

Valuing Illness

“Physicians and nurses, medical ethicists and philosophers, economists and political scientists express opinions about what care society owes or does not owe ill persons. As an aging population combines with advancing medical technology, more people will need treatment, and more treatment will be available. The question is who will get what and who will pay. But in all that has been written, the ill themselves have had little to say, or no one else has listened. From the perspective of an ill person, the root issue is suffering. Is society willing to recognize the suffering of the ill as a common condition of humanity, and can we find value in illness? I believe that when society learns to value the ill, the other questions of rights- the complicated questions of payments and technologies and treatments- will fall into place with remarkable ease.”
(Frank, 2002, p. 115)

University of Alberta

Chemotherapy at Home: Keeping Patients in Their 'Natural Habitat'

by

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Abstract

Escalating cancer rates and an increase in the complexity and duration of chemotherapy regimens have brought the issue of cancer treatment at home to the forefront. For the participants of this study, home chemotherapy was offered as a potential treatment choice. Ten patients who accepted were interviewed using the methodology of Interpretive Description. They shared their experiences of receiving chemotherapy at home, and identified home as being a 'natural habitat' in which they were better able to adapt to their circumstances. Patients were able to redistribute their resources including time, energy, and finances in ways that were meaningful to them. They felt the care provided was enhanced and they were more receptive to teaching. Lastly, participants viewed themselves as being less ill and were better able to cope with their treatments. Given the results of this study and other research available, chemotherapy at home should be considered an option for patients with cancer.

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Chapter One

Introduction

Background

Recent reports have shown a major shift in medical care, and have identified home care as the fastest growing service delivery model in industrialized nations (Boothroyd & Lehoux, 2004). In the 1800s and early 1900's, home care was offered only to those who could afford it. Most home care nurses focused on health education, disease prevention, and pregnancy. By the 1940's, hospital care improved and patients began to look at medical facilities as the preferred sites for receiving medical care. Society is now seeing a shift back to home care; home care involving increased technology, in particular. Advances in cancer treatment and knowledge of toxicities, improvements in supportive medications, and technological changes have now made it possible for chemotherapy to be given in the home.

The Canadian Cancer Society (2008) reported that an estimated 166,400 new cases of cancer and 73,800 deaths from cancer will occur in Canada this year. On the basis of current incidence rates, almost 40% of Canadian women and almost 45% of Canadian men will develop cancer during their lifetimes. The increased number of new cases of cancer, exclusive of non-melanoma skin cancers, is primarily due to a growing and aging population. It can be expected that the number of aging individuals will result in a yearly increase in the demand for cancer care. Cancer incidence is also rising in women aged 20-39 (Canadian Cancer Society).

In addition to increasing cancer rates, there are several other factors that have resulted in strain on chemotherapy services. The development of biological therapies, plus the consideration that these therapies are in addition to (rather than replacing) standard treatment, means that patients are required to increase the frequency and duration of their treatments. The focus on health promotion in the Canadian health care system has resulted in earlier diagnosis for many types of cancer. The demand for cancer services will be temporarily amplified as we try to handle the increased number of cases uncovered through early screening methods. Finally, an increase in the complexity of treatment regimes, such as the addition of several chemotherapeutic agents in the treatment of a single cancer type, has resulted in longer treatment times.

Escalating cancer rates, changes to treatment, and earlier diagnosis raise a number of significant concerns and implications for health care professionals and patients. Home chemotherapy is currently being proposed as one possible solution to this crisis. The provision of chemotherapy at home or at work to patients may potentially free up hospital space, and allow young people to continue work and manage their families. On the other hand, there is worry that the costs of care may be shifted from the health care system to family and friends who may not be able to afford it. (King, Hall, Caleo, Gurney, & Harnett, 2000). Research is needed to determine the extent to which home chemotherapy resolves the problems currently experienced by the health care system without placing undue pressure on patients and families.

Studies of home chemotherapy programs have focussed on cost effectiveness, safety, patient compliance – all important issues, but with a focus on the concerns of the health care system and health care professionals (Appelin & Bertero, 2004; Bakker, DesRochers,

McChesney, Fitch & Bennett, 2001; Borrás et al., 2001). There has also been some research on patient perceptions and concerns. This research has focussed on quality of life, satisfaction and preferences. However, with the exception of one adult UK study and a Canadian pediatric study (Hall & Lloyd, 2008; Stevens et al., 2006), all of the research has been quantitative and with a narrow focus. Little research has been conducted that has explored patients' own views about the strengths and potential problems of home based chemotherapy. In addition to this, the current research on home chemotherapy has been obtained only from patients who have participated in home chemotherapy services. In order to truly understand patient perspectives of home chemotherapy, we must also understand the views of patients who choose not to accept treatment at home.

In order to provide patients with the information to make an informed choice about home chemotherapy, we need to know more than statistics. What we need to know is patients' perceptions of home chemotherapy. Examining the perspectives of patients receiving home chemotherapy and the perspectives of those who decline home chemotherapy allows us to gain a greater understanding of how patients feel about receiving treatment in the home. Qualitative research would allow us to obtain a full range of perceptions and can help us identify potential areas for acceptability and enhancement of this form of care. There is a great deal of controversy surrounding the topic of home chemotherapy, and many health care professionals are questioning the potential for success of such a program. Qualitative research on home chemotherapy may also help health care professionals to understand the experience of receiving treatment at home, troubleshoot potential issues, and over time, determine which patients are more likely to benefit from treatment at home. It can also help us identify why it may not be suitable for all patients,

and whether policy makers should protect individual choice, or consider mandatory shifting of some chemotherapy regimes into the home. Currently, by offering chemotherapy in the home, we are providing patients with choice in a situation where they are often left feeling vulnerable and powerless. As a society, we require qualitative research to ascertain if the potential benefits outweigh any potential harm, and what we are prepared to accept in return for this choice. Home chemotherapy may not be appropriate in all circumstances, but it does allow greater independence for those who meet the eligibility criteria.

The question for the proposed research was: “What are the perspectives of adult patients receiving active treatment for cancer regarding home chemotherapy?”

Aims and Objectives

The ultimate aim of the study was to identify areas for improving quality of care for patients receiving home chemotherapy.

Specific aims:

- To explore and describe the perspectives of cancer patients receiving active treatment who chose to receive or refuse home chemotherapy

Objectives:

- To identify perceived strengths in the administration of chemotherapy at home
- To identify perceived areas for concern in the administration of chemotherapy at home

- To generate hypotheses for future quantitative and qualitative research

Definition of Home Chemotherapy

Home chemotherapy refers to any modality of administration of chemotherapeutic agents for cancer cure or control at home. This includes intravenous, subcutaneous, intramuscular, or oral preparations. Examples may include short term infusions, injections, and multi-day continuous infusions started and continued by a nurse in the home (Boothroyd & Lehoux, 2004).

Chapter Two

Literature Review

Using the concept of home chemotherapy as described above, a comprehensive literature review was conducted to identify research that has been undertaken thus far. As previously mentioned, some aspects of home chemotherapy have already been examined. “The emphasis has not been on clinical efficacy or effectiveness, but rather on associated costs, safety, patient preferences, and effects on psychosocial factors.” (Boothroyd & Lehoux, 2004, p.12) The following research areas were reviewed and delineated to outline existing knowledge in home chemotherapy. Gaps are identified, and the place for the proposed research has been described in the context of what is already known about patient perspectives of home-based chemotherapy for cancer.

Quality of Life

Improved quality of life is often cited as a key reason for development of home chemotherapy programs. Patients’ ability to remain at home and in familiar surroundings while undergoing treatment, reduction in travel and wait times, and the presence of family and pets are all thought to be reasons why quality of life might increase with home chemotherapy programs. A fundamental issue, however, is the nature of the relationship between quality of care associated with a program or service delivery method, and quality of life (Hanchett, 2001). Some researchers argue that an improvement in health might not necessarily lead to an overall improvement in quality of life if there are deficits in other categories. Indeed, health is only one of several domains of quality of life. However, a service delivery method such as home

chemotherapy could potentially have an impact on many other components of quality of life, including social and economic considerations, psychological/spiritual well being, and relationships.

Bearing these arguments in mind, the research results on quality of life with home chemotherapy programs are equivocal. According to King, Hall, Caleo, Gurney, and Harnett (2000), treatment location did not have an impact on quality of life and quality of life did not change over time. No differences in quality of life were also reported by Borrás et al., (2001) and Hanchett, (2001).

In contrast, Payne (1992) found an increase in quality of life for palliative cancer patients receiving chemotherapy at home. These differences could be related to the patient population, as Payne chose not to include patients receiving chemotherapy with curative intent. Hospital chemotherapy was perceived by patients as more distressing than home-based chemotherapy. Regression analysis showed anxiety and depression as accounting for the largest variances in quality of life. It also was reported that patients who received treatment in hospital were less active than those treated at home. Maintenance of activities of daily living is generally perceived as beneficial in reducing stress levels experienced by patients. An increase in activity levels among children receiving home chemotherapy was also demonstrated by Lashlee and O'Hanlon Curry, (2007). By providing patients with treatment at home, travel and wait time can also be reduced, allowing patients to spend more time with their families, and ensuring less disruption to the family schedule, something which is of particular importance in pediatrics (Lashlee & O'Hanlon Curry, (2007). Within the palliative population, the ability to receive services into the home allows patients to receive care even when they are too frail to travel.

A systematic review of home care programs for patients with incurable cancer was conducted by Smeenk, van Haastregt, de Witte and Crebolder (1998). This paper was the only relevant literature review uncovered in the search. Smeenk et al. examined the quality of life experienced by palliative cancer patients, and whether or not home care programs had an effect on the amount of time spent in hospital. Of the six studies that measured physical symptoms, only two reported fewer symptoms associated with chemotherapy, and one reported less physical dependency among patients who received treatment at home. However, lowered readmission rates to hospital were reported in all but one study. From these results, it appears as though home care programs provide greater opportunity for independence, and the ability to more closely monitor patient progress when compared to the outpatient clinic. Although few differences were noted between the intervention groups and standard treatment groups in terms of quality of life, they identified that none of the home care programs reviewed resulted in a negative influence on quality of life or time spent in hospital. In addition, the ability for team members to visit patients in their home and holding regular multidisciplinary meetings seemed to be important elements in the success of home care programs.

Interestingly, a study in children diagnosed with leukemia, performed by Stevens et al. (2006), showed an increase in emotional distress after three months of switching from hospital to home care. They reported that the “novelty of receiving chemotherapy at home may have worn off and resulted in more stress because home was no longer free of medical interventions.” (Stevens et al., 2006, p.290) The argument for home-based chemotherapy has usually identified home as a comfortable, familiar environment. By introducing chemotherapy into that environment, we may be disrupting the very characteristics that make it a relaxing and secure place. Boothroyd and Lehoux (2004, p.29) recognize that “patients with cancer may discover that

home is a less comforting (or comfortable) place than originally expected...” Patients may also find that odours and noises are disruptive, privacy is reduced, ‘visiting hours’ are continuous, and social stimulus is lacking. Further research is needed to identify if there are measures that could be taken to reduce this disruption and to preserve the sheltered setting of the home.

These findings suggest the need for ongoing evaluation, as perceptions can change over time. Looking deeper at the question of quality of life, the importance of examining psychosocial aspects of treatment at home becomes obvious. Experts agree that quality of life measurement is subjective, complex and multidimensional, sensitive, and requires repeated measurement (Hanchett, 2001). The existing literature on home chemotherapy has not resulted in this repetition as of yet. Therefore, further investigations into quality of life in home chemotherapy are required.

Preference

The subject of patient preference in home chemotherapy has been the subject of much debate. Some authors argue that results are inherently skewed, as patients who are not interested in home chemotherapy would not provide consent or be included in the study. Given the limitations, preference for home chemotherapy has shown to be very strong. In a prospective evaluation of home chemotherapy conducted by King et al. (2000), a randomized crossover design was developed to measure preferences and outcomes. 73% of patients expressed a preference for treatment at home. This was directly linked to the amount of time patients were prepared to wait for treatment; for example, 10 of the 29 patients who preferred home treatment changed their preference to hospital if home treatment meant waiting an extra hour for the nurse to arrive. Interestingly, carers were asked about their preference for location and 68% preferred

treatment at home, a difference of 5% from patients themselves, which did not reach statistical significance. Therefore, although treatment at home was preferred by patients, their family members or caregivers were more divided. The reasons for declining home chemotherapy in the study provided some insight; 4 patients felt safer with hospital care, 2 patients thought their home was unsuitable due to social problems, 1 patient did not want to associate home with chemotherapy, and 6 patients thought that being in the study would be more inconvenient than regular hospital care (King et al., 2000).

Patient preference for home chemotherapy was also studied by Rischin et al. (2000) who found that there was universal agreement among patients that home chemotherapy was preferred. Patients were randomised to receive their first cycle of chemotherapy treatment in either the home or hospital setting and the second treatment in the alternative setting. None of these patients were able to identify any concerns with home chemotherapy. Small sample size (n=20) may have been a contributing factor to these results. Also important to note is that although all patients stated a preference for home chemotherapy, 70% of patients in this randomized crossover trial expressed a desire to have both treatments at home. With qualitative research, we may be able to determine why patients felt this way, and which treatment they would have preferred to have in hospital. In most research, there appears to be strong patient preference for home chemotherapy although samples might have been biased.

Satisfaction

Several other psychosocial issues are involved in the choice of home or hospital chemotherapy, including satisfaction. It could be argued that these variables would be directly influenced by the structure and implementation of each individual program, as few researchers

have examined patients receiving home chemotherapy outside of their own service. The examination of these psychosocial issues is imperative, especially in consideration of the distressing side effects of chemotherapy and the emotional impact of a cancer diagnosis.

Two prospective assessments of home and hospital chemotherapy have been commonly cited in the debate over home chemotherapy. The first, by Vinciguerra et al. (1986), observed services provided by the Don Monti Home Oncology Medical Extension (HOME) program. Services included: physical examinations, pain control, psychosocial interventions, chemotherapy and blood transfusions, nutrition counselling, and bereavement counselling. According to Vinciguerra et al., benefits of home chemotherapy included decreased narcotic analgesic requirements and increased fat stores for female patients. In relation to this, a greater percentage of hospital patients reported nausea, vomiting, dysphagia, diarrhoea, and altered taste. Vinciguerra et al. also describe family acceptance of home treatment as 'excellent'. Borrás et al. (2001) also reported an increase in satisfaction of care received by patients with colorectal cancer receiving fluorouracil at home. There did not, however, prove to be any difference in survival rates between hospital and home comparison groups.

The second study undertaken by Watty et al. (2003) outlined several comments made by patients receiving home chemotherapy in Melbourne, Australia. In this study, 98% of patients reported no problems with treatment at home. However, concerns included difficulty having intravenous lines started, having to restrain or remove pets while a nurse was visiting, fear that if an allergic reaction occurred, it would not be handled as efficiently as in the hospital, and having to receive treatment over two days (one day for blood work and one day for chemotherapy). A chart compiled by Boothroyd and Lehoux (2004) in Appendix A outlines potential advantages

and disadvantages to home chemotherapy. Some additional apprehension expressed about home chemotherapy by patients include feelings of isolation, fears about safety, communication barriers, and fragmentation of care (Appelin & Bertero, 2004; Bakker, DesRochers et al., 2001; Borrás et al., 2001). Other potential problems include a lack of biomedical expertise, limited resources, lack of program/protocol standardization, and a decrease in multidisciplinary interaction. Anecdotally, the lack of access to emergency response teams, disruption of family routines and increased responsibility placed on family members are reported as disadvantages to home chemotherapy (Harrison & Fitch, 1995). Once again, these results appear to be greatly influenced by program structure.

Despite the strong evidence for improved satisfaction with home chemotherapy, there are additional issues to consider. The idea that home chemotherapy is more convenient and therefore improves satisfaction rates was challenged by King et al. (2000), by saying that some patients find it more convenient to make and keep a hospital appointment rather than waiting for the arrival of a nurse at home (King et al.). Presently, home chemotherapy is offered as a choice, and should it become mandatory for certain regimens, satisfaction rates could change. Magid and colleagues speculate that not all patients might “understand how chemotherapy is administered on an outpatient basis, nor have confidence in their ability to receive chemotherapy in their homes.” (Magid et al., 1989, p.143) This can greatly impact the level of satisfaction they express overall. Interpreting the perspectives of patients having home chemotherapy might open discussion to how health professionals can improve care, and identify which patients would benefit most from receiving care at home.

Cost

Consideration of the financial implications in developing home chemotherapy programs is necessary for maintaining accountability to society. Once again, the existing research shows controversy and little generalizability, due to the variety of measurement tools utilized. Most of the studies completed on the cost effectiveness of home chemotherapy have compared home to the hospital setting, and examined hospital charges rather than resource use (King et al., 2000). The delivery of chemotherapy in the home setting is generally assumed to be more expensive than hospital care, but an argument was made by King et al. that if numbers should increase beyond outpatient capacity, “moving chemotherapy into the home could provide a less costly strategy for the expansion of a chemotherapy service without compromising patient outcomes.” (King et al., 2000, p.557) There is also the belief that home chemotherapy results in cost shifting from the hospital to the patient and their caregivers. This is an idea that has not been examined in home chemotherapy research as of yet. In defence of the potential increased cost, King et al. (2000, p.574) questioned the value that the cheaper option should be favoured. “How much is the community prepared to pay to meet patient preferences for service aspects of treatment as opposed to health gain?” The increasing prevalence of cancer and resulting strain on health care services will inevitably result in consideration of these factors. A qualitative study of patient perspectives might identify what other non-monetary costs are associated with home chemotherapy, including time spent away or with family and the ability to continue (or not continue) work. The non-monetary costs such as level of burden incurred by families are important to consider as well. These trials provided us with some useful monetary figures, but they do not allow us to identify other key issues in the administration of home chemotherapy.

Patient Perspectives

Looking specifically at patient perspectives of home chemotherapy, an extensive search of this topic revealed one published article from the adult population. Hall and Lloyd (2008) evaluated the experiences of patients receiving home and hospital chemotherapy. The patient population was limited to breast cancer patients and randomization was used to divide the group into their respective sections. Using the humanistic approach of phenomenology, Hall and Lloyd uncovered several themes: comfort and security, privacy, practicalities and relationships.

The theme comfort and security showed two contrasting perspectives. Some patients felt at ease in their homes, whereas others felt the security of the hospital was essential. It appears that the increased security was based on the sense that if something were to occur, they would have the most appropriate, immediate care.

Within the theme of privacy, discretion and solitude was decidedly an advantage to home chemotherapy. This came at a cost, however, as some participants mentioned the contact with other cancer patients was missed.

There was an observed reduction in travel costs and time for home chemotherapy recipients, and these patients felt as though the time they spent waiting at home for the nurse was not 'wasted time'. Although the authors do not discuss cost explicitly, it is worth noting that this might include not only direct travel expenses, but also parking fares, food and beverage purchases, and time away from paid or unpaid work. These costs can quickly become overwhelming for patients, especially considering most are on reduced incomes. Another practical advantage to home chemotherapy included distraction from the negative thoughts some

patients found themselves having while surrounded by the busy, stark environment of the hospital. Being able to have family/children present, read, or watch television while the chemotherapy was infusing provided a diversion from the anxiety that can sometimes exist in the hospital setting.

Lastly, in the theme of relationships, there was agreement between home and hospital-based patients regarding the significance of a good relationship with the chemotherapy nurse. While patients receiving chemotherapy at home expressed satisfaction with having the nurses' "undivided attention" and felt they were better able to grasp the teaching provided at each treatment session, hospital patients felt that their nurses' attention was shared between other patients. Home chemotherapy recipients also believed there was a greater opportunity to ask questions freely and felt the continuity of care was more apparent than in the hospital setting.

Hall and Lloyd (2008) present thought provoking research that encourages the reader to consider the implications of receiving chemotherapy at home. The interview questions were not explicitly outlined, but the discussion was presented in a way that leads the reader to believe they were broadly based questions, focussing on both the advantages and disadvantages of receiving chemotherapy at home and in the hospital. This openness allows for discussion beyond a pre-determined hypothesis, perhaps relating to quality of life or satisfaction with care. Secondly, they provided contrasting perspectives between home-based and hospital-based patients. Although Hall and Lloyd add significantly to our knowledge of the perspectives of patients receiving chemotherapy at home, there were areas that require further exploration in future research. The interview questions were not reported, which makes it difficult to place the findings into context. One of the inclusion criteria of the study was that participants had to receive at least four cycles

of anthracycline based chemotherapy for breast cancer. It is not clear what chemotherapy was actually provided in the home or hospital setting, or if the participants completed their respective courses of treatment. This would result in varying degrees of toxicity, and potentially differing opinions in treatment satisfaction or concerns. The study was conducted in the United Kingdom, which undoubtedly has different geographical issues when compared to Canada. Limiting the patient population to breast cancer might also affect the applicability of results. There is a greater proportion of breast cancer patients with young children as compared to other cancer types in the Hall and Lloyd study, and therefore, chemotherapy treatment at home may be more (or less) appropriate. It is important to understand the perspectives of patients having home chemotherapy in a general cancer population. Subsequent research needs to further distinguish the views of patients who prefer home chemotherapy from those who prefer hospital chemotherapy, so that home chemotherapy programs can be improved and to determine who is best served by them.

Pediatric Patient and Family Perspectives

The experiences of children receiving chemotherapy at home has been studied in greater detail compared to those of adults. A pediatric study by Stevens, McKeever, Law, Booth, Greenburg and Daub (2006) used descriptive exploratory methods to determine the perspectives of children and their parents receiving cancer care at home. They revealed five main categories including: financial and time costs, disruption to daily routines, psychological and physical effects of chemotherapy, recommendations and caveats and preference for home chemotherapy. Children attending school reported increased attendance and ability to continue daily activities. Siblings were offered the opportunity to observe treatment, allowing them greater involvement and understanding of the process. Some children reported fewer side effects with home

chemotherapy, including anxiety-related nausea and vomiting. Despite enormous levels of positive commentary, there appeared to be a lack of paediatric expertise available in the community (compared with in-hospital settings); for example, local laboratories used venous sampling when finger stick sampling would have been sufficient, causing unnecessary discomfort for children and parents. The timely application of EMLA anaesthetic cream was affected by the uncertainty of the nurse's arrival time. Overall, home chemotherapy was widely accepted by both parents and children.

Perspectives of Health Care Professionals

The perspectives of health care professionals are integral to sustaining a home chemotherapy program. Without support, referrals would be non-existent. The safety of this treatment modality can be directly linked to the suitability of patients chosen for the program. Therefore, the perspectives of health care professionals are required to provide quality care for cancer patients. Stevens, McKeever, Booth, Greenburg, Daub and Gafni (2004) interviewed pediatricians, community nurses, hospital clinic nurses, administrators, and pharmacists using a prospective descriptive study design. Perceived family benefits, human resources and service delivery considerations and impact on the role of the health care professionals were discussed as key concepts. Overwhelmingly, health care professionals supported the idea that home chemotherapy reduced disruption to family life and psychological stress. Community health care professionals reported an increase in job satisfaction despite increased work load and frustration related to scheduling. Consistency in care, centralized communication, and specific chemotherapy training for nurses were cited as essential characteristics of a successful program. Aspects of fiscal responsibility and safety were also evident in a qualitative study by Dudek-

Tuliszka, Rivadeneyra and Vardanyan (2005). Health care professionals felt pressure to contain cost, as well as provide a safe, competent service.

Patient Perspectives of Palliative Home Care

There is growing literature on patients' experiences of palliative care in the home, and this may be useful in the topic of home chemotherapy. Many patients receive chemotherapy for symptom control or palliation. Appelin and Bertero (2004) produced a valuable piece of research in this area influenced by Giorgi's phenomenology. Giorgi's phenomenology attempts to identify the 'essence' of lived experiences. The researchers identify several themes, including "safe but unsafe at home", "a sense of powerlessness", "change of everyday life", and "hope and belief in the future". Patients reported frustration with being at home and not being able to maintain their normal activities. They also illustrate the sense of guilt that comes with increased pressure on caregivers and family. Providing care to a family member presents a physical, emotional, and at times financial challenge. It is important to illustrate the thoughts of families and caregivers when examining perspectives of home chemotherapy. It is not known whether these opinions transfer into the administration of chemotherapy at home.

In summary, there is a paucity of qualitative literature regarding home chemotherapy. The greatest number of studies has been completed in the pediatric and palliative care populations. These populations are known to have unique perspectives pertaining to treatment at home. Communication difficulties with health care providers, a potential reduction in side effects, increased comfort, security, privacy, and improved relationships with the nurses administering treatment were all mentioned as potential consequences of receiving home chemotherapy. Canada is currently experiencing a movement towards high tech home care due to

increased demand for cancer services, and the perspectives of patients receiving chemotherapy at home are necessary to ensure the quality, safety, and satisfaction of the program.

Significance

The Canadian health care system possesses unique strengths and challenges, and therefore there is a need for quality investigations in the adult Canadian acute care cancer population. The concept of home chemotherapy is an emerging one, and research on this subject may help to inform decision-making by clinicians and administrators as well as patients and families. Research may enhance the ability of health care professionals to provide appropriate support and treatment; more specifically, to reflect on the potential suitability of individual patients and to assess when hospital-based vs. home-based chemotherapy is appropriate. The administration of chemotherapy in the home presents many practical, psychosocial and ethical issues. Understanding the broad range of issues for this treatment to ensure beneficence and non-maleficence is crucial. This research will increase our general knowledge base and empower patients to make more informed decisions relating to their cancer care.

Chapter Three

Study Design/Methods

Design- The study was qualitative in design, utilizing Interpretive Description. This method was chosen for the capability of portraying a shared health or illness phenomenon from the perspectives of those who live it. It is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of the health illness experience, yet also allows for shared realities (Thorne, Reimer-Kirkham & MacDonald-Emes, 1997). According to Thorne et al., non-categorical description can assist the nursing profession to develop knowledge about human health and illness experience phenomena by using a methodological foundation rooted in nursing's epistemological mandate. The underlying belief is that the unique individual characteristics of a sample can be recognized while maintaining applicability to the general population.

Population- Ten patients over the age of 18 were convenience sampled by nurses from the Cancer Treatment at Home (CTH) program; a pilot project being conducted by Alberta Health Services. This number was chosen to investigate as many perspectives as possible within the confines of a master's thesis. There was also a larger ongoing evaluation to examine cost, safety and satisfaction as part of the pilot project. Several chemotherapy drugs were used in the pilot study, and it is important to note that none of these treatments were benign. The medications administered were of varying toxicity, and may have resulted in side effects such as myelosuppression, nausea/vomiting, alopecia, diarrhoea, etc. Chemotherapy drugs that were vesicants or commonly result in anaphylaxis were excluded from the pilot study. The original intent was to select four or five patients who had chosen to receive services from program, as

well as four or five patients who had chosen not to have services from the program. Difficulties in recruiting patients who declined cancer treatment at home occurred, and therefore, a further five patients who accepted treatment at home were chosen. Of these ten patients, one interview was lost due to technological malfunction. This resulted in an end total of nine interviews with patients who accepted home chemotherapy. Patients who had chosen to receive services from the program would have received at least one cycle of treatment at home prior to interview. They were recruited if they could speak, read and understand English. Patients were chosen to represent a variety of cancer types, cytotoxic treatment combinations, gender, ages, and treatment locations (work, home, family member or caregiver's home). Demographic data including age, gender, marital status, occupation, ethnic background, diagnosis, and type of chemotherapy received was collected along with the interview questions. The participation of the caregiver themselves was not a requirement, although the impact of home chemotherapy on the caregiver was explored through the perspective of the patient.

Program Description- The Cancer Treatment at Home program was located at the Cross Cancer Institute, Edmonton. The pilot project ran for approximately one year and aimed to recruit 100 patients in the Edmonton area. Randomization into the program was not used and participation in the pilot project was strictly voluntary. Patient selection criteria and a treatment protocol list, consisting of basic infusional chemotherapy, were developed with the input of medical oncologists. Please see Appendix B for a complete list of referral criteria. A full assessment of the patient and his/her home was completed before the patient was admitted to the program in order to ensure the safety of both the patients and staff. The treatment was administered by trained oncology nurses with additional home care orientation. Patients still attended the outpatient clinics at the Cross Cancer Institute for blood work, assessment, and to see the

clinicians. Evaluation including economic analysis was completed to determine the feasibility and further roll out of this program. Unfortunately, the provincial economic climate suffered during the course of the pilot project and further funding was not approved. The pilot project came to a close on July 31, 2010 having reached the goal of recruiting all 100 patients.

Ethical Considerations- Ethics approval was obtained from both the Ethics Review Committee at the Cross Cancer Institute and the Health Ethics Review Board at the University of Alberta prior to initiation of data collection. Patients received verbal information from home chemotherapy nurses and written information via a letter from the researchers, outlining the study and asking if they were interested in participating. Written consent was obtained prior to each interview. Patients were informed that their participation was voluntary and that they could decline to answer any questions they did not feel comfortable with. They were also informed that they were free to withdraw from the study at any point and non-participation in the study did not affect their ability to continue with the Cancer Treatment at Home Program or any other treatments at the Cross Cancer Institute. Participants were assigned pseudonyms to ensure confidentiality. Field notes and interview tapes were stored in a secure place, and patient names or identification were known only to the primary researcher. Summaries of the research results were offered to all participants.

Data collection- Selection criteria included (a) the willingness to participate and share their experiences, (b) ability to communicate in English and (c) being a cancer patient offered home chemotherapy as part of the pilot program. Interviews were completed in the patients' homes and at the Cross Cancer Institute using semi-structured questions. There was no restrictive time limit for the interview. The guiding questions for the study were as follows:

1. Please tell me about the experience of receiving chemotherapy in your home. What are the advantages? What are the disadvantages?
2. How do you think your family is affected by your getting chemotherapy at home? How do you think you or your family would be affected if you received your chemotherapy at the hospital instead?
3. Tell me about your decision to receive chemotherapy at home; how did you come to make that choice?

Analysis- Constant comparative analysis and ongoing engagement with data was used to confirm and explore conceptualizations. The information was analysed by the researcher, focussing on inductive rather than deductive analysis. The researcher used field notes, in-progress diagrams and audio recordings to ensure that all concepts were identified and developed throughout the process of research. After each interview, key concepts were taken from the field notes and audio recordings and added to a whiteboard diagram. If concepts were repeated, expanded, or uniquely identified in future interviews, this was also noted in the diagram. When all ten interviews were completed, they were transcribed verbatim and reviewed a final time to ensure that valuable information was not disregarded. Research was conducted in pursuit of a master's thesis, and therefore, there was partnership between the student and the supervisor to ensure thorough identification of concepts and accurate description in theme headings.

Rigor- Operational techniques with the aim of supporting credibility, dependability, confirmability and transferability were constantly undertaken. Credibility and dependability can sometimes be supported using member checking or verification of themes and descriptions with research participants. Working within the confines of a master's thesis did not allow the

researcher to dedicate the time required to this activity. However, presentation of research findings will be made at conferences or symposiums when possible, with the aim of attaining evidence from colleagues that the research findings resonate with them. The researcher's background and training was constantly considered in context to the study. The researcher was involved in administration of chemotherapy at home and in the medical outpatient department, and therefore, patients who had received treatment from the researcher were not chosen to reduce bias. Detailed field notes were kept to verify and confirm concepts described by the research participants.

Vignettes

These vignettes were created to provide the reader with a backdrop for future discussion of themes. The names provided are pseudonyms and in no way reflect the patients' actual given names to protect confidentiality.

JACK

Jack is a 45 year old Ukrainian married man with pancreatic cancer. He has young children and worked as a heavy duty mechanic prior to his illness. Jack received FUFA (fluorouracil and leucovorin) chemotherapy in addition to surgery for management of his cancer. He appears several years younger than his stated age, partially due to his outgoing nature and secondary to his physical build. He uses humour throughout the interview, but not in an awkward way. He speaks fondly of his family and expresses gratitude for the opportunity to have treatment at home so that he can be more accessible to them.

LISA

Lisa is a 40 year old married mother of two with breast cancer. She recently completed treatment with surgery, TCH (Taxotere, Carboplatin and Herceptin), and maintenance Herceptin. She received her TCH chemotherapy at the Cross Cancer Institute and her maintenance Herceptin at home. She is an ESL instructor by occupation and this is evident in her articulate, thoughtful account of receiving cancer treatment at home. Lisa speaks about the importance of being able to accept her situation and move on with her life. She is an ideal conversationalist and made several poignant comments. She has an obvious loving connection with her children and a desire to protect them from the stress of her cancer diagnosis.

MARJORY

Marjory is a 40 year old Native Canadian woman and former administrative assistant. She is receiving treatment with Gemcitabine for an unknown primary with palliative intent. Marjory is married with teenage children. She has a quiet, introspective nature and although she is not wordy, her meanings are most evident in her non-verbal cues. She spoke of her ability to cope with her diagnosis by not having constant reminders of illness from seeing other patients and the meaning of the word 'cancer'.

HELEN

Helen is a 60 year old married woman with peritoneal cancer. She had to give up her occupation as a seamstress due to the peripheral neuropathy she experienced as a result of her treatment. She was receiving Topotecan at home, but had disease progression on chemotherapy and at the time of the interview, was waiting for a new plan from her medical oncologist. Helen had significant weight loss from treatment, but was beautiful with piercing eyes and a flowing, soft head scarf. Helen suffers from Irritable Bowel Syndrome and has difficulty travelling back and forth from hospital as a result. She has a calming personality and expressed gratitude for the friends and family that assist with her care.

EVA

Eva, the youngest of the participants, is a 36 year old married woman with a young daughter. She recently immigrated to Canada from the Philippines and is on leave from her retail sales position. Eva is petite, soft spoken but quietly powerful in her demeanour. She is receiving maintenance Herceptin at home for management of breast cancer. Eva expressed that, when she was diagnosed, she was concerned she might be treated differently as an immigrant or that she

might not be able to communicate effectively with her health care providers. She described her appreciation and relief that these fears have not been realized.

DIANE

Diane is a 58 year old married woman with two grown children. She is a former dental hygienist and instructor at a local college. She is in her fourth year of treatment and is currently receiving treatment with maintenance Herceptin at home for breast cancer. She appears younger than her stated age due to her high energy and liveliness. Diane speaks with conviction and vigour and is very driven to see home chemotherapy continue. She brought forward the concept of 'natural habitat' and the significance of living a life without constant reminders of being ill. She and her family wrote several moving letters to local members of parliament and employees of Alberta Health Services. She is outspoken, positive, and driven. Overall, she has a clear love for her family and new grandchildren.

VLADIMIR

Vladimir is a 70 year old married civil engineer. He is receiving FUFA (fluorouracil and leucovorin) for treatment of colorectal cancer. He speaks with a thick Russian accent and is succinct and to-the-point; a true business man. Having treatment at home has allowed him to continue to operate his home based company. Vladimir mentioned that he is usually reluctant to participate in interviews but felt clear about his intent to thank the pilot project staff for allowing him the opportunity to receive home chemotherapy.

JOHN AND CAROL

John is a 72 year old retired man with colorectal cancer receiving FUFA (fluorouracil and leucovorin). His former career was in the manufacturing industry. He is personable and talkative. His wife, Carol, contributes to the interview by clarifying treatment dates and encouraging John to elaborate on certain concepts. It was enjoyable to see the relationship between husband and wife and made the consequences of his diagnosis on both individuals more obvious. John is tall, warm, and quietly intelligent, but spoke about feeling overwhelmed by the hospital setting and bombarded by information. He described the benefits of ‘personalized care’.

ELEANOR

Eleanor is a 78 year old married, retired woman with colorectal cancer. She is receiving treatment with 5-fluorouracil in a Baxter pump every 2 weeks. At the time of the interview, she had developed Bell’s palsy, and was having some difficulty enunciating words. Eleanor is relaxed, composed and tends to take a broader view of her cancer and chemotherapy. Unfortunately, audio recording of the last third of the interview was lost due to technical issues.

Chapter Four

Findings and Discussion

Audio transcribed interviews were completed with nine patients, and field notes were written during a total of ten sessions. Participants were interviewed in the context of a pilot project for home chemotherapy, which was undertaken in a large metropolitan area. Length of treatment among participants ranged from months to nearly four years. There was a mix of patients receiving treatment for palliative and curative intent. During these interviews, participants described their experiences of receiving chemotherapy at home. They discussed the impact of receiving these medications at home and what this meant to them. Many of these patients were so grateful to receive treatment at home that the topic of conversation immediately went to the benefits of the program. Oftentimes the patient would then return to the question of describing their particular experience in greater detail.

Overall, the concept of home as a ‘natural habitat’, in which the patient was more adaptable and care was personalized, emerged as a powerful message from the participants. Natural habitat is the environment in which we exist and interact, including the home. Currently, when patients are diagnosed with cancer, they are displaced from their homes to a contrived, heavily scheduled setting such as a hospital. Routines are lost, and the patient becomes bound by ‘the system’. Although health care professionals strive to promote patient independence and self care, there are still aspects of treatment that seem to pull the patient back into the traditional ‘sick role’. For many, cancer can be an all-consuming illness.

By keeping patients in their homes, there is a greater focus on adaptation. Adaptation generally refers to a feature which is especially important for an organism's survival, and in this study, refers mainly to the ability to cope with cancer and cancer treatment. Being at home for treatments held great significance for some patients. The meaning of home has been studied by other researchers, and has been described by some as a 'therapeutic landscape'. (Williams, 2002). Williams' research beckons us to recognize that home not only represents a dwelling, but also a multitude of meanings, including: personal identity, security, and privacy.

The overarching concept of natural habitat was comprised of several recurring sub themes. These were: realignment of resources with values, adapting to the experience of illness, and improved care provision and reception.

Chemotherapy in a 'Natural Habitat'

One patient, Diane, as she was trying to explain her experience of home chemotherapy, spoke of her recent attendance at a seminar by Dr. Jane Goodall. Dame Jane Morris Goodall is a British primatologist, ethologist, anthropologist, and UN Messenger of Peace. Considered to be the world's foremost expert on chimpanzees, Dr. Goodall has dedicated her life to animal research, education and conservation. Diane spoke of the fact that society works very hard to protect animals by keeping them in their natural habitat, yet, this is something that is not valued in the treatment of illness in humans.

You know, we went to listen to Dr. Jane Goodall speak. Amazing. Amazing woman.

Worked years with the chimps and all that. What do they want to do? They want to keep everybody in their natural habitat. She travels the world to maintain that integrity for her

animals and yet, they don't kind of get that for people. You look at the whales. [Laughs] Anywhere on the planet. What's the best? You know? You keep them safe. You keep them warm. You keep them well fed. You keep them in their natural habitat. But yet for us, it seems kind of weird. (Diane)

Home was therapeutic because it represented comfort and warmness and security.

I find it really warm. It's not even like I'm a different ethnicity. I never felt like an outcast. I feel like they were here to take really good care of me. That's what they do. If I would have said, "Ooh, I sense something", I'd just go to the hospital and have my treatment there, but no, they were really very nice. (Eva)

Others, such as Helen, talked about how being in the home setting kept them thinking positively.

I think (treatment location) plays a part in your frame of mind. The more positive you are, the better you are going through treatments. (Helen)

Yet others did not want to be exposed to the potentially traumatic circumstances of others in the hospital and wanted to move forward with their normal day to day routines.

Maybe because I am a little bit younger than some of the other people that are here, I just found it to be that you walk in and nobody smiles. If I tried to make eye contact with somebody, people would look away. I try to smile. I'll smile at somebody if they make eye contact because we're in the same boat so why not say, "Oh good job! You know what I'm going through." So I found it's just that nobody wants to be here, right? Nobody wants to be given this diagnosis, and when you're at the Cross, you'll see varying degrees

of the diagnosis or you'll see people who are really, really sick and ill. And you'll see other people who maybe aren't quite so sick. In a way, you almost don't want to see the people who are really, really sick, because then you think, "Oh my gosh, is that the room I'm going to be in? Is that where I'm heading?" You know, it just kind of makes you worry more than you need to, right? You just need to focus on me. This is my medicine and I'm getting it and moving forward with my life. Coming to the Cross, it's more that you're aware of your situation and I think if people think about their situation too much, it doesn't help them. I think it's important to accept your situation but move forward with your life. The treatment at home program allows you to do that. The whole idea – it's so nice and comforting that people don't have to know... and you get a little bit of privacy back in your life. You're able to just to do what needs to be done and get through it.

(Lisa)

I always say it has been a gift from God because it's just so much easier to receive it at home than to go for me personally to the Cross. So to me, those girls [referring to the nurses] are beautiful. They come, they're in, and they're out. There's really no stress for me. No disrespect to anybody; I don't have to worry, "How am I going to be treated? How long am I going to have to wait?" There are the dynamics that come from sitting in that environment. I'm very visual and I wear my heart on my sleeve and I see what's going on around me. That really bothers me. So to have this (chemotherapy) at home and watch TV or sit and chat with somebody who is monitoring, to me is amazing.

(Diane)

Discussion

Arthur Frank, author and cancer patient, wrote about the need for patients to protect and maintain their day to day lives in his book “At the Will of the Body: Reflections on Illness.” (2002). Frank said,

“It is difficult to accept the realities of what physicians can do for you without subordinating yourself to their power. The power is real, but it need not be total. You can find places for yourself in the cracks. I want to affirm the importance, both for yourself and for those around you, of holding onto the person you still are, even as medicine tries to colonize your body. Disease cannot be separated from other parts of a person’s identity and life.” (Frank, 2002, p.56-57)

Many of the participants in this study talked about their abilities to ‘find places for themselves in the cracks’, or empower themselves by maintaining their personal identities. Being offered cancer treatment at home protected the participants’ capacity to make choices. Home was seen as a place of comfort, security, and normalcy. It was also described as a ‘natural habitat’ and a key factor in helping patients adapt to the stress of receiving chemotherapy for cancer. This is consistent with previous research relating to preference, satisfaction and quality of life, although the actual description of ‘natural habitat’ has not previously been expressed. The concerns in a study by Stevens et al. (2006), regarding an increase in emotional distress after three months of treatment at home, were not reproduced. In fact, several participants talked about their disappointment in having to return to hospital when the pilot project finished. One patient experienced anxiety related vomiting on his way back to hospital.

Linked to the central concept of home as a ‘natural habitat’, other areas were commonly described as part of the experience of receiving home chemotherapy.

Realignment of Resources with Values

The first, realignment of resources with values, outlined exactly what the participants found to be significant in their lives. By receiving chemotherapy at home, participants described their ability to spend more time with family members and dependent children, focus on paid or unpaid work, or preserve physical strength for activities that were meaningful to them. They also appreciated the reduced financial burden associated with travel, parking and childcare expenses. The majority of participants described a combination of all these elements. Individuals or activities that were valued by the patient were kept as priorities, and the patients had greater freedom in terms of how they wanted to spend their time, energy and money. Participants were also able to, as one patient put it, ‘ripple’ these benefits onto their caregivers.

Several of the participants in this study had young children and talked about their desire to be involved in their lives. One patient stated,

I think especially, because my kids are so young... I wanted to spend every waking minute with them. As much as sometimes when they’re having their tantrums or whatever and you’re okay, okay! Do I really want, you know? I’m just happy that I’m there to hear the tantrum. You know...it’s completely taken on a new perspective. (Lisa)

Jack also discussed the importance of being accessible to his children.

It's good for them I'm home so in case they need something from school, they can always phone me. You know, for me being home and being there for them, that was really important. (Jack)

Some participants mentioned that they were also concerned about asking other family members, friends, and neighbours to care for their children. They were concerned about burdening them or creating a negative association.

They started to almost associate... my husband's mom lives on Vancouver Island and she came over to help look after us and she was really worried that the kids were going to associate her with Mom being sick. Because she would only come when I was having treatments or when I needed help. (Lisa)

I'd rather take good care of my daughter, than have my daughter taken care of by my friends. Although they were very nice. (Eva)

For other participants, work and business commitments were more easily kept by having cancer treatment at home. Chemotherapy was actually given in the workplace to one individual during the pilot project, although that particular patient is not included in this group of interviews. Others, such as Vladimir and Helen, had home-based businesses that ran with fewer interruptions.

I operate my business at home and the people save a lot of time for me because I just have to spend probably more than one hour for travel to the (hospital) and waiting in line. Sometimes I'm very busy with meetings and the service at home saves me a lot of time to do the great job that I have to do. (Vladimir)

My husband – now that we only have one income in this family, has not had to, you know... he's in construction in his own business. He had to put his customers to the side in order to take me to the (hospital) because I was not able to drive myself when I was at my worst. (Helen)

Certainly, finances are a stressful aspect of treatment, especially when the patient or spouse is self employed. In general, many patients often experience financial strain while undergoing treatment for cancer. In this study, savings pertaining to travel costs, parking costs, and childcare costs were mentioned on multiple occasions as being a benefit to receiving home chemotherapy.

When my husband worked out of town, I had to cab it. For winter months I had to cab it. So the money was (long pause)... it's costly. (Marjory)

Travelling back and forth to the hospital also appeared to come at a physical cost to the patients. Some alluded to an improvement in fatigue after they began receiving their treatment at home, leaving more energy for what they deemed to be important.

I found even driving (to the hospital) and getting my chemo, by the time I got home, I'd have to have a nap. I found myself getting tired from it really quick.

And then after I had the first week of (home chemotherapy), I found it really convenient, you know? They come to your house and get it all done. I get to stay in a warm environment, especially winter time. Yeah, it was nice. I looked forward to having that.

(Jack)

Discussion

The theory that having chemotherapy at home might improve patient fatigue is something that would lend itself well to future quantitative research. For the participants in this study, energy was one of the many resources that they were able to redistribute in order to make their experience with cancer more tolerable. The research previously completed by Hall and Lloyd (2008), also touched on resource conservation, but focussed more on time and finances. Other studies examining the cost of home chemotherapy have compared the economic feasibility of administering treatment at home versus in hospital, but neglect to address the direct and indirect cost to patients. In this study, having chemotherapy at home allowed many participants to spend their valuable time, money, and energy on what mattered most to them. This is considered by many to be something of great value, especially in the context of a life threatening illness.

Realignment of Resources with Values and its Effects on Caregivers

Woven into the experience of the participants receiving cancer treatment at home, there was mention of the effects this had on their caregivers. This is an obviously crucial element in

the delivery of cancer treatment at home. It has been previously suggested by health care professionals that shifting services from hospital to home may increase the level of caregiver strain or burden. While describing their experiences of home chemotherapy, participants in this study did not feel that there was a negative impact on care providers, but rather, a 'rippling' of reduced stress and responsibility. Participants described their experience of home chemotherapy as being less stressful for caregivers.

It's made a huge difference for them. I think when you get diagnosed with this it just throws everything that you know for a loop, right? Including your children. I mean, we have such a close family. And we're so involved with each other and I think for my children to see me happy and settled is a gift for them. It just ripples. Right? It just ripples. (Diane)

Generally with my parents for sure, it's just less stressful for them and it's less involvement for them, which again I think, helps them deal with my situation as well. So it's the same thing where if I'm always thinking about it, it doesn't help. But if they're always thinking about it or if they're always driving me to appointments or looking after my kids and stuff like that, they can't forget about it, right? It's too much in their face all the time, so it's nice for them with chemo at home because I didn't have to involve them. My mom would call at the end and say, how was the chemo? Oh good, good, good, so what else did you do today? You know, it was just this little blip because she needed to ask about it because she was aware that it happened, but then on to more important stuff. (Lisa)

I think (my husband) felt more at ease that there was a nurse coming here. And he could see everything was okay. (Helen)

Unlike many other home based programs, the participants of this pilot project had to be ‘medically stable’ and possess no other chronic or unstable health conditions. (Appendix B) This meant that the main responsibilities of caregivers included activities such as housework, driving, child rearing, shopping, etc. Participants described a reduced sense of burden in terms of these activities.

It would be bothersome (to have chemotherapy in hospital) because my daughter would have to come and because I don’t like to go to the cancer clinic by myself. I want somebody there. So I think with my daughter (living) at home, she’d have to come and she’d probably get tired of it. [Laughs] (Marjory)

My family shifting their work load... of course, they didn’t mind. You know, I’m a lucky person to have the family I have. But it still bothers a person (to think), who’s going to take me today or who’s going to take me next week? (Helen)

Discussion

Although the caregivers themselves were not formally included in the study (aside from one interview, in which a patient’s wife was keen to elaborate on what her husband was saying), their experiences are described through the eyes of the patient themselves. Having treatment at

home meant that many participants were able to better distribute their resources, and therefore, ‘ripple’ this effect onto their caregivers. Research into palliative home care by Appelin and Bertero (2004), described the guilt that some patients felt by asking their family or friends to assist with care at home. In contrast, the participants of this study describe a reduced sense of burden, as treatment at home often relieved caregivers of the tasks they were assisting with. Interestingly, a requirement of participation in the pilot project was that the patients had to have a caregiver willing to participate in care. The results of this study would suggest that cancer treatment at home should be considered for patients without social support or caregivers, who have even more difficulty travelling or finding child care. Other research relating to caregiver’s experiences of home chemotherapy have not currently been published. Therefore, this is a much needed area for future research.

Adapting to the Experience of Illness

In this study, patients depicted greater privacy and enhanced management of aspects of their treatment. Examples included using their own bathrooms for vomiting or diarrhoea or taking steps to make intravenous insertion easier. They were also able to use their home treatments as contrasting opportunities to teach and withhold information. Throughout the course of interviews, several participants described how having chemotherapy at home changed their self image and left them better able to deal with the diagnosis of cancer. Patients actually viewed themselves as less ill. Participants in this study appear to be better able to cope with cancer by not having constant reminders of illness dominating their lives. Therefore, they were better able to adapt to their experience of illness.

Several participants described how receiving treatment in hospital made them feel.

When you're diagnosed with cancer there's a big adjustment period where you have to get it through your head okay, this is happening to me. This isn't a dream or a nightmare. This is really happening to me. So once you get through that, and once you accept that, I think then you want to do whatever you would in your regular life. So every time I came to (the hospital), every time I had to lie in the bed, I felt I was sicker than I really was, right? Because of the atmosphere... (Lisa)

I kind of find (the hospital) quite depressing. Whereas here in the home environment, it's a little better. I view myself as a happy go lucky guy and like to joke around a bit. And then when I come in here, it's just; I don't know. There are so many sick people that it kind of brings you down. I don't see myself as being sick anymore. I'm more on the healthy side now. Whereas everyone here is just... no emotion. Just stone cold. Well, there are sick people here, right? So that's understandable. But I didn't think it would be that dramatic. (Jack)

These comments were contrasted against the home environment.

It's like I'm not sick. Because you go to the Cross Cancer Institute and, it's this big word. You know, cancer blah blah blah. You don't hear it here. I don't like the fact that

you go there and it's like you're sick. (At home), it's like I'm not sick. It doesn't bother me as much I guess. (Marjory)

I think when you're home, it doesn't remind you or it doesn't; how can I say this?

Receiving your treatment at home, it sort of feels more natural. When you have to go (to the hospital), to me, it just keeps reminding you that you're still sick. And I try to live my life as if I'm not. (Diane)

Lisa further articulates why having fewer reminders of illness is important.

I think cancer is a mental need in a lot of ways. If you think about something and you continue to think about it, it starts to disrupt your life and it starts to take over and it starts to eat at you. If you're not able to think about it but still realize that it's part of your life I think it's a healthier way to be and that will ultimately help you live a better life for however long you have left. (Lisa)

Although patients had fewer reminders of illness, there was some suggestion that participants might risk becoming too secluded. One patient mentioned that social interaction might be missed by some patients, but was clear to identify that this was not an issue for herself. A second participant described the concern that her husband had for the amount of time she spent at home.

(My husband) said I should get out more, because I stay in my room and watch TV a lot.

(I miss) seeing people. I could probably spend five days in the house. And not do anything.
And not see anybody. [Laughs] (Marjory)

Marjory continues to say that she would prefer to interact with people away from the hospital, for example, at the mall. Should home chemotherapy become a future model of care delivery, nurses must address this need in their patients and encourage them to continue to seek interaction outside the home.

Patients also adapted more easily to treatment by being able to manage aspects of their care. Jack had difficult venous access and was initially worried about having to return to the hospital if the nurses were unable to insert his intravenous (IV) device. However, at home, he could spend more time using warm compresses and mentally prepare himself for the insertion attempts. Over time, he realized that he actually had improved IV access at home.

I didn't have a lot of energy and did not deal with the cold well. Even at zero, I was getting chilled really bad. So in that sense, (home chemotherapy) was really good. I could be in my home staying warm and getting it done. My veins are pretty internal.

[Laughs] They have difficulty sometimes finding a vein for me. Whereas sometimes in a warm environment, they said it was better for them too. (Jack)

Helen suffered from Irritable Bowel Syndrome (IBS), and described her difficulties travelling back and forth to the hospital. At home, she had the luxury of using her own washroom and reported having less frequent attacks as a result of reduced anxiety.

It was the best that I've had and I've had a few treatments; because I do have irritable bowel syndrome. On a bad day, it's hard for me to get from point A to point B without having to look for a public washroom on the way. There was a time when my legs were like tree trunks because of the swelling. It was very difficult for me to travel from home to the (hospital).

Participants also used their treatments to control the flow of information to their family members.

One participant talked about sharing the experience of treatment at home with her young daughter:

She was very curious. She would ask "what's that, mama?" When we're in (the hospital); when she's in that different kind of situation, she would just observe. But when we were at home, she would keep on asking, "What was that thing they did to you?"

If there are questions that I can't answer, she would ask her papa. So there's another different answer. (Eva)

In contrast, Eva was able to hide the fact that she was having treatment for cancer from her mother, who had a heart attack and lived in the Philippines.

She doesn't know. No one knows. My mom just had a mild heart attack after 10 years last February. So I never told her anything about it. She would just; she would just be thinking and thinking and thinking about it. (Eva)

Lisa was also concerned about protecting her children from the harsh realities of cancer. She would schedule her appointments while her children were in school, and if they asked questions, tell them she had to see the dentist.

Instead, I would say, "Oh I have a dentist's appointment and my tooth's bothering me." And they were a lot happier with that. So with the treatment at home, it was excellent because I didn't have to worry about any of that (stress on the children), right? I could just have my treatments done and then I would go pick up my son from from pre-school with a band aid on my hand. So that's why the dentist helped a little bit. I'm sure they kept thinking 'Mom has really bad teeth!' [Laughs] (Lisa)

In both of these cases, the participants believed that the result was reduced anxiety for their family members. In other words, patients were able to manage the flow of information, depending on the perceived needs of their family members.

Discussion

All of these experiences provided the patients with a greater ability to adapt to their treatment. They had greater privacy, and therefore, could control the flow of information to family members. Participants appeared to have better adjustment or adaptation to their

circumstances at home. “The concept of engulfment provides an apt description of the overwhelming impact imposed by cancer and the transformation of self-concept over the course of the disease, its treatment, and the subsequent period of survivorship.” (Beanlands et al, 2003). According to Beanlands et al (2003), because cancer is associated with social stigma, “a cancer diagnosis thus distinguishes one from others in ways that redefines the self as devalued and compromises the sense of self worth.” Reduced engulfment and fewer reminders of illness were described as key components in the experience of receiving cancer treatment at home. This feeds back into the theme of home as a ‘natural habitat’ and a place of peace for participants. Overall, the flexibility of receiving chemotherapy at home proved useful for several reasons. Relating to adaptation, the nurses were able to provide additional support and teaching to assist them through this transition. The participants were also more receptive to this information and support.

Improved Care Provision and Reception

Throughout the interviews, several terms were recurring, including: ‘one-on-one’ and ‘personalized care’. The participants’ experiences of receiving treatment at home were affected by the additional care that the nurse was able to provide during the visit. This included teaching about the side effects of medications and emotional support. Participants were able to ask ‘embarrassing questions’. They also retained information better and were not overwhelmed by the hospital setting. Due to the nature of the pilot project and small numbers of staff, there was a high level of trust developed between the nurse and the participant.

Regarding the improved education time, and the ability to retain that information, John and Lisa said:

I found out that when I went to the (hospital) in the beginning, it was really overwhelming. They give you a lot of information. And probably a lot of it went over my head. I might have had a question and I might have had several questions. But I think I only asked one. And I don't even remember what the question is now. I felt a little better being able to do it at home. One on one. And so, that was important because it made my next sessions easier. I think it was no fault on the (hospital) at all, but with the one on one here at the house, the questions were asked and answered and remembered.
(John)

I was able to really talk to the nurses and the nurses had a lot more time with me. It was one on one time. So I got way more information from my treatment at home meetings than with my doctor. Every time you're (at the hospital) you fill out a form. Any concerns and stuff like that. I would say 8 out of 10 times, the concerns aren't even brought up. I'd write them down, but they're not even brought up with the doctor. I found that with the nurses, I was able to get so much more information. My concern "can I drink beer with Tamoxifen?" or something like that; if they didn't know the (answer), I would get a phone call that night or the next day from the pharmacy, saying yeah you can drink beer, or whatever. [Laughs] (Lisa)

Lastly, patients enjoyed the social context of their interactions with the nurses and felt there was an improved understanding of their circumstances. Diane describes this by saying:

It's not that it's personal. I mean, we don't sit down and have a beer. It's not like that. There's such a professionalism to them and there's a fine line between knowing they're the nurse and knowing I'm the patient. But it's total respect and total care. Total care. I can't say enough about those girls. It's knowing who's there and trusting them with all my heart. (Diane)

Discussion

Frank (2002) further articulates this by writing,

“After persons receive a diagnosis of serious illness, the support they need varies as widely as humanity itself. The caregiver's art is finding a way to allow the ill person to express his needs... I reserve the name “caregivers” for the people that are willing to listen to the ill persons and to respond to their individual experiences. Caring has nothing to do with categories; it shows the person that her life is valued because it recognizes what makes her experience particular. When the caregiver communicates to the ill person that she cares about that uniqueness, she makes the person's life meaningful. And that person's life story becomes part of her own, and the caregiver's life is made meaningful as well. Care is inseparable from understanding, and like understanding, it must be symmetrical.” (Frank, 2002, p.47-48)

Understanding a particular patient's situation is vital in providing care, and according to the participants of this study, by providing treatment in the home, nurses were able to better understand who they were as individuals.

Summary

For the participants of this study, receiving home chemotherapy was a “godsend” (Diane). Patients were eager to describe their perspectives of treatment at home, and often focussed strongly on the benefits of the program. Participants were, at times, encouraged by their spouses to participate in the pilot project. Overall, participants viewed the experience of receiving chemotherapy at home as in their ‘natural habitat’, facilitating their adaptation to the stresses of treatment. Subthemes were: realignment of resources with values; adapting to the experience of illness; and improved care provision and reception. Patients were not only satisfied with their treatment, but empowered to take greater control over aspects of their care. They were also better able to keep the focus on health, rather than illness. This service delivery model was highly regarded by all participants, and should be considered as a possible option in future cancer care planning.

Chapter Five

Implications

The demand for quality cancer care continues to grow. The aging population, increasing cancer rates among women aged 20-39 and the addition of biological agents to treatment regimes has created a need for improved service provision for patients.

In this study, participants described home as a ‘natural habitat’; a place of comfort, convenience, and security. Traditionally, many people argue that chemotherapy is best given in the hospital setting, but this research demonstrates that there are several reasons why we should consider moving cancer treatment into patients’ homes. Patients are often forced to fit the current health care system, rather than being permitted flexibility. Cancer is a chronic illness, one which can take years of treatment. The loss of control that patients experience is often frustrating, depressing and wearisome for the individual diagnosed. As healthcare providers, we must keep maximum focus on meeting the needs of our patients and not ourselves. By keeping day to day life as normal as possible, and creating that ‘natural habitat’, we allow individuals to enjoy the life that is extended or preserved by receiving chemotherapy. This promotes the goals of quality that most healthcare providers possess.

Safety is often in question, and as nurses, we always strive to protect our patients. Fortunately, the participants of this pilot project experienced no adverse events at home. One should also consider the risks of receiving treatment in hospital. For example, hospital acquired infections are quickly becoming a serious issue. According to Zoutman et al (2003), we can

expect that 220,000 occurrences of nosocomial infections will result in nearly 8000 deaths in Canada in one year. The nature of chemotherapeutic drugs makes our patients even more susceptible to these infections. Many of these infections no longer respond to antibiotic interventions. By treating patients at home, we might avoid this potential complication. However, the option of returning to hospital should always remain if chemotherapy at home becomes troublesome for the patient. Patients should be offered opportunities to interact with other cancer patients if this is a need they are experiencing. Investigations into the long term issues with home chemotherapy and constant re-evaluation should be undertaken.

Another part of the debate, as so often occurs in health care, relates to cost. Participants of this study spoke not only of the financial benefits of home chemotherapy, but also of their ability to redistribute time and energy to activities they valued. The literature in this area shows great disparity, and appears to be based on a variety of direct or indirect costs. It is often applicable only to the program under study. The question we need to ask ourselves is what are we willing to pay for quality cancer care? Should cost savings be valued from the perspective of the health care system or from patients living with cancer?

A recent article published by the Cancer Support Community (2010), an American organization, discussed the vulnerability of patients with financial strain and the potential for development of post-traumatic stress disorders. The report found that 81 percent of patients experienced 'moderate to severe' stress levels from the monetary burdens associated with care. According to Dr. Buzaglo, "the levels of post-traumatic stress reported were even greater than that of those who witnessed the terrorist attacks in New York City on September 11th and akin to

that of underprivileged, displaced survivors of Hurricane Katrina.” (Cancer Support Community, 2010). These findings are echoed in Canadian research. Longo, Fitch, Deber & Williams (2006) found that “a sizeable minority of cancer patients find the burden of out of pocket costs to be significant or unmanageable, even in a health care environment where much of the care falls within the public funding envelope.” The effects on caregivers were also noteworthy, with family members losing one third of their potential work days in a given month. Although some patients did receive government sponsored home care, 35 percent of patients overall used unpaid caregiver assistance. (Longo, Fitch, Deber & Williams, 2006). Reduced financial costs were certainly described by patients as an advantage to receiving chemotherapy at home. It would be extremely difficult to ever truly measure the economic complexities of this service delivery model. Therefore, we might need to focus on other aspects of the argument.

The concept of better adaptation to treatment or improved coping was a second concept described by participants. Some patients viewed themselves as less ill when they received treatment at home. There were fewer reminders of illness at home. Critics might argue that this is fostering an environment of denial. However, it is not that participants did not acknowledge their illness or take the appropriate actions to care for themselves, but rather, avoided the constant bombardment of their diagnosis. Suzanne Miller (2009) recently published an article on ‘healthy denial’ and describes this as “being able to acknowledge the diagnosis, communicate with the family, discuss a plan with the healthcare team, and then having processed it, move on to other life tasks. While it might look to others that we’re in denial, what we’re really doing is blunting the impact of the diagnosis so that it has the least psychological effect on our life and our psyche. This is actually a positive way to deal with the challenges of needed medical procedures, office

visits and other interventions.” (Miller, 2010) Anxiety and depression rates among cancer patients remain shockingly rampant, and it could be hypothesized that home chemotherapy might improve these figures. This is an area to be addressed by future research.

Improved care provision and reception was also described as a key component of the experience of receiving treatment at home. Participants were more likely to remember to ask questions and to remember the answers provided. The participants were better prepared to receive treatment, knew what to expect, and knew when it was important to seek help. It is possible that this may have resulted in fewer calls to triage nurses, saving time and hospital resources. From a nursing perspective, staffing levels are constantly under strain. In an outpatient department, a nurse may be managing anywhere from four to six patients at a time. Being in a patient’s home, although somewhat disorienting at times for an acute care nurse, allows the nurse to focus on the needs of that one patient in particular.

Limitations

Although the experiences described provide much information for consideration, several limitations should be kept in mind. Recruitment for this research study was conducted by the nurses working on the pilot project, and therefore, the potential for bias in patient selection must be acknowledged. Nurses may have chosen patients they felt were very satisfied with the program rather than those who had more negative views about home chemotherapy. An external evaluator, however, was also involved in this pilot project, and found similar positive results using likert scale questions.

Some of the participants may have had difficult treatments in hospital prior to participation in the pilot project, and therefore associated fewer side effects with being at home, when this was not necessarily the case. Nonetheless, although the majority of the treatments given in the home had low risk of anaphylaxis or extravasation, they had the same risk as treatments given in the hospital for neutropenia, nausea, vomiting, and alopecia. Furthermore, patients would have received at least one treatment in hospital prior to being accepted into the pilot study.

Patients with multiple co-morbidities were not accepted into the program, and therefore, results are limited to this population. Recruitment of patients who declined home chemotherapy was unsuccessful. There should be recognition that home chemotherapy may not be appropriate for all patients.

Areas for Development with Future Research

Further research is needed to describe the experiences of patients who receive harsher treatments at home and in those who are more acutely ill if care providers choose to expand this program. Although the effects on caregivers were described by the patients in this study, the views of caregivers themselves should also be examined in greater detail.

Quantitative research could be undertaken to examine the rates of anxiety-related nausea and vomiting, infection rates, depression or other measurable concepts comparing hospital administered chemotherapy to home chemotherapy. Finally, there should be continued efforts to describe the experiences of patients who choose to decline cancer treatment at home.

Summary

In summary, the experiences described in this research were undoubtedly positive and inspiring. For some participants, the option of having home chemotherapy allowed realignment of resources, adaptation to the experience of illness and improved care provision and reception. They received this treatment in a ‘natural habitat’; an idea that is strongly promoted amongst animal conservationists, but rarely among health care professionals. With the right level of care in the home, we can promote adaptation, or coping, to cancer treatment. Several of the participants in this study were receiving chemotherapy for palliative cancer, and having treatment at home allowed them to preserve precious hours for things they valued most. I strongly believe that this research suggests that the provision of treatment at home improves the experience of receiving chemotherapy for some patients. As the rates of cancer escalate, and the demand on the health care system increases, there will be pressure to shift services from the hospital to the community. The participants of this study not only accepted treatment at home, but saw it as a gift. There will always be situations where the provision of chemotherapy in hospital is necessary. But alongside this, home chemotherapy should remain a choice for patients with cancer.

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Appendix A

Eligibility and Exclusion Criteria for the Cancer Treatment at Home Program

Eligibility Criteria

1. Patient agrees to have home chemotherapy
2. Patient has a caregiver willing to participate in patient's care
3. Patient is medically stable
4. Patient and caregiver agree with treatment plans
5. Home is suitable for safe administration of chemotherapy
6. Home has phone, electricity and running water
7. Patient resides in Edmonton (and area)
8. Patient has access to emergency care
9. Initial course of chemotherapy given in hospital
10. Chemotherapy protocol approved for home administration

Exclusion Criteria

1. Previous anaphylactic reaction to currently prescribed chemotherapy
2. Severe physical or mental disability
3. Patient has multiple, chronic or unstable health conditions
4. Patient is on clinical trial protocol
5. Patient is receiving home care/palliative care service from other providers
7. Patient has poor venous access and is unwilling or unable to have a central line inserted

Note: The Cancer Treatment at Home program staff has the right to decline a referral if deemed necessary due to patient/nurse ratio.

Appendix B

November 1, 2009

Dear Sir/Madam,

We would like to invite you to take part in a study looking at your views of home chemotherapy. We are hoping to speak with people who have been offered treatment at home, and either accepted or declined. This study is not part of the Cancer Treatment at Home program. It is part of a thesis project being conducted by a student from the University of Alberta.

We are trying to understand the experience of receiving chemotherapy in the hospital or at home. We also want to know what factors lead to your decision about where to have your treatment. Our aim is to improve the quality of care received by cancer patients in the future.

Your taking part in this study is optional and will not affect the care you receive. Please read the enclosed consent form, and if you wish to take part, contact the investigators at the telephone number or email address below.

We recognize that you may have already taken part in other research projects, and appreciate your valuable contribution to this study. Thank you, in advance, for considering this project!

Sincerely,

Principal Investigator
Dr. Priscilla Koop, PhD, RN

Co-Investigator
Nicole Crisp, RN, BScN

If you wish to participate, please contact:

Simone Thompson
(780)432-8221
simone.thompson2@albertahealthservices.ca

Appendix C

INFORMATION SHEETPatient Perspectives of Home Chemotherapy

Principal Investigator(s): Dr. Priscilla M. Koop, PhD, RN

Sub-Investigator(s): Nicole Crisp, RN, BScN, Masters in Nursing Candidate

Background: You are being asked to take part in this study because you have been offered cancer treatment at home.

Little research has examined patients' own views about the strengths and potential problems of home based chemotherapy. We are interviewing patients to help us understand the experience of getting chemotherapy in the hospital or at home. We also want to know what factors contributed to your decision about where to have your treatment.

Purpose: We hope to identify benefits and drawbacks of home chemotherapy. Over time, we may be able to determine which patients are more likely to benefit from treatment at home. It can also help us identify why it may not be suitable for all patients.

We plan to use the information you give us to improve the quality of care for cancer patients having chemotherapy.

Procedures: In this study, you will be asked to participate in one interview, at a time and place convenient for you. This could be in your home or in a private meeting room at the Cross Cancer Institute. You will be asked five general questions about your views of home chemotherapy and your decision to accept or decline cancer treatment at home. This interview should take approximately 45 minutes. The interview will be audio-taped, but you can choose to turn the recorder off at any time. We will only interview you once, but we may call you if we are unclear about something you have said.

About 10 people will take part in this study at the Cross Cancer Institute. Five of these patients will have received chemotherapy at home, and five of these patients will have received chemotherapy in the hospital.

Possible Benefits: There may or may not be any personal benefits to participating in this study. Some participants may feel gratified that, based on the results of this study, patient care can potentially be improved.

Possible Risks: There is no expected physical risk involved with participation in this study. For some people, however, discussion of cancer treatment might be upsetting. If you are feeling distressed as a result of the interview, or for other reasons, a referral can be made to a psychologist/counselling services.

Confidentiality: Personal health information and interview transcripts relating to this study will be kept confidential. Any research data collected about you during this study will not identify you by name, only by your initials and a coded number. Your name will not be disclosed outside the research clinic. Any report published as a result of this study will not identify you by name.

Data will be kept for a minimum of five years, in a locked storage cabinet in the Clinical Sciences Building, University of Alberta. This will be under the care of the principal investigator. After this period, all material will be shredded.

Voluntary Participation: Your participation is optional, and you may decline to answer any of the questions. Participating in this study will have absolutely no effect on any services you receive from the Cross Cancer Institute or the Cancer Treatment at Home Program. You can choose to withdraw from the study at any time.

Contact Names and Telephone Numbers:

If you have concerns about your rights as a study participant, you may contact the Patient Relations Office of Alberta Health Services, at (780)342-8080. This office has no affiliation with the study investigators.

Please contact the individuals identified below if you have any questions or concerns:

Name	Email	Telephone Number
Nicole Crisp	nicole.crisp@albertahealthservices.ca	(780) 432-8221
Simone Thompson	simone.thompson2@albertahealthservices.ca	(780) 432-8221
Priscilla Koop	priscilla.koop@ualberta.ca	(780) 492-4338

CONSENT FORM**Part 1 (to be completed by the Principal Investigator):**Title of Project: *Patient Perspectives of Home Chemotherapy*Principal Investigator: *Dr. Priscilla Koop, PhD, RN*Phone Number:
(780)492-4338Co-Investigator: *Nicole Crisp, RN, BScN, Masters in Nursing Candidate*Phone Number:
(780)432-8221**Part 2 (to be completed by the research subject):**

	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to the information you provide?	<input type="checkbox"/>	<input type="checkbox"/>

Who explained this study to you? _____

I agree to take part in this study: YES NO

Signature of Research Subject _____

(Printed Name) _____

Date: _____

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT

Appendix D

Patient Demographics

Patient	Gender	Age	Marital Status	Occupation	Diagnosis	Treatment
A	f	60	Married	Seamstress	Peritoneal Cancer	Topotecan
B	m	70	Married	Civil Engineer	Colorectal Cancer	FUFA
C	f	36	Married	Retail Sales Associate	Breast Cancer	Herceptin
D	f	40	Married	Administrative Assistant	Unknown Primary	Gemcitabine
E	f	40	Married	ESL Instructor	Breast Cancer	Herceptin
F	m	45	Married	Heavy Duty Mechanic	Pancreatic Cancer	FUFA
G	m	72	Married	Retired	Colorectal Cancer	FUFA
H	f	78	Married	Retired	Colorectal Cancer	5- Fluorouracil
I	f	58	Married	Dental Hygenist/Instructor	Breast Cancer	Herceptin

FUFA- 5-fluorouracil, leucovorin combination chemotherapy

Appendix E

Field Notes and Interview Template

Patient Name:

Telephone Number:

Gender:

DOB:

Marital Status:

Ethnic Background:

Occupation:

Diagnosis:

Type of treatment received:

Treatment Location:

Scheduled Interview Date:

Scheduled Interview Time:

Interview Questions

1. Please tell me about the experience of receiving chemotherapy in your home.

2. What are the advantages?

