
By allowing the patient to define who the right people are, the person-centred care team can determine who will be on the team. Therefore, each person-centred care team will be tailored to meet the needs, wants, values, and priorities of the patient. This allows for fluidity and flexibility, as some healthcare providers will be invited to join and others will not and some healthcare providers will be involved at differing stages of the journey. By doing this, a person-centred care team acknowledges all the different facets of healthcare. |
| **Nurturing the Relationship** | *Maintaining a Trusting Bond*  
Once the relationship has been established amongst the members of a person-centred care team, the patient, the caregiver and the healthcare providers, must collectively work together to build trust. This needs to be a constant process throughout the cancer journey. The team should be continually checking in with each other in order to foster a working relationship. By doing this, trust and respect can be strengthened, enabling open communication. |
| **Creating an Open Space for Dialogue** | *Enabling a Non-Judgmental Environment*  
Members of a person-centred care team must build trust in order to have open and honest communication. In order to create a judgment free zone, relationships and trust need be established from the beginning. It must be known that each person’s voice, opinion, perspective is listened to and valued. It is essential that all team members embrace the beliefs of each other and ultimately do what is best for the patient. |
| **Ensuring the Cancer is Part of their life but not their Whole life** | *Shifting the Focus from Disease to Person*  
Acknowledging a patient as a person helps to maintain normalcy in the person’s life and restore their personal identity. A person-centred care team can do this by recognizing the wishes, needs and wants of the patient. Along with making the decision to accommodate the person by modifying the patient’s plan to meet the person’s priorities. |
Healthcare Providers: Educating with Empathy

Healthcare providers are considered the experts in the field of medicine and because of their knowledge they can be perceived as the leaders of the team (Bilodeau, Dubois & Pepin, 2015; Lazure et al., 2014). Often patients feel that their healthcare providers make the important decisions and their role is to simply comply (Bilodeau, Pepin & Dubious, 2015). The implementation of shared decision-making was founded on the need for healthcare providers to make decisions with patients and not for patients (Coulter & Collins, 2011). This perpetuates the narrative that healthcare providers are the decision makers on the team and patients and caregivers are passively receiving care from them. When in fact, in this study, healthcare providers were adamant that patients are the leaders and decisions makers of their own team. Based on my findings, one of the most important roles healthcare providers play is that of an educator (Matthews, Bulman & Ryan, 2017).

When discussing team-based care and the assembly of interdisciplinary teams, the literature is singular in its audience and describes a healthcare team compromising of healthcare professionals (Azar et al., 2017; National Academy of Medicine, 2015; Nancarrow et al., 2013; Tremblay; Vogel & Hall, 2016). Many healthcare teams have implemented person-centred care strategies and state that they have a focus on patients in their practice (Calisi et al., 2015); however, unless patients are considered team members, this language still illustrates the idea that healthcare providers work together with their colleagues for the patient not with the patient. In this Oncology Center, healthcare providers stated that they do not make decisions for the patient.
Therefore, the engagement of patients and caregivers is not to have them follow the agenda of the healthcare providers but for everyone to work together as a team.

The patient-provider relationship has been discussed in the literature and most often is presented as the strength of patient-provider communication (Lin et al., 2014; Tremblay et al., 2017). On a person-centred care team listening is a basic task and seen as just a starting point, as healthcare providers can listen and educate without displaying empathy. On a person-centred care team, the foundation is listening, but the elevated requirements are acknowledgement, connection, and action. According to Lacovara et al., (2015) part of the definition of a “good” healthcare provider is one that shows an interest in getting to know the patient outside of their disease status. Participants recounted several stories of modifying treatments for the patient not for the purposes of the patient’s physical health, but for their mental and emotional health. Part of being an patient advocate and truly caring for the patient is embedding personal touches to a patient’s care plan and making exceptions to the “rules” when they feel the person needs it (Matthews et al., 2017; McCormack, 2004).

Delineating a traditional team from a person-centred care team is healthcare provider’s empathetic approach to educating patients. Much of the empathetic literature focuses on either pediatric cancer patients or palliative cancer patients (Orioles et al., 2013; Sinclair et al., 2016; Snaman et al., 2016). With research emphasizing these audiences, it appears that empathy is used as a temporary tool to address specific circumstances, rather than an approach used for all cancer patients. The present study was set in the context of an adult oncology center and found that healthcare providers have embedded empathy into their day-to-day practices. The achievement of a
consistent empathetic approach lies in the forming of a caring relationship, because without the presence of empathy, patients perceive their care to be de-personalized (Boman et al., 2018; Lacovara, 2015).

Along with empathy being a key factor in the delivery of person-centred care, the literature outlines that it is a factor in high quality care (Lacovara, 2015; Lin et al., 2014; Quirk et al., 2008). It was mentioned by Lin et al., (2014) that empathetic delivery of care from physicians is not a determinant for treatment agreeance from patients. Within the scope of the current project, participants identified that though they believe treatment would be helpful, they do not use an empathetic approach for the purposes of adherence. Using empathy to increase adherence to treatment has also been explored in other healthcare settings, such as diabetic and HIV patients (Beach et al., 2006; Ciechanowski et al., 2001). Healthcare providers educate with empathy to treat the patient like a person, have respect for the patient, and to assist the patient in making a decision (Boman, Sandelin, Wengstrom & Silen, 2018; Lin et al., 2014). This is where my study adds to the literature, as the healthcare providers at this oncology center underpin their genuine empathetic approach with forming a caring relationship and supporting patients without judging them.

**Patients: Informed Personal Advocates**

As it stands today, we have yet to define the role of the patient and caregiver on a healthcare team or an oncology healthcare team (Lederman et al., 2016). The reason person-centred care has become top of mind over the past several years is demonstrated by the desire of patients to still feel like a person during their cancer journey (Calisi et al., 2016; Jacobsen et al., 2015). With this shift in mindset, healthcare
providers spoke about a “new” wave of patients who express an interest in being a part of their healthcare team. Many participants illuminated the concept of two types of patients (Pongthavornkamol et al., 2018) and associated generational differences. Healthcare providers explained that there are patients who want to be involved and others who would rather defer to their healthcare team. This is supported by the literature, noting that young adult patients are looking for healthcare providers to include them as a unique individual on the team (Bilodeau, Pepin & Dubious, 2015; Jacobsen et al., 2015; Lederman et al., 2016). The desire of young adults to be a part of their healthcare team may be a shift in team makeup and patient profile. Conversely, healthcare providers recalled that some patients are comfortable with a hierarchal system where the healthcare providers are the leader of the team. In meeting both of these distinct desires, a person-centred care team is guided by the individualized goals of the person.

With adjustments made in oncology care to serve the current wants and needs of patients, unfortunately it is outlined in the literature that healthcare teams fail to “invite” the patient to be part of the team (Bilodeau, Pepin & Dubious, 2015). Speaking with healthcare providers in my study, this was not proven to be the case. In fact, the healthcare providers stated that patients are not only on the team but they are the most important part of the team. The inconsistencies in perspective and experiences from healthcare providers and patients illustrates why it is vital that the literature highlights all viewpoints (Lederman et al., 2016). Person-centred care cannot be delivered unless patients, caregivers, and healthcare providers are communicating their wants, needs
and expectations (Tremblay et al., 2017) and this requires a commitment from each team member to work together.

The concept of self-advocacy in healthcare has emerged from delivering person-centred care, demonstrating the importance of patients taking an active role in their care (Matthews et al., 2017). Patient self-advocacy encompasses making informed decisions and communicating effectively with the oncology care team (Jacobsen et al., 2015; Tremblay et al., 2017; Walsh, Burke & Marcusen, 1999). Patients do see the value in advocating for themselves, Matthews et al., (2017) stated that patients believe that they receive better care when they actively engage and are persistent with their healthcare team about their ideals. This aligns with the findings of my research, as healthcare providers were insistent that communication in oncology care is a two-way street and healthcare providers want patients to speak-up.

Some diagrams depicting person-centred care and team-based care have put the patient and/or caregiver in the middle (American Hospital Association, 2011; Johansson et al., 2006; Quality Assessment and Improvement, 2014; Saskatoon Naturopathic Medicine). When putting the patient in the middle, it can be perceived that everyone circles around them and distributes information to them. The present diagram (Figure 4), there are several arrows pointing outwards, illustrating that patients and caregivers make important contributions to the team. Different from the context of this study, the majority of self-advocacy literature identifies strategies within oncology care specific to cancer survivors rather than current cancer patients (Borofka, Boren, & Ellingson, 2015; Hagan & Donovan, 2013; Hagan et al., 2017; Walsh et al., 1999). This study illuminates the need for patients to be advocating and actively engaging in their
care during cancer diagnosis and treatment. This study also provides patients an idea of what healthcare providers are specifically wanting from them during their care journey.

If the literature, healthcare providers, and prominent cancer based organizations are encouraging patients to advocate for themselves, the culture of care must shift to accept and listen to the voices of the patient. Discussed by some of the participants in the current study was the apprehension some patients feel advocating for themselves (Hagan, Rosenzweig, Zorn, van Londen, & Donovan, 2017; Matthews, Bulman, Ryan, 2017). Patients worry about the use of their voice and the practice of advocating for themselves, as they perceive it will compromise the relationship they have with their healthcare providers (Hagan et al., 2017; Matthews et al., 2017). The present study demonstrates that healthcare providers do encourage their patients to speak up, as they perceive open and honest communication as an asset to the team rather than a barrier; however, some patients believe that if they speak up too much, if they ask too many questions, if they gather a second-opinion or if they disagree with their healthcare team, their patient-provider relationship may be ruined. Re-orienting and equalizing power amongst the team, shifts the focus from provider-centred care to person-centred care (Bilodeau, Pepin & Dubious, 2015).

**Caregivers: Being the Rock**

In the context of this study, a caregiver was defined as anyone who accompanied the patient throughout their cancer journey and offered emotional support to the patient. The contribution of a caregiver is not limited to a family member, rather this role can be assumed by a family member or a close friend. It is clear through this study's findings along with the literature that caregivers play an integral role on the healthcare team.
(Catlin, Ford & Maloney, 2016; Jacobsen et al., 2015; Longacre et al., 2018; Lin et al., 2018; Matthews, Bulman & Ryan, 2017; McComb & Hebdon, 2013). Each role on the team is unique; however, the caregiver role is often loosely defined (Lederman et al., 2016; Longacre et al., 2018). Caregivers are not assumed to have the medical expertise as healthcare providers, nevertheless they are caring for the patient and often are the sole care provider at home (McCarthy, 2014). Healthcare providers in this study described their oncology center as an outpatient clinic, where the majority of patient’s time is spent in their community (McCarthy, 2014).

As mentioned previously, healthcare providers will often see the caregiver as the centre of care, sharing space with the patient; however, there are inconsistencies with the perceived placement of the caregiver. To this end, it is interesting to note that most of the oncology literature pertaining to caregivers highlights the burden and stress experienced by them in the patient’s cancer journey (McMillan et al., 2006; Miaskowski et al., 1997; Schulman-Green & Feder, 2018; Wittenberg et al., 2017;). Healthcare providers do acknowledge the plethora of responsibilities caregivers take on, as they are often assumed to act as a patient advocate, supportive decision maker, and home-care provider (Matthews et al., 2017; Longacre et al., 2018); however, when discussing the formation of partnerships and the importance of communication, the literature most often presents that dynamic as patient-provider, patient-nurse, or patient-provider-nurse (Bilodeau, Pepin & Dubious, 2015; Boman et al., 2018; Tremblay et al., 2017). In the current study, it was apparent through the healthcare provider’s stories and experiences that caregivers absolutely fit as their own separate entity on the team, contributing an equal but different role as the rest of the team members.
There is an undefined space on the healthcare team, when it comes to caregiver’s role and contribution to the team (Bilodeau, Pepin & Dubious, 2015; Coniglio, 2013; McComb et al., 2012; Longacre et al., 2018). The current study’s findings clearly define the role and responsibilities of the caregiver on a person-centred care team, detailing what healthcare providers expect and would like caregivers to contribute. My study suggests that caregivers play a dual role on the team. They provide support to the patient and also support the healthcare providers (Longacre et al., 2018). Caregivers are seen as advocates for the patient and carry out organizational and structural tasks for the patient that ensure the smooth transitions of care (Longacre et al., 2018; Matthews et al., 2017). Caregivers also offer the history they have with the patient, prompting the healthcare team to identify blind spots throughout the care journey.

The important role caregivers have on the healthcare team, equally highlighted in this study and in the literature, what seems to be missing is the creation of resources, strategies and supports for caregivers. As previously mentioned, there a rising concern for caregivers with regards to the stress and burden they experience; however, through analysis of 15 documents collected from the oncology center, it was noted that none of the documents were specifically targeted to caregivers. Even though caregivers are seen as part of the healthcare team and their knowledge of the patient and support they provide is valued, in the current landscape of literature there lacks specific educational resources or supports tailored to their needs. It is important to nurture a relationship with the caregiver to help them carve out their role on the team. As most patients and healthcare providers noted, caregiver’s involvement does range from patient to patient;
however, when they do contribute, even a little, it is appreciated by patients and healthcare providers (Longacre et al., 2018).

Defining the roles and responsibilities of each team member sets the foundation moving forward, each team member must adopt practices, strategies and a team mindset in order to function as a cohesive team. The guiding principles outlined in Table 6, demonstrate how the individual contributions of patients, caregivers and healthcare providers are utilized to function as a person-centred care team. The idea of a person-centred care team, where patients and caregivers are equal team members, and the healthcare providers work with them to deliver person-centred care has not been discussed in the literature. The formation of this new kind of team aligns with some of the fundamental principles of a healthcare team, but also deviates from the traditional structure.

The National Academy of Medicine states that team-based care includes five main principles and those are: shared goals; clear roles; mutual trust; effective communication; and measurable processes and outcomes. Previously defined were the “clear” roles of a person-centred care team and the team’s shared goals. The literature speaks about shared goals as though they are what the team wants to accomplish. From a bio-medical perspective, the goal of a traditional healthcare team is defined by the healthcare providers. On a person-centred care team, the team is guided by the patient’s goals of care, and the patient is expected to specify them for their healthcare team.

Having patients identify their goals of care is a concept discussed extensively in the palliative care literature (Coyle et al., 2015; Harle et al., 2017; Schulman-Green &
Feder, 2018). In situations where a person’s cancer is terminal or incurable, goals of care are often considered to aid in the transition from cancer care to comfort care (Canzona et al., 2018); however, using the term “goal” is not evident in the person-centred care literature for curable, non-terminal or non-palliative patients. Rather identifying wants, needs, values, and preferences are most often cited (Calisi et al., 2015; Dawood, 2005). A “goal” puts into perspective what a patient feels is most important to them, their priorities and what it is they want, need, and value. In the present study, healthcare providers wanted patients to identify their goals of care right from the beginning, as they recognize that their goals may not meet the healthcare provider’s initial agenda or expectations. On a person-centred care team, patients define those shared goals, and they could reflect a focus on physical health, but they could also identify different goals that are more focused on emotional, social, financial, or psychological health (Vinckx et al., 2018).

Charles and McGuire (2006) created a healthcare team effectiveness model with three interactive elements, including task design, team processes and team effectiveness. These three components outline the composition of the team, the functionality of the team and the expectations. Collectively, the variables in this model provide context to “how to create and maintain a high-functioning team” (p. 295). It also illuminates, similarly to the current study, variability and the acceptance of multi-dimensional and complex relationships in healthcare. As noted, the findings from the current study are similar to the team-based models of the National Academy of Medicine (2015) and Charles and McGuire (2016); however, the current components
and guiding principles of a person-centred care team offer insight into new concepts and demonstrate a different mindset in comparison to a traditional healthcare team.

The exemplification of a person-centred care team through the identified components and associated guiding principles should not be interpreted as steps. Rather the four components listed are iterative processes requiring each team member on a person-centred care team to be adjusting their daily practices to continually be meeting these guiding principles.

**Establishing the Team Makeup**

Flexibility is a unique indicator of a person-centred care team. Establishing the Team Makeup denotes a novel concept in the team literature (Tremblay et al., 2017), as it demonstrates that the team is not defined at conception. By not defining the team makeup at the beginning of a person’s cancer journey, there can be the perception that the care is fragmented (Browall, Koinberg, Falk & Wijk, 2013). A tenant of person-centred care outlined by Cancer Care Ontario and further supported by the patient’s perspective is the need for continuity in the patient’s care (Browall et al., 2013). Conversely, Browall et al., 2013, argues that patients interacting with the same healthcare providers at each point of their care was not as important to some patients when they were receiving high quality care. On a person-centred care team, the mandate is to assemble a team that meets patient’s individual and personal needs, wants and goals. Therefore, based on two other tenants of person-centred care (knowing the patient as an individual and tailoring the care to the person) (Cancer Care Ontario, 2015), each team’s composition will be made to deliver the care for that individual person.
When using team models and frameworks, it can often be perceived that teams are strict in their structure and processes. On a person-centred care team, fluidity is one of the most important characteristics. Charles and McGuire (2016) first demonstrated the concept of team variability when discussing team processes. In healthcare, it is best that frameworks, guidelines, outcomes and expectations be tailored to each team, based on “the type of team, patient population, care delivery settings and work processes” (p. 265). This demonstrates that the use of the word team may have an overarching definition; however the specifics depends on each individual team. In the present study, some healthcare providers questioned the use of the word team to describe the integration of patients and caregivers. Based on Charles and McGuire’s (2016) identification of team variability, it is reasonable to continue using the word team to describe the collective actions and discourse among patients, caregivers, and healthcare providers.

With the use of this new framework for team interaction, it is equally as reasonable to expect that there will be core team members and extended membership (Charles & McGuire, 2016). From the current case study, it was evident that the core members of a person-centred care team are the patient, the physician and the nurse. Supplementing the team are supportive care and the caregiver, and their involvement and extent of contribution is decided by the patient. This extends what is currently found in the literature by enhancing what is included in the current definition of person-centred care. If personalizing a patient’s care is based on the patient’s beliefs and their wants and needs, a person-centred care team must provide patients with the power and leadership to choose who they feel is right for their team.
Nurturing the Relationship

Trust, respect, communication and empathy are the foundations of a patient-caregiver-healthcare provider relationship on a person-centred care team. On this kind of team, forming a caring relationship from the beginning is essential. As previously mentioned, much of the literature around patient-provider relationships focuses on the importance of communication (Song, Hamilton & Moore, 2012; Tremblay et al., 2017); however, this is merely one aspect of the connection made between patients, caregivers and healthcare providers. In order for patients to feel comfortable sharing and communicating with their healthcare providers, it is important for patients to feel that their healthcare providers truly care about their well-being (Bilodeau, Pepin & Dubious, 2015; Jones, 2010).

According to the National Academy of Medicine, mutual trust is a key component of a team. Salas et al. (2005) agrees with the importance of mutual trust by citing it as one of the top 5 components needed for the formation of any team. It has been documented that without trust, when interrupting other team members’ behaviours, they are more likely to perceive them to be negative (Simon & Peterson, 2000). Jones (2010) supports this as it was reported that without efforts being made by healthcare providers to personally get to know the patient, patients feel that their healthcare providers do not care about them. Therefore, they could interpret the healthcare provider’s actions as provider-centric.

Previous literature outlines the need for patients and caregivers to have trust in their healthcare providers; however the perspective has shifted, now all team members must have trust in each other. Jacobsen et al. (2015) demonstrated that having
confidence in the healthcare team enabled the building of trust. Currently the literature lacks in its perspective of healthcare providers. If healthcare providers are going to deem patients as the decision-makers of the team, trust, respect and communication must be the foundation of the patient-caregiver-provider relationship.

Another requirement of nurturing a relationship is time. This is a challenging subject in the literature, as wait times have been top of mind in Ontario for several years. In the current study, healthcare providers acknowledged the value of patient’s time and recalled moments where they would be with one patient and think about the patients sitting in the waiting room, as they feel the pressure of time. Mostly documenting on the nurse’s perspective (Jones, 2010; Vinckx et al., 2018), the factor of time has been cited as a barrier to the delivery of person-centred care. Simply put, person-centred care takes time (Vinckx et al., 2018). This kind of care requires healthcare providers to build trust, openly communicate, and sometimes participate in “small talk”, which demanding their time (Browall et al., 2013). Vinckx et al. (2018) provided several strategies to relieve time pressure from nurses. Two in particular speak to the fundamentals of a person-centred care team. The first is using your team members, by delegating responsibilities, referring to other healthcare professionals, and asking for support. The present study differs and contributes to the literature by extending the roster of team members. Now healthcare providers can interact and engage with caregivers and patients as team members. Another strategy is setting priorities, which on a person-centred care team, is defined by the patient. By initially forming a relationship with the patient and nurturing it over time, each person is cared for in a way that makes sense for them.
Creating an Open Space for Dialogue

The healthcare environment and culture of care dictates the ability of healthcare providers to deliver person-centred care and team-based care. A “healthy practice environment” in oncology care has several requirements, and according to Lacovara (2015) one important factor is having respect for different disciplines and recognizing the expertise of others. This is further supported by Charles and McGuire (2016) who prompted the question: “what expertise is needed and how can it be mobilized within a team?” (pg. 290). With a person-centred care lens and a team-based care approach, patients and caregivers bring their own expertise to the team (Coulter & Collins, 2011). If healthcare providers are interested in knowing the wants, needs, values, and goals of the patient, it becomes necessary that they become part of the team (Coutler & Collins, 2011).

A person-centred care team has an appreciation for diverse knowledge; however, most studies have taken the stance of respecting and honouring healthcare professional-roles and colleague’s contributions (Azar et al., 2017; Nancarrow et al., 2013; National Academy of Medicine, 2015; Tremblay; Vogel & Hall, 2016). It was mentioned by participants in the current study that all healthcare providers must value each other’s perspective and that this oncology centre was advanced in their actions to equalize nurses and supportive care’s viewpoints. Additionally, taking a person-centred care approach, healthcare providers demonstrated respect and value for patients and caregiver’s inputs.

Communication is seen as a bedrock for effective teams (Charles & McGuire, 2016; Mitchel et al., 2015; Salas et al., 2005; The National Academy of Medicine, 2015).
Part of effective communication in healthcare is have all team members participating in candid conversations. When speaking about the “two-way street”, defined in the literature as patient-provider, much of the literature highlights the importance of patients having the ability to ask questions (Browall et al., 2013). Actively participating that way is important, as patients must be comfortable to express their concerns; however, on a person-centred care team, patients are also encouraged to provide information and opinions. Creating a respectful and non-judgmental environment while personalizing care, enables patients and caregivers to participate (Boman et al., 2018). Equally as important is to encourage healthcare providers to openly communicate. Patients are interested in knowing the truth about their diagnosis, they see it as preparation for what is ahead of them (Lin et al., 2014; McCarthy, 2014). This is a part of their ability to make informed decisions about their goals of care (Lin et al., 2014).

Another aspect of creating an open space for dialogue is the interactions between healthcare providers, patients, and caregivers. In my study, participants cited that there is a camaraderie amongst healthcare providers, patients and their caregivers. Jacobsen et al. (2015), who explained that the friendliness of the staff promotes an environment where patients and caregivers feel comfortable and on some level enjoy coming to the oncology center, the present study further supports this. Healthcare providers in the current study demonstrated that by all parties participating in conversations that do not focus on the cancer itself, asking personalized questions, and getting to know each other as individuals (Calisi et al., 2016; CCO, 2015; Browall et al., 2013), an environment can be created that enables trust and respect to be built, fuelling communication and empathy.
Ensuring the Cancer is Part of Their Life but not Their Whole life

The guiding principle associated with this component of a person-centred care team describes the mindset of shifting the focus from disease to person (Bilodeau, Pepin & Dubious, 2015; Glynn et al., 2008; Hobbs, 2009; Pongthavornkamol et al., 2018). Salas, Sims and Burke (2005) outline that a team must have a shared mental model to work cooperatively together. Identifying an agreed upon mindset, allows for all team members to have an understanding of the priorities and direction of the team (Salas et al., 2005), which helps to bring everyone together as a cohesive unit.

The literature is vast in its perspective on person-centred care and outlines several recommendations on how it can be delivered (Calisi et al., 2016; CCO, 2015); however, what seems to contradict those ideals is the presence of a treatment-centred culture (Bilodeau et al., 2015). The physicians specifically in the current study identified with a treatment-centred culture in their own practice. Physicians acknowledged that they may be quick to suggest a treatment plan that is focused on the physical health of the patient, and not consider other factors. Similarly, from a nursing perspective, Vinckx et al. (2018) found that nurses identified that the physical health of the patient was their first priority. On a person-centred care team the priorities and goals of the team are related to the patient’s identified goals of care. What was illuminated by the present study was the need to find a balance between physical, emotional, mental, and psychosocial priorities (Vinckx et al., 2018). Similarly, Pongthavornkamol et al., (2018) highlights the intent of nurses to support patients through their cancer journey by ensuring that daily activities and normal behaviours of the patient can be incorporated into the patient’s care plan. With a person-centred care approach on a healthcare team,
every aspect of health and well-being is taken into consideration, as this kind of team does not focus on one facet of health; rather it takes a holistic approach to care.

Team effectiveness and measures of success for a person-centred care team looks very different in comparison to a team that takes a bio-medical approach. From a bio-medical perspective, physical health comes first, and other aspects of health must be adjusted (Vinckx et al., 2018). Now the healthcare system is recognizing and respecting all the dimensions and facets of health and well-being. Therefore, in some cases, as demonstrated in this study, healthcare providers are adjusting the treatment plan to meet a new set of health priorities (McCormack, 2004; Pongthavornkamol et al., 2018). The mindset of a person-centred care team puts the person first, ensuring patients are maintaining a sense of normalcy, if desired (Pongthavornkamol et al., 2018). This new mindset accompanies the shift in language from patient-centred care to person-centred care. Ensuring the cancer is part of their life but not their whole life further solidifies the idea that decisions are to be made to serve the person not necessarily the cancer. This is a new concept in the oncology literature, but the idea is supported by team literature. Charles and McGuire (2006) explains that the effectiveness of a team should not be judged based on pre-determined criteria applied to all healthcare teams, rather it should be evaluated based on each individual team’s shared goals (Bilodeau, Pepin & Dubious, 2015; Mitchel et al., 2012), which in this case, are defined by the patient.

Summary

The underlying theme in the team-based care and person-centred care literature is the discussion about context, including context of care, organizational context, and
policy context (Jacobsen et al., 2016; McCormack, 2004; McCormack & McCane, 2006). What was illuminated in the current study is the assembly of a new kind of a team, therefore a new context. The literature is extensive in the value placed on patient participation; however, current processes to involve patients are not working (Pongthavornkamol et al., 2018). The present study has examined the use of person-centred care on an interdisciplinary healthcare team to understand the role of the patient, caregiver and healthcare provider in active engagement, patient participation, and healthcare partnerships.

Cancer is unique for many reasons, one being the extent of stress experienced by patients and their caregivers and another is the perceived acute nature of cancer (Lacovara, 2015). It has now been illuminated that survivorship, identity and life after cancer are still impacted by the cancer journey (Battley & O-Reilly, 2011). Just by way of the word, patient-centred care keeps the person in a sick role, rather person-centred honours the notion of humanity in healthcare. On a person-centred care team, the emphasis is not on convincing the patient or having the patient follow the healthcare provider’s agenda, rather person-centred care is patient/person directed. Deeming the patient as the decision-maker is not fulfilling a person-centred care mandate, rather my findings demonstrates that it is a necessary reality. Several participants stated that patients must make the final decision because it is their health and their life.

Based on these findings, a person-centred care team broadens the traditional definition of a team and presents a new kind of team. It is suggested by these findings that an oncology team is fluid, lacking structure in its composition and multi-layered in its membership. Participants explained that the use of the word ‘team’ has sparked
misconceptions among patients, prompting them to ask if there is a team and whether they are on it (Bilodeau, Pepin & Dubious, 2015; Lazure et al., 2014). Patients have a perception that they will be invited to join the healthcare team and healthcare providers, from this oncology center, perceive the patients to be automatically on the team. This may explain why much of the literature suggests that patients don’t feel they are a part of their team (Bilodeau, Pepin & Dubious, 2015; Lazure et al., 2014; Lederman et al., 2016). Whether or not patients and caregivers assume the full capacity of their role, they are considered team members, partners in care and will be actively engaged whenever possible.
Chapter 6 – Conclusion

Most recently, person-centred care and team-based care have been top of mind in the literature and in practice to determine how both approaches can be delivered, how they can be improved, and how they can be used to improve patient outcomes and patient experience. The current study is the first of its kind to explore the inner workings of an oncology center and provide an understanding of how healthcare providers in their day-to-day practices work towards taking a person-centred care approach on an interdisciplinary healthcare team. In this oncology center, healthcare providers have adopted person-centred care ideologies and translated them into strategies for actively engaging and partnering with patients and their caregivers to make them feel a part of the healthcare team.

These findings couple two concepts that are often kept separate in the literature: person-centred care and team-based care. Mostly, the literature highlights healthcare teams made up of healthcare providers delivering person-centred care. This oncology center has helped to illuminate the roles of team members on a person-centred care team, which includes the healthcare providers, the patients, and the caregivers. With defined roles, shared goals, open communication, and keeping in mind the person in the middle of all the care transactions, the focus becomes finding a balance between what is best for the ‘patient’ and what is best for the ‘person’. Emphasis is put on forming relationships with patients and nurturing the relationship through the patient’s cancer journey. Building a caring bond with the patient and their caregiver not only provides the information and knowledge the healthcare providers need to take a person-centred care approach, but it also seems to have a lasting positive impact on patients.
Participants reiterated in several interviews that their focus is on patients, and their interest is to provide the best care for the patients, and through a person-centred care team this can be accomplished.

**Limitations**

The main limitation in this study stems from the participant sample, including participant representation, research site and participant volunteers. The participant representation included physicians, nurses and providers/staff/other team members. Physicians and nurses were both represented by chemotherapy and radiation professionals, however, the depth of the third category may not have been saturated. Clerical staff, volunteers and some supportive care staff did not participate in interviews. Therefore, though the participant sample is diverse, some voices and perspectives were not represented in the study’s findings. Furthermore, in the context of this study only healthcare providers were highlighted, a more holistic perspective would have been gained if healthcare providers, patients and caregivers were involved. With the scope of this project and research purpose being from a healthcare provider’s perspective, it was not necessary to include both patients and caregivers.

The findings from this study are from one local oncology center that services adult cancer patients in southern Ontario. The sample of this study was diverse, including physicians, nurses, supportive care, and staff. Additionally, varying specialists amongst physicians and nurses were represented, including chemotherapy and radiation; however, the nature of a single case study demonstrates a singular perspective and it can be argued that it is not representative of all oncology centers. The healthcare providers that participated did not speak about pediatric cancers nor did
they provide examples or experiences of certain types of cancers, rather they spoke more broadly. To this end, the literature does suggests that pediatric and palliative cases of cancer differ in terms of context, care and circumstance (REF).

Finally, there is an inherent bias when participants volunteer to engage in a research study. The majority of the participants provided positive examples and experiences of their time at this oncology center. The volunteer nature of this study could have elicited more eager staff to participant. Additionally, the use of the terms person-centred care, patient-centred care or team-based care could have resonated with some staff and not others. Therefore, participation could have been skewed to those staff who recognized the terms, providing an advanced understanding of these concepts. This limitation was unavoidable due to ethical guidelines and regulations on recruiting participants.

**Future Directions**

There are three main areas of future direction from the current study. The first is for further studies to explore the concept of a person-centred care team from the collective experiences of patients, caregivers and healthcare providers. The purpose of this study would be to provide a well-rounded understanding of the operationalization of this kind of team. Speaking with patients, caregivers, and healthcare providers would highlight the barriers or challenges when gathering all three perspectives. Studies have been conducted on the concept of interprofessional patient-centred practices from the perspectives of patients, caregivers and healthcare providers (Bilodeau, Dubois, & Pepin, 2015; Calisi et al., 2016). The completion of this study would further explore the
concept of a person-centred care team and determine the effectiveness of the guiding principles.

Secondly, research should be conducted on the translation of identified guiding principles into actions, steps, and practices. Guiding principles are used to demonstrate ideal attitudes, behaviours and thought processes. For example, one of the guiding principles is to ensure a non-judgmental environment. Participants explained that they support patients without judgment, but how do other oncology centers harness this behaviour and implement in their care environment? The next step would be to take the guiding principles and explore the actions associated with their successful application. The purpose of this study would be to provide a guiding document with operational steps and recommendations on how to form a person-centred care team. This study adds the guiding principles but further research would solidify the assembly of a person-centred care team and would aid other oncology centers to adopt this kind of approach to care.

Finally, as mentioned previously, caregivers play a crucial role on a person-centred care team, as they reside in the middle layer between the patient and the healthcare provider. Caregivers play a dual role as supporters of both patients and healthcare providers. As caregivers have been highlighted as a key player on the healthcare team, future research should explore the team dynamic when there is no caregiver present. Documented in the findings is that healthcare providers encourage their patients to bring a family member or friend with them through the cancer journey. It was mentioned in the interviews that sometimes caregivers are not actively involved, and a healthcare provider mentioned that part of their role is to accompany patients if a
caregiver is not present. To this end, it seems that from the healthcare provider’s perspective it is crucial that someone is with the patient to support them and carry out logistical tasks such as listening, writing things down, asking questions and being an emotional support them. The purpose of this study would be to explore the shift in responsibilities amongst the team when an active caregiver is not present.

**Implications**

There are several implications resulting from the current findings with regards to practice and policy in oncology care. This is the first study of its kind to explore the day-to-day routine of healthcare providers with the intent to understand how they translate best practice into action. Person-centred care has been studied extensively and as a research community, we have a solid understanding of how patients, caregivers and healthcare providers perceive person-centered care. We also have a guiding document created by Cancer Care Ontario on how to integrate person-centred care into an oncology center; however, what has yet to be discussed is the merging of person-centred care and team-based care. Although person-centred care is not a new concept in oncology care, a person-centred care team is a novel idea as it combines two main approaches in oncology care, person-centred care and team-based care. This kind of team denotes that a healthcare team, consisting of healthcare providers, actively engages and partners with the patient and their caregiver to collectively make decisions and function as a cohesive team. With the emphasis put on actively engaging and partnering with patients, along with declaring that patients are the most important part of the oncology team, person-centred care teams need to become a focal point of conversation.
What this study contributes is a definitive answer to the question of whether patients and caregivers are considered part of the team. These findings support the integration of patients and caregivers as part of the healthcare team, as well as outline how all team members can work together. Additionally, this study highlights a unique perspective in the person-centred care literature – the healthcare providers. The healthcare provider’s perspective was a blind spot that I identified in the literature. It became necessary to gain the perspectives of healthcare providers to operationalize a person-centred care team, as they are the ones expected to deliver person-centred care. An upstream approach was taken to identify what it is they need to work with patients and caregivers in a collaborative model.

With the current study’s findings, other oncology centers are given the tools and practices to form a person-centred care team. Although the literature offers guidance on this topic and highlights some of these concepts, this study helps to clarify how each element interacts with the other, unifying person-centred care ideologies and the collective actions of team-based care. Highlighted through these findings is the change in the culture of care in oncology. On a person-centred care team, healthcare providers invite and genuinely welcome patients and caregivers to the team, appreciate their insight and tailor care for each individual patient, regardless of their own professional judgments.
References:


Hodge, L., & Lockwood, S. (2013). Meaningfulness, appropriateness and effectiveness of structured interventions by nurse leaders to decrease compassion fatigue in healthcare providers, to be applied in acute care oncology settings: a systematic review protocol. JBI Database of Systematic Reviews and Implementation Reports, 11(12), 81-93.


Johansson, I., Hildingh, C., Fridlund, B., Ahlstrom, G. I., Anic, P. R., Rnt, P. R., & Rnt, P. R. (2006). NURSING THEORY AND CONCEPT DEVELOPMENT OR ANALYSIS.


Jones, S., Torres, V., & Arminio, J. (2014). Meeting the Obligations of High Quality Inquiry. (Chapter 2)


Lederman, L., Madden, D., Battle, D., Connolly, H. K., & Smith, M. L. (2016). Patient Advocates Collaborate to Ensure Patients Are Members of Their Own Oncology Care Teams.


Orioles, A., Miller, V. A., Kersun, L. S., Ingram, M., & Morrison, W. E. (2013). “To be a phenomenal doctor you have to be the whole package”: Physicians’ interpersonal behaviors during difficult conversations in pediatrics. *Journal of Palliative Medicine, 16*(8), 929-933.


Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research?. Family Practice, 19(2), 135-139.


Taylor, C., Finnegan-John, J., & Green, J. S. (2014). “No decision about me without me” in the context of cancer multidisciplinary team meetings: a qualitative interview study. *BMC health services research, 14*(1), 488.


Appendices

Appendix A: Health Canada’s Public Involvement Continuum

Health Canada's Public Involvement Continuum

Level 1: Low level of public involvement and influence
Inform or Educate
Communications
Level 2: Mid level of public involvement and influence
Gather Information
Listening
Level 3: Public Involvement Continuum
Discuss
Consulting
Level 4: High level of public involvement and influence
Engage
Engaging
Level 5: Partnering
Partnering

Adapted from Patterson Kirk Wallace
Appendix B: Letter of Invitation

Who is on the Team? Exploring a Person Centred Care Approach on an Interdisciplinary Oncology Healthcare Team, from the Healthcare Provider’s Perspective.

Principal Investigator: Dr. Madelyn Law, Associate Professor, Department of Health Sciences, Brock University

Student Principal Investigator: Miss Bianca Fucile, MA Candidate, Department of Health Sciences

I, Dr. Madelyn Law, Principal Investigator, and Miss Bianca Fucile, Student Principal Investigator, from the Department of Health Sciences, Brock University, invite you to participate in a research project entitled Who is on the Team? Exploring a Person Centred Care Approach on an Interdisciplinary Oncology Healthcare Team, from the Healthcare Provider’s Perspective.

You are invited to participate in a study that involves research. Within oncology, there are two main foundational models of care; person centred care and team-based healthcare. Recent literature has made a call to action for integrating patients and caregivers as team members within oncology services. However, to date, no research has explored the healthcare provider’s perspective on this new care approach. We are then left wondering about the feasibility of including patients and caregivers as active team members. Therefore, the purpose of this study is to understand the healthcare provider’s perspective on the role of the patient within an interdisciplinary oncology team from the lens of a person centred care approach.

There are no direct benefits to you as a participant. However, the potential benefits to the scientific community will be an enhanced understanding of the role of patients and caregivers within an oncology team, which will aid in the further development of person centred care. Your participation in this study would include one interview lasting approximately thirty minutes to an hour. The interview will take place at your Oncology Center, in one of the meeting rooms. As well, you do have the option of selecting another space within the hospital to conduct the interview.

Privacy and confidentiality of data are ensured, as your organization’s name will not be used in the reporting of the data, and pseudonyms will be used when using employee quotations. Your name will not appear in any thesis report or results from this study; however, with your permission, anonymous quotations may be used. The only identifying information that will be used is the employee’s job title, which will be concealed under three categories: Nurses, Physicians, or Staff/Provider/Other Team Member in the reporting of results. This information will be linked to the data as it will be important to assess whether there are differences between profession’s view of the operationalization of patients as active team members under a person centred care approach.
This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [17-167 LAW]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

If you have any questions, please feel free to contact me (see below for contact information).

Thank you,

Madelyn Law, Ph.D. Assistant Professor, Principal Investigator (905) 688-5550 ext. 5386 mlaw@brocku.ca
Appendix C: Informed Consent

Date:

Project Title: Who is on the Team? Exploring a Person Centred Care Approach on an Interdisciplinary Oncology Healthcare Team, from the Healthcare Provider’s Perspective.

Principal Investigator: Madelyn Law

Associate Professor, Department of Applied Health Sciences, Brock University, (905) 688-5550 ext. 5386, mlaw@brocku.ca

Student Principal Investigator (SPI): Bianca Fucile

MA Candidate, Department of Applied Health Sciences, Brock University, bf11pd@brocku.ca

INVITATION
You are invited to participate in a study that involves research. The purpose of this study is to understand the healthcare provider’s perspective on the role of the patient within an interdisciplinary oncology team from the lens of a person centred care approach, specifically aiming to uncover the barriers and enablers to incorporating patients and caregivers as active team members. Your oncology center provided a list of all employees in various roles and departments, and you were 1 of 15 employees invited to participate in this interview.

WHAT’S INVOLVED
As a participant, you will be asked to participate in an individual interview that will take approximately thirty minutes to an hour of your time. The interviews will take place at your Oncology Center, in one of the meeting rooms. As well, you do have the option of selecting another space within the hospital to conduct the interview. Your interview will be audio recorded and transcribed for research purposes.

After the interview has been conducted you will be given the opportunity to be a part of the member checking process. This will be when the researcher presents you with the preliminary findings and results (themes), this will give you the opportunity to provide your feedback on the accuracy and interpretation of your conversation. These will be sent through email. You will have a week to review and provide any comments or concerns, you do not give any feedback to the researcher, they will proceed as followed.

POTENTIAL BENEFITS AND RISKS
There are no immediate benefits to participating in this research study. However, this process will provide you the opportunity to share your perspective for the betterment of oncology care services. Benefits to the scientific community include a better understanding of this topic with regards to patients and caregivers being considered
active team members on an interdisciplinary oncology team. This project will shine a light on the feasibility of this and provide some operational steps to engaging and integrating patients and caregivers as part of the team. There are minimal risks associated with your participation in this study, however there may be psychological risks. Since the researcher will be discussing with you, your care practices, you may feel there is a “right” answer. However, this will be mitigated by conducting the interview in a comfortable space (your work environment), you will be reminded throughout the research process that you can withdraw from the study if you feel it is necessary, and if you begin to feel uncomfortable with a question or prompt, the researcher will move to another question.

CONFIDENTIALITY
The information you provide will be kept confidential. Your name will not appear in any thesis report or results from this study; however, with your permission, anonymous quotations may be used. The only identifying information that will be used is the employee’s job title, which will be concealed under three categories: Nurses, Physicians, or Staff/Provider/Other Team Member in the reporting of results. This information will be linked to the data as it will be important to assess whether there are differences between profession’s view of the operationalization of patient’s as active team members under a person-centred care approach. During the analysis phase of my research, I will send you a copy of the preliminary findings (themes) to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. There are limits to your confidentiality as a participant, as we will be conducting interviews at your workplace. Due to this, we can meet outside of the oncology center in another part of the hospital. As well, myself and the principal investigator will take every other precaution to ensure your confidentiality.

Data collected during this study will be stored in a locked research cabinet in Dr. Madelyn Law's office and on a password protected computer. Data will be kept for two years, for publication purposes, after which time all transcript hard copies and field notes will be shredded/destroyed, and electronic copies of audio recordings, field notes, document analysis forms, and transcripts will be deleted. If you choose to not be a part of this study once you have completed the interview portion of data collection, your data will be destroyed. Your transcript will be shredded and your audio recording will be deleted.

Access to this data will be restricted to Dr. Madelyn Law and Miss Bianca Fucile.

VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Furthermore, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS
Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available in a report document, that can
be emailed to you at your request. The approximate date of the final results and report completion is January 2019.

CONTACT INFORMATION AND ETHICS CLEARANCE
If you have any questions about this study or require further information, please contact Dr. Madelyn Law using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [insert file #]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM
I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: ________________________________________________________________

Signature: _____________________________________________________________

Date: ___________________________
Appendix D: Interview Guide

BF: Thank you for taking the time to participate in my study, I am very appreciative. Before we begin the interview, I would like to tell you about my research study. I am currently a graduate student at Brock University pursuing a Master's degree in Community Health Sciences, and I am interested in the field of patient-centered care and team-based care. I want to learn about the intersection of these two care models from the healthcare provider perspective. I want you to know that you are not obligated to answer any questions that may make you feel uncomfortable. I hope this can be a relaxed conversation between the two of us. Do you have any questions or comments before we begin?

To start off I first wanted to ask you about your years of experience in your current healthcare professional role in Oncology Care?

1. What is your definition of person-centred care?
   a. Probe: How did you come to this personal definition? Ie. school, in service workshops, organizational structure, personal beliefs or experiences? The oncology center?

2. What are 3 words you’d use to describe PCC?
   a. Probe - Ask to elaborate on each.
   b. Probe: Why?

3. How are oncology services aligned with person-centred care?
   a. Prompt: How do you get to know the patient?
   b. Prompt: How do you encourage/engage/enable them to participate
   c. Prompt: What do you mean?

4. Organizationally, how does Niagara Health and the Walker Family Cancer Centre advocate for PCC in oncology?
   a. Probe: How has the culture at this oncology center shaped the delivery of PCC
   b. Probe: Messaging in staff resources? Patient resources? Staff in-services? Educational resources you were provided with around the delivery of person-centred care?

5. What are some core strategies that you have integrated into your practice that ensure you are delivering person-centred care?

6. What is the nature of the interdisciplinary interactions that you have with your colleague’s care that you provide to patients?
   a. How do you currently collaborate with patients and caregivers during their time at this oncology center?
7. When working with and helping a patient, what do you see as your role as a healthcare provider?

8. Can you please explain your perspective on team-based care delivery?
   a. Probe: Who is doing what? What are you seeing?
   b. Probe: Describe the quality of your interactions with other healthcare providers.
   c. Probe: Given your experience with person-centred care, how would you advise other providers, patients, and caregivers to form a person-centred care team?

9. What are some of the challenges you encounter when integrating the patient as a member of the team? Explain why?
   a. Prompt: Why do you consider those challenges?

10. What do you perceive as some of the enablers that would help you incorporate the patient and caregiver as team members?
   a. Probe: What do you need from the patient to make you feel as though they are a team member?

11. Describe to me an ‘ideal’ (e.g., your dream) PCC collaboration.
   a. Probe: What does that look like? What is the patient doing? What is a caregiver doing? What are you doing? What are your colleagues doing?

12. What needs to happen in order for the ‘ideal’ PCC collaboration to become a reality for every person who comes through these doors?
   a. Probe: The President of the health care system asks you to tell him/her 1 organizational change that needs to happen to encourage PCC practices. What do you tell him/her?)

13. In person-centred care, a patient has an active role in his/her ‘care’. Based on your experience, what do you perceive the patient role to be?
   a. Probe: Can you give me an example of a care experience where the patient played an active role? What actions did s/he take? What impact did that have on him/her, the healthcare team members, his/her care?
   b. Probe: Can you give me an example of a care experience where the patient didn’t play an active role? What impact did that have on him/her, the healthcare team members, his/her care?

14. In PCC, a caregiver has an active role in their loved one’s care. Based on your experience, what do you perceive the caregiver role to be?

15. The practice of PCC varies greatly from person to person. Can you speak to components of PCC that your team excels at? Struggles with?
### Appendix E: Alignment of Interview Questions with Research Questions

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your definition of person centred care?</td>
<td>Gathering background information to address my purpose statement and answer my research questions</td>
</tr>
<tr>
<td><strong>Probe</strong>: Why?</td>
<td></td>
</tr>
<tr>
<td>Can you describe core values and beliefs of person centred care from your perspective?</td>
<td></td>
</tr>
<tr>
<td><strong>Prompt</strong>: How do you get to know the patient?</td>
<td></td>
</tr>
<tr>
<td><strong>Prompt</strong>: How do you encourage/engage/enable them to participate</td>
<td></td>
</tr>
<tr>
<td><strong>Prompt</strong>: What do you mean?</td>
<td></td>
</tr>
<tr>
<td>What are some of the educational resources you were provided with around the delivery of person centred care?</td>
<td></td>
</tr>
<tr>
<td>What are some core strategies that you have integrated into your practice that ensure you are delivering person centred care?</td>
<td></td>
</tr>
<tr>
<td>What do you see as your role as a healthcare provider when treating a patient?</td>
<td>How do healthcare providers at an oncology center perceive the role of all team members, patients, caregivers, and healthcare providers on a person-centred care team?</td>
</tr>
<tr>
<td>Describe your interactions with other health care providers.</td>
<td></td>
</tr>
<tr>
<td>What is the nature of care that you provide to patients?</td>
<td></td>
</tr>
<tr>
<td>Can you please explain your perspective on team-based health care delivery?</td>
<td></td>
</tr>
<tr>
<td>How do you currently collaborate with patients and caregivers during their time at this oncology center?</td>
<td></td>
</tr>
</tbody>
</table>
**Probe**: From your perspective, what is the patient’s role?

**Probe**: From your perspective, what is the caregiver’s role?

What are some of the challenges you encounter when integrating the patient as a member of the team? Explain why?

**Prompt**: Why do you consider those challenges?

What do you perceive as some of the enablers that would help you incorporate the patient and caregiver as team members?

**Probe**: What do you need from the patient to make you feel as though they are a team member?

Can you provide an example of a patient who you felt was part of the team?

**Probe**: What made you feel they were part of the team?

**Probe**: Were there any demographic characteristics that differentiated them from other patients?

Can you provide an example of a patient who you felt was not part of the team?

**Probe**: What made you feel they weren’t part of the team?

**How can healthcare providers, patients, and caregivers work together to form a person centred care team?**
Appendix F: Document Analysis Form

Site:

Document: ____________________________

Date Received or Picked up: ____________________________

Name or Description of document:

Date: ____________________________

Event or contact, if any with which is associated:

Significance or importance of document:

Brief Summary of contents:
Appendix G: Brock University REB Clearance

Certificate of Ethics Clearance for Human Participant Research

DATE: 1/18/2018
PRINCIPAL INVESTIGATOR: LAW, Madelyn - Health Sciences
FILE: 17-167 - LAW
TYPE: Masters Thesis/Project STUDENT: Bianca Fucile
SUPERVISOR: Madelyn Law
TITLE: Who is on the Team? Exploring the Application of a Person Centred Care Approach on an Interdisciplinary Oncology Healthcare Team, from the Healthcare Provider's Perspective

ETHICS CLEARANCE GRANTED
Type of Clearance: NEW Expiry Date: 1/1/2019

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement. Clearance granted from 1/18/2018 to 1/1/2019.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 1/1/2019. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at http://www.brocku.ca/research/policies-and-forms/research-forms.

In addition, throughout your research, you must report promptly to the REB:
   a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
   b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
   c) New information that may adversely affect the safety of the participants or the conduct of the study;
   d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

[Signature]
Ann-Marie D'Blase, Chair
Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.
Appendix H: Hamilton Integrated Research Ethics Board REB Clearance

![HiREB Logo](image)

Jul-20-2018

**Project Number:** 4H19

**Project Title:** Who is on the Team? Exploring a Person-Centred Care Approach on an Interdisciplinary Healthcare Team from the Healthcare Provider's Perspective

**Student Principal Investigator:**

**Local Principal Investigator:** Mrs. Brenda Luscombe

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Document Date</th>
<th>Document Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent Form (HiREB)</td>
<td>Jul-17-2018</td>
<td>Consent Form</td>
</tr>
<tr>
<td>Document Analysis Form</td>
<td>Apr-03-2018</td>
<td>Document Analysis</td>
</tr>
<tr>
<td>Letter of Invitation</td>
<td>May-14-2018</td>
<td>Letter of Invitation</td>
</tr>
<tr>
<td>Recruitment Email (HiREB)</td>
<td>Jul-17-2018</td>
<td>Recruitment Email</td>
</tr>
<tr>
<td>Research Study Protocol (HiREB)</td>
<td>Jul-17-2018</td>
<td>Study Protocol</td>
</tr>
<tr>
<td>Semi-Structured Interview Guide (HiREB)</td>
<td>Jul-17-2018</td>
<td>Interview Guide</td>
</tr>
</tbody>
</table>

The following documents have been acknowledged:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Document Date</th>
<th>Document Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cover Letter: Summary of Changes (HiREB)</td>
<td>Jul-17-2018</td>
<td>Cover Letter</td>
</tr>
<tr>
<td>LP1 Ethics Certificate</td>
<td>Jul-17-2018</td>
<td>Ethics Certificate</td>
</tr>
</tbody>
</table>

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a *Study Completion Form*.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an *Annual Review Form* with your request.

**PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE.**

Good luck with your research.

[Signature]

Kristina Tom, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph’s Healthcare Hamilton, Research St. Joseph’s Hamilton and the Faculty of Health Sciences at McMaster University and operates in compliance with and is committed in accordance with the requirements.