AMBULATORY 5-FLUOROURACIL INFUSORS: EXPERIENCES OF PATIENTS

AMBULATORY 5-FLUOROURACIL INFUSORS: EXPERIENCES OF PATIENTS DIAGNOSED WITH GASTROINTESTINAL CANCER

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LAY ABSTRACT

Some patients diagnosed with a cancer in the gastrointestinal (GI) system receive a medication called 5-Fluorouracil (5-FU) through a small infusion device that they take home. This device slowly infuses the medication over 46-hours. While there are many conveniences in receiving treatment at home, the infusor can interfere with daily activities and patients must know how to monitor the device. This study aimed to explore patient experiences receiving 5-FU through an ambulatory infusor at home for the treatment of GI cancers. Results showed that patients receiving 5-FU at home through an infusor experience psychosocial distress, find it difficult to keep up with the many cancer-related appointments, and would benefit from improved education regarding psychosocial supports and venous access devices. It is important that patients are prepared for the challenges that this infusion device may present to their daily life and well-being.

ABSTRACT

Background: Treatment for advanced gastrointestinal (GI) cancer frequently requires continuous administration of 5-Fluorouracil (5-FU) over 46-hours through an ambulatory infusor. While convenient, evidence suggests that infusors may impact day-to-day activities and health-related quality of life (HRQL). There is limited research on the impact of this technology on patients' health, or if current practices meet their health needs. This study aimed to explore patient experiences receiving 5-FU through an ambulatory infusor at home for GI cancers.

Methods: A qualitative descriptive design was employed. Participants were patients diagnosed with a GI cancer who had received 5-FU through an ambulatory infusor for 46 hours within the last twelve months at a cancer centre in Southwestern Ontario. Semi-structured interviews were conducted by telephone, transcribed verbatim, and analyzed using content analysis methods to code data and identify relevant patterns and themes. Results: Ten patients with four types of GI cancers participated in the study. Their experience with ambulatory infusors ranged from 8 to 54 treatment cycles. Common themes included the psychosocial impact of having an infusor, the intense work of patient self-management, and supporting patients in self-management.

Conclusions: Results indicate that use of an infusor may have a more negative effect on patients' mental health than previously understood. Psychosocial assessment and support should be routinely utilized, and significant efforts should be made to prepare patients for living with an infusor. Streamlining services and reducing the number of cancer care-related appointments would also lessen the burden currently placed on patients.

Keywords: Infusor, 5-Fluorouracil, Patient Experience, Gastrointestinal Cancer, Nursing Role

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To my research participants, thank you for sharing your stories with me. I made it clear early on that this research was unlikely to benefit participants directly and was more likely to impact the cancer journey for those coming after them. Still, people showed up to share, hopeful that those walking this same road after them would have fewer stumbles. I sincerely hope that this work will honour your experiences.

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LIST OF ABBREVIATIONS

5-FU	5-Fluorouracil
AOPSS	Ambulatory Oncology Patient Satisfaction Survey
CCO	Cancer Care Ontario
CPAC	Canadian Partnerships Against Cancer
CVAD	Central Venous Access Device
GI	Gastrointestinal
HRQL	Health-Related Quality of Life
ISMP	Institute for Safe Medical Practice
PICC	Peripherally Inserted Central Catheter
RN	Registered Nurse
RNAO	Registered Nurses' Association of Ontario
QD	Qualitative Description

DECLARATION OF ACADEMIC ACHIEVEMENT

I, Tracey Huber, declare that this work is my own and, if not, I have acknowledged the original source using APA or another approved citation format.

Date: March 2023

Graduate Thesis: Ambulatory 5-Fluorouracil Infusors: Experiences of Patients Diagnosed with Gastrointestinal Cancer

Signature: Tracey Huber

CHAPTER ONE: INTRODUCTION

In 2022 at least 43000 Canadians were diagnosed with a gastrointestinal (GI) cancer, of which colorectal cancer is the most prominent (Canadian Cancer Society, 2022). Colorectal cancer was predicted to be the fourth most diagnosed cancer in Canada in 2022, with an estimated 24300 new cases (Canadian Cancer Society, 2022). Furthermore, the diagnosis of colorectal cancer is associated with significant morbidity and mortality as the second and third leading cause of cancer-related death for men and women, respectively (Canadian Cancer Society, 2022).

The drug 5-Fluorouracil (5-FU) is commonly used in treatment regimens for GI cancers, including colorectal cancer (Hammond et al., 2016). While most intravenous chemotherapy regimens can be delivered onsite at an ambulatory clinic within a matter of hours or even minutes, 5-FU requires continuous infusion because it has a short half-life (just ten minutes for bolus doses) and its impact on cancer cell growth is during a specific, short-lived phase in the cell cycle (MacMillan et al., 1978). The continuous infusion of 5-FU maximizes the duration of tumour cell exposure, producing maximal tumour cell death (Lokich et al., 1981).

Historically, patients receiving continuous 5-FU infusions over long periods would require hospitalization or five daily visits to the cancer clinic (Finley & Balmer, 1998). The continuous administration of 5-FU using ambulatory infusion pumps in the outpatient setting began in the early 1980s and was aided by the availability and use of central venous access devices (CVAD) (Lokich, 1998). Now, patients can be sent home with an ambulatory infusor that administers 5-FU using elastomeric pressure over the prescribed period, avoiding admission to the hospital or repeat visits to the cancer clinic for treatment (Hammond et al., 2016).

Ambulatory Infusor Process and Considerations

An ambulatory elastomeric infusor's hard, plastic shell is approximately six inches in height and two-and-a-half inches in diameter. This shell houses and protects an elastic balloon filled with 5-FU and has a three-foot-long line that connects to the patient's central venous access device. CVADs, such as a peripherally inserted central catheter (PICC) or port-a-cath, are used to safely administer therapies with irritant or vesicant properties (Bostelman, 2019). In the case of continuous 5-FU, the use of a CVAD mitigates its risks as an irritant and facilitates the prolonged infusion time required (Kreidieh et al., 2016). Once the bottle is attached to the CVAD, the flow of medication becomes active and uses elastomeric pressure to infuse slowly into the patient. The infusor is then placed into a small, zippered pouch with a buckled attachment that can be utilized as a belt, placed over the shoulder or around the neck to decrease the possibility of snagging the line or dropping the infusor (Moran, 2017). It is also important to note that a sensor at the end of the 5-FU line (attached to the CVAD) is secured to the patient's skin with tape. This sensor utilizes the patient's skin temperature to manage the flow of medication, which can vary the rate by +/- 15% (Goirand et al., 2018). The balloon infuses at approximately 5 ml/h and should finish in 46 hours. However, it is acceptable for the 5-FU to take 41-51 hours to infuse completely (Goirand et al., 2018). Once the infusion is complete, the patient is responsible for coordinating with their closest community nursing clinic (for Ontario residents) for a certified nurse to disconnect the infusor.

Before going home with their first 5-FU infusor, an oncology nurse educates patients about what to expect, watch for, and avoid in order to receive their infusion through the pump safely. Patients are advised to avoid extreme temperatures and keep the infusor below the heart to keep the medication flowing at the desired rate. Additionally, patients are taught to ensure the balloon within the plastic casing is decreasing in size, indicating the medication is infusing, keep the infusor dry, and avoid sharp objects that could damage the line or infusor (Cusano et al., 2018). This education also includes troubleshooting strategies and providing contact numbers should any issues or adverse events arise from the infusor or 5-FU medication (Baxter Corporation, 2014). As a cytotoxic medication, when a patient is exposed to 5-FU due to infusor damage or through contact with bodily waste (i.e., vomit, urine, feces), the cleanup must be handled using special precautions (Cancer Care Ontario [CCO], 2022a). Patients are sent home with a spill kit, which includes the instructions and required materials to safely handle, clean, and dispose of any leaked cytotoxic material from the 5-FU infusor or line.

Increasing Use of Infusors

Overall, the use of ambulatory infusors to deliver 5-FU for gastrointestinal cancers can be expected to increase over the next twenty years. While recent cancer statistics show that colorectal cancer incidence is declining in Canada, recent trends predict that the absolute number of new cases and deaths for the five major types of gastrointestinal cancer (esophageal, liver, pancreatic, gastric, and colorectal) are likely to increase in the next twenty years (Arnold et al., 2020; Canadian Cancer Society, 2022). Locally, the use of 5-FU infusors to treat these five types of gastrointestinal cancer has been steadily increasing at the outpatient cancer clinic in Southwestern Ontario where this study took place. Between 2012 and 2017, the cancer centre used 1200-1350 infusors per year. In 2018, this annual number rose to 1460 and further increased to 1800 infusors in 2019. This is the equivalent of 35 patients receiving ambulatory infusors weekly over one year. The decline in colorectal cancer incidence but increase in 5-FU infusor use may be due to the increase in survival rates with more patients living longer with a diagnosis of colorectal cancer. For example, between 2010-2014, colorectal cancer five-year survival rates increased by 10% compared to 1995-1999 (CCO, 2019).

It is also possible that the increase in ambulatory infusors is linked to the increasing number of treatments using 5-FU for gastrointestinal cancers. Ambulatory infusors of 5-FU can be used in combination with several drugs (e.g., Irinotecan, Leucovorin, Oxaliplatin, or Docetaxel) as part of several treatment regimens for different types of GI cancers (Dekker et al., 2019). Depending on the regimen, these different combinations of chemotherapy drugs are administered intravenously over several minutes or hours prior to attaching the 5-FU infusor. These regimens treat GI cancers (gastroesophageal, appendix, colorectal, rectal, anal, pancreatic, and hepatobiliary) and are often used with palliative intent (Dekker et al., 2019).

Given the increasing use of ambulatory infusors in Canada since 2006 to administer 5-FU for gastrointestinal cancers at home, there is a heightened need for research to understand the impact of this technology on patients. In general, the cancer care system is asking patients to take on more responsibility for their care. From managing complex supportive therapies (e.g., anti-emetics, anti-coagulants, granulocyte-colony stimulating factors) to coordinating dressing changes and at-home injections with their respective community clinics, patients are expected to take on more self-management in their cancer journey (McCorkle et al., 2011). The COVID-19 pandemic has likely intensified this effect due to changes in how cancer services are provided to minimize in-person contact. Patients receiving 5-FU for GI cancers must learn about their diagnosis, how to manage their CVAD and treatment side effects, and for some, come to terms with a life-limiting prognosis. Patients with 5-FU infusors have the added responsibility of understanding what their 5-FU infusor is for, whom to call when there are issues with the infusion, and what to do if there is a leak/spill or the device accidentally detaches from the CVAD (Baxter Corporation, 2014). Additionally, patients may worry about how the infusor could impact their activities of daily living, such as working, exercising, sleeping, socializing with young children or pets, and bathing (Baxter Corporation, 2014).

Patient Experiences with Ambulatory Infusors

Patient health care experiences and perceptions are shaped by interactions with providers and the culture of an organization across the continuum of care (Beryl Institute, 2022). Discussions surrounding patient experience frequently stem from the desire to understand the patient's perspective on the health care they have received (Oben, 2020). Understanding patient perspectives regarding their health care experiences can identify strengths and gaps in the delivery of patient-centred care. This data can be the catalyst for changes in health care services to match patient needs effectively, such as improvements to patient education or models of care delivery (Doyle et al., 2013; Weldring & Smith, 2013).

Related to cancer care, patients often encounter challenges that are specific to their diagnosis and treatment, making their experiences and perspectives unique (Pelzang, 2010). Ambulatory 5-FU infusors provide a unique way of delivering cancer treatment. While 5-FU infusors are commonly used for patients diagnosed with gastrointestinal cancer, other cancer types generally do not include this method of treatment delivery. However, as research continues to develop new regimens and treatments for cancers that may require similar technology, and with ambulatory 5-FU infusor use on the rise, understanding the patient experience related to 5-FU infusors is becoming increasingly important.

It is also essential to consider that for many patients receiving chemotherapy regimens involving ambulatory 5-FU infusors, this treatment is being given with palliative intent for advanced staged cancer. As a result, in addition to home infusions, these patients may also be managing a myriad of physical, psychological, social, and practical health care issues associated with the impact of advanced cancer (Dekker et al., 2019). Physiologically, these issues could include abdominal pain, fatigue, cumulative neuropathy, change in bowel habits, diet restrictions, liver toxicity, and impaired bladder function (Dekker et al., 2019). Understanding the impact of this infusor on the patient experience and quality of life is crucial for this patient population as their time on treatment may impact their final years or months of life.

Ambulatory Infusors in Non-Cancer Populations

Outside of cancer care, ambulatory infusors are used today to deliver a variety of medications to patients with varying conditions, such as diabetes, chronic pain, or acute post-operative pain management (Paparella, 2018). The benefits of these infusors include the reduced need for staff, supplies, cleaning, and other costs associated with inpatient treatment, resulting in cost savings of approximately twenty thousand dollars per patient annually (Cusano et al., 2018).

Overall, there is limited research on the use of infusors in cancer or other populations. Most studies focus on diabetes or pain management and suggest that the hassle of wearing an external device and its negative effect on body image are barriers to patient satisfaction (Capdevila et al., 2003; Tanenbaum et al., 2017). Other studies of infusors in non-cancer patients suggest they may significantly impact patient experience and quality of life (Sharp et al., 2014). In the following chapter, relevant literature about patient experiences with 5-FU infusors will be discussed in more detail.

Conceptual Framework: Picker’s Model of Patient-Centred Care

Patient-centred health care is described by the Institute of Medicine (2001) as "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (p. 40). A systematic review of the literature regarding patient-centred care and its connection to patient outcomes found that patient-centred care processes are positively associated with patient experience. Particularly, patient-centred care is positively associated with patient satisfaction, well-being, and self-management (Rathert et al., 2013).

In the late 1980s, the Picker Institute collaborated on a study with Harvard Medical School to identify the characteristics of patient-centred care (Picker Institute, 2022). Their work involved gathering information about health care experiences from focus groups with diverse participants, including physicians, patients, families, and other hospital staff. What matters most to patients was determined through these focus groups and a thorough review of relevant literature (Registered Nursing Association of Ontario [RNAO], 2015). From the study results, eight theoretical dimensions of patient-centred care were identified, including respect for patients' preferences; coordination and integration of care; information and education; physical comfort; emotional support; involvement of family and friends; continuity and transition; and access to care (Picker Institute, 2022; RNAO, 2015). Since the development of these dimensions, the Picker Institute and its model of care have been utilized to spearhead research and develop survey tools that explore the patient experience for mental health services, pediatrics, and cancer care (Picker Institute, 2022). A summary of the eight dimensions of the model can be found in Appendix A. This conceptual model was utilized in this study due to its focus on the patient experience. The relevance of Picker’s Model to cancer care and its use in this study will be discussed in detail in Chapter Two.

Summary

In this chapter, the increasing use of ambulatory 5-FU infusors for the treatment of GI cancers was described along with care delivery processes, and potential impact on patient experiences. The need for research to better understand how the use of infusors impacts on cancer and non-cancer patient populations was identified. Additionally, the conceptual model guiding this study, Picker’s Model of Patient-Centred Care, was introduced.

Thesis Organization

This thesis explored the patient experience of having a 5-FU infusor at home for patients diagnosed with GI cancers. This thesis document contains five chapters in total, inclusive of this introduction. The remaining four sections will form the body of the thesis, with the final chapter including conclusive remarks.

Chapter Two contains a comprehensive review of the literature to examine what is already known about patient experiences with 5-FU ambulatory infusors. First, the search strategy, search terms, and relevant studies are described. Key findings from the literature are presented, including gaps in patient knowledge about 5-FU infusors and the infusor's impact on health-related quality of life (HRQL) and day-to-day activities. The conceptual model chosen to guide this research study, Picker's Model of Patient-Centred Care, and its application in cancer care are also discussed. Finally, the research problem statement and research question are presented.

The third chapter includes a description of the qualitative description (QD) methodology utilized in this research study and the rationale for selecting this methodology. Additionally, details of the study's setting, sampling criteria, and participant recruitment strategies are outlined. Next, an overview of data collection, data storage, and the analysis method used to generate the findings of this study is discussed, followed by a description of activities to ensure the study's trustworthiness, rigour, and ethical considerations.

In Chapter Four, the characteristics of study participants are described, and a detailed overview of the study results is presented. This chapter concludes with a summary.

Chapter Five includes a detailed discussion of study findings within the context of Picker's Model of Patient-Centred Care to identify areas of alignment and misalignment in the current model of cancer care. Next, key study findings are discussed in conjunction with current evidence from the literature, followed by an outline of study strengths, limitations, and implications for clinical nursing practice, education, policy, and future research. This section concludes with a project summary and final remarks.

CHAPTER TWO: LITERATURE REVIEW

In this literature review, what is known regarding patient experiences with 5-FU ambulatory infusors will be examined. The search strategy will be clearly described, including the question which informed the search strategy, subheadings and keywords, and parameters to filter the literature review to relevant studies. The literature review resulted in the selection of five publications for review.

Search Strategy

To examine what was already known about patient experiences with ambulatory infusors, a comprehensive literature review was conducted using PubMed and Ovid MEDLINE. The search strategy was conducted in consultation with a medical librarian to identify studies focusing on patient experiences with ambulatory elastomeric infusors for GI cancers. The following question informed the search strategy: What are patient experiences receiving 5-FU through an ambulatory elastomeric infusor for gastrointestinal cancer at home? Subheadings and keywords included: 5-Fluorouracil, colorectal neoplasms, infusion pump, elastomeric, and ambulatory. Results were limited to the last ten years (2012-2022) to provide recent and relevant results, as recommendations regarding the use of elastomeric ambulatory infusors in oncology were only published in 2007 (ISMP, 2007). Articles deemed relevant for review included any research study involving patient exposure to an ambulatory elastomeric 5-FU infusion pump with a limit to adult populations published in English. Less than 300 articles were identified, of which five were relevant and selected for review. Two additional articles were identified from the reference list of included articles. Given the small number of relevant articles and to ensure that no important articles were missed, a follow-up search for earlier articles published between 2007-2012 was conducted in PubMed using the same subheadings and keywords as the initial search. This additional search did not yield relevant articles for review. A summary of the search strategy and the number of included articles is found in Appendix B, while the characteristics of the included articles and key results are outlined in Appendix C.

Preliminary findings from the literature suggested that patient experiences with ambulatory elastomeric infusion pumps were an important area to explore. The results indicated a preference for elastomeric infusors by health care providers and gaps in patient knowledge regarding the use and function of 5-FU infusors. In the following sections, details from the identified studies regarding the preference for elastomeric rather than electronic infusors, gaps in patient knowledge of infusors and their impact on patient HRQL and activities of daily living are discussed.

Preference for Elastomeric Infusors

In 2006, an incorrectly programmed electronic pump providing a continuous 5-FU infusion led to the death of a patient in Alberta. Unfortunately, the patient received their total prescribed dosage of medication in four hours rather than four days. The Institute for Safe Medicine Practices Canada (ISMP) investigated the event. Several factors contributed to the fatal error, including a lack of programming safeguards, intricate pump programming, and complex calculations required to achieve the desired flow rate. Subsequently, the ISMP published recommendations for the use of disposable, elastomeric ambulatory pumps in outpatient oncology units (Broadhurst, 2012; Cusano et al., 2018; ISMP, 2007).

Compared to electronic pumps, elastomeric pumps are more cost-efficient, quicker to prepare, safer, and preferred by patients due to being smaller, more lightweight, quieter, and more convenient (Cusano et al., 2018). In addition, nurse managers have reported a reduction in nursing visits related to elastomeric pumps, which has led to lower nursing costs (Broadhurst, 2012). A study by Broadhurst (2012) surveyed 56 health care providers (home care nurses, n=39; case managers, n=3; medical supply clerks, n=4; and pharmacy technicians, n=10) from Ontario to assess their satisfaction with elastomeric versus electronic infusion pumps. Participants were asked to complete a one-page questionnaire with questions regarding their satisfaction with various aspects of the infusors. A 5-point Likert-type scale was used for each question. The questionnaire also included an area for additional comments used for qualitative analysis. Overall, there were high levels of satisfaction with both types of pumps but mean satisfaction scores for the elastomeric pump were equal to or higher than electronic pumps for each question across all provider groups. When asked which pump they would recommend, 80% of the study participants recommended the elastomeric pump. While this study shows a distinct preference for elastomeric pumps among health care providers, it does not explore patient preferences or experiences with these infusors. This study also would have benefitted from a larger sample size and a description of how representative the surveyed sample was of the underlying population. Finally, a rationale or justification for the chosen sample size also would have strengthened this study.

Of note, from the reference list of an included article, two additional articles reporting on studies on infusers were identified. The first article outlined a randomized crossover study in Switzerland that investigated patient preferences related to the elastomeric pump or electronic pump for continuous 5-FU infusion. Participants used one device for three weeks, then the alternative pump for the following three weeks. Patients were then surveyed to determine their preferences. The results showed a patient preference for the elastomeric pump over the electronic pump (p-value < 0.01) (Zahnd et al., 1999). Similar results were achieved in the second article involving a study comparing patient satisfaction with electronic and elastomeric pumps for postoperative analgesia (Capdevila et al., 2003). These early studies alongside the findings of the more recent research done by Broadhurst (2012) suggest that health care providers and patients have a preference for elastomeric pumps.

Gaps in Patient Knowledge of Infusors

A two-phase study in the United Kingdom evaluated infusion volumes and care delivery practices over six months for patients receiving home chemotherapy via elastomeric pumps over 48-hours at three GI medical day units (Salman et al., 2017). In phase one, a cross-sectional study was conducted to assess the pump status and the volume remaining at the scheduled time for disconnection. If the pumps were not finished, the action taken by the district nurse was documented to evaluate the consistency of practices with the hospital policy. The additional time the patient waited for the infusor to empty was also recorded. The results showed that 46 of the 92 (50%) pumps did not finish on time, which subsequently caused disruption to patient and ambulatory home chemotherapy service schedules as nurses would have to return later to disconnect patient pumps. If nurses or patients could not wait, the bottle would be disconnected early, leading to sub-therapeutic dosing as pumps would be discarded with medication remaining. The results also revealed that there was no formal policy to guide nurses when infusions were not completed over the anticipated period. As a result, nurses developed their own approaches to address variation in pump performance, including immediate disposal of the pump (73%), asking the patient to wait in the medical day unit before being disconnected (11%), sending the patient home from the unit and having them return the next day (8%), or providing the patient with advice over the phone (8%).

Phase two of this study included a survey of 35 hospital and district nurses to understand their level of knowledge and expertise with these pumps. The survey included photos of pumps with varying volumes remaining and asked the nurses to identify which pumps they would consider empty. The results showed that 50% of the nurses had no formal training about the elastomeric pumps, and a significant number of the nurses considered pumps with more than 20 mL remaining as empty (i.e., 8.3% of the full volume). These findings have important therapeutic implications since almost 10% of 5-FU medication was being discarded with each infusor resulting in the under-dosing of anti-cancer medication which may negatively impact on treatment response and patient health outcomes. These findings highlighted the need for increased nurse training and support regarding elastomeric pumps. In the same study, a survey completed by 65 patients also identified gaps in patient knowledge. For example, some patients placed the pumps under their pillows while they slept, which may increase temperature and affect the flow rate. Nevertheless, despite the variation in pump performance 34% of patients indicated they were satisfied, while 64% reported being very satisfied with the ambulatory infusion pumps. While this study did highlight the issue of unfinished infusors being discarded, remaining volumes were visually estimated using photos for reference. This method lacks precision and using a scale to identify remaining volume would make the results more accurate and reliable.

Infusor Impact on HRQL and Activities of Daily Living

Few studies involving ambulatory infusors related to cancer therapies have employed qualitative study designs to examine patient experiences with this treatment delivery method. One qualitative descriptive study done in South Australia examined patient experiences with PICC lines, the significance of arm choice for the PICC line, and device impact on daily activities (Sharp et al., 2014). This study used a purposeful sampling approach to select participants based on diagnosis (e.g., haematologic and solid tumour cancers or infection) and previous difficulty with peripheral intravenous access. Patients booked to have a PICC line inserted in the radiology department of a public, metropolitan 680-bed hospital were invited to participate. Of the ten study participants, five had PICCs for antibiotics to treat an infection, one due to difficult peripheral intravenous access, and four due to a cancer diagnosis and the need for chemotherapy treatment. Of the four patients with PICCs for the delivery of outpatient chemotherapy (two for haematologic cancers and two for solid tumour cancers), the exact cancer diagnosis and treatment regimen were not identified. Semi-structured telephone interviews were conducted eight weeks post-PICC insertion. The results of this study suggest that disposable ambulatory pumps connected to PICC lines may significantly impact activities of daily living and HRQL. Participants noted that the infusion pump and line connected to it from the CVAD significantly affected their life more than the PICC (Sharp et al., 2014). Of note, participants in this PICC line study were connected to the pump system for many weeks without a rest period. It is possible that the increased burden of the infusion pump may be due to this lack of a break in treatment. As this study was conducted in Australia and included just two patients with unspecified solid tumour cancers, the findings may not be transferable to patients in Canada receiving 5-FU for GI cancer. Additionally, recruiting participants from a single site may reduce the transferability of the study, as the results can only reflect the practices and experiences associated with that service.

Al-Kadhimi et al. (2019) presented the findings of a questionnaire completed by 72 patients diagnosed with GI cancers who had completed two or more treatments with an infusor. The questionnaire had eleven specific "yes or no" questions related to the pump's interference with activities of daily living, such as bathing, exercising, sleeping, and travelling. There was also an opportunity to add comments if desired. Results indicated that while most patients felt prepared by their medical team about what to expect from the infusor (93.1%), the majority of patients (73.6%) reported that the infusor negatively affected their ability to bathe, and almost 38% reported disturbed sleep. Furthermore, a large proportion of patients reported negative impacts of the infusor related to exercise (31%), intimacy with their partner (26%), social interactions (25%), and anxiety (25%). While the results provide valuable insight into the impact of infusion pumps on patients, an in-depth understanding of the patient experience was not gained as researchers were unable to ask clarifying questions, and participants could not explore their feelings, thoughts, values, or opinions in any depth. A more complete review of this study and its study methods was not possible, since it was only published as a meeting abstract.

Finally, a recent systematic review of the literature conducted by Ivziku et al. (2022) examined the experiences of adult oncology patients living with a CVAD. The study included nine publications, from which four themes were identified: (1) During catheter implantation, oncology patients typically experience reluctance, apprehension and acceptance; (2) The nature of the information, knowledge transmission, and health care provider competence all influence the patient's confidence; (3) How the presence of a catheter impacts the patient's daily life, their self-perception, and their social behaviour; and (4) The catheter is a symbol of disease, a friend that helps prevent problems, and its removal is perceived as physical and psychological liberation. While this recent and comprehensive systematic review of the literature provides valuable insight into the experience of adult oncology patients with a CVAD, elastomeric 5-FU infusion pumps were not the focus of this review. However, the few instances where infusion pumps were mentioned in the study suggest that they may negatively impact patients' well-being and quality of life. While systematic reviews are considered the gold standard of evidence for clinical decision making, some qualitative studies published in languages other than English or Italian may have been missed, and the results may be limited to patients living in Western countries where all the included studies were from. However, this is the first meta-synthesis to provide insights into adult oncology patients' experiences with CVADs (Ivziku et al., 2022).

In summary, there is a gap in the literature regarding the patient experience with an ambulatory infusion pump used to deliver chemotherapy at home. Preliminary findings suggest that this is an important area to explore further due to the potential for a negative impact on physical and mental well-being. The literature search produced seven studies that were chosen for further review including one systematic review from 2022. These studies provided valuable insights into patient and provider preferences for elastomeric over electronic infusors, gaps in patient knowledge of infusors, and the impact of infusors on HQOL and day-to-day activities. The results of this literature search highlight the increasing use of infusors for the treatment of GI cancers and the need to improve our understanding of how to better support patients in managing this therapy at home as the use of elastomeric ambulatory infusors.

Application of Picker's Model in Cancer Care

Since 2005, the CCO, its regional cancer programs, and health system partners have recognized patient-centred care as one of six compulsory dimensions of multi-year strategic plans for cancer care. These plans aim to improve the quality and performance of Ontario's cancer system, reduce Ontarians' risk of developing cancer, and improve outcomes for those affected by cancer (CCO, 2022b). Patient-centred care is a central feature of developing, monitoring, and evaluating cancer services in Ontario and Canada [Canadian Partnership Against Cancer (CPAC), 2018]. In addition to clinical outcomes, patient experience is an important indicator of care quality, and patient-centred care is a strategic objective for achieving excellence in cancer care in Ontario (CCO, 2022b).

The eight dimensions of patient-centred care outlined in Picker's Model are the backbone of tools that report on the patient experience, such as the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) (Bridge et al., 2019). In partnership with CCO and regional cancer centres, the CPAC compares AOPSS results across provinces to gain data on the patient experience in outpatient cancer care (Bridge et al., 2019; CPAC, 2018). Understanding the patient experience is essential for determining the extent to which cancer services are patient-centred and identifying ways the quality of cancer care can be improved to better meet patient needs. As such, Picker's Model was an appropriate framework to explore patient experiences to improve the quality of patient-centred care in the context of outpatient cancer services (Klazinga et al., 2011).

Understanding the patient experience through a patient-centred lens within each of the eight dimensions provides valuable data to drive improvements in the quality and delivery of health care services (Doyle et al., 2013; Weldring & Smith, 2013). For example, when patients feel they have received patient-centred care, they are more likely to have a positive health care experience which may contribute to better health outcomes and increased adherence to medications and treatment plans (Bridge et al., 2019). Alternatively, if patients do not perceive that they have received patient-centred care, tools developed based on Picker's Model can identify improvement priorities within a health care setting.

The experience of having an ambulatory elastomeric infusor for cytotoxic medication at home is unique to patients receiving cancer treatment and is not well understood, as noted by the lack of published research evidence on the topic. To provide effective patient support, including patient education, referrals to other services, and evidence-based resources/tools, the experience of having this infusor must be understood and explored through a patient-centred lens. This qualitative study considered the eight dimensions described in Picker's Model as a guiding conceptual framework. The framework is highly relevant to the delivery of patient-centred care in ambulatory cancer care settings both provincially and nationally and provided guidance to ensure that patient experiences receiving 5-FU through an elastomeric infusor were fully explored.

Research Problem Statement and Research Question

The use of ambulatory elastomeric infusors in patients' homes has increased, especially for the delivery of 5-FU for patients diagnosed with GI cancers. Existing research has focused primarily on the effectiveness of the infusor itself (i.e., electronic pump versus elastomeric pump), the efficacy of continuous 5-FU as a cancer treatment, or health care provider perspectives on the use of 5-FU infusors. While the use of ambulatory infusors is convenient for patients because it allows them to be at home and avoid frequent clinic visits or hospital admission, some evidence suggests that this technology may have a negative impact on activities of daily living and HRQL (Sharp et al., 2012). Additionally, patients may not have the information or resources required to manage these devices at home. There is limited research from a patient-centred perspective about the impact of this technology on their health and health care or if current practices meet their health needs. A qualitative approach was used in this study to explore the patient experience and what it means to receive 5-FU through ambulatory infusors at home. These experiences can be used to understand the impact of ambulatory infusors on HRQL and day-to-day activities and what it means to receive 5-FU through an infusor, identify the quality and types of patient experiences, and to drive improvements in nursing practice and the quality and delivery of health care services (Doyle et al., 2013; Weldring & Smith, 2013). To address the gap in existing evidence, this study aimed to address the following research question: What are patient experiences receiving 5-FU through an ambulatory elastomeric infusor for gastrointestinal cancer at home?

Summary

In this chapter, a review of literature pertinent to patient experiences with ambulatory infusors was presented. A total of seven studies were reviewed; Canadian and international studies were referred to, and gaps within these studies were highlighted. A qualitative methodology was selected as appropriate because it will allow for an in-depth understanding of the patient experience with 5-FU infusors and is discussed in the following chapter.

CHAPTER THREE: METHODOLOGY

The experience of having a 5-FU infusor at home for patients diagnosed with gastrointestinal cancer was explored using a qualitative description (QD) study design. This qualitative research design was essential to achieve an in-depth understanding and new insight into the experiences of having a 5-FU infusor for patients diagnosed with gastrointestinal cancer. The chapter begins by providing a rationale for QD as the best study design to address the research question, followed by a description of the study methods related to setting, participants, sampling, sample size, and recruitment. Next, the methods for data collection are presented, along with approaches for data management, analysis, and ethical considerations. Finally, the chapter concludes with a discussion of the methods used to ensure rigour and trustworthiness, focusing on the credibility, reliability, transferability, and dependability of the results.

Design

To gain an in-depth understanding of the patient experience with a 5-FU ambulatory infusor and how nursing practices and cancer services can be improved for patients diagnosed with gastrointestinal cancer, a QD design was utilized. Qualitative description is a pragmatic research approach that provides broad insights and straightforward descriptions of experiences and perceptions to understand a specific event (Doyle et al., 2013; Sandelowski, 1995). This study design aimed to gain an accurate account of the phenomenon of interest, including the meaning attributed to it (Maxwell, 1992; Sandelowski, 2000). This methodology was relevant to the aim of this study to gain insight into patient experiences of having a 5-FU ambulatory infusor at home. QD is especially useful for gaining clear answers and explanations for questions posed to participants such as patients, practitioners, policymakers, or other stakeholders regarding their concerns, thoughts, feelings or attitudes towards a service or event (Sandelowski, 2000). As such, the results of QD studies are also helpful for informing the development, refinement, and assessment of clinical interventions (Sullivan-Bolyai et al., 2005).

QD draws on a naturalistic approach, which considers the context of the phenomena under examination and does not involve manipulation of the participants' environment (Bradshaw et al., 2017; Sandelowski, 2000). In this study, the environment and context are related to patients receiving 5-FU through an infusor at home. This research aimed to understand the patient experience with the infusor and the meaning they have attributed to their experiences as they naturally occurred. In addition, study methods were used to identify, from patient perspectives, the strengths and limitations of the current model of care and to provide new insight into possible solutions to improve nursing care and the delivery of patient-centred services at the cancer centre for people receiving 5-FU through an infusor.

Philosophical Underpinnings of Qualitative Description

Though QD is not especially theory- or philosophically-based, it does draw on some essential philosophical perspectives (Bradshaw et al., 2017). First, QD is an inductive process, meaning the qualitative data is collected, observed, and analyzed, then a general theory is created to explain or understand the patterns found in the analysis (Bradshaw et al., 2017). In this study, information about patient experiences with 5-FU infusors and patterns in the collected data informed potential theories to understand why or how those patterns emerged and inform practice improvement.

Qualitative description embraces subjectivity and is designed to describe and develop an understanding of the phenomenon or life experiences from a participant's perspective and to give them meaning (Bradshaw et al., 2017). In this research, patients described their experiences and what it means to receive 5-FU through an ambulatory infusor. As part of this process, some key assumptions were that patients would be willing and able to describe their experiences with 5-FU infusors in rich detail. This detailed information provided a comprehensive understanding of patient experiences with 5-FU infusors at home. Given that the researcher is an outpatient oncology nurse, pre-existing experiences and understandings may have influenced what data was collected and how it was collected. Based on the researcher's experience in oncology, one assumption was that patients diagnosed with gastrointestinal cancer receiving 5-FU via an infusor are a vulnerable patient population. It was also assumed that, for some patients, the use of a 5-FU infusor might increase the burden of their illness and negatively impact activities of daily living and HRQL. Data was continually revisited and evaluated alongside the thesis supervisor to ensure that pre-existing assumptions did not override patient perspectives.

Setting

This study was conducted at an outpatient cancer clinic in Southwestern Ontario. The cancer centre specializes in outpatient cancer care, including systemic therapy, radiation, supportive care, urgent care, pain and symptom management, palliative care, clinical trials, and lung/prostate diagnostic assessment programs. Patients receive care provided by the interdisciplinary team, including but not limited to medical oncologists, radiation oncologists, nurses, social workers, dieticians, and pharmacists.

Participants

Eligible participants were patients diagnosed with gastrointestinal cancer who had received a treatment regimen that required the delivery of 5-FU through an ambulatory elastomeric infusor for 46-hours. To facilitate adequate recall of experiences, patients who had completed treatment must have done so within the last 12 months. Eligible participants also had to speak and understand English and be over 18 years of age, as the cancer centre where this study was conducted does not provide clinical care to pediatric patients. The most common gastrointestinal cancers treated with 5-FU infusors are colorectal, esophageal, liver, gastric or pancreatic cancer. Patients were eligible to participate at any time since diagnosis and with any cancer stage (e.g., localized, locally advanced, or advanced/ metastatic disease). Patients must have completed at least one 5-FU treatment cycle with the infusor to have some knowledge of the study topic. There was no restriction on the number of treatment cycles received as this can vary by patient depending on their response to 5-FU and treatment side effects. Recruitment of patients with different types of gastrointestinal cancer at varied treatment stages and with a varying number of treatment cycles allowed different experiences with the infusor to be captured.

To prevent actual or perceived conflict of interest and ensure that all participants could freely express their views, patients who had been cared for by the student lead were excluded from the study. Similarly, patients who agreed to participate in the study did not receive care from the student lead for the duration of the study period.

Sampling

Purposive sampling was utilized to identify and select information-rich cases related to the phenomenon of interest (i.e., use of 5-FU infusors) (Palinkas et al., 2015; Patton, 2015; Sandelowski, 2000). Patients that fit the inclusion criteria and who were willing to share in-depth descriptions of their experiences and perceptions of having a 5-FU infusor at home were purposely selected for the study (Patton, 2015; Sandelowski, 2000).

Patients were purposely selected with contrasting experiences and varying perceptions of the 5-FU infusor and its impact on activities of daily living and HRQL (Patton, 2015). Patients with a varying amount of experience (e.g., less than ten cycles versus more than fifty cycles) and different types of experience (e.g., uncomplicated versus complicated) with the infusor were considered. A complicated experience related to the infusor itself (e.g., not infusing on time, damaged line or leak) or issues with care coordination (e.g., contacting the community clinic for bottle removal or the cancer centre for infusor problems). Disease type, stage, and demographic differences (i.e., gender, age, socioeconomic status, and marital status) were also considered, as these factors may play an underlying role in determining the type of experience a patient describes related to the infusor.

Sample Size

The sample size necessary for qualitative research has been debated. Typically, sample sizes for qualitative research studies are small due to the intensive contact with study participants (Bradshaw et al., 2007). The principle of 'data saturation' has been used to help determine sample size; however, this concept is difficult to operationalize in practice. Some research designs suggest that data saturation is reached when no new information is gained from participants during data collection, when additional coding is no longer feasible, or when enough information has been gathered to replicate the study (Coyne, 1997; Guest et al., 2006; Walker, 2012). Alternatively, other qualitative research designs insist that the uniqueness of each individual experience suggests that data saturation can never be reached (Ironside, 2006). Therefore, it has been established that there is no set rule to determine the most appropriate sample size in qualitative research. Instead, it is suggested that the following factors be considered to determine the sample size: research design, sampling procedure, and how frequently the phenomenon of interest occurs (LoBiondo-Wood & Haber, 2014). Additionally, Malterud et al. (2016) suggest 'information power' as a concept to consider: as the amount of information a sample holds which is relevant to the study increases, the required number of participants decreases. Overall, an adequate sample size is one that can sufficiently answer the research question (Fawcett & Garity, 2009). For this study, it was estimated that seven to fifteen people would be needed. After ten patient interviews, considering the previously mentioned factors, it was determined that the data collected was rich, and was able to represent a range of treatment cycles and types of experiences with the infusor (e.g., positive or negative), and held enough 'information power' to sufficiently answer the research question (Malterud et al., 2016).

Recruitment

When conducting the study, the student lead was a registered nurse at the study location and already had a working relationship with the cancer centre's clinic teams, including oncologists and registered nurses, who were considered 'gatekeepers' of the research sample (Creswell, 2009). To make health care team providers aware of the study's purpose and to engage their cooperation in recruiting patients, relevant staff were briefed through a short (2-3 minute) presentation about the study at their daily huddle/meeting. Posters to remind the care team about the study and inclusion criteria were placed at the nursing/oncologist workstations with permission from the manager of the cancer centre (Appendix D). Members of the primary cancer care team made eligible patients aware of the study at scheduled clinic or treatment visits, gave them a study information letter to review (Appendix E), and, if interested, sought their permission to be contacted by the student lead via telephone. The names of interested patients who had consented to be contacted were given to the student lead via telephone. Recruitment was an expeditious process, occurring over a 3-week period, suggesting that patients were ready and willing to share their stories and experiences with the infusor.

The student lead contacted interested patients within one week via telephone to confirm their eligibility and provide information necessary to obtain informed consent (Appendix F). This information included: the purpose of the study, the time required, the types of questions that would be asked, potential risks and benefits, the voluntary nature of participation, and contact information for questions or concerns about the study. Informed consent was obtained verbally during this call as in-person contact was restricted due to the COVID-19 pandemic. E-mail consent was not feasible as not all patients have the technology or computer skills required to receive e-mail, print, scan and return a consent form electronically.

Data Collection

The data collection stage of a QD methodology study focuses on answering the 'who,' 'what,' and 'where' of an event or experience of interest, usually through interviews or focus groups (Neergaard et al., 2009; Patton, 2015; Sandelowski, 2000). As this study aimed to explore the perceptions and experiences of patients diagnosed with gastrointestinal cancer with ambulatory 5-FU infusors at home, patient interviews were the most appropriate data collection method. Semi-structured interviews with open-ended questions were conducted via telephone in adherence with the COVID-19 restrictions at the time of the study to avoid unnecessary in-person contact (Sandelowski, 2000).

Current literature suggests that interviews are the most commonly used data collection method in qualitative research, with semi-structured interviews being the most popular technique (Kallio et al., 2016). This data collection method allows participants to express their thoughts, experiences, and values more freely and permits interviewers to ask clarifying questions of the participants (DiCicco & Bloom, 2006; Polit & Beck, 2004). Additionally, these interview methods allow participant responses to be more accurately interpreted and analyzed to drive the development of patient support resources.

Semi-Structured Interview Guide

The semi-structured interview guide for this study was developed using Picker's Model of Patient-Centered Care as a conceptual framework (Appendix G & H). For example, model concepts related to each dimension of Picker's Model (e.g., respect, care coordination, physical comfort) were integrated within interview guide questions. In addition, questions were developed based on the review of the literature regarding infusors, and the student lead's professional experience in chemotherapy administration and 5-FU infusor attachment/removal for patients diagnosed with gastrointestinal cancer. Questions regarding patient experiences with managing the infusor at home on a typical day (e.g., activities of daily living, social interactions), coordinating care with the cancer centre and community clinics, available supportive resources, and positive/negative experiences with their infusor at home were utilized. These questions were pre-determined and open-ended, enabling the researcher to explore issues brought forward by each participant during the interview (McGrath et al., 2019). Open-ended questions also allowed for flexibility and detailed responses (Jackson et al., 2007; Jacob & Furgerson, 2012).

The appropriateness of the interview guide in eliciting appropriate responses from patients was ensured by conducting one pilot interview with a registered nurse colleague (Jacob & Furgerson, 2012; McGrath et al., 2019; McNair et al., 2008; Van Teijlingen & Hundley, 2002). This pilot interview allowed the student lead to review interviewing skills with the thesis supervisor before data collection, check the comfort of the peer interviewee with the interviewing process, and explore the clarity of the interview questions (O'Callaghan et al., 2002; Jacob & Furgerson, 2012; McGrath et al., 2019). The pilot interview also ensured that the digital audio recording device used for the interviews was functioning correctly. In cooperation with the thesis supervisor, adjustments to the interview guide were completed based on the pilot interview experience (Nkulu Kalengayi et al., 2012).

Semi-Structured Interviews

Once a patient had consented to participate in the study, their chart was accessed to collect relevant information about their cancer and treatment history, including cancer type and stage, date of diagnosis, number of treatment cycles, date of last treatment and age (Appendix H). This data was collected to ensure inclusion criteria (e.g., had treatment with 5-FU infusor in the last 12 months) were met, and confirm that the sample of participants included a range of ages and number of treatments as to capture varying patient experiences. Next, the interview was scheduled at a convenient time for the participant. Participants were encouraged to choose a comfortable environment for the interview that allowed them to speak freely about their thoughts and experiences.

At the scheduled interview time, participants were contacted by the student lead via telephone to begin the interview. Patients participated in semi-structured interviews ranging from fifteen minutes to one hour. The average length of the interviews was forty minutes, providing in-depth information that detailed their experiences with a 5-FU infusor at home. The student lead performed interviews in a locked, private personal office to prevent distractions and ensure confidentiality. Demographic data related to gender, education level, marital status, employment status and annual household income was collected first using a structured questionnaire, followed by the interview questions. The demographic information was collected to be considered in data analysis as patients may have different experiences as a result of their unique context. For example, if negative experiences with the infusor were reported mostly by patients who continued to work during treatment.

All interviews took place via telephone to support the social distancing required during the COVID-19 pandemic. This method was also more convenient for patients as they could complete the interview in an environment they chose, decreased costs related to parking, and ensured a consistent approach to data collection. Telephone interviews are comparable to in-person interviews with no increased risk of data loss or distortion and do not compromise the quality or interpretation of data (Novick, 2008). In fact, telephone interviews may allow participants to feel freer to convey personal or sensitive information that would provide rich data for the study (Novick, 2008). One drawback of telephone interviews is that there are no visual cues to demonstrate active listening to the participant. To address this issue, verbal cues of active listening were provided by occasionally offering encouragement to continue and clarifying questions as needed.

With participants’ permission, interviews were audio recorded to facilitate transcription. All study files, including digital audio files, were stored in a password-protected folder in MacDrive – a secure cloud storage system privately hosted by McMaster University.

A transcriptionist professionally transcribed interviews with access to the password protected MacDrive server. While the audio files were transcribed verbatim, identifying information was omitted (e.g., names or addresses), and participants were only identified by their unique study code. These de-identified transcripts were password-protected and kept secure through MacDrive. The student lead's thesis supervisor reviewed the transcribed interviews to monitor the quality and consistency of the interviews. In addition, transcribed data were regularly reviewed and re-reviewed by the student lead to identify emerging patterns, themes, and ideas from the data (Elo & Kingas, 2008; Sandelowski, 1995).

Data Analysis

Clinical and demographic data collected from patients’ charts and interview questionnaires were sorted and analyzed manually. Data were grouped and displayed in ranges to ensure results were easy to understand while protecting patient confidentiality.

Content analysis is a primary method for analyzing interview data in QD research and was used in this study to create findings that can be shared (Sandelowski, 1995). Inductive content analysis generates concepts or categories that describe the phenomenon to develop a broad but condensed description of the phenomenon of interest (Elo & Kingas, 2008). This analysis method also seeks to identify core consistencies and interpret their meaning via patterns and thematic analysis (Patton, 2015).

Transcripts from each interview were coded using an inductive open coding process. As initial codes were identified, a codebook was generated. Coding was performed manually and using NVivo, a qualitative analysis computer software (Seale, 2000). The analysis involved constant comparison of the data with movement from data analysis to data collection and between analyses of individual patient transcripts and experiences.

The generated codes were further analyzed, examined, compared, and sorted into themes. Data analysis was stopped when no significant themes resulted from further refinement, and there were clear distinctions between data within themes (Braun & Clarke, 2006). Within each theme, relevant subthemes were identified, and overlapping data were eliminated, with final themes being refined and clearly defined. Lastly, the final themes and subthemes were considered within the context of the eight dimensions of patient-centred care described by Picker's Model. This qualitative content analysis has brought a fuller understanding of the patient experience with a 5-FU infusor at home and could lead to the generation or re-evaluation of interventions, services, patient support resources and patient education. The resulting themes and their relationship to Picker’s Model will be discussed in detail in the following chapter.

The student lead's supervisor was involved in all aspects of the data analysis, including review of all transcripts, double coding of 60% of the data, development and agreement on the codes and codebook, and refinement of final themes. This level of investigator triangulation ensured that biases from a single observer were addressed, increasing the credibility of research findings (Noble & Heale, 2019).

Rigour

Credibility, confirmability, dependability, and transferability are used to ensure rigorous qualitative methodology and establish trustworthiness (Lincoln & Guba, 1986). Study rigour was maintained, and trustworthiness was demonstrated through strategies that fall within these criteria. Additionally, the student lead of this study is an oncology nurse, and members of the thesis supervisory committee have experience with oncology-related research. This expertise was an asset to this study and supported rigour in the research process.

Credibility

Credibility means that the study results are believable and reflect the phenomenon of interest from the participants' perspectives (Lincoln & Guba, 1986). The student lead's supervisor reviewed the transcripts to achieve investigator triangulation. This process helped to reduce biases from a single observer, thus strengthening the credibility of the research findings (Noble & Heale, 2019).

Confirmability

Confirmability demands that the researcher remains objective in their data analysis and that another researcher can corroborate the results (Forero et al., 2018; Lincoln & Guba, 1986). Reflexivity, the process of regular self-reflection on the research process to reduce researcher bias, was demonstrated through a personal journal with written reflections of the student lead's beliefs, values, and experiences (Lincoln & Guba, 1986). Any relevant data and its potential effect on the study were declared. For example, the student lead is an oncology nurse employed at the study's location, which could have impacted how data was gathered or analyzed. Transcripts were reviewed alongside the student lead's supervisor to ensure that the data could support the identified themes and patterns.

Dependability

Dependability refers to transparency in describing the steps taken throughout the research project (Korstjens & Moser, 2018). An audit trail, including all raw data and field notes, was used to demonstrate dependability in the proposed study. This clarified why decisions were made throughout the research process and showed that the content analysis followed a logical path dependent on the participants' described experiences.

Transferability

Transferability is the degree to which the findings can be generalized or transferred to other contexts, such as patients with gastrointestinal cancer in other cancer care settings (Forero et al., 2018; Lincoln & Guba, 1986). This can be achieved through the detailed description of participant experiences and the characteristics of the study setting and participants so that readers of the published results can determine the extent to which study contexts are similar to their practice setting and patient population (Korstjens & Moser, 2018). In this study, the reporting of chart data and demographic data collected at the beginning of interviews supports the transferability of the study findings. In addition, the use of purposive sampling promotes transferability, as it includes a wide range of experiences which may increase applicability to another context (Forero et al., 2018; Korstjens & Moser, 2018; Lincoln & Guba, 1986).

Ethics

Approval from the appropriate research ethics board was achieved before the study began (See Appendix J). All study files, including recorded interviews, transcripts, demographic and chart review data, and participant tracking documents, were individually password protected and saved in a secure MacDrive folder to maintain confidentiality and prevent disclosure of personal data (Bradshaw, 2017). These actions ensured that participants felt safe sharing their experiences with the student lead. In addition, information was removed that identified individuals in the transcripts; transcripts and demographic data were labelled with a numbered code, and a separate, password-protected document linked each patient to their respective code. Study data was reported confidentially by removing any identifying information that could link a reader to the participant. Additionally, pertinent demographic data was reported in groups/ranges, not individually identified (Morse & Coulehan, 2014).

Detailed information about the study was written in English layman's terms and provided to all participants alongside a consent form. The consent form included all relevant information, including potential risks and benefits, the voluntary nature of the study, the ability to withdraw at any time, and the potential time requirements of the participants.

The use of semi-structured interviews in this study increased the potential for emotions or unexpected feelings from participants (Lowes & Gill, 2006). The student lead ensured all participants were informed of their right to leave the study, take a break, or end the interview at any time if required to minimize any distress (Atkinson, 2016). Participation in the study was entirely voluntary, and participants could withdraw at any time.

The risk of emotional stress to the student lead due to the interviews was managed through written reflection in a personal journal, family support, and supervisor guidance with debriefing sessions as required.

Summary

In this chapter, the rationale for choosing the qualitative descriptive design to guide this research study was presented. The conceptual framework, study setting, and recruitment procedure were clearly described, and the sampling procedure was outlined with descriptions of experience during the data collection stage. Guidelines on the university's management and storage of data were maintained and discussed concerning confidentiality.

In the results and discussion chapters to follow, a rich and clear presentation of the study's findings is supported by appropriate quotations and meaning units (Graneheim & Lundman, 2004).

CHAPTER FOUR: RESULTS

This study examined the experience of managing a 46-hour 5-FU infusor at home for patients diagnosed with gastrointestinal cancers. Ten participants were interviewed, and the information shared provided a rich understanding of what it is like to live with cancer treatment delivered through a 5-FU infusor. This chapter begins with a summary of study participants and their demographic characteristics, followed by the major findings. Illustrative statements made by participants are included so that patient experiences can be best understood using their own words and descriptions. Finally, the chapter will conclude with a summary of the key themes which arose from the data.

Participants

Of 11 patients who were invited to participate in the study, 10 provided informed consent and completed an interview. All participants were diagnosed with gastrointestinal cancer and were currently on treatment or had been treated with a 46-hour 5-FU infusor in the last 12 months. The participants answered basic demographic questions before the interview, and information regarding their cancer diagnosis and treatment history was gained from electronic health records after consent was obtained. A summary of this information describing participant characteristics is presented in Table 1.

There was a good representation of participants across age groups, covering a forty-year age range. Most participants were male (n=7), well-educated with a college or bachelor's degree (n=7), and married (n=8). Additionally, most patients were not working (n=7) and had an annual income of at least $60000/year (n=6).

All participants had stage IV disease resulting from a variety of gastrointestinal cancers. Most (n = 6) were diagnosed with colorectal cancer, followed by esophageal (n=2), pancreatic (n = 1), and appendix (n=1) cancer. Finally, the number of treatment cycles ranged from 8 to 54, with most participants (n=6) receiving 10 to 20 cycles, and most participants (n=9) were on active treatment at the time of the interview.

Table 1
Characteristics of Participants

Characteristics	**Parameters**	**N (%)**
Age	31-40	1 (10)
	41-50	1 (10)
	51-60	3 (30)
	61-70	2 (20)
	> 70	3 (30)
Gender	Male	7 (70)
	Female	3 (30)
Education	High School	3 (30)
	College Diploma	6 (60)
	Bachelor's Degree	1 (10)
Marital Status	Married/Common Law	8 (80)
	Separated/Divorced	2 (20)
Employment Status	Full-Time	2 (20)
	Part-Time	1 (10)
	Leave of Absence	2 (20)
	Retired	5 (50)
Annual Household Income	$30000-$59999	4 (40)
	$60000-$89999	4 (40)
	> $90000	2 (20)
Cancer Type	Esophageal	2 (20)
	Pancreatic	1 (10)
	Colorectal	6 (60)

	Appendix	1 (1)
Cancer Stage	Stage IV	10 (100)
Number of Treatment Cycles	< 10	1 (10)
	10-20	6 (60)
	21-50	2 (20)
	> 50	1 (10)
On Active Treatment at Time of Interview	Yes	9 (90)
	No	1 (10)

Overview of Major Findings

Analysis of the coded and categorized data led to the identification of three themes. The first theme encapsulated patient experiences involving the psychosocial impact of having an infusor with subthemes related to mental exhaustion, fear, the constant physical reminder of having cancer, and experiencing restriction and relief. The second theme illustrated how participants kept up with the intense work of patient self-management. Subthemes related to the heavy burden of coordinating multiple appointments and managing any problems involving the infusor. Finally, the third theme highlighted the importance of supporting patients in self-management and touched on strategies to improve the patient experience with a 5-FU infusor. A summary of themes and subthemes can be found in Table 2. The three major themes will be discussed in detail in the sections below.

Table 2

Summary of Themes and Subthemes

Theme	**Subtheme**
Experiencing the Psychosocial Impact of Having an Infusor	Mental Exhaustion and Managing the Infusor
	Fear of Toxic Medication in the Home
	Visibility and the Reminder of Having Cancer
	Experiencing Restriction and Relief
Keeping Up with the Intense Work of Patient Self-Management	The Heavy Burden of Cancer Care Appointments
	Managing Problems with the Infusor
Supporting Patients in Self-Management	Preparing Patients for the Day-to-Day and Psychosocial Impact
	The Importance of Trust and Safety in Self-Management Support
	The Impact of CVAD Type

Experiencing the Psychosocial Impact of Having an Infusor

The data analysis revealed that receiving 5-FU through a take-home infusor presents unique challenges for patients. This type of treatment delivery comes with additional responsibilities, impacts daily life, and affects physical and mental well-being. The psychosocial impact of having an infusor was related to four identified subthemes:

mental exhaustion, fears related to having toxic medication at home, the visibility of the infusor, and experiencing restriction and relief.

Mental Exhaustion and Managing the Infusor

Every participant commented on the tremendous work and mental wear associated with their cancer care and how treatment using the infusor resulted in additional responsibilities. Two main issues were identified in relation to mental exhaustion and infusor management. First, it became mentally exhausting to constantly coordinate appointments for their cancer care and infusor. Second, managing and monitoring the infusor was mentally draining for participants, as they had to be constantly aware of it to keep it safe, prevent problems, and assess if the 5-FU was being infused. Some participants even expressed that this mental exhaustion triggered thoughts and feelings of depression.

The Work of Coordinating Appointments

Participants explained that coordinating appointments became mentally exhausting. Patients felt like they were constantly coordinating and going to appointments between cancer treatments, scans, doctor's visits, bloodwork, CVAD maintenance, and bottle detachment.

> You know, it was like… you always had to be on the phone, like, you had to keep track of everything because you have to keep track of your chemo when you had it, and then you had to phone [the community clinic] and line them up, then when you're going to get your chemo you've got to get bloodwork done first, and then you've got to make an appointment at [community lab] for that. Sometimes it got

> complicated, and sometimes they would call you up and say, you know, we want you in earlier, can you come in earlier? Like, that just throws everything else off-kilter, then you've got to go through all that stuff again, you know? (5FU-07)

While participants understood why they had so many appointments, what they were for, and why they were important, patients expressed that the constant demands were mentally draining and "it can be a lot when you put it all together" (5FU-03).

Added Responsibility of Monitoring and Managing the Infusor

In addition to the mental exhaustion of managing their various appointments, patients described how having an infusor lengthened the treatment process and increased their responsibilities for managing other aspects of their care. For example, patients on other regimens receive their intravenous treatment at the cancer centre and then go home to immediately begin recovery. In contrast, patients with 5-FU infusors also receive the intravenous portion of their treatment at the cancer centre, and then must manage their treatment at home for an additional two days.

Participants also described the mental wear of constantly having to be aware of the infusor and if it is infusing appropriately. Some participants found that monitoring the infusor, tubing, and infusion of the 5-FU remained top of mind even when interacting with their loved ones, especially young children. For example, one participant explained that when their children would come to sit or cuddle with them, their first thought was whether the infusor and tubing were safe from potential damage.

Participants also described the weight of worry they experienced related to concerns that the 5-FU was not infusing correctly. Some explained that this mental wear even manifested itself in feelings of depression, "… you're very over-cautious, you're very aware of it, almost 24/7 you're thinking about it especially while it's on you… I don't get depressed easy, but it did have a mental effect on me…" (5FU-07)

Patients found themselves constantly checking the tubing for a pinched line or a kink and were looking at the bottle itself to be sure that the balloon inside was getting smaller, indicating proper function. This participant illustrated this constant level of awareness and monitoring:

> "I also do find that I'm kind of obsessively looking at it, so I'll take it out of the sleeve just to make sure that it's properly infusing and… I don't have a kink somewhere, it's not clamped off, I don't have to let the nurse know to come in early to try and fix it or adjust it. So, it's not really ever not top of mind that it's there…" (5FU-09).

Participants expressed a deep sense of relief when they saw that the infusor was working properly as the balloon reduced in size. This visual aspect of the treatment was seen as a benefit and even a comfort, as it assured patients that they did not have to worry, the infusor was working as it should, and they did not have to troubleshoot or manage any complications.

Fear of Toxic Medication in the Home

Providing emotional support and alleviating fear and anxiety is a central concept of patient-centred care, yet all 10 participants described disconcerting levels of fear that the chemotherapy would leak and voiced concerns about the toxicity of 5-FU. Moreover, participants described fear of the impact of toxic chemotherapy on their partners, children, other loved ones, and even their pets.

Fear Related to the Impact of Toxic Medication and Leakage

Every participant explained that the toxicity of the medication was fear-inducing. The information and equipment provided to patients emphasized that the 5-FU was toxic and outlined instructions on how to contain a cytotoxic spill and how to decrease the likelihood of having the medication impact others (e.g., flush the toilet twice, wash soiled clothes twice separately in hot water). Additionally, the toxicity of the 5-FU and the need to be very careful with the infusor was reinforced to patients while they were at the cancer centre as they saw the nurses wearing impermeable gowns and extra-thick gloves when handling chemotherapy medications. One participant likened the infusor to a nuclear power plant, saying, "…they gave me that whole kit and there was the write-up about the leaking, it does make it sound so scary. Like, you do feel like you've got Chernobyl attached to you by that type of explanation" (5FU-03).

While a leak from the infusor was a concern for all participants, only one had this experience. The patient woke up in the early morning to find their 5-FU infusor had been steadily leaking 5-FU while they were sleeping. The cytotoxic material was in their bed, on their sheets, and even on their torso. When asked about this experience, the participant said,

> "I was a little concerned because when you first get the bottle, they give you this kit that's got, like, a suit and a mask and gloves, they act like it's radioactive and if you touch it, you're going to die… So, with that in mind, when it leaked like

> that I thought ‘holy mackerel, I’ve got a real problem here, this is toxic and it’s on my sheets now, maybe it touched my wife and everything else” (5FU-07).

Fear Related to the Impact of Toxic Medication on Others

Participants also described the fear and stress associated with being “ultimately responsible for preventing toxics from hitting other people" (5FU-09). This stress was primarily related to family members, children, and close friends that would be in direct contact with the patient or the bottle itself.

While loved ones were not directly interviewed, participants explained how their partners and children also experienced the fear of a cytotoxic spill and the 5-FU medication. One participant even described their partner as being 'terrified' of the infusor, saying, "I tell you my husband is terrified of it… he won't get close to me for those two days, because of that bottle. Yeah, I guess [he’s] not just afraid, just he kind of wants to stay away from it I think… because it’s cytotoxic (5FU-05).”

Another participant described how the cytotoxicity of the infusor and fear of a spill impacted how their children interacted and showed physical affection with them. The participant described that the possibility of a cytotoxic spill “put [the children] on edge” and that they were becoming “more apprehensive about coming around me and hugging me” (5FU-09).

Visibility and the Reminder of Having Cancer

Participants described how they routinely attempted to keep the infusor hidden from others. The possibility of the infusor being seen in public triggered such strong feelings of embarrassment that some participants began to purposefully distance themselves from loved ones, leading to social isolation and psychosocial distress. Additionally, patients felt that the infusor acted as a constant physical reminder that they have cancer and are not healthy.

Impact on Social Interactions and Feelings of Embarrassment

Participants expressed how they often made a significant effort to hide the infusor to lessen feelings of public embarrassment and decrease its impact on social interactions. For example, one participant explained, "I started worrying about, am I going to have this thing on me all the time, and are people going to see me, are they going to know that I've got cancer and everything?" (5FU-05).

While efforts were made to hide the infusor and avoid conversation with others, one participant had a stranger ask questions about it. Overall, while they described being 'okay with [the conversation],' the experience made them feel they should take more care to be sure the infusor was completely hidden in the future.

Some participants intentionally isolated themselves and chose not to go out at all to avoid social interactions while the infusor was attached. One participant even limited their interactions with family members:

> Well, I don't want a big deal if I went in the store, and they see my shirt sticking out four inches. You know, they think I'm bigger on the top there, just basically keep away so kids and that don't see it. Like, I don't get out to my nephews so the kids can see it, I just stay away for a few days. (5FU-08)

The Physical Reminder of Having Cancer

There was a secondary motivation to hide the infusor apart from decreasing instances of public embarrassment. Participants described that the infusor acted as a physical reminder of having cancer, leading to psychological distress. As this participant (5FU-07) described, "Psychologically, it was a shock… because now you've got a constant reminder hanging on you. That you're not healthy, that you've got a problem, a serious problem."

In some instances, participants also described that the infusor could be a helpful tool to facilitate positive discussions about patient experiences with cancer treatment and the medical system. One participant felt that the conversations and discussions generated by the infusor helped prepare loved ones, including children, for the possibility of death.

However, there are instances where the infusor acted as a 'constant' visual reminder of the illness for their loved ones and was no longer serving as a positive discussion point. As this participant (5FU-09) stated, "… you see [loved ones] look at [the infusor], you can see them processing it, and it's just not being discussed, it's just being a reminder."

Experiencing Restriction and Relief

Participants expressed how the infusor had an extensive impact on nearly every aspect of day-to-day life, forcing patients to problem solve, plan ahead, and constantly adjust their daily activities while the infusor was attached. These disruptions in their daily life led to an overwhelming sense of relief and freedom when the bottle was detached.

The day-to-day impact of the infusor and feeling of liberation upon detachment will be discussed in the following sections.

Impact on Day-to-Day Life

Participants described that the infusor had an impact on almost all everyday activities. Basic physical and social day-to-day activities were affected, including the most intimate and essential needs like elimination, bathing, and sleeping, but also activities more unique to each patient, such as hobbies or social interactions.

Sometimes, having an infusor impacted the patients' ability to perform a task. For example, patients could not adequately bathe while the infusor was attached since the infusor and any access device cannot be submerged in water. Sleeping was also particularly challenging as the infusor was described as physically obtrusive but also mentally distracting (i.e., constantly worrying about kinking the line or damaging the infusor while sleeping), making it difficult to have a good night's rest. In addition, one participant found cooking to be a troublesome activity as they did not want to expose the temperature sensor on the infusor to extreme heat from the barbecue or oven when preparing food. The impact of the infusor on the ability to wear a seat belt was also mentioned by multiple participants. If a patient has a port-a-cath, its placement can be where the seat belt crosses the torso, meaning they must sit on a particular side of the vehicle. Additionally, the infusor placement is cumbersome around the waist since it is in the way of the seatbelt across the hips.

In other cases, tasks were not made impossible or overly difficult, but the patient had to consider and accommodate the infusor. For example, considerations were made when getting dressed, as sleeves cannot be too tight around a PICC line, and necklines cannot be so high or tight that they restrict access to a port-a-cath. Specific household tasks made participants worried about those activities affecting the functioning of the bottle or pulling on the tubing. Going to the washroom meant always considering where the infusor could rest safely. Finally, one participant who maintained a full-time career during treatment found that the 46-hour infusion was very intrusive to their work week. To address this issue, they had to negotiate for the treatment to occur on specific days of the week to reduce work disruptions.

Overall, the infusor had an extensive impact on the daily activities of all participants. Additionally, patients described having to constantly problem solve, plan, and adjust to accommodate the infusor in their day-to-day activities. As 5FU-07 summarized, “It is on your mind a lot of the time, you’ve got to be aware of where you’re doing, where you are, what you’re doing, where the tubing is. You change your lifestyle a little bit to accommodate that.”

The Overwhelming Sense of Relief and Freedom with Bottle Removal

With the infusor having such a profound impact on so many day-to-day activities, all participants described an overwhelming sense of relief when bottle removal was discussed. Some likened it to "freedom" (5FU-07), or “having an anchor taken off your neck” (5FU-09). One participant even described that when the bottle is removed, they “feel like a different person altogether" (5FU-08) as they could enjoy daily life without constant worry or disruptions. As this participant explained:

> It was nice because it was like freedom… once it's off it's like 'oh, thank god, I can move around and not think about it, and I can go to bed and sleep and not worry about it'… And it's a thing that every time it's taken off, there's that sense of freedom, just even for a split second, but it's there and it's a nice mental reaction, actually. It's a positive reaction. (5FU-09)

This positive mental reaction from infusor removal was also described as a "gift" and that "at least every two weeks you've got something to look forward to" (5FU-07). The removal of the infusor also signalled the end of the chemotherapy cycle and represented the beginning of recovery for some patients.

Keeping Up with The Intense Work of Patient Self-Management

In outpatient cancer care, patients are responsible for managing and coordinating a myriad of appointments – the details of which will be reviewed in the following section. For patients with 5-FU infusors, the burden of schedule coordination is increased as they have additional appointments to manage. The burden of self-management is even more complex when patients experience issues with the infusor and have to problem-solve. The following section highlights the extensive nature of care coordination and the burden placed on patients to manage the infusor.

The Heavy Burden of Cancer Care Appointments

The burden associated with cancer care appointments was a common concern for participants and consisted of multiple factors. First, the sheer volume of this work was wearing as patients felt like they were constantly going to cancer-related appointments in addition to any personal appointments they may have outside of their cancer care.

Secondly, coordination could be challenging as it is affected by the timing of other appointments, the patient's health, and bloodwork results. Finally, patients found themselves angry or frustrated by the constant need to manage and coordinate aspects of their care. As discussed in the previous section, the volume of appointments, difficulties with care coordination, and feelings of frustration are compounded by the psychosocial weight of living with and managing the infusor.

Volume of Appointments

The mental drain patients felt concerning appointments was heavily driven by the volume of appointments that must be remembered and managed. Blood tests, doctor's visits, infusions, CVAD management, and infusor removal are a non-stop cycle in their care. Overall, participants described feeling like they were going to appointments so frequently that it became one of the most wearing parts of cancer treatment. One participant stated,

> … one week you go and get your PICC line cleaned… Then the next week you're working around the time for your bottle, and then the next week… you're going every week, so you're constantly going to appointments, and that wears on you. (5FU-02)

It is also important to note that these patients have other responsibilities and health considerations outside their cancer care. Some of these patients are caregivers for their children or parents, have other life-altering health conditions, or maintain a part- or full-time work schedule. As a result, these other responsibilities made managing the large number of appointments related to the infusor and cancer treatment even more complex.

Participant 5FU-06 mentioned how managing transportation could be a challenge, especially with children, saying, "the scheduling of the driving to get [to appointments], and just juggling with my [children] being in school, and who's going to pick them up from school… all of that definitely has played into the anxiety surrounding the bottle."

Coordinating Appointment Times

Maintaining consistent appointments is a challenge with 5-FU infusors since the timing of bottle removal depends on when the chemo appointment is booked at the cancer centre. Adding to the inconsistency for patients, while the 5-FU infusor is meant to infuse in 46 hours, the acceptable infusion time is 41-51 hours. Participants described how variable infusion rates made booking the bottle removal complicated and frustrating. For example, if they booked their removal appointment too early and the chemotherapy was still infusing, they would be sent away to come back later. Alternatively, suppose they book the appointment later in the day, the bottle may infuse completely before their appointment, and patients were nervous about having an empty bottle attached.

There is also the potential problem that when the infusion day arrives, patients are unwell, or their bloodwork is not appropriate for chemotherapy, so treatment is cancelled. While sometimes physicians choose to 'skip' treatment, meaning the patient will return at their next scheduled appointment, other times treatments are 'delayed' by one week. This means that all appointments the patient had set up for bottle removal, blood work, transportation, etc., must also be moved by one week. As this participant (5FU-07) explains, "So now you've got to call them up and rearrange, and it just throws everybody off-kilter including yourself. You know, it plays on your mind sometimes."

Frustration and Anger Related to Appointment Burden

Participants noted that the stress of managing appointments created instances of heightened emotions, including anger and frustration. For example, one participant described how the mental wear alongside the constant coordination of appointments resulted in an angry outburst at the [community clinic]:

> I went one time [to the community clinic] and I thought my appointment was for 10:30 or 10:00, and I was late, and they gave me heck, and I kind of blew my top. You know because you get frustrated with this, overall, what you're going through. Your level of patience is not what it is. I get mad, I even get mad at myself sometimes, and I just say, 'oh god, I've just had enough.' But when you go there and they start telling you that and giving you heck, like that's enough, you're already agitated… that can be enough to set you off a bit. (5FU-02)

Overall, patients find the ongoing management and number of appointments to be frustrating, wearing, and inconvenient. One participant summarizes this point well:

> I find it extremely inconvenient. I want to go out and do things, so how do I get everything I need to get done and accomplished before and/or after [the bottle], what can I put off, and making those trade-offs. It's a lot to think about that I wouldn't have to think about if I didn't have the bottle on me… [it makes me feel] frustrated, mostly. It's wearing. (5FU-09)

Managing Problems with the Infusor

While few study participants experienced serious problems with their infusor at home, they are responsible for monitoring the infusor for signs of equipment malfunction and must know when to seek help, whom to contact, and how to access that assistance. In cases where infusor issues arose, patients used these experiences to demonstrate their ability to prevent the infusor from being damaged, manage a leak/spill, and troubleshoot when their infusion was not finishing on time. However, some of these experiences were described as 'stressful,' and gaps in patient knowledge were identified in some cases.

Managing a Dropped or Fallen Infusor

If the infusor falls and tugs heavily on the line, it could disconnect the infusor from the CVAD or the CVAD from the patient. For example, one patient accidentally dropped their infusor, which tugged on their PICC line hard enough to require a replacement of the PICC line. Another participant had the infusor accidentally fall from its holder and hang from the port-a-cath in their chest. Thankfully, the fall did not cause any damage or disconnection from the infusor, but the participant described feeling shocked and initially panicked that the port-a-cath had been 'ripped' out of their chest.

After this incident, the participant mentioned that they changed the holder used for the bottle to a fanny pack to be more secure. This a simple but important example of how participants self-managed the infusor and implemented strategies to mitigate risks.

Managing a Cytotoxic Spill at Home

Every participant discussed their fear of cytotoxic leakage at home but also indicated that they felt prepared due to the resources and education provided by the cancer centre. Participants identified appropriate phone numbers to call and the spill kit that could be used to contain a cytotoxic spill.

One participant experienced a spill at home but stated that they “knew what to do” and was going to call the cancer clinic, but “couldn't call [the cancer clinic] because it happened at 6:30 in the morning, they weren't open. I went right to the emergency" (5FU-07). According to the participant, "emergency couldn't do anything" so they went to the cancer clinic in person since it was open by that time. In this case, the participant understood that the spill was a serious issue and that they needed to alert their care team. However, the participant did not know whom to contact when the cancer clinic was closed, and it is unlikely that emergency department staff would be knowledgeable about managing cytotoxic spills. While this incident shows that the participant took the need to report the spill seriously and was seeking professional assistance, it also highlights some confusion about whom to contact when the cancer clinic is unavailable.

Managing an Infusor That Did Not Infuse on Time

Patients are instructed to monitor the bottle to assess if the 5-FU is infusing too slowly, too quickly, or not infusing at all. Infusion issues could be due to the clamp on the CVAD being closed, the connection between the line and the CVAD being loose, the tubing from the CVAD or the infusor line being kinked, having the sensor be exposed to extreme temperatures, or from a malfunctioning bottle. Additionally, 5-FU bottles flow at only ~5mL/h, making it difficult to know on an hour-by-hour basis whether the infusor is properly functioning. While most patients find their infusors finish within the acceptable window of time, one participant did discuss their experience with an infusor that infused too slowly, which required calling the oncologist to determine if the infusion should be discontinued or not. The participant described this as "a stressful experience" because "there is an expiration on the bottle label and things like that… and then it's like… 'is this expired poison going into my body?' and that "does kind of add that level of fear to it" (5FU-06). Another participant had their bottle empty a couple of hours before their bottle removal time and was "panicked" about having an empty bottle attached to them for multiple hours.

> I phoned up the clinic, actually, and I said look, I've got a problem here, can I come to the hospital and you guys take this off, and I explained it to them. And they said [5FU-07], don't worry about it on, it can be on you for 6, 7 hours, it's airtight, you're not going to get a blood clot, you're not going to get a bubble, don't worry about it... But it was a shock. That's probably one of the more scarier things that happened in my life... I really thought there's going to be a major problem. (5FU-07)

While these participants demonstrated an understanding that the appropriate response is to contact the cancer centre for further instruction, they also revealed a gap in their knowledge about how serious it is if the infusor does not finish on time or if an empty bottle is attached to them. This lack of knowledge contributed to patients experiencing unnecessary worry and psychological distress.

Supporting Patients in Self-Management

Before their first chemotherapy treatment and 5-FU infusor attachment, patients are provided with education, resources, and contact information to support them. While participants in this study had some positive things to say about the information and resources provided, the data suggests that patients did not feel adequately prepared for how the infusor impacted their daily life and psychosocial well-being. Participants also discussed how their experiences with the cancer clinic and community clinic nurses affected the level of trust and safety with nursing care. Finally, as patients receiving 5-FU through an infusor require a CVAD, participants reported that the type of CVAD (PICC or port-a-cath) profoundly impacted their experience managing the 5-FU infusor at home.

Preparing Patients for the Day-to-Day and Psychosocial Impact

Overall, participants described that the education provided to them in verbal and written form focused on cytotoxicity precautions, infusor function, and troubleshooting common issues with the infusor (e.g., pinched line), but lacked information on managing day-to-day activities while having the infusor connected, and the potential psychosocial impact. It is important to note that patient education may have been negatively impacted during this study which occurred during the COVID-19 pandemic. As a result of the pandemic, the in-person chemotherapy education class that usually runs at the cancer centre was cancelled.

One participant described that the resources given to them triggered some fear. “It was the pieces of paper they gave me… I wasn’t afraid of that beforehand, but I was after” (5FU-03). However, they went on to express gratitude saying, “…in the big scheme of things, I think it’s good that I got that printout, even if it did make me fearful that [the infusor] was going to leak." This fear experienced by patients suggests that information may be provided without context, and patients do not understand how common or how serious potential issues are.

While participants described this information given to them as helpful, they also described a lack of information and support about practical strategies for managing the infusor at home day-to-day.

> … [the resources were] helpful, but it didn't necessarily offer a lot of day-to-day, like how to handle this in your regular life sort of experience. It was more about 'how does the bottle work and run', and 'carrying it around your neck', and just 'be careful with it'… and 'monitor for fever' sort of deal. So, it definitely wasn't necessarily about, you know, 'some people find that it's easier to do this, or just make sure when you're sleeping that you're not going to pinch the line', things like that. (5FU-06)

All participants described feeling prepared to manage the infusor physically but not emotionally. They felt they were equipped to handle the infusor but were surprised and unprepared for how much the infusor would impact daily activities and mental health. As 5FU-01 stated, "Yeah, nobody really said much about [what] the effect of wearing [the infusor] would be… I do think they should warn people of the emotional and psychological effects of it."

The Importance of Trust and Safety in Self-Management Support

From the data analysis, two subthemes related to trust and safety in self-management support were identified. The first subtheme related to the support provided by friends and family they could rely on, while the second subtheme related to the experiences with the cancer centre and community clinic nurses and confidence in the care received. Patients described positive care experiences when they felt safe and trusted the people (loved ones or nursing care team) providing cancer care support.

Relying on Family and Friends

Participants described “a lot of support from many different layers of life” and that “it makes a giant difference” to have people they trust doing “all of those life things that I just took for granted for so long, being able to do myself” (5FU-06). When asked how they felt about having the infusor around their friends, one participant said, “It’s fine. I know them well. I trust them” (5FU-08). Overall, when participants described a trusting relationship with the people trying to support them, it was associated with a more positive care experience.

When asked about family or friends, a positive experience was when others attempted to understand what the participant was going through. One participant described feeling like they had a ‘good’ friendship and family base to rely on, then went on to articulate that these are “people understanding or trying to understand what I’m going through” (5FU-02). Another participant described that the understanding shared between patients was valuable to them. They explained that when they see other patients at the cancer centre with infusors, “they know what I’m experiencing, and I know what they’re experiencing… you see other people getting the bottle on, it is kind of like this weird feeling of comradery” (5FU-06).

Patients also received psychosocial support by being able to share their experiences with family members and friends. Through these conversations, they were able to normalize the experience of having an infusor. As one participant explained,

> I said you've just got to live with [the infusor], I said 'I'm no different from what I was before.' … We more or less embrace it as that's just part of who I am now, and it's my little buddy… You know, mentally, that really helps you. Like my grandkids will joke about it with me sometimes and that really helps you, because you don't feel abnormal. (5FU-07)

Cancer Centre Nursing Care

Nursing staff at the cancer centre administered the chemotherapy, attached the 5-FU bottles, and were heavily involved in educating and equipping patients to manage the bottle on their own at home. When patients called the cancer centre with care questions, the nurse working directly with the patient's oncologist was often the one to interact with the patient and answer their questions. Participants commented that the compassionate and specialized oncology nursing care they received at the cancer centre allowed them to feel safe and trust the team's knowledge and skills.

The nursing staff were described as nice, accommodating, empathetic, sensitive, and helpful. Participants described their experiences with responsiveness to patient needs at the cancer centre generally positively. As one patient stated, "…if you have any problems, you just say, I'm having this, and they sort it out right there" (5FU-08). However, because the cancer clinic is in a hospital setting, there were participant concerns regarding the unpredictability of the hospital environment. As one participant stated, "you just never know what could happen. There's just so many things that could just drop on [the cancer centre] out of nowhere and delay things" (5FU-01).

The level of experience and specialized knowledge that the cancer centre nurses have was appreciated by participants and added a note of comfort to their treatment days and time at home, knowing they can call for support if needed. As one participant stated,

> … with the cancer clinic nurses, this is what they do, they know all the tricks of the trade… there's just that level of safety there, there's that level of trust with the cancer clinic nurses that they know what they're doing, they've experienced it before… (5FU-06)

Community Clinic Nursing Care

Nurses at local community clinics were responsible for infusor and port-a-cath detachments, and PICC dressings/maintenance between treatments. While the nurses were described as friendly and accommodating by all participants, care experiences were mixed and inconsistent, leading to decreased feelings of trust and safety.

One participant had previous experience with a community clinic that included several errors in the nursing care of a drain following a procedure. This experience made the patient wary when they had to go to a community clinic for CVAD maintenance and bottle removal. The participant also explained that they preferred some nurses over others, as they felt that some nurses were making errors with the port-a-cath and bottle, creating anxiety for the patient.

Another participant also expressed some nervousness with community clinics, saying, "in regards to the [community clinics], I have a lot more doubts. A lot more doubts, and a lot more anxiety…" (5FU-06). When asked to elaborate on these doubts, the participant described an experience where they felt the [community clinic] did not have as much knowledge surrounding the infusor or CVAD troubleshooting and were told to go to the emergency department. 5FU-06 felt they were put into "a panic mode" as the community clinic immediately wanted to "send someone who is already immunosuppressed… into the emergency." Meanwhile, the cancer centre had other strategies to employ before sending the patient to the emergency department.

While participants did not describe community clinic care as solely negative, 5FU-06 did explain, "as a level of trust that [the community clinic nurses] know how really to handle the bottle… I would say I have less of a trust…" They continued, "you kind of feel like you're taking a little bit of a risk having to go outside of the cancer clinic to have someone else deal with the bottle removal…" (5FU-06). This participant did show a level of understanding that community clinic nurses "have to have such a giant bag of knowledge for everything that they deal with that I don’t know, like, how much they could absorb correctly, understanding the nature of chemotherapy and bottles and things like that” (5FU-06).

The Impact of CVAD Type

Patients with 5-FU infusors must receive their medication through a CVAD, which means all participants in this study had either a PICC or a port-a-cath. Several participants had experience with both devices and could compare the two, while others had only one device. Findings from the data analysis indicate that port-a-caths were not only the preferred device but also had a lesser impact on day-to-day activities.

For participants who had PICCs, experiences were primarily described as being negative. First, participants described the PICC as uncomfortable and, because it requires a dressing at all times, could be itchy and irritating to the skin. One participant was "sensitive to the glue that the tape is made of… then you've got a skin problem, you've got that for sometimes two or three weeks until it heals up… It's a constant aggravation when you have a PICC line" (5FU-07).

Participants also felt more restricted with the PICC line. One participant (5FU-07) even said, "psychologically and physically, [the PICC] is really worse than actually having the bottle on". Another issue was the constant worry about the tubing tugging on something with a PICC compared to the port-a-cath. One participant who had experienced both devices felt the PICC was more precarious and required closer monitoring, while the port-a-cath was more secure (5FU-03). Participant 5FU-07, who also had both devices throughout their treatment, described how the port-a-cath was less intrusive. "You don't even think about [the port-a-cath]… it's as if it's not even there." In contrast, this participant described how the PICC was restrictive by saying, "with the PICC line you're always running for something, your life is not your own. You can't go on a vacation, … because you've got to have it serviced all the time… Where the port, it's like nothing's there" (5FU-07).

One restriction specific to PICC lines is that you are not supposed to lift more than 5-10 lbs or move your PICC arm in a repetitive motion. For participants that had young children, this restriction was very difficult. Participant 5FU-06 had very young children at the time of their treatment and explained that being unable to lift their child was very hard for them emotionally and practically. Another participant with children found that the

PICC limited the type of activities they could do together, while the port-a-cath offered more freedom.

It is also important to note that while some participants reported being given a choice between a PICC or a port-a-cath, most participants did not describe being offered a choice of CVAD by their care team. One participant even had three PICC insertions due to complications before being offered a port-a-cath. Overall, participants reported more positive experiences with the port-a-cath than with the PICC line, as it improved quality of life with the bottle and had a lesser impact on daily activities.

Summary of Findings

This chapter presented the findings on patient experiences of living with 5-FU infusors at home. The three emerging themes were discussed and supported using meaningful quotations from participant interviews.

The first key theme was experiencing the psychosocial impact of having an infusor. The overwhelming mental exhaustion of having an infusor was discussed, followed by the fear reported by all participants concerning the toxicity of the 5-FU was explored. Next, the participants described the impact of the visibility of the infusor as a reminder of their illness and potential point of public embarrassment. Finally, the lengths to which the infusor restricts day-to-day activities and quality of life and the subsequent relief when the infusor is detached were revealed.

The second theme was keeping up with the intense work of patient self-management. In this section, the overwhelming burden of appointments and care coordination that comes with having an infusor were reviewed. In addition, the types of problems participants experienced with the infusor and how they managed them at home were identified.

The third theme was supporting patients in self-management. Here, the types of resources patients received, and their need for psychosocial impact preparedness and day-to-day support were described. Next, the importance of trust and safety in self-management support was explored in the context of family and friends, as well as the cancer clinic and community clinic care teams. Finally, the impact of the type of CVAD a patient has (PICC or port-a-cath) was discussed as participants shared and compared their experiences with both types of devices.

In the following chapter, findings from this study will be compared to current relevant literature and explored in relation to the conceptual model that guided this research. Finally, the strengths and limitations of this study will be discussed, along with the potential implications of this research for clinical practice, nursing education, policy, and future research.

CHAPTER FIVE: DISCUSSION

This chapter aims to further examine the meaning and implications of the study findings regarding the experience of having a 46-hour 5-FU infusor at home for patients diagnosed with gastrointestinal cancer. Ten participants completed semi-structured interviews, providing rich data from which the analysis revealed three key themes: (1) experiencing the psychosocial impact of having an infusor, (2) keeping up with the intense work of patient self-management, and (3) supporting patients in self-management. First, study findings will be discussed within the context of Picker's Model of Patient-Centred Care to identify areas of alignment and misalignment in the current model of cancer care (Picker Institute, n.d.). Next, key study findings will be examined against existing research evidence on the impact of nursing expertise on patients' feelings of trust and safety, the psychosocial impact of living with an infusor, selecting a CVAD, and scheduling and coordinating cancer care appointments. Finally, study strengths and limitations, transferability of the findings, and implications for practice, policy, and future research will be identified.

Relationship of Study Findings to Picker’s Model and Patient-Centered Care

Picker's eight dimensions of patient-centred care are the result of research done by the Picker Institute and Harvard Medical School in their search to determine what matters most to patients in health care (Picker Institute, n.d.). Nursing care guided by Picker's Model has been shown to positively impact patient outcomes, including patient satisfaction, well-being, and self-management (Rathert et al., 2013). Additionally, patient-centred care has been noted to increase patient empowerment, autonomy, and self-confidence (Morgan & Yoder, 2012). As participants reported several experiences suggesting the current model of care is not meeting their needs, further examination of the results through the lens of Picker's Model of Patient-Centered Care may provide valuable insight into specific areas for improvement and possible solutions. The results were compared to definitions for each of the eight dimensions of the Picker model. Results consistent with these definitions are viewed to reflect patient-centred care. In contrast, those that are inconsistent suggest misalignment or areas in which the delivery of patient-centred care could be improved. Table 3 identifies the eight dimensions of the Picker model and how study findings are consistent or inconsistent with patient-centred care for patients receiving 5-FU through an infusor at the cancer centre where this study was conducted.

Table 3
Picker's Eight Dimensions of Patient-Centred Care

	Dimension	**Definition**	**Example from Findings**
Areas of Alignment	Continuity and Transition	Alleviate concerns about self-management by providing information to patients regarding access to available supports, medications, nutrition, transportation, and ongoing treatment/care details.	- Contact information for support resources was given. - Patients knew which support team to call and when/how. - Patients were able to transport themselves as needed to required destinations.
	Information and Education	Provide complete and up-to-date information to patients regarding prognosis, clinical status, and progress; this supports patient	- Patients identified available resources for practical infusor self-management support.

		autonomy and self-management.	
	Access to Care	Mainly with respect to ambulatory care, ensuring access to multiple health care settings/teams and transportation.	- Dressing changes were easy to coordinate with community clinics. - Patients were able to make most appointment bookings themselves.
Areas of Misalignment	Involvement of Family and Friends	Acknowledge and respect the role of the patient's family/friends in their health care experience.	- Cancellation of chemo education class. - Family/friends unable to attend physician or treatment appointments.
	Physical Comfort	Enhance physical comfort, including pain management, supporting activities of daily living, and an inviting hospital environment.	- Infusor is physically bulky and uncomfortable, impacting the ability to perform daily activities. - CVAD itself could be uncomfortable and impact the ability to perform daily activities.
	Coordination and Integration	Coordinate and integrate clinical and patient care services to reduce fear and vulnerability.	- Managing appointments in multiple locations with different providers was burdensome for most participants.
	Emotional Support	Help to alleviate fear and anxiety with respect to health status, the impact of illness on self or family, and financial concerns.	- Experienced fear related to a potential spill of toxic material leading to social isolation. - Embarrassment being seen in public.
	Respect for Patient Values,	Treat individuals with respect, maintain their dignity and demonstrate sensitivity to cultural	- Lack of informed choice regarding the type of CVAD.

Preferences and Needs	needs. Involve patients in decisions regarding their care, keeping them informed about their condition. Focus on the patient's quality of life.	- Lack of awareness surrounding the intense impact the infusor would have on nearly every facet of day-to-day life.

Alignment with Patient-Centered Care

Patient experiences consistent with patient-centred care related to the following areas of Picker's Model: continuity and transition, information and education, and access to care.

Continuity and Transition

Continuity and transition are essential elements of patient-centred care, which focus on alleviating concerns about self-management by providing patients with information regarding available support, medications, nutrition, transport, and ongoing treatment details (Picker Institute, n.d.). This dimension is crucial for patients living with 5-FU infusors, as each treatment begins at the cancer centre but then transitions to patient self-management and coordination of their own care (e.g., dressing changes, bottle removal) and care provided in community clinics. The data showed that contact details for support resources (i.e., community clinic and cancer centre) and when it would be appropriate to use them were given to and reviewed with patients. Patients also described knowing who and when to call and showed the knowledge and ability to access appropriate resources when required. In addition, when patients had issues, they could access the required care team (i.e., community clinic or cancer centre) and transport themselves to the needed destination. Overall, most patients described having the support they needed to smoothly transition between the cancer centre, community clinics, and home.

Information and Education

According to the Picker model, patients often fear that information is being withheld from them. One way to reduce this fear is to provide patients with understandable information and education to reduce anxiety and facilitate autonomy, self-care, and health promotion (Picker Institute, n.d.). Participants in this study demonstrated autonomy and the ability to self-manage by knowing how to monitor the infusion, whom to call, and how to seek help for practical infusor issues. All participants described the written information they received in detail and whom they could call if they needed support. Multiple participants had issues or questions about their infusor and contacted the cancer centre for support. One participant (5FU-06) even advocated for themselves, encouraging the community clinic team to contact the cancer centre when there was a disagreement about the next steps regarding a problematic infusor. The understanding of available resources was also demonstrated when 5FU-07 revealed that they had experienced an infusor leak overnight, then appropriately called the clinic as a first response. Additionally, patients showed an understanding of their limited prognosis and disease process, which can help to support their autonomy and self-management.

Access to Care

Patient-centred care is also achieved when patients have easy access to the services they need when they need them, and when appointments can be scheduled with ease (Picker Institute, n.d.). This dimension is particularly applicable to ambulatory care and requires that patients have access to multiple health care settings/teams and transportation. These elements of patient-centred care were illustrated by participant comments expressing that dressing changes were easy to coordinate with the community clinic, and they could do most of this appointment booking themselves.

Misalignment with Patient-Centered Care

Results showed misalignment with patient-centred care related to the following dimensions of the Picker model: involvement of family and friends, respect for patient values, preferences and expressed needs, emotional support, physical comfort, and coordination and integration.

Involvement of Family and Friends

Patients described the importance and support of family and friends, including how caregivers helped them with day-to-day activities affected by the infusor, such as driving, childcare, and housework. Study participants did not describe interactions between family members and their cancer care team, involvement of family in treatment decision-making, or the types of supports caregivers have received from the cancer clinic care team. It is possible that the interview questions did not adequately explore these aspects of patient-centred care. However, it is important to note that the lack of discussion about family/friend caregiver involvement with cancer care providers could be due to restrictions resulting from COVID-19, which prevented them from attending patients’ clinic appointments. In addition, the chemotherapy education class for new patients and family/friends was cancelled because of the COVID-19 pandemic. As a result, when this study took place, there was limited in-person contact between the cancer centre care team and the family/friends of patients. Prior to the pandemic, they would have been included in physician visits and infusion and bottle attachment appointments.

Physical Comfort

Physical comfort is an outcome that is highly desired by patients and their families, making it a fundamental goal of patient-centred nursing care (Kim & Kwon, 2007). Additionally, when patients experience increased physical distress, their psychological distress also increases, further demonstrating its importance (Yang et al., 2000). Supporting patients to engage to their fullest capacity in activities of daily living is another important indicator of patient-centred care (Yang et al., 2000). In this study, patients continuously described the infusor as bulky and physically uncomfortable to wear and manage at home. The intense psychological relief participants felt when the infusor was disconnected further underscores the extent to which it was restrictive and negatively affected their mental state and ability to perform day-to-day activities. Participants were also very vocal about CVADs required for treatment, particularly PICC lines, and how they caused discomfort and placed physical restrictions on daily life (e.g., unable to golf or shower). Notably, the port-a-cath had fewer impacts on day-to-day life when the infusor was not attached and was an effective way to increase physical comfort in patients receiving treatment with 5-FU infusors. These findings illustrate the importance of patient comfort in relation to psychological well-being and ability to perform daily activities. These results also indicate the need for strategies to optimize patient comfort related to the size and positioning of the infusor and also the selection CVADs.

Coordination and Integration

Cancer care pathways are known to be challenging to manage, as patient conditions are complex and require an increasing number of specialty or subspecialty providers (Christ et al., 2021). However, good care coordination improves the patient experience and contributes to patient satisfaction (D'Angelo et al., 2015). Participants in this study received treatment for metastatic (stage IV) cancer, which has a poor prognosis (Langley & Fidler, 2011). Treatments for metastatic gastrointestinal disease involving 5-FU may control but not cure the cancer, and as a result patients live with ongoing uncertainty about how long the treatment will be effective and their overall life expectancy. This uncertainty makes efficient coordination and integration of care more imperative to decrease stress and enhance patient quality of life in their final years or months.

The study results suggest a need to improve the coordination and integration of care for patients receiving 5-FU. Particularly, there is a need to reduce the burden associated with scheduling a myriad of appointments and optimize the time patients have to engage in activities that enhance their quality of life.

Patients receiving 5-FU through an infusor have numerous appointments for bloodwork and other diagnostic tests such as CT scans, monitoring and assessment by their oncologist, visits to their pharmacy, CVAD care, and removal of the infusor. Participants could articulate the immense burden of coordinating and managing this number of health care appointments. Integrating care services to reduce fear and vulnerability is critical in patient-centred care. Nevertheless, study findings suggest that patients were not given options to reduce the number of appointments or assistance with care coordination, especially between the cancer centre and community clinics. Ideally, patients would benefit from a single oncology care source (i.e., the cancer centre) rather than forced to have some aspects of their care managed by care teams outside the cancer centre. Some patients also described how when one appointment was moved or changed, this caused a ripple effect, meaning every appointment from every provider also had to be moved. They felt like they "always had to be on the phone" (5FU-07).

Cancer services in other provinces (i.e., Alberta, Manitoba, and British Columbia) have implemented procedures where patients can disconnect themselves from the infusor. This reduces the need for nursing care support and decreases the number of patient appointments (Alberta Health Services, 2016; Cancer Care Manitoba, 2020; BC Cancer, 2018). Implementing a program in which patients could disconnect themselves from their 5-FU infusors in Ontario, assuming they are capable and comfortable with doing so, would be an excellent strategy to prioritize patient-centred care. This would decrease the number of cancer-related appointments that need to be coordinated and attended, and consequently, reduce costs for community nursing care support.

Emotional Support

Patients commonly experience psychological distress throughout their cancer journey. For example, Mehnert et al. (2018) conducted a cross-sectional study to screen patients diagnosed with cancer for various concerns related to physical health, practice issues, family, emotional well-being, and spirituality. The results showed that 52% of patients experienced high levels of psychological distress. In patients diagnosed with cancer, psychological distress is associated with non-adherence to treatment, poorer quality of life, higher mortality, and suboptimal cancer-related decision-making (Mazzocco et al., 2019). In contrast, several studies have found that patient-centred communication positively impacts patient satisfaction, including emotional well-being (Niu, 2021; DiMatteo, 2004; Willis & Holms-Rovner, 2003).

In this study, patients described feelings of emotional distress such as anxiety, fear, embarrassment, and mental wear of living with the infusor. Fear and anxiety were primarily related to the toxic medication inside the infusor and the need to avoid exposing others to its harmful effects. The fear of infusor breakage was so prevalent that some patients resorted to social isolation, refusing to go out or see loved ones until the infusor had been removed. Other participants described feeling embarrassed to be seen with the infusor and wanted to avoid the potentially awkward conversations or looks from strangers who could see it attached to them. Seeing the infusor every day also reminded participants of their illness and felt like a constant reminder that they are not well. While participants consistently described feeling prepared to manage the infusor, mentally, patients felt unprepared for the emotional distress the infusor would cause. These results suggest that patient-centred approaches are needed to prepare patients emotionally for the infusor's day-to-day impact and address their psychological concerns related to the infusor and cancer diagnosis.

Respect for Patients' Values, Preferences, and Expressed Needs

Respect for patients' values, preferences, and expressed needs is an aspect of patient-centred care that is demonstrated by recognizing and focusing on medical treatments that promote patient quality of life (Picker Institute, n.d.; Ortiz, 2018). A key finding from this study was that patients were unaware of and unprepared for how the infusor would disrupt almost every facet of their daily activities and quality of life. It is unclear if having this information would have changed their decision to receive treatment involving 5-FU. Patients also found that they were not given the information they needed to make an informed choice regarding which CVAD (PICC or port-a-cath) they would like to have. Several participants expressed a lack of knowledge of their options and identified that they were not given a choice even though the two types of CVADs used are associated with different risks and benefits. A randomized-controlled trial by Epstein et al. (2017) found that patient-centred communication strategies increased patient engagement in discussions about their cancer care including treatment plans and prognosis. Patient-centred communication regarding CVADs would involve making patients aware of their access device options and their benefits and risks. The lack of informed choice experienced by patients concerning their CVAD is a critical gap in patient-centred care.

The results of this study suggest that patient-centred care could be improved by meeting information needs about the infusor's impact on day-to-day life, and supporting patients to make informed decisions about their cancer treatment and CVAD in a way that aligns with their values, preferences, and expressed needs.

In summary, patient-centred care is linked to improved adherence to treatment and self-management behaviours, and subsequent improvements in patient satisfaction and well-being (Rathert et al., 2013). Comparing study results to the eight dimensions of Picker's Model of Patient-Centered Care has identified several areas of alignment with the model, but also some gaps with room to improve care delivery. Patients living with 5-FU infusors experience emotional distress that affects nearly every facet of their daily life making improvements to patient-centred care that much more essential. Future improvement efforts should also focus on strengthening the involvement of family and friends with the cancer care team, alleviating physical discomforts associated with the infusor and CVADs, streamlining and facilitating the integration and coordination of care, assessing, and addressing patient needs for emotional support, and respecting patient values, preferences and expressed needs.

Comparison of Results to Existing Evidence

In the following section, results from this study will be compared to existing evidence. Findings related to the impact of nursing expertise on patient feelings of trust and safety, the psychosocial impact of living with an infusor, selecting a CVAD, and scheduling and coordinating cancer care appointments will be discussed.

Impact of Nursing Expertise on Patient Feelings of Trust and Safety

Patients receiving treatment with 5-FU infusors are initially connected to the infusor by nurses at the cancer centre, but the device is disconnected by nurses in community clinics. Community nurses are also responsible for CVAD maintenance (i.e., port-a-cath/PICC flushes, dressings) between treatments. In the current study, participants who expressed a lack of trust in community clinic nurses perceived gaps in their knowledge and skills. This mistrust was primarily founded on inconsistent nursing practices related to their care. However, in some cases, the community nurses overtly explained that they were uncomfortable with the skill they were performing.

On the other hand, participants reported feelings of trust and safety with the nurses at the cancer centre due to consistent care practices across nursing staff, and their level of experience and specialized oncology knowledge compared to the community clinics. These experiences related to trust in nursing care are supported by other studies found in the literature. For example, Rajcan et al. (2020) found that trust is generated between nurses and oncology patients when nurses demonstrate proficient procedural skills, and the patient perceives the nurse to be knowledgeable and competent. Another study by Ozaras and Abaan (2018) supported this finding, concluding that a nurse's skill set, including caring for vascular access lines, influences the patient's level of trust in the nurse.

These findings imply that improved education for community nurses regarding the management of CVADs and 5-FU infusors may benefit the nurse-patient relationship and patients’ trust in nurses who work in the community setting. Alternatively, as integrating care services to reduce fear and vulnerability is vital in patient-centred care, it would be ideal for all 5-FU infusors and CVADs being used for anti-cancer purposes to be managed by specialized oncology nurses.

The Psychosocial Impact of Living with an Infusor

All participants described psychosocial impacts of the infusor, such as feelings of mental wear, fear of the medication's cytotoxicity, restriction, and intense relief. Patients also felt that the infusor constantly reminded them of their cancer diagnosis. Additionally, participants expressed that the psychosocial impact was a surprise to them and that they did not feel prepared for the mental effect the infusor would have.

There is a paucity of research on the psychosocial impact a 5-FU ambulatory infusor has on patients. However, there is research evidence about the psychosocial impact of other devices like CVADs and diabetes technology (particularly insulin infusion devices), which may have relevance to patients receiving cancer treatment via technology such as a 5-FU infusor. For example, the systematic review by Ivziku et al. (2022) found that patients viewed CVADs as a symbol of disease or a friend the helps prevent problems, and its removal is perceived as physical and psychological liberation. These findings are consistent with the results of the current study, where the infusor is seen as both a reminder of disease and of treatment to fight cancer, and infusor disconnection is associated with intense feelings of relief and freedom.

Tanenbaum et al. (2017) surveyed people with type 1 diabetes to examine barriers to the uptake of technology for continuous subcutaneous insulin infusion and continuous glucose monitoring. At least half of the respondents reported that wearing the device was a hassle (i.e., not having enough time to learn how to use it or not wanting to take more time in the day to manage diabetes) and a barrier to its use. Nearly 35% (n=526) of patients also disliked wearing the device on their bodies, and 26% (n=390) had concerns about body image. Finally, over half of the participants reported that using diabetes infusion pumps made them feel stigmatized and like a burden on the health care system (Tanenbaum et al., 2017). With this in mind, it is unsurprising that psychosocial factors such as distress, burden, anxiety, and depression arising from diabetes management remain prevalent (Kubiak et al., 2020). While diabetes technology is not the same as the 5-FU infusor, the results of this study are similar to that of Kubiak et al. (2020) related to the psychosocial impact of wearing a medical device. For example, study participants similarly described the hassles or constant disruption of the 5-FU infusor on daily activities. They also expressed concerns about the infusor being attached to their body and desire to reduce the visibility of the infusor when in public situations to avoid stigmatization and being made to feel different.

Notably, a study by Pugliese et al. (2006) examined the feasibility of an integrated approach to care in which patients diagnosed with advanced colorectal cancer were provided with a primary medical oncologist and a clinical psychologist. Outcome measures assessed adaptation and awareness, anxiety and depression, and subjective perception of medical treatment quality, including impact on HRQL (Pugliese et al., 2006). Participants in this study were treated on an outpatient basis, and their chemotherapy regimen included an external, portable, computer-programmed pump. These participants were chosen for this study because of the complexity of the patient responses to the external pump. The study found that the pump could be considered 'good' in that it provides survival, 'demanding' in that it requires continual dependence, and 'bad' in that treatment side effects may threaten psychosocial well-being (Pugliese et al., 2006). The required presence of a CVAD was also considered a psychological risk, as it impacts body image and view of self (Pugliese et al., 2006). Overall, the complexity of this type of cancer treatment delivery identified an at-risk group of patients for increased levels of psychological distress and non-compliance to care that may benefit from an integrated approach to care. Study results revealed that after four months, patients followed by an integrated care team had a more stable HRQL than pre-treatment, were less anxious, and reported more positive experiences regarding their medical therapy (Pugliese et al., 2006).

The results of the study by Pugliese et al. (2006) are consistent with those of the current study, identifying that patients receiving 5-FU via an ambulatory infusor experience considerable psychological distress. These findings are important because psychosocial distress has been associated with lower satisfaction with care and poorer health outcomes among cancer patients.

Selection of CVAD

It was not the intent of this study to examine patient experiences with a CVAD; thus, a surprising finding was the extent to which patients reported issues related to CVAD impact on health and quality of life. In fact, there were no questions in the semi-structured interview related to CVADs, thus discussions regarding patient concerns with their access device were participant-led. All participants in this study had a PICC or port-a-cath, though some participants that had a PICC initially had it replaced with a port-a-cath during treatment. In all cases of patients having had both types of devices, the port-a-cath was preferred over the PICC due to convenience, comfort, and the port-a-cath having a lesser impact on day-to-day life. Participants also perceived they had fewer complications with a PICC compared to a port-a-cath.

These findings are consistent with those from a randomized controlled trial by Moss et al. (2021) that evaluated the overall complication rates of PICCs, port-a-caths, and Hickman catheters. There were eight secondary outcomes, three of which were measures of quality of life using three different recognized QOL scales (i.e., EQ-5D visual analogue for general health, cancer QOL via Quality of Life of Cancer Patients Questionnaire, and a venous access device-specific QOL questionnaire). The results showed that many aspects of quality of life were significantly better with a port-a-cath than with a PICC, including hygiene, hobbies, and exercise (Moss et al., 2021). Additionally, while all CVADs are associated with risks including occlusion, venous thrombosis, and infection, port-a-caths are less likely to cause harm than PICCs, reducing the adverse event rate by approximately 50% (Taxbro & Chopra, 2021; Moss et al., 2021). PICCs are five times more likely to cause venous thrombosis but slightly less likely to cause infection than port-a-caths (Moss et al., 2021, p. 412).

Similar results were also found in studies by Corti et al. (2020) and Taxbro et al. (2019), which found that complication rates were significantly higher in PICCs than in implanted central venous catheters. However, PICCs remain the more convenient option for short-term therapy and for treatments that need to start urgently as they can be inserted by specially trained RNs (Taxbro & Chopra, 2021). In contrast, port-a-caths require interventional radiology suites to be inserted and require a more invasive and less readily available procedure. That said, a study by Shao et al. (2022) found that port-a-caths were 96% more likely to be cost-effective compared to PICCs when they were inserted and used for at least six months. While the convenience of insertion is undoubtedly an important factor to consider (especially if the patient requires urgent chemotherapy initiation), avoiding adverse events, maximum patient satisfaction, and quality of life must be a priority when selecting a CVAD (Taxbro et al., 2019).

In summary, there are distinct differences in HRQL and adverse events between PICCs and port-a-caths, which is consistent with patient experiences reported in this study. In contrast to the principles of patient-centred care, patients in this study receiving treatment with 5-FU infusors are not well-informed about CVAD options or how the choice of device could impact on their HRQL.

Scheduling and Coordinating Cancer Care Appointments

Cancer treatment involves more than doctor’s visits and chemotherapy appointments, especially for patients receiving 46-hour 5-FU infusions at home. Between their appointments at the cancer centre, bloodwork lab, and community clinic, participants felt burdened by the number of care appointments they had to manage and coordinate.

Care coordination refers to "deliberate efforts to harmonize patient care" (Mollica et al., 2021, p. 446). For patients receiving 5-FU via an infusor, this could mean streamlining to one care delivery system (i.e., not bouncing back-and-forth between the cancer centre and community clinics) or scheduling appointments to occur on the same day to decrease appointment burden. Care coordination appears to be a gap in the care of patients with 5-FU infusors as they manage a myriad of appointments from various providers. Levit et al. (2013) found that patients with cancer often experience poorly coordinated care, which is associated with poorer symptom management, under- and over-utilization of care, increased costs, and medication errors. Conversely, efficient care coordination is essential in helping patients overcome health-system barriers and can positively affect health outcomes (Young et al., 2020).

In addition to reducing and improving the coordination of cancer care appointments, patient-centred care reduces psychological distress and burden on patients by lessening their responsibility for scheduling and coordinating care. Participants reported concerns about the volume of cancer care visits overlapping with other health appointments or interfering with general life (e.g., errands, parenting, recovering/resting). Two strategies to reduce appointments and the burden of scheduling and streamline the number of services involved (e.g., reducing community clinic visits) will be discussed in the following sections: use of the same-day treatment model and patient self-disconnection from the infusor.

Same-Day Treatment Model

The same-day treatment model refers to when patients see their oncologist and undergo their chemotherapy on the same day (Lau et al., 2014). As the number of patients requiring systemic cancer treatment has significantly increased due to an aging population and prolonged survival rates, chemotherapy suites are facing capacity constraints, necessitating more efficient modes of delivery (De Angelis et al., 2014). To combat these challenges, local outpatient cancer centres have been moving to a two-day model in which patients see their oncologist on one day, then return to the cancer centre the next day for their treatment (Trillium Health Partners, 2014). Evaluations of the two-day model indicate that it helps to decrease the amount of medication wasted due to cancelled patient appointments and reduces patient wait times by as much as 90 minutes (Trillium Health Partners, 2014). However, a study by Lau et al. (2014) comparing patient preference (n=198) between same-day and two-day treatment models found that the majority of patients (85%) preferred the same-day model. Difficulty with transportation and convenience were the most common reasons for this preference (Lau et al., 2014). While capacity limits do not allow for a return to the same-day treatment model for all patients, patients with 5-FU infusors could be prioritized and given a choice about which model they prefer, given the excessive care demands associated with their treatment. Moving to a one-day model would help decrease the number of appointments and the time patients spend on their cancer care.

Self-Disconnection from the Infusor

Currently, patients receiving 5-FU through an elastomeric ambulatory infusor must have the bottle disconnected from their CVAD by a nurse at a community clinic (CCO, 2022a). This means patients must book removal appointments based on when the infusor was attached (as the 5-FU should take 51 hours to infuse at most) and arrange transportation to and from the clinic every two weeks. However, other Canadian provinces, such as British Columbia, Alberta, and Manitoba, have created policies, procedures, and resources that allow patients or caregivers to disconnect the infusor at home (BC Cancer, 2018; Cancer Care Manitoba, 2020; Alberta Health Services, 2016). In British Columbia the 'Infusor Home Discontinuation Program' was piloted in 2008, and is now their standard of care (Evans et al., 2016; BC Cancer Agency, 2010). This pilot program ran from April to August 2008, and aimed to determine if expressed concerns were justified related to potential for increased infection or occlusion rates with infusor disconnection at home by the patients themselves or a caregiver (BC Cancer Agency, 2010). Results showed no increase in the incidence of catheter occlusions or infection in devices that were disconnected at home. Patients also reported numerous advantages to self-disconnection at home including increased independence and self-control, as well as decreased travel time, and decreased feelings of being a “burden.” It was concluded that chemotherapy infusors can be safely disconnected at home by the patient or a caregiver provided that the following key elements are in place: (1) a thorough assessment process to determine patient/caregiver capacity to perform the procedure at home; (2) a system to provide supplies as required for infusor disconnection and CVAD flush; (3) a system to order and dispense prescription medication (e.g., heparin) to patient; (4) a scheduled session to teach caregiver or patient to perform the disconnection procedure; and (5) a “backup” system to support caregivers/patients experiencing difficulties with the procedure or device at home (BC Cancer Agency, 2010).

Evans et al. (2016) conducted a three-pronged study consisting of a literature review, an international jurisdictional scan, and two case studies within Ontario. The literature search reviewed research- and practice-based evidence on home-based chemotherapy models, which included self-disconnection from 5-FU pumps. The results from the literature review and jurisdictional scan indicate that home-based chemotherapy care improves patient-centred care by offering patients more choices about how, when, and where they receive their cancer treatments. The review also made several recommendations regarding the importance of care coordination and continuity of care including the improvement of patient appointment scheduling, appointing a nurse coordinator to liaise between different organizations and providers, and standardizing education/training for care providers, patients, and caregivers (Evans et al., 2016).

These findings align with the current study, as coordination of care is key to patient-centredness as discussed in Picker’s model, and self-disconnection may improve the experience of care coordination for patients with 5-FU infusors. Additionally, self-disconnection may promote patient autonomy and self-management. For example, one participant explained that their partner was a nurse for several years and that in one instance where the patient could not access the community clinic during a storm, their partner disconnected the infusor (5FU-04). This participant also said, "I’ve never had to take it off myself, but … I feel confident that I could do it" (5FU-04). Evidently, some patients with 5-FU infusors may feel some readiness to learn about self-disconnection and should be pursued as an evidence-based option or standard of care in Ontario.

Study Limitations

Methodological aspects of this study that may limit the transferability of the study results include the use of only one site for recruitment, a small sample size, and imbalances in the characteristics of the sample related to gender and the number of treatment cycles. These aspects will be discussed in more detail in the following sections.

All participants in this study were recruited from one cancer centre located in an acute care hospital. Because this study was carried out in one site, findings may only be directly applicable to the site where the study was conducted and not to patients receiving 5-FU via an infusor in other cancer centres (Polit & Beck, 2004). Future studies should consider recruiting participants from different cancer centres in the region or province would strengthen the transferability of the findings (Thorne, 2016).

The number of participants needed in qualitative research has been long debated, and the criteria for reaching 'data saturation' is unclear (Bradshaw et al., 2007; Coyne, 1997; Guest et al., 2006; Walker, 2012). It was estimated that seven to fifteen people would be needed for this study, and ten participants were recruited. While the ten participants provided more than sufficient and detailed data to answer the research question, a larger sample may have provided richer information or differing experiences.

Of the ten participants in the study, the majority (n=7) were male. While all participants provided detailed information, the study may have benefitted from a more even distribution of men and women. During the interviews, participants with long-term infusor experience could reflect on their early experiences and recall troubleshooting and adapting strategies they implemented over time. While participants in the study sample had received a wide range of treatment cycles (8-54), the perspective of participants who were earlier in their treatment with fewer treatment cycles (less than eight) may have been valuable. Patients with fewer than five treatment cycles may have different or heightened concerns compared to those who have had more cycles and become accustomed to issues over time.

Study Strengths

This study demonstrated several strengths, including the range of patient experiences with the infusor, the quality of the interviews, and a broad representation of patients with varied ages and with different types of GI cancers.

While the sample size was small (n=10), participants in this study also represented a range of positive and negative experiences with the infusor, improving the transferability of the findings. Positive experiences were associated with feelings of trust and safety with cancer centre nurses due to their specialized oncology knowledge and experience, and the convenience of a community clinic rather than a hospital. Negative experiences involved reports of CVAD complications (e.g., lymph drainage, infection, line occlusions) from PICCs and port-a-caths, an infusor that leaked at home, or dropped infusors. Inconsistent care from nurses in community clinics also contributed to negative experiences for some participants. Overall, the sample was able to represent a variety of experiences despite its small size.

Restrictions to support social distancing and reduce the spread of COVID-19 did not allow for face-to-face interviews during this study. While in-person interviews are the preferred method of data collection for qualitative studies, telephone interviews have some benefits, including decreased parking costs, no increased risk of data loss/distortion, and allowing participants to choose the environment in which they conduct the interview (Novick, 2008).

In this study, participants were able to articulately describe how the infusor impacted every facet of daily life and provided extensive detail and insight into their experiences with 5-FU infusors. Overall, the recruitment and interview processes were efficient, and ideas flowed freely during their interviews. The degree to which participants chose to share how the infusor affected even the most intimate details of their lives was unexpected but helpful for providing detailed insights into their experiences. While face-to-face interviews allow non-verbal cues to be utilized and considered, interviews over the phone may have strengthened interviews, allowing patients to feel freer to be honest and explicit while sharing their experiences.

The sample in this study represented a 40-year age range, with the youngest being below 40 years of age and the oldest being greater than 70 years of age. In 2021, over half (56%) of colorectal cancer diagnoses occurred between the ages of 50-74, and only 8% occurred before the age of 50 (Canadian Cancer Society, 2021). Therefore, the study sample was representative of the colorectal cancer population concerning age. Interviewing patients from different age groups was valuable as the impact of the infusor on roles and responsibilities, and the experience of managing the infusor could be impacted by factors unique to the patient's stage of life. For example, varied participant experiences in managing the infusor with younger children, adult children, and grandchildren were captured in this study.

Implications

French (2005) suggested that all practical disciplines need mechanisms to transfer research results into practice. Thus, for the remainder of this chapter, recommendations and implications for nursing practice, education, policy, and research will be discussed.

Implications for Nursing Practice

Patient-centred nursing interventions contribute to patient well-being and quality of life (Radwin et al., 2009). The participants in this study represented a patient population with advanced stage cancer and an unfair burden of complex care needs. This burden is further compounded by increased self-care demands associated with receiving 5-FU via an infusor. Given their shortened life span due to their diagnosis (i.e., just 12% of patients with stage IV colorectal cancer survive five years from diagnosis), contributing positively to a patient's well-being and HRQL should be of utmost importance for health care leaders and providers in cancer care centres and nursing practice (Canadian Cancer Society, 2022).

Patient-centred education and communication are two of the most efficient ways health care teams can influence the quality of care patients receive (Back, 2020). The results of this study indicated that increasing patients' understanding of CVAD options and prioritizing the preparation for the potential psychosocial impact of the infusor would benefit quality of life and well-being.

Education Regarding CVAD Options

As stated previously, avoiding adverse events and maximizing patient satisfaction and quality of life must be a priority when selecting a CVAD (Taxbro et al., 2019). Educating patients on their CVAD options is vital, especially when differences in quality of life associated with PICCs vs port-a-caths are commonly reported (Corti et al., 2020). A systematic review by Ivziku et al. (2022) found inconsistencies in how adult oncology patients felt about their choice of CVAD and its insertion. Some wished to have some control or choose their device, while others felt this decision was shared openly with their health care providers (Ivziku, 2022). It should be standard practice to provide patients with all necessary CVAD information, including risks and benefits, to empower patients to make an informed choice.

This information can be presented in written form alongside other cancer treatment resources and can be a point of discussion during initial appointments with their oncologist and oncology nursing team. Patient-centred communication and care strategies will be critical to supporting patients in the selection of a CVAD.

Prioritizing Preparedness for Psychosocial Impact

The psychosocial impact of the 5-FU infusor was primarily described as an unanticipated 'side effect' by study participants. To mitigate this, education resources and discussions with the care team about receiving treatment regimens that include 5-FU should include information on this potential psychosocial effect. Of note, a chemotherapy education class for patients newly referred to the cancer centre for treatment is usually offered at the cancer centre but was cancelled during the COVID-19 pandemic to support social distancing. This class could also be attended by peers or family members supporting patients in their cancer care. This loss was noted by participants and negatively impacted patients' feelings of preparedness for living with the infusor. In the future, it is recommended that potential psychosocial impacts and resources be included in this education class.

Patients diagnosed with stage IV GI cancer receiving 5-FU are at risk for high levels of psychosocial distress due to disease and treatment side effects and poor prognosis. This risk may be heightened by disruptions to day-to-day activities caused by the infusor and the increased demands placed on patients to coordinate more appointments and manage the infusor at home. Therefore, nurses need to assess patients' psychological distress levels regularly and initiate discussions about overall well-being. These care discussions should include coping strategies for mental exhaustion, stress, burnout and depression, the importance of trusted relationships with loved ones, and referrals to support resources such as social work or psychosocial oncology as needed. Additionally, all information given to the patient regarding the infusor should be put into context. For example, one participant (5FU-03) described that the written resources emphasized the importance of cytotoxic precautions and how to avoid leaks but did not indicate that this was a rare occurrence. This lack of context led to the patient experiencing unnecessary fear and anxiety about 5-FU leaking from the infusor. It is crucial to provide patients with the information they need to troubleshoot problems and to understand the likelihood of occurrence.

Written educational resources should also be augmented to include practical advice from patients who have experienced treatment with a 46-hour 5-FU infusor. Engaging patients to help develop and review medical education materials through focus groups or one-on-one discussions is associated with feelings of empowerment, improved communication with the health care team, and enhanced quality of care (Jha et al., 2013; Le Var, 2002). Based on the results of the current study, patients could provide advice about clothing choices with an infusor/CVAD, different ways to wear the infusor holder, tips for sleeping with the infusor, and how to function in day-to-day life. These resources could also include patient experiences or advice regarding the infusor's potential psychosocial impact, what to expect, and coping strategies utilized by patients who have received 5-FU via an infusor.

Implications for Health Care Policies Related to the Delivery of Cancer Care

The results of this study have implications for health care policies related to the delivery of cancer care. First, improved education and training for nurses working in community clinics that provide CVAD management and care is needed as patients report inconsistent practices leading to mistrust in nursing care. Next, introducing the option of the same-day treatment model for patients receiving treatment with a 5-FU infusor and the initiation of policies related to self-disconnection from the infusor as is being done in other provinces of Canada has several advantages. Allowing same-day treatment and creating opportunities for self-disconnection will streamline care services, increase patient satisfaction, and decrease psychosocial distress related to care coordination. These two strategies to support health care policies related to the delivery of cancer care will be discussed in the sections below:

Funding for Community Clinic Education Regarding CVAD Management

Study participants often had less consistent care experiences, had less trust and felt less safe with community clinic nurses compared to cancer clinic nurses due to their lack of specialized knowledge and skill in oncology care. Continuity of care and consistency of care providers may improve patient care experiences with nurses in community clinics (Gannan et al., 2019). Additionally, CVADs are not specific to oncology patients, and their access and management should be skills in which community nurses are comfortable and competent. Therefore, health care funding should be allocated to support clinical skill development of community clinic nurses performing CVAD management.

A scoping review by Ganann et al. (2019) found seven domains which influence the optimization of home care nurses in Canada. The first of these seven domains is continuity of care and consistency of care provider. In this domain, it is suggested that continuity improves quality of care, decreases confusion, enables therapeutic relationships, and allows the care provider to develop a deeper knowledge of clients (Gannan et al., 2019). Additionally, both clients and nurses value consistency in the care provider. This means that for patients receiving 5-FU via an elastomeric infusor, their care experiences may be made more consistent, and patients may have an improved therapeutic relationship with their home care providers if health care policies support continuity of care and consistency of care providers in the community setting. Consistent scheduling and assignments, and stable caseloads for home care nurses are two ways to allocate resources and funding to support consistency in the nursing care experience for patients (Gannon et al., 2019).

A study by Nailon et al. (2019) examined patient experiences with CVADs over 14 days. Study results highlighted patients' exposure to inconsistent CVAD care and the need to examine the extent to which care practices are standardized across health care settings. These results were relevant to this study, when participants described specific examples of community clinic nurses not displaying competence in performing a skill or even explicitly stated that they were uncomfortable with specific aspects of CVAD management. Implementing a standardized 'CVAD care bundle' in ambulatory care settings proved successful at decreasing central line-associated blood infection rates by 48% over 24 months in a pediatric oncology population (Rinke et al., 2013). This 'bundle' involved twice-weekly or quarterly audits of central line maintenance techniques related to three areas: (1) aseptic entries (i.e., hand hygiene and alcohol swab use before access), (2) aseptic central line component changes (i.e., appropriate personal protective equipment and aseptic technique when changing caps/dressings/needles), and (3) assessment (i.e., assessing central line issues or line education needs) (Rinke et al., 2013). These findings suggest that implementing a similar bundled intervention along with routine monitoring to assess and promote intervention uptake may help to improve the consistency and quality of care in CVAD maintenance provided by nurses in community clinics. As such, the results of this study imply that health care funding should be allocated to the education and building of skills for community clinic nurses providing CVAD management services.

Same-Day Treatment and Self-Disconnection from the Infusor

The outpatient cancer centre where this study was conducted recently moved to a two-day treatment model to align with other regional cancer centres. However, Lau et al. (2014) discussed that 85% of patients prefer the same-day model. The results of the current study demonstrate that patients with 5-FU infusors feel overwhelmed by the number of appointments they must attend and manage. The two-day treatment model adds to this burden and is not preferred by most patients, as indicated by Lau et al. (2014). Ultimately, this is not patient-centred care, as the two-day model contributes to lower patient satisfaction and well-being. Regional cancer centres, including the clinic where this study was conducted, should consider allowing some patients to choose the same-day treatment model if they are particularly burdened by appointments and the complexity of their treatment regimen – including patients with 5-FU infusors.

Self-disconnection from infusors is currently implemented in several Canadian provinces, meaning Canadian policies are currently in place to guide this practice. A trial home infusor discontinuation program done in British Columbia determined that self-disconnection is safe provided the appropriate safety systems and processes are in place (BC Cancer Agency, 2010). Allowing patients the choice to be trained to safely disconnect themselves from their infusor at home would decrease the number of appointments they must manage, as well as decrease the burden on the health care system and health care costs.

Implications for Future Research

The findings of this study shed light on the profound impact ambulatory 5-FU infusors have psychologically and physically on the day-to-day lives of patients diagnosed with a gastrointestinal cancer. It is essential for future research to focus on developing and evaluating the effectiveness of nursing interventions that aim to reduce psychosocial distress and improve the quality of life for patients receiving 5-FU via an infusor. Additionally, models of cancer care delivery that consider the complexity of patient health care needs and experiences (such as patients diagnosed with an advanced gastrointestinal cancer receiving 5-FU via an infusor) should be evaluated.

The findings related to CVAD preferences and concerns were a surprising result of this study. Participants who had experience with a port-a-cath and a PICC line preferred the former, and overall, there were more concerns reported with PICCs. For example, this study found that the maintenance associated with a PICC compounded the already-heavy burden of appointments from the infusor, while port-a-caths did not. While studies do exist that discuss some experiences with CVADs, the experience of a CVAD for an ambulatory elastomeric 5-FU infusor is unique to the oncology patient and presents its own set of challenges and concerns (Sharp et al., 2014; Rinke et al., 2013; Corti et al., 2020; Taxbro et al., 2019). Therefore, it would be beneficial to research issues and experiences related to medical device use specifically in cancer care.

One of the most valuable ways to improve patient-centred care in oncology would be to include patients in designing and developing the delivery of cancer care services, interventions, and policies. For example, participants in this study explicitly mentioned that it would be beneficial for education regarding the 5-FU infusor not to be limited to the physical/logistical preparation but also to include strategies and 'what to expect' information for the day-to-day life with an infusor. Therefore, utilizing patient input to develop patient-centred resources for others who will receive this type of treatment in the future would be a valuable and honourable use of their experiences and knowledge. In addition, the effectiveness of these patient-led resources could be assessed in future research studies.

Finally, involving patients as the end-users of medical devices (i.e., infusors, CVADs) and hearing their concerns, ideas, and suggestions for improvement may inform ways to improve patient health and quality of life in cancer care. For example, a participant in this study felt they had the ability to disconnect themselves from their infusor if it was necessary, but self-disconnection has not been implemented in Ontario. This insight from the patient and device user provides an opportunity to improve the delivery and experience of cancer care, as well as patient quality of life.

Conclusion

This study sought to understand the experience of having an elastomeric ambulatory 5-FU infusor for patients diagnosed with gastrointestinal cancers. Data analysis revealed three key themes: (1) experiencing the psychosocial impact of having an infusor, (2) keeping up with the intense work of patient self-management, and (3) supporting patients in self-management. The results of this study highlighted how 5-FU infusors negatively impact the quality of life and well-being of patients undergoing this unique delivery of cancer treatment. Additionally, this study added to the paucity of qualitative research about 5-FU infusors in the adult outpatient oncology population, emphasizing the value of qualitative research and how foundational it is to patient-centred care and the improvement of patients' quality of life and well-being.

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APPENDIX A

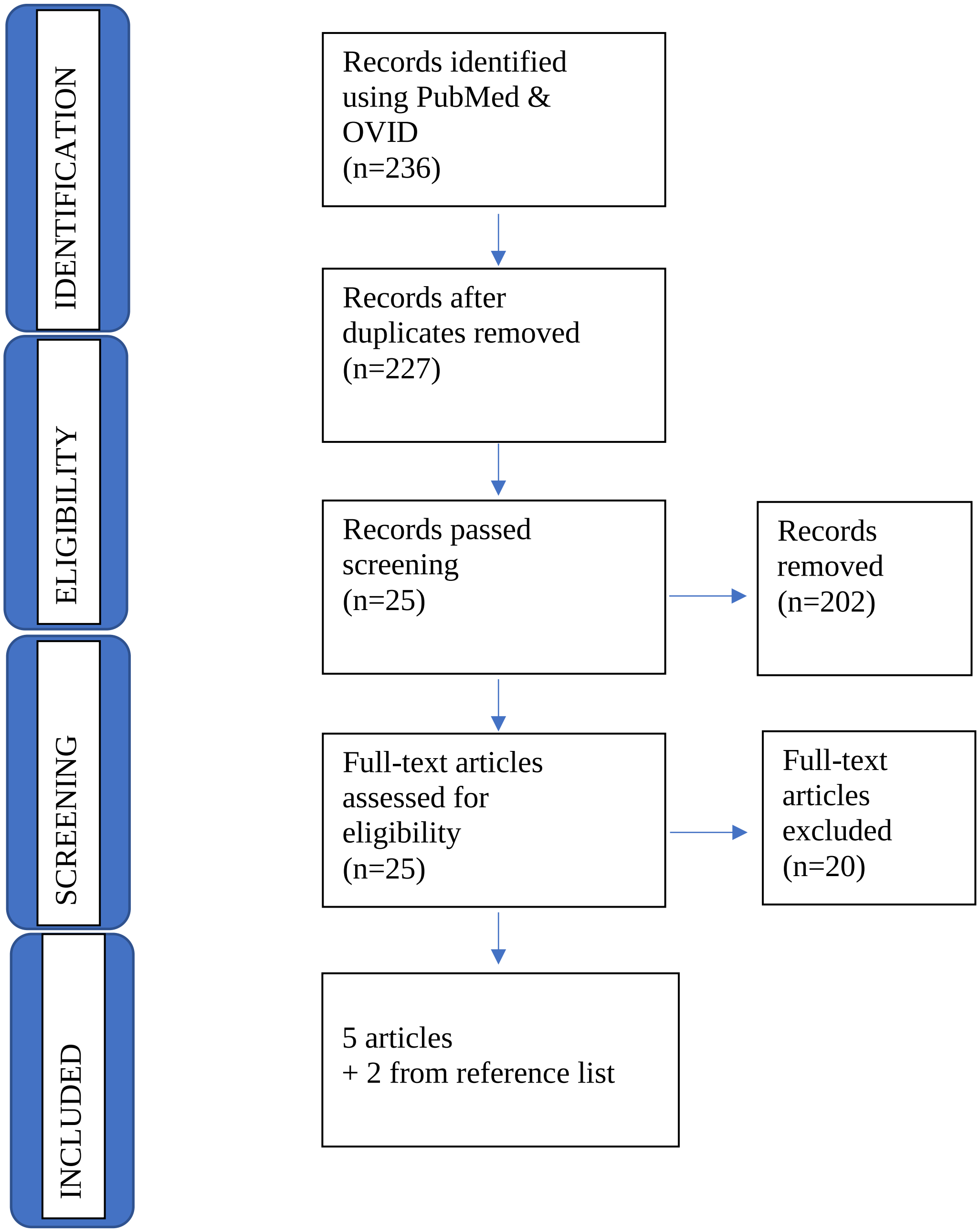
Picker's Eight Dimensions of Patient-Centred Care

The following eight dimensions are the result of the research done by the Picker Institute and Harvard Medical School in their search to determine what matters most to patients in health care. Patient-centered care guided by these dimensions has been known to have a positive impact on patient outcomes including patient satisfaction, well-being, and self-management (Rathert, 2013).

1. Respect for patients' values, preferences, and expressed needs
    - Treat individuals with respect, maintaining their dignity and demonstrating sensitivity to cultural needs.
    - Involve patients in decisions regarding their care, keeping them informed about their condition.
    - Focus on the individual's quality of life.
2. Coordination and integration of care
    - Coordinate and integrate clinical and patient care services to reduce fear and vulnerability.
3. Information and education
    - Provide complete and up-to-date information to patients regarding prognosis clinical status and progress; this supports patient autonomy and self-management.
4. Physical comfort
    - Enhance physical comfort including pain management, supporting activities of daily living, and an inviting hospital environment.
5. Emotional support and alleviation of fear and anxiety
    - Help to alleviate fear and anxiety with respect to health status, impact of illness on self or family, and financial concerns.
6. Involvement of family and friends
    - Acknowledge and respect the role of the patient's family/friends in their health care experience.
7. Continuity and transition
    - Alleviate concerns about self-management by providing information to patients regarding access to available supports, medications, nutrition, transportation, and ongoing treatment/care details.
8. Access to care
    - Mainly with respect to ambulatory care, ensuring access to multiple health care settings/teams and transportation.

APPENDIX B

Search Strategy



APPENDIX C

Summary of Articles Selected for Review

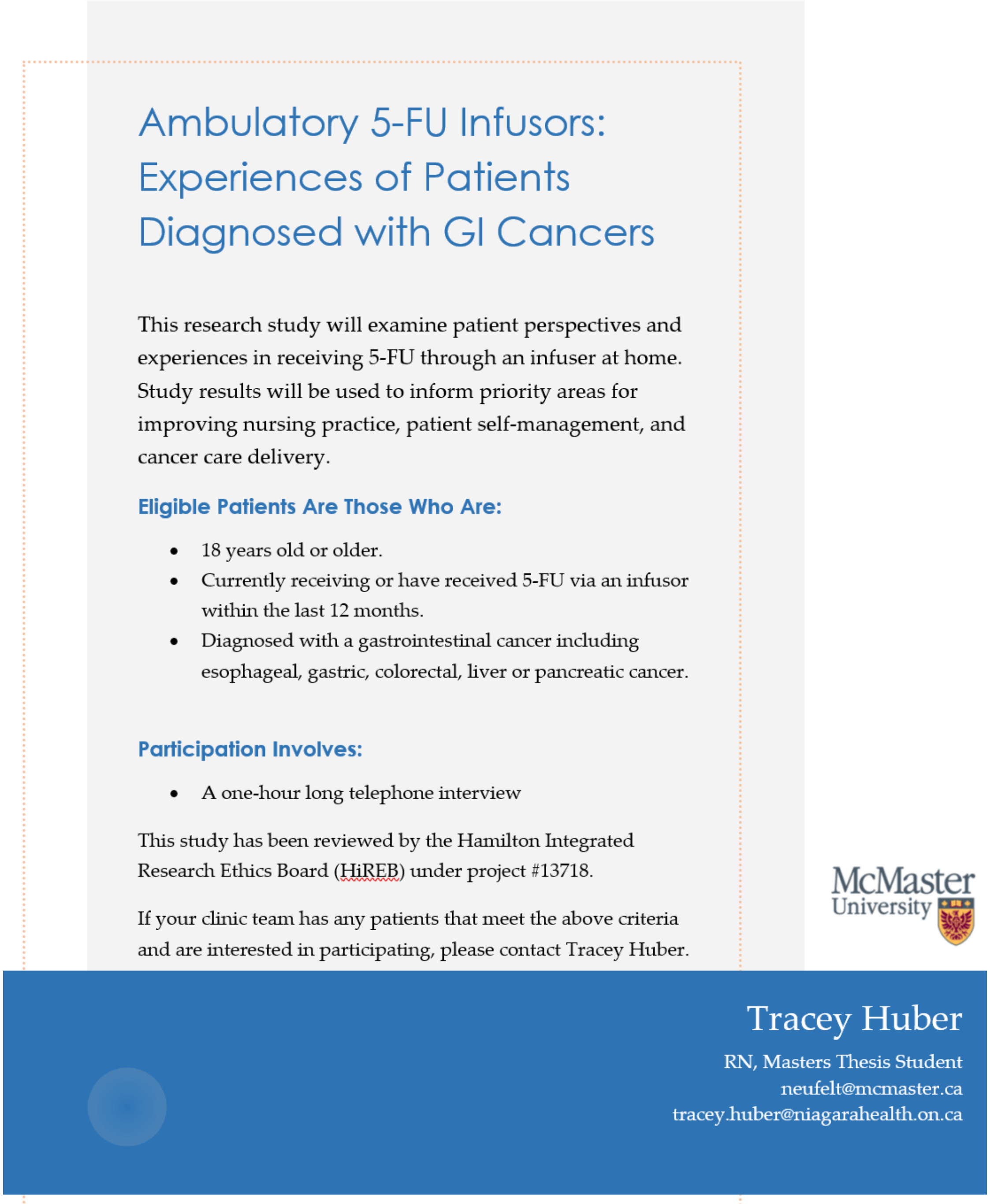
Author/Year/ Country	Aim	Methods	Key Findings	Critique
Al-Kadhimi et al. 2019 United States	To allow patients to report their experiences with ambulatory 5-FU infusors, using results to inform the education of future patients with this treatment.	A cohort of 76 patients who had received two or more treatments with a 5-FU infusor were invited to complete a de-identified questionnaire (11 yes/no questions with an opportunity to add comments) about their experiences.	Most patients felt prepared about what to expect from the infusor (93.1%), but the majority of patients (73.6%) reported that the infusor negatively affected their ability to bathe, and almost 38% reported disturbed sleep. A large number of patients reported negative impacts of the infusor related to exercise (31%), intimacy with their partner (26%), social interactions (25%), and anxiety (25%).	Researchers were unable to ask clarifying questions about participants' experiences or explore participants' thoughts or feelings in any depth. This review was published only as a meeting abstract, so further critique of methods was impossible.
Broadhurst, D. 2012 Canada	To describe and evaluate the transition to an elastomeric infusion device from an electronic infusion device in home-based chemotherapy treatment, providing guidance for nurses on the integration of devices in their practices.	Chemotherapy infusion pump program case managers, pharmacy and medical supply staff, and home health care nurses (n=56) were asked to complete a one-page health care provider satisfaction survey including a 5-point Likert-type scale. The questionnaire also included an open-ended question for comments.	All provider domains were highly satisfied with both types of pumps. However, 80% of the health care providers would recommend the elastomeric pump over the electronic pump.	Does not explore patient preferences or experiences with infusors. Would have benefitted from a larger sample size and a description of how representative the surveyed sample was of the underlying population. A rationale or justification for the chosen sample size would have strengthened this study.
Capdevila, 2003 France	To compare the efficacy of three pumps [Group 1: disposable elastomeric pump; Group 2: Graesby patient-controlled analgesia (PCA) pump; and Group 3: a microject PCA pump] for postoperative analgesia.	This was a prospective, randomized study. Seventy-eight patients who had received ambulatory orthopaedic surgery recorded pain scores (0-100) four times a day over 48-hours, and overall satisfaction scores (0-10) regarding analgesia and ease of pump use were recorded at the end of the 48-hour period.	Median pain scores were low (6-13 min. and 21-25 max.) and did not differ significantly between groups. Median satisfaction scores were 9, 8 and 6 in groups 1, 2 and 3 respectively (i.e., highest in the disposable elastomeric pump group).	A randomized trial is the gold standard for quantitative research methods. Participants could not be blinded due to the nature of the study (i.e., utilization of a type of pain-control device).

Author/Year/ Country	Aim	Methods	Key Findings	Critique
Ivziku et al. 2022 Italy	This systematic review aimed to systematically synthesize the evidence of the qualitative studies on the experience of adult oncology patients with CVADs to report the implications of living with this device, and to inform healthcare professionals (HCPs) about problematic aspects of care for this population.	A comprehensive literature review was conducted. Nine studies fulfilled the inclusion criteria. The evidence was synthesized using the meta-aggregation approach proposed by the Joanna Briggs Institute. Two reviewers carried out the evaluation independently.	Nine studies, published between 2008 and 2019, fulfilled the review criteria; three studies originated in the UK and the remaining six in Italy, Spain, Denmark, Sweden, Australia, and Brazil. Four themes emerged: (1) During CVAD insertion oncology patients experience reluctance, apprehension, and acceptance; (2) The nature of the information, knowledge transmission and HCP competence influence patient confidence; (3) A catheter impacts daily life, self-perception, and social behavior; and (4) The catheter is a symbol of disease, a friend that prevents problems, and its removal is perceived as physical and psychological liberation.	Systematic reviews are considered the gold standard of evidence for clinical decision making, however some qualitative studies published in languages other than English or Italian may have been missed. Results may be limited to patients living in Western countries where all the included studies were from.
Salman et al. 2017 United Kingdom	The aim of this research was to observe the performance elastomeric pumps in clinical practice, evaluating infusion volumes and care delivery practices over six months for patients receiving home chemotherapy via elastomeric pumps over 48-hours at three GI medical day units.	Phase one: an observational cross-sectional study was conducted to assess the pump status and the volume remaining at the scheduled time for disconnection. If pumps were not finished, the action taken by the district nurse was documented to evaluate consistency of practices with hospital policy. Additional time the patient waited for the infusor to empty was also recorded. Phase two: A survey of 35 hospital and district nurses to understand level of knowledge with elastomeric pumps. The survey included photos of pumps and asked the nurses to identify which pumps they would consider empty.	Phase one: The results showed that 46 of the 92 (50%) pumps did not finish on time. If nurses or patients could not wait for the infusor to finish, the bottle would be disconnected early, leading to sub-therapeutic dosing. The results also revealed that there was no formal policy to guide nurses when infusions were not completed over the anticipated period. Phase two: Results showed that 50% of the nurses had no formal training about the elastomeric pumps, and a significant number of nurses considered pumps with more than 20 mL remaining as empty (i.e., 8.3% of the full volume), leading to subtherapeutic dosing and potential impact on treatment outcomes.	While this study did highlight the issue of unfinished infusors being discarded, remaining volumes were visually estimated using photos for reference. This method lacks precision and using a scale to identify remaining volume would make the results more accurate and reliable. Additionally, the sample size for this study was not justified.

Author/Year/ Country	Aim	Methods	Key Findings	Critique
Sharp et al. 2014 Australia	To investigate the patient experience of Peripherally Inserted Central Catheter (PICC) insertion, the significance of arm choice and the impact of the device on activities of daily living.	This was a qualitative descriptive study, which utilized a purposeful sampling approach to select participants based on diagnosis and previous difficulty with peripheral intravenous access. Patients booked to have a PICC line inserted in the radiology department of a public, metropolitan 680-bed hospital were invited to participate. Seventeen people were recruited, and ten participated in the study. Semi-structured telephone interviews were conducted eight weeks post-PICC insertion.	Four themes emerged from the data: (1) apprehension/ adaptation/acceptance; (2) impact of treatment; (3) asking questions (trusting doctors); and (4) freedom. Additionally, results indicated that whether the patient's dominant or non-dominant arm was used for insertion did not have a significant impact on participants' activities of daily living. However, the results of this study did suggest that disposable ambulatory pumps connected to PICC lines may significantly impact day-to-day activities and HRQL. Participants noted that the infusion pump and line connected to it from the CVAD affected their life more than the PICC.	This study included a small sample of ten participants and may have benefitted from an increased number of participants. Participants were also recruited from a single site. This may reduce the transferability of the study, as the results can only reflect the practices and experiences associated with that service.
Zahnd et al. 1999 Switzerland	To assess patient preference between two differing pump types (elastomeric versus electronic) frequently used in clinical practice.	A randomized crossover study examined ten patients with varying cancers receiving continuous 5-Fluorouracil. They were randomly assigned to start treatment with an elastomeric infusor or a mechanical, electronically controlled pump and crossed over to the alternative model after three weeks. After exposure to both pumps, patients were asked to indicate their preferred device with a questionnaire.	The study was closed after ten participants due to statistically highly significant preference for the elastomeric infusor. The reasons for this preference were lower pump weight in 100%, smaller pump size in 89%, less interference with daily activities in 89%, user friendliness in 56%, less impact on sleep in 44%, and lack of technical problems in 22% of the study participants.	Randomization of study participants was a strength in this study. The published study article did not include the detailed statistics or comparisons between the two groups. Additionally, exact questions in the questionnaire were not shared in the study findings or discussion.

APPENDIX D

Research Poster for Cancer Care Providers



Ambulatory 5-FU Infusors: Experiences of Patients Diagnosed with GI Cancers

This research study will examine patient perspectives and experiences in receiving 5-FU through an infuser at home. Study results will be used to inform priority areas for improving nursing practice, patient self-management, and cancer care delivery.

Eligible Patients Are Those Who Are:

- 18 years old or older.
- Currently receiving or have received 5-FU via an infusor within the last 12 months.
- Diagnosed with a gastrointestinal cancer including esophageal, gastric, colorectal, liver or pancreatic cancer.

Participation Involves:

- A one-hour long telephone interview

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) under project #13718.

If your clinic team has any patients that meet the above criteria and are interested in participating, please contact Tracey Huber.

McMaster University

Tracey Huber

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neufelt@mcmaster.ca
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APPENDIX E

Study Information Letter

Title of Study: Ambulatory 5-Fluorouracil Infusors: Experiences of Patients Diagnosed with Gastrointestinal Cancer

Student Lead:
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WHY IS THIS RESEARCH BEING DONE?

For the purposes of my Master of Nursing Thesis at McMaster University, I am conducting a research study to learn about the experience of receiving the anti-cancer drug 5-Fluorouracil (5-FU). This medication is given through an infusor at home for patients diagnosed with cancer of the gastrointestinal tract (i.e., esophageal, stomach, liver, pancreatic or colorectal cancer). I hope to explore patient thoughts and feelings about their cancer care experiences and managing this infusor at home. I also hope to learn about its impact on activities of daily living (bathing, exercise, social interactions etc.) and quality of life. This research will require approximately 7-15 participants.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you choose to participate in the study, you will be asked to take part in an interview that will take place by telephone at a time that is convenient for you. The interview will last approximately one-hour, and you will be asked questions about your experience with a 5-FU infusor. This will include questions about its attachment, managing it at home, impact on daily life, and care coordination. I will also ask for some personal information like your gender, level of education, marital status and household income. With your permission, the interview will be audio-recorded and then transcribed into a written document. Also, I will briefly review your medical chart to obtain accurate details about your cancer diagnosis and treatment history.

WHAT ARE THE POSSIBLE HARMS, RISKS OR DISCOMFORTS?

The risks involved in participating in this study are minimal. You may feel anxious about answering questions or relaying information about past experiences. You do not need to answer any questions that you do not want to answer or that make you feel uncomfortable. You can stop and take a break at any time, or you may choose to withdraw from this study at any point in the research process.

WHAT ARE THE POSSIBLE BENEFITS?

This research is unlikely to benefit you directly. I hope to learn more from patients about what it is like to have a 5-FU infusor at home. This information will be used to improve nursing care, cancer services, and the resources and supports provided to future patients receiving this type of treatment. The information/results from this study may be published and/or presented at a professional conference.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Should you choose to participate in this study, your name or any identifying information will not be revealed to anyone except myself or as required to members of the research team. All interviews will be recorded and transcribed with your permission, and the information shared during the study will be kept on a secure cloud storage system privately hosted by McMaster University. Once the study is completed, an archive of the data, without identifying information, will be kept for 10 years before being permanently deleted.

CAN PARTICIPATION IN THE STUDY END EARLY?

Your participation in this study is completely voluntary and you may choose to withdraw at any time, even after signing the consent form or part-way through the study process. You can choose not to answer any question during the interview process and still remain in the study. Should you choose to withdraw from this study part-way through the study process, any data collected up to that point will be used for analysis unless you request otherwise. Your decision whether or not to participate in this study will not impact your continuing access to services at the[facility name]. Enrollment in other studies while participating in this research is permitted. By participating in this study, you are not giving up any rights to which you may be entitled under the law.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions or concerns about the study, please contact either of the following:

Tracey Huber
Email: neufelt@mcmaster.ca
Phone: 289-969-1774

Denise Bryant-Lukosius
Email: bryantl@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions abut your rights as a research participant, please call the Office of the Chair, HiREB, at 905-521-2100 x42013.

APPENDIX F

Initial Call Script and Informed Consent

Introduction:
Hello, my name is Tracey Huber, and I am a Registered Nurse with experience in cancer care. I am also a Masters Thesis nursing student of McMaster University. I am contacting you because you are a patient at the [facility name]and you gave permission to be contacted regarding a research study I am conducting.
I would like to discuss the study with you in a bit more detail so you can decide if you want to participate; do you have 15 minutes to talk to me now?

If YES ⇨ proceed to Section A
If NO ⇨ schedule a time with the participant to call back

Section A:
Before we review the details of the study, I just want to confirm that you are eligible to participate:

For each question:
If YES ⇨ proceed to next question/section
If NO ⇨ "Unfortunately you are not eligible to participate. Thank you for your interest in this study and have a great day."

1. Are you 18 years of age or older?
2. Have you been diagnosed with a cancer of the gastrointestinal tract? (i.e., esophageal, gastric (stomach), liver, pancreatic, or colorectal cancer)
3. Are you currently receiving, or have you received treatment that requires the delivery of 5-FU through an infusor in the last twelve months?

Section B:
You meet all the eligibility criteria for this study. Your [nurse/doctor] provided you with a letter of information about the study which we will review in more detail now. Please feel free to ask questions at any time.

Section C: Purpose of Study
For the purposes of my Master of Nursing Thesis at McMaster University, I am conducting a research study to learn about the experience of having an ambulatory 5-Fluorouracil (5-FU) infusor at home for patients diagnosed with cancer involving the gastrointestinal tract. This includes esophageal, stomach, liver, pancreatic or colorectal cancer. I hope to explore patient opinions, thoughts, and feelings about their cancer care experiences and managing this infusor at home. I also hope to learn about its

impact on activities of daily living such as bathing, exercise, social interactions etc., and quality of life.

Section D: Procedures Involved in the Research

If you choose to participate in the research study, you will be asked to take part in an interview that will take place by telephone at a time that is convenient for you. The interview will last approximately one-hour, and you will be asked questions about your experience with a 5-FU infusor. This will include questions about its attachment, managing it at home, impact on daily life, and care coordination. I will also ask for some personal information like your marital status, education level, and annual household income. With your permission, the interview will be audio-recorded and then transcribed to provide a written document of our conversation. Also, I will briefly review your medical chart to obtain accurate details about your cancer diagnosis and treatment history.

Section E: Risks & Benefits

The risks involved in participating in this study are minimal. You may feel anxious about answering questions or relaying information about past experiences. You do not need to answer any questions that you do not want to answer or that make you feel uncomfortable. You can stop and take a break at any time, or you may choose to withdraw from this study at any point in the research process.

This research is unlikely to benefit you directly. I hope to learn more from patients about what it is like to have a 5-FU infusor at home. This information will be used to improve nursing care, cancer services, and the resources and supports provided to future patients receiving this type of treatment.

Section F: Confidentiality

Should you choose to participate in this study, your name or any identifying information will not be revealed to anyone except myself or as required to members of the research team. All interviews will be recorded and transcribed with your permission, and the information shared during this research study will be kept on a password protected computer.

Section G: Participation and Withdrawal

Your participation in this study is completely voluntary and you may choose to stop participating at any time, even after signing the consent form or part-way through the study process. You can choose not to answer any question during the interview. Should you choose to withdraw from this study part-way through, any data collected up to that point will be used for analysis unless you ask us not to. The care you receive at the [facility name] will not be impacted whether you participate in this study or not.

Section H: Follow Up

Do you have any questions about the why I am doing this study or what your participation would involve?

If YES ⇨ address questions
If NO ⇨ Proceed to Section I

Section I

Now that you know more about the research study, are you still interested in participating?

If YES ⇨ Proceed to Section J
If NO ⇨ Thank you so much for taking the time to speak with me today. Have a great day.

Section J

Thank you for volunteering to be a part of my study. I will now ask for your verbal consent to participate by having you repeat the following statements after me:
I understand the information provided about this study and have had the opportunity to ask any questions about my involvement. I agree to participate in this study.

Document verbal consent and proceed to Section K

Section K

I would like to set up a time to complete the research interview that is convenient for you. Remember that this interview will take approximately one hour. Is there a particular day or time in the next few weeks that works for you?

Proceed to schedule interview date/time and confirm phone number to contact for the interview.

Thank you for taking the time to speak with me today – I look forward to speaking with you again soon. In the meantime, if you have any questions or concerns, please contact me. You can find my contact information by referring to the study information sheet.

APPENDIX G

Interview Guide

Good morning/afternoon/evening _______________. Thank you for choosing to participate in this study. I really appreciate your willingness to share your thoughts and experiences with me today. My name is Tracey Huber. I am a registered nurse with experience in cancer care and a graduate student leading this research at McMaster University. While I am a registered nurse, my role will be strictly as a student researcher during this conversation with you today.

The purpose of this research is to understand what it is like from a patient perspective, to receive chemotherapy at home for gastrointestinal cancer, using an infusor bottle. I hope to use the results of this study to identify the strengths and weaknesses of how care is provided to better support patients receiving cancer treatment using an infusor bottle. Study results will also be used to create new education materials and other resources to improve how patients manage the experience having a chemotherapy infusor at home.

With your permission, we would like to record this interview so that I can have a transcribed or written document of our conversation. This document will remain confidential. Your participation in this study will remain confidential should any portion of the results be used for presentation or publication. None of your personal information will be shared, and all of the results will be shared in a grouped format so that no individual data can be linked back to you during the reporting of study data. Quotes from this interview may be used, but your identity will remain confidential.

Additionally, I want you to know that you can feel free to stop this interview at any time and for any reason. There will be no negative consequences to you should you choose not to answer any question or choose not to continue with the interview. You may also request a break at any time.

I will begin this interview by asking you some basic demographic questions. Then I will ask you some questions regarding your experiences with a chemotherapy infusor.

Do you have any questions before we start?
Do you consent to this interview being recorded for transcription purposes? I am going to begin recording now.

With what gender do you most identify?

- Male
- Female

  - Other

What is the highest level of education you have completed?

- Elementary School
- High School
- College Diploma
- Bachelor’s Degree
- Master’s Degree
- PhD

What is your current employment status?

- Employed
  - Part-time
  - Full-time
  - Leave of Absence
- Unemployed
- Retired

What is your marital status?

- Single
- Common Law
- Married
- Divorced
- Widowed

What is your approximate annual household income?

- Less than $30,000/year
- $30,000-$60,000/year
- $60,000-$90,000/year
- More than $90,000/year

Now I will ask you some questions about your experience with a chemotherapy infusor:

1. Tell me about when you first learned about the infusor.
   - **a.** How did you feel when you found out that this would be a part of your treatment plan? What were some of your concerns?
   - **b.** How involved were you in the decision-making regarding treatment?
   - **c.** What are your thoughts about this form of treatment now?

2. Tell me about the first time you received treatment using an ambulatory infusor bottle.
    - **a.** What happened?
    - **b.** How did you feel?
    - **c.** Does anything stand out about this experience?

3. What information was given to you about how to manage the 5-FU infusor at home?
    - **a.** How prepared did you feel to manage your 5-FU infusor?
    - **b.** What resources were you aware of that you could use for support in managing your infusor if you needed it?
    - **c.** How helpful were these resources? How did you use them or why didn't you use them?

4. Describe a typical day with the infusor.
    - **a.** What has it been like to have an infusor for two days?
    - **b.** How has this process worked for you?
    - **c.** In what ways, if any, has having an infusor impacted your daily activities (e.g., driving, bathing, exercise etc.)?
    - **d.** How has it impacted your relationships and interactions with your partner, family and friends?
    - **e.** How has it impacted your ability to work or perform other activities (i.e., gardening, chores etc.)?

5. Tell me about your first experience with having the bottle removed.
    - **a.** How involved were you in coordinating your first visit for bottle removal?
    - **b.** What happened?
    - **c.** How did you feel?

6. How have your family or friends been involved with your care related to treatment using the infusor?
    - **a.** How are they involved? (E.g., roles, responsibilities, types of support)
    - **b.** How has having an infusor affected your family or friends?

7. What was your most challenging experience with the infusor?
    - **a.** What made it challenging?
    - **b.** If you haven't had any challenges with the infusor, what do you think contributed to this?

8. What positive experiences have you had with the infusor?
    - **a.** How/why was this a positive experience?

    b. What factors contributed to your positive experiences?

9. What negative experiences have you had with the infusor?
    a. How/why was this a negative experience?
    b. What factors contributed to your negative experiences?

10. What surprised you about having a 5-FU infusor?
    a. How/why was it surprising?

11. How have nurses in the community and the cancer centre been involved in your care related to the infusor?
    a. What positive/negative experiences did you have with the care that was provided to you?
    b. What part of the care provided to you was the most helpful for managing the infusor at home?
    c. How could nursing care related to the infusor be improved?
    d. How was care coordinated between the community clinic and cancer centre?

12. What advice would you give to a patient who is about to undergo their first treatment using an infusor?

13. Is there anything else that you would like to share about your experience with 5-FU infusors, that we haven't already discussed?
    a. Is there anything specific you would like me to understand or highlight?

Do you have any questions for me?
Would you like me to share results with you at the completion of this study?
If YES ⇨ get email address and enter in tracking document
If NO ⇨ Proceed

Thank you for your participation in this interview!

APPENDIX H

Interview Questions in Relation to Picker's Model

Interview Questions	Related Picker Concepts
Tell me about when you first learned about the infusor.	Respect Information & Education Emotional Support
Tell me about the first time you received treatment with the ambulatory infusor bottle.	Coordination of Care Information & Education Physical Comfort Access to Care
What information was given to you regarding management of the 5-FU infusor at home?	Information & Education Emotional Support Continuity/Transition Access to Care
Describe a typical day with the infusor.	Respect Physical Comfort Emotional Support Family/Friends
Tell me about your first experience with having the bottle removed.	Coordination of Care Continuity/Transition Access to Care
How have your family or friends been involved with your care related to treatment using the infusor?	Respect Emotional Support Family/Friends
What was your most challenging experience with the infusor?	Respect Coordination of Care Physical Comfort Emotional Support Family/Friends
What positive/negative experiences did you have with the infusor?	Respect Coordination of Care Physical Comfort Emotional Support Family/Friends
What surprised you about having a 5-FU infusor?	Respect Coordination of Care Information & Education Emotional Support Family/Friends

How have nurses in the community and the cancer centre been involved in your care related to the infusor?	Coordination of Care Continuity/Transition
What advice would you give to a patient who is about to undergo their first treatment using an infusor?	ALL
Is there anything else that you would like to share about your experience with 5-FU infusors, that we haven't already discussed?	ALL

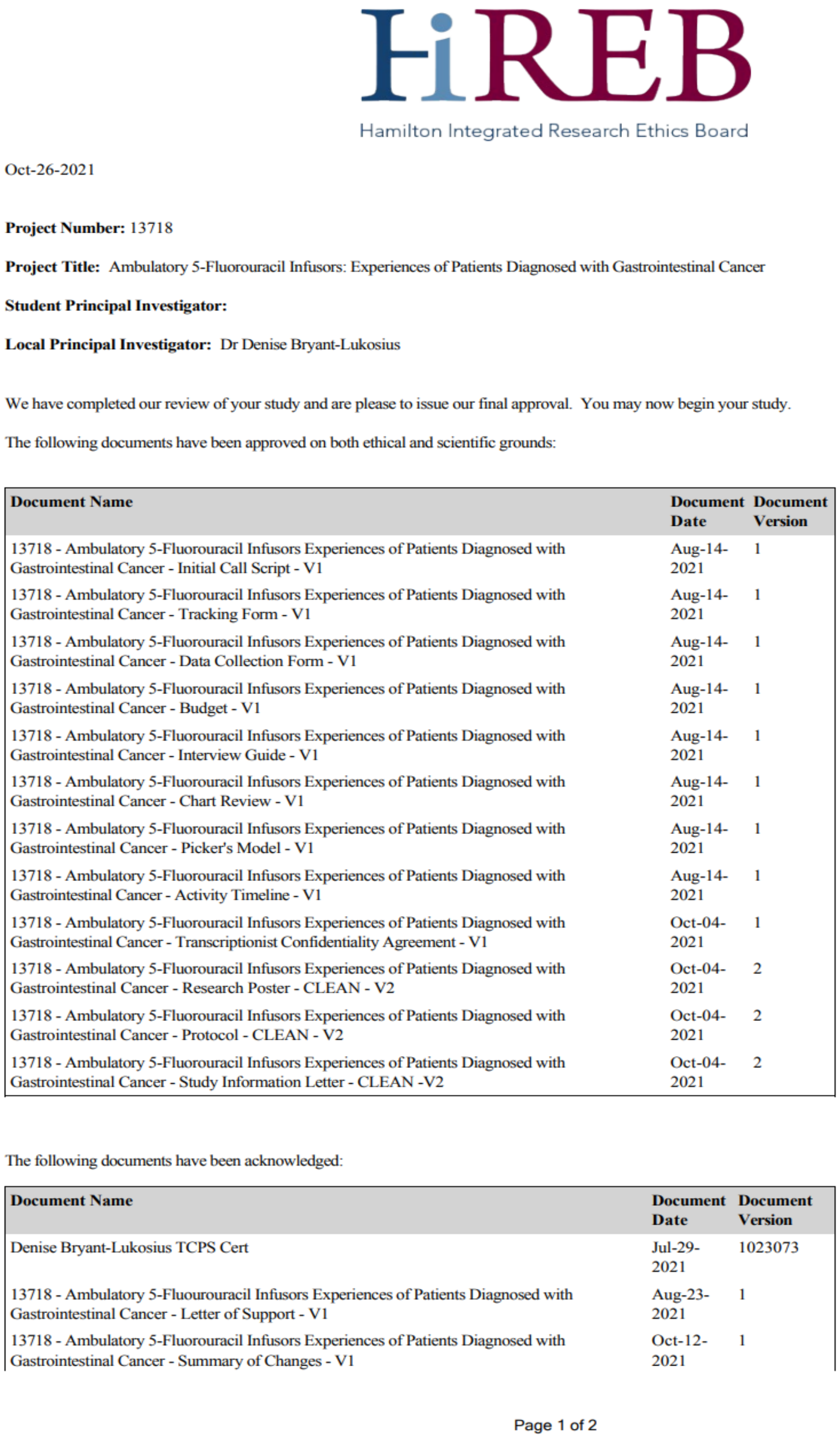
APPENDIX I

Chart Review

1. Cancer type
    - Esophageal
    - Liver
    - Pancreatic
    - Colorectal
    - Gastric
    - Other (specify): ______________________________
2. Cancer stage
    - Stage I
    - Stage II
    - Stage III
    - Stage IV
3. Date of diagnosis (first consult):
4. Date of last 5-FU treatment:
   On active treatment at time of interview? Y/N
5. Number of treatment cycles:
6. Age:

APPENDIX J

HiREB Approval Letter



HiREB
Hamilton Integrated Research Ethics Board

Oct-26-2021

Project Number: 13718

Project Title: Ambulatory 5-Fluorouracil Infusors: Experiences of Patients Diagnosed with Gastrointestinal Cancer

Student Principal Investigator:

Local Principal Investigator: Dr Denise Bryant-Lukosius

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

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

Document Name	**Document Date**	**Document Version**
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Initial Call Script - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Tracking Form - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Data Collection Form - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Budget - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Interview Guide - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Chart Review - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Picker's Model - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Activity Timeline - V1	Aug-14-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Transcriptionist Confidentiality Agreement - V1	Oct-04-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Research Poster - CLEAN - V2	Oct-04-2021	2
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Protocol - CLEAN - V2	Oct-04-2021	2
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Study Information Letter - CLEAN -V2	Oct-04-2021	2

The following documents have been acknowledged:

Document Name	**Document Date**	**Document Version**
Denise Bryant-Lukosius TCPS Cert	Jul-29-2021	1023073
13718 - Ambulatory 5-Fluourouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Letter of Support - V1	Aug-23-2021	1
13718 - Ambulatory 5-Fluorouracil Infusors Experiences of Patients Diagnosed with Gastrointestinal Cancer - Summary of Changes - V1	Oct-12-2021	1

Page 1 of 2

In light of the current COVID-19 pandemic, while HiREB has reviewed and approved this application, the research must be conducted in accordance with institutional and/or public health requirements.

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,

Kristina Trim, 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, the Faculty of Health Sciences at McMaster University, and Niagara Health and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practice Guideline (ICH GCP); Part C Division 5 of the Food and Drug Regulations of Health Canada, Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada.