

Transition journey from hospital to home in patients with cancer and their caregivers: a qualitative study

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Abstract

Background The National Cancer Institute Singapore initiated the NUH2 Home program in January 2014, referred to as “Caring Across the Cancer Continuum,” a nurse-led cancer transitional care service (CTCS) that provides home care to patients with cancer and their caregivers. The study aimed to explore the transition experiences of patients with cancer and their caregivers.

Method Using a purposive sampling, 12 patients with cancer and 12 caregivers were recruited. Audiotape interviews were conducted until data saturation was achieved. Each interview was transcribed verbatim, and thematic analyses were performed to extract significant themes and subthemes.

Results Four themes emerged from the data including (1) ongoing concerns, (2) needing timely help, (3) resuming control and normality of life, and (4) appreciating the transition care. The transition journey of patients and caregivers provided them with an ability to regain control and normality in their lives, be reassured and confident in being able to care for

themselves and manage the physiological and psychological strains associated with the multiple vicissitudes associated with having cancer and its treatment while at home.

Conclusion Our study addressed the nature, patterns, conditions, and responses to transition care. Our findings provided relevant contextual knowledge to further improve the transition care service based on the recommendations of the patients with cancer and their caregivers who first experienced the new service.

Keywords Cancer · Caregivers · Chinese · Nurse-led · Singapore · Transition · Qualitative

Introduction

The global incidence of cancer is projected to have a 68 % increase, up to 23.6 million cases per year by 2030 [1]. In Singapore, the local National Registry Disease Office reported an approximate 10 % increase in the incidence of cancer from 2008 to 2012 [2]. The availability of new cancer treatments and advances in methods of detection has decreased mortality rates and longer survivorship requiring long-term treatment and follow-up care [3]. Singapore is facing a nursing shortage as the number of nurses to resident ratio sits at 60 nurses per 10,000 people thereby increasing the recruitment of international nurses from 11 % in 2011 to 24 % in 2012 to fill this shortage [4, 5]. With the hospitals also facing a bed crunch along with the shortage of nurses, the model of cancer care is evolving with increasing shifts away from institutions and to transitional care [6–8]. With these problems, the Singapore Minister of Health encourages hospitals to establish transitional care services. Thus, transitional home care services are increasingly being offered by hospitals in recognition of the population’s belief that “there is no place like home” [9]. However, without proper support and resources, this model

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of care could lead to increasing number of cancer patients that fall out of the protective environment of the hospital and a greater reliance on informal caregivers [10].

Transition care is defined as a broad range of services designed to promote the safe and timely passage of patients between levels of healthcare and across care settings [11]. Transition care provides home care services to individuals and families [12] such as in patients with heart failure and those needing palliative care [13, 14]. It has been found to benefit patients, their caregivers, and the healthcare system in reducing re-admission, improving post-hospitalization outcomes, minimizing healthcare costs, and ensuring continuity of care [15]. However, studies also reported that cancer patients and their caregivers experience numerous care breakdowns when transiting across care settings with caregivers assuming greater responsibility in managing patients at home [16, 17]. Unpredictable changes in disease conditions and responses to treatment make cancer patients susceptible to events that impact their physical and psychosocial life [18] such as fear of recurrence, depression, and loss of safety net at home [19]. Patients also reported the need to readjust their expectations of care receive at home and the sudden shift of responsibility to care for themselves [20]. Moreover, disease chronicity and complexity coupled with knowledge deficits and patients' functional decline accounts for the stress felt by caregivers of cancer patients at home such as grasping a new role without preparation leading to feelings of caring inefficiency and frustration [21, 22], anxiety, depression, fatigue, sleep disturbance [23], as well as managing their own health and well-being [24]. Despite these reported problems, home is still the preferred place for transitional care as patients perceived that being at home is consistent with meaningful recovery [21, 23]. In addition, home was found to increase their self-control over their condition and the type of care received [25, 26]. Similarly, caregivers reported that the home environment is the ideal place for delivering care after hospitalization [27]. These along with increasing complexity of care are the main drivers for the development of transitional care in oncology.

In January 2014, the National Cancer Institute Singapore (NCIS) established the NUH2 Home Program, referred to as *Caring Across the Cancer Continuum*, a nurse-led cancer transitional care service (CTCS) that provides home care to cancer patients and their caregivers. The service enrolls patients who are referred by their primary physician. The CTCS provides home visits and "Cancerline" telephone service by the nurses from 8 am to 5 pm, Monday to Friday. Home visits are scheduled based on patient's condition and needs with the initial visit within 2 days after discharge from the hospital. Patient assessment, advice for home and lifestyle modifications, reinforcement of caregiver training, education on the management of side effects from cancer treatment, management of central lines, and the administration of subcutaneous or intravenous

medications are types of home nursing care provided by the nurses. The frequency of subsequent visits is determined by patient's acuity. Such program is new in Singapore for cancer patients, and thus, the experiences of patients and caregivers need to be explored to provide guidance to further improve this new service. The purpose of this study was to explore the experiences of transition from hospital to home in patients with cancer and their caregivers.

Methods

Design and participants

The study employed a descriptive qualitative design consisting of a purposive sample of 12 patients with any cancer diagnosis, 21 years old and above, admitted to the CTCS more than a week, and had at least a single visit by the transitional care nurse. There were also 12 caregivers nominated by the patients recruited for this study. The inclusion criteria of being in the CTCS service more than 1 week was to ensure that there was sufficient exposure and experience in the service prior to the interview. Ethical approval was obtained from the Domain Specific Review Board (DSRB). All participants were informed about the purpose and nature of the study and obtained signed consent.

Study procedures

Eligible participants were recruited from the CTCS. One of the researchers conducted the face-to-face interviews at a time and place convenient to the participants. The interview guidelines (Appendix 1) were based on Meleis' Theory of Transition which comprises of four holistic concepts: nature of transition, facilitators and barriers of transition, responses to transition, and nursing therapeutics [28]. Broad, open-ended questions asking the participants to describe their experiences were used to start the interview, and the SOLER approach was adopted (sitting Square to the patient, with an Open position, Leaning slightly forward while maintaining Eye contact in a Relaxed position) [29]. Interviews were conducted in English for 22 participants and in Chinese for the other two participants. Data collection continued until data saturation was achieved that is when repetition of information and no more new information can be gathered from further interviews [30]. Patients and caregivers were interviewed separately using audio recorder ranging from 30 to 60 min.

Data analysis

Thematic analysis was conducted following Braun and Clarke [31]. The audiotape interviews were transcribed verbatim by the researcher who conducted the interview within 2 days after

the interview. The two interviews conducted in Chinese were transcribed verbatim in the native language. Two members of the research team who are well versed in the Chinese language verified the accuracy of the Chinese transcripts with the audiotape recordings. One bilingual team member translated the Chinese transcripts into English, and this was reviewed by another bilingual team member for accuracy. Two other members of the research team reviewed the transcripts with the audio recording to ensure accuracy. The English transcribed texts were read repeatedly and independently by all members of the research team, and recurrent words were manually identified and colour-coded. Texts which represented similar meanings were highlighted using the same colour to generate the codes. Tables were used to tabulate and collate the codes which appear to fall under a common meaning and compared among the researchers to ensure that there were no lapses in identifying the codes. Similar codes were condensed to concise the data into manageable themes that truthfully represent the participants' experiences, and differences were discussed until consensus was reached. Credibility, dependability, confirmability, and transferability as outlined by Elo et al. [32] were used to ensure trustworthiness of this study.

Findings

There were a total of 24 participants (12 patients and 12 caregivers) who consented to be interviewed. There were nine female and four male patients; the mean age was 53 (range=28 to 74); ten are Chinese, seven had retired from work, and seven were diagnosed with non-Hodgkin's lymphoma. The patients were cared for by either mothers, spouses, sisters, or children. The mean age of caregivers was 56.8 (range=35 to 76). Among the caregivers, seven were employed full-time or part-time. The duration of being in CTCS was between 17 and 135 days. The number of home visits by nurses ranged from 1 to 11 visits. A detailed description of the patients' and caregivers' characteristics is shown in Table 1.

Four themes emerged from the data including (1) ongoing concerns, (2) needing timely help, (3) resuming control and normality in life at home, and (4) appreciating the transition care. These four themes illustrated the participants' transition journey from hospital to home. The first theme depicted the multifarious vicissitudes experienced by patients and caregivers. The second theme revealed their need for timely help and their suggestions to further improve the CTCS. The third theme described the participants' contentment of being at home while the fourth theme exemplified the benefits of transition care to both the patients and caregivers. Within each of the theme, the subthemes provided the similarities and difference between the patients' and

caregivers' experiences of their transition journey as shown in Fig. 1.

Theme 1. Ongoing concerns

Patients and caregivers verbalized ongoing concerns with different antecedents. For the patients, the fight against cancer is often a difficult one. While they agreed that treatments were effective, being under the CTCS brought physiological and psychological strains in patients with cancer at home.

Patient (50yo, Male): The pain comes and goes. It is not like static. Today I felt this experience; the next one is a totally different experience. The pain was quite the same but things like feeling cold suddenly and feeling very hot, are two different sensations I also experienced.

Psychological strains were often associated with these physiological strains which were initially due to lack of readiness and feelings of shock from being transferred to home after treatment. They mostly reported physical fatigue that led to psychological strain at home.

Patient (60yo, Female): I started to feel a little depressed and sad in feeling so tired. Usually the first 7 to 10 days at home. I didn't feel so great, you just sit down, just feel lethargic, don't feel like doing anything, just sit by myself in solitude.

For the caregivers, their ongoing concerns were first related to assuming the new role, the difficulty in anticipating what was needed, and inability to effectively perform caregiving roles. They struggled with many uncertainties especially when dealing with patient's ever-changing symptoms from cancer and its treatment.

Caregiver (45yo, Male): These uncertainties made me feel incompetent as caregiver. You are not prepared for the role because you are not trained and not specialized to look after cancer patients.

The second ongoing concern was related to financial strain. While patients are covered by insurance, majority of insurance providers do not provide coverage for outpatient treatment. In particular, the CTCS is a novel health service in Singapore and, thus, there is still a lack of financial support mechanisms. For the full-time caregivers, they were mostly concerned with the loss of income.

Caregiver (62yo, Female): I have given up my job to look after my sister, so no income. So maybe there could be some kind of negotiations, like a scale or range where payment for home care is made within reasonable costs.

Table 1 Patients' and caregivers' characteristics

Patients	Age	Gender	Diagnosis	Marital status	Ethnicity	Employment	Caregivers	Age	Relationship	Employment
P1	32	Male	Hodgkin's lymphoma	Single	Chinese	Employed	C1	60	Mother	Part-time
P2	62	Female	Non-Hodgkin's lymphoma	Married	Chinese	Retired	C2	73	Husband	Retired
P3	60	Female	Hodgkin's lymphoma	Single	Malay	Retired	C3	62	Sister	Unemployed
P4	29	Female	Hodgkin's lymphoma	Married	Chinese	Employed	C4	58	Mother	Part-time
P5	67	Female	Non-small cell lung cancer	Married	Chinese	Retired	C5	35	Son	Employed
P6	56	Female	Hodgkin's lymphoma	Divorced	Chinese	Retired	C6	45	Son	Employed
P7	28	Female	Hodgkin's lymphoma	Single	Chinese	Employed	C7	50	Mother	Unemployed
P8	74	Female	Non-small cell lung cancer	Married	Chinese	Retired	C8	57	Son	Employed
P9	40	Female	Rectal cancer	Married	Chinese	Employed	C8	48	Husband	Employed
P10	68	Male	Hodgkin's lymphoma	Married	Chinese	Retired	C10	76	Wife	Retired
P11	50	Male	Non-small cell lung cancer	Married	Indian	Unemployed	C11	29	Daughter	Employed
P12	71	Female	Breast cancer	Married	Chinese	Retired	C12	60	Sister	Unemployed

Caregiver (48yo, Male): It's a little steep (transitional care cost), to the high side, you to apply for medical subsidy and the application process is very troublesome. The cost for transition care should be lowered as much as possible to help us.

Caregiver (48yo, Male): Saturday and Sunday I have no help, because you know the Cancer line is not available on weekends. So if, they can provide a 24-h service, it will be good because things always happen during night time like, pain management. I just need to talk to somebody to feel reassured.

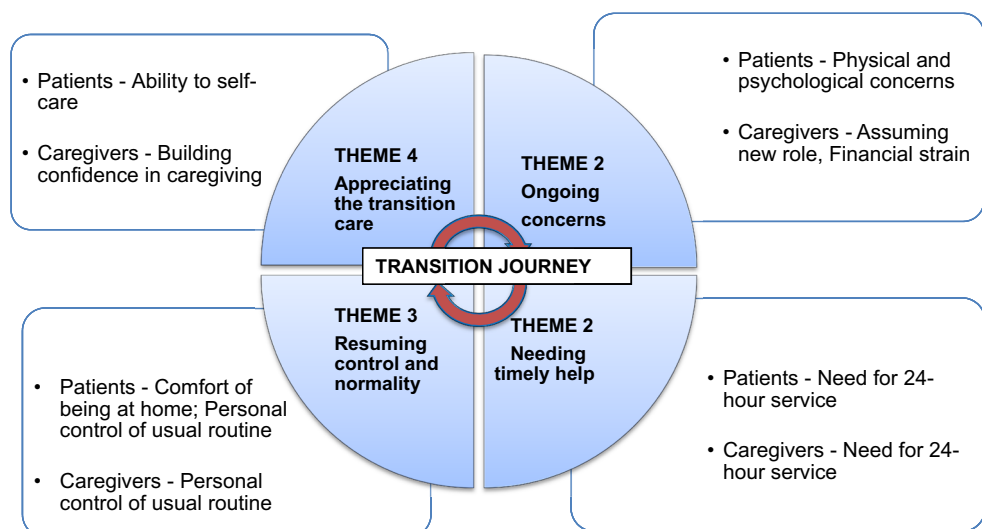
Theme 2. Needing timely help

With the ongoing concerns reported by the patients and caregivers, they voiced the need for timely help from the CTCS especially after hours and during weekends and public holidays as the current service is only from 8 am to 5 pm during weekdays. This was an issue especially during night time when community polyclinics and general practitioners are not readily available.

The need for timely help from the CTCS was also seen to reduce the need to travel to the polyclinic or hospital facilities that may further exacerbate their cancer or affect their condition.

Patient (28yo, Female): During non-office hours or during the weekends, if you do not have anyone to ask, if anything happens... you would just automatically go to the A&E which is not necessarily a good thing because

Fig. 1 Transition from hospital to home setting: themes and subthemes



there are so many people there and there are all sorts of funny diseases.... I just rather suffer the pain than to go to the polyclinic and get some infection.

Theme 3. Regaining control and normality in life at home

Patients and caregivers reported that transition care enabled them to once again regain control of their lives when living at home compared to being in the hospital setting. Patients cherished to be back to the comforts and familiarity of their home and being with family members and able to plan their own routine and usual practices (e.g., when to sleep, wake up, eat, listen to music, watch TV, exercise).

Patient (50yo, Male): In the hospital, I cannot make noise, I cannot do anything I want to do but at least at home, I feel happy, I can be with her (wife). I just walk here, walk there without restrictions.

Beyond the comfort, familiarity and personal control, being at home facilitated patient's spiritual healing. Patients turned to religion to alleviate their physiological and psychological strains as they see their home as the place for daily worship and fellowship.

Patient (71yo, Female): The only thing I can pray is to my God for divine healing. Turning on the radio station from Batam (Indonesia), because it is Christian, I keep listening to it and pray. Also, sometimes my church people come and pray with me.

Majority of the patients and caregivers verbalized having enjoyed the convenience of being at home. Without having to go to the hospital for appointments did not disrupt their routine lives as nurses visited them at home. In addition, being at home and visited by the nurses minimized the disruptions to their family members' routines as they do not have to go to the hospital to visit them or take them to the hospital for treatment and follow-up care.

Patient (67yo, Female): I am very weak. I cannot travel to the hospital by myself. I come from a small family. There is no one to drive me over, no one to accompany me to the hospital. They have to go to work as usual. I do not want to disrupt their lives as well. So when the nurse comes over to my house, it was a great help, a convenience to everybody.

For the caregivers especially those who are employed, they reported that they could plan their time better. They can go to work and leave the patient at home with family members,

domestic helper, or neighbor. They can call them when needed, and they can make arrangement to leave work.

Caregiver (29yo, Female): This kind of home nursing to me is very helpful because I am working. In the morning I have to go to work to support the family. With home nursing, I can go back to work full-time. I also felt reassured that I can leave my mother at home as she can call me any time when needed.

Caregiver (45yo, Male): In a Chinese family, I have to take care of them especially you are a son. I need to take care of my family.

Theme 4: Appreciating the transition care

The visits and care from the nurses provided reassurance and desire for patients to continue staying at home. They described the qualities of the nurses as the main reasons for feeling reassured. Although cancer and its treatment is disabling, many patients found ways to self-care. In particular, the education provided to them was useful in meeting their informational needs to better care for themselves.

Patient (67yo, Female): You see them working along with you, and they take the trouble to study your background first. She (nurse) knows all about my treatment and everything else. It helped me to know that even after I was discharged, there is some follow up to check up on my condition.

Patient (68yo, Male): I learned many things from the nurses. I can take care of myself and feel confident. I also do not need to disrupt the routines of my family but I know that if I need help, I can call on them [nurses and family members] anytime.

For the caregivers, in spite of the burden they experience in assuming the new role, the nurses' teachings and demonstrations at home increased their confidence to perform their caregiving tasks and, thus, alleviated their fear of making a mistake.

Caregiver (35yo, Male): They showed me how to do the dressing, how to put a tape properly and nicely. Even though I am a male caregiver, I learned so much from the nurses. Knowing what to do, I feel more confident. After a while, it was no longer a burden. We have to be filial, this is my responsibility as Chinese.

Caregiver (60yo, Female): They [nurses] taught me how to use those (commode and enema), to help my husband in passing motion. If fever is too high, then they teach us what to do, as well as taking blood pressure and all these.

Discussion

Transition care service for patients with cancer is a fairly new service in Singapore. The service needs to be evaluated, and this study was undertaken to provide information on the experiences of the patients and their caregivers. The sample size of patients in this study was small and mostly those with lymphoma because the transition care service at the time when this study was undertaken only comprised mostly of lymphoma patients. There were also more female (75 %) than male patients during our study compared to the current transition care gender distribution (55 % females). The ethnic distribution of interviewed patients was mostly Chinese when compared to the 82 patients in current transition care comprising of Chinese (63), Malay (17), Indian (1), and Eurasian (1). However, although this study reported differences in the diagnosis and ethnic profile when compared to the total cancer patients in the current CTCS, the type of needs and nursing care provided to the patients at home were similar in both genders and ethnic groups.

Ongoing concerns and needing timely help

The first two themes highlighted the strains experienced by both patients and caregivers but from different causes. Patients reported side effects and symptoms from cancer and its treatment because the eligibility criteria for admission to the CTCS are for those receiving active cancer treatments. The caregivers reported that the psychological strains they experiences were mostly related their lack of readiness and preparation to assume the role, which concurs with other studies [33]. In addition, caregivers experienced financial strains. There are several reasons that accounted for this strain. First, while the patients' basic medical service is free, medical insurance coverage does not cover costs for transitional care service and consumable items such as normal saline, catheters, and flushing of central lines are chargeable. Second, there is no financial and social benefits provided for full time caregivers. This result is similar to the study by Mittman et al. [34] where utilization of home care services has resulted in a greater financial strain in patients and caregivers.

Unlike other studies reported in the literature where children caregivers are usually daughters [33], the culture, context, and ethnicity of our participants, mostly Chinese, espoused familial responsibility. The Chinese cultural beliefs of Confucianism of filial piety dictate that the children especially the eldest son should be responsible for the care of their parents with respect, loyalty, and devotion [35]. Although caregivers reported financial strain, they accepted the transition care at home as they are then able to go back to work part-time or full-time to cover the expenses of the household and make up for their loved one's loss of income. In addition, the Asian culture, specifically Chinese, which made up majority

of the study population and among them, sons generally, assume financial responsibility [34]. In the Chinese culture, the son must be able to keep his obligation to one's family and should place the family's needs above his own by protecting and supporting the entire family [36]. In addition, the acceptance of caregivers for the patients with cancer to be cared for at home is that in the Chinese culture, a child that sends his/her parents to a nursing home might be seen as bringing shame on the family [37].

Resuming control, normality, and appreciating transition care

The ongoing concerns and the lack of 24-h service are somewhat overshadowed because both patients and caregivers saw the benefits of the CTCS. First, both patients and caregivers verbalized having the control and resuming the normality of their lives being at home. An increased control over their lives, better perception of health, and a reduction of the impact of cancer at home were also reported in other studies [3, 4, 8]. Our study also found that an increased personal control over their lives has increased patients' ability to engage in social activities as well as continue their religious practices. This reconnection with spirituality was valued because as it alleviated their psychological strains. As most of the Chinese participants in our current study practices Buddhism and Taoism, being at home was valued as they can practice their religion which helped them accept the reality of life with serenity [38]. In other studies, spirituality was also found to provide patients a beacon of hope [39, 40]. For the caregivers, transition care brought convenience, reduced the need for hospital visits, and provided reassurance, confidence in their caring abilities. Caregivers were able to return to work without too much worry about the patient being at home. This could be further explained because Asian family tends to have several generations living under the same roof, thus providing its members the support, security, and meeting the patient's needs while the main breadwinner is at work [41].

The participants appreciated the level of competency of the nurses conducting home visits and providing educational information. However, participants both agreed that there is a need for 24-h telephone hotline service to meet their needs at home. This hotline service is especially important especially when it was found that a timely access to telephone service helped patients better manage their condition at home and for caregivers to alleviate their anxiety and fear [42].

Study limitations

First, generalizability of our findings was limited due to the small sample size of 12 patients and 12 caregivers and predominantly Chinese. The transitional care service in our study is fairly new with an enrollment of 82 patients during the

commencement of data collection. Because of the high turnover rate of patients in the service, there were only few eligible patients who were well enough to participate in our study during the 6 months of data collection. Second, the study was limited in exploring the experiences of the Malay and Indian patients, and caregivers as participants in this study predominantly represent the Chinese participants' experiences. Third, participants were only interviewed once because of the cross-sectional design. It would have been worthwhile to determine how the experiences of patients and caregivers in transition care evolved over time.

Conclusion

Some of our findings are consistent with previous studies concerning ongoing concerns of patients in transition care. To the researcher's knowledge, there is no existing study that explored the transitional care experiences of Asian cancer patients. Thus, our study provided relevant contextual knowledge to further improve the transition care service based on the recommendations of the patients with cancer and their caregivers who first experienced the new service. Our study addressed the nature, patterns, conditions, and responses to transition care. In considering these elements, the findings highlighted that in spite of the strains experienced during transition journey, patients, and caregivers valued the transition care service as it provided them with an ability to regain control and normality in their lives, be reassured and feel confident in being able to care for themselves, and manage the physiological and emotional strains associated with the multiple vicissitudes associated with having cancer.

Compliance with ethical standards Ethical approval was obtained from the Domain Specific Review Board (DSRB). All participants were informed about the purpose and nature of the study and obtained signed consent.

Conflict of interest The authors declare that they have no conflict of interest.

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