



# An ethnographic inquiry into the psychosocial care for oncology patients in the community: Healing from the 4Es

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## ABSTRACT

**Purpose:** The aim of this study was to explore how the provision of community care in a cancer support center can help cancer patients and survivors cope with the demands of cancer and its treatment.

**Methods:** A focused ethnographic approach was adopted. Data were collected through participant observations and focus groups with various stakeholders. The data from the focus groups were transcribed verbatim and analyzed using constant comparative analysis.

**Results:** Four main themes emerged: 1. Enabling users to achieve mental well-being on their coping journey, 2. Empowering users to deal with their uncertainties, 3. Enhancing meaningful nurturing interactions through the design of spaces and colors in the Centre, and 4. Evolving through seeing more value in themselves. These 4Es occurred through intimate human interaction in the Centre, which resulted in psychological renewal and the rebuilding of a sense of self among the users.

**Conclusions:** This study provides insights on the provision of community support services for cancer patients/users, specifically on how to help them to regain control over their lives, not only through providing services for psychosocial renewal by engaging in intimate human interactions, but also by contributing to an understanding of the effect of the physical environment and space on healing. The results also reveal a virtuous circle of the 4Es as the synergies from the services, activities and the environment in the Centre, which provide a harmonious context for the users in coping with their cancer journey.

## 1. Introduction

Cancer care is undergoing an important shift from disease-focused management to a person-centered approach (European Partnership Action Against Cancer consensus group, 2014). However, owing to the busyness of clinical settings, attending to the physical care of the patients still takes precedence over the provision of psychosocial care. The need for improved psychosocial care for people living with cancer has been well documented but implementation into routine care is limited and health care providers experienced barriers in delivering the care (Dilworth et al., 2014). Hence, the lack of guidance and support for patients often leads to psychosocial distress. Patients with poor social networks exhibit worse mental functioning, higher levels of distress, and a lower overall quality of life than patients with good social networks (Parker et al., 2003). For cancer survivors, support from other survivors can relieve the stress that they feel from the fear of experiencing a relapse of their disease and discrimination by others (Wang et al., 2015). This makes it important to provide ongoing community support for patients. Currently, different kinds of care in the community

are available to cancer patients. There is the kind of care that is provided using an interdisciplinary team approach, involving oncologists, psychologists, psychiatrists, and social workers working together to train peer volunteers to provide emotional, social, and spiritual support to cancer patients (Hammer and Klein, 2012). Other kinds of support are available from trained peer counselors, such as community resources and information on trauma symptoms (Giese-Davis et al., 2016). Yet another form of support comes through the Internet, which enables patients to share their technical and emotional knowledge and experiences (Gill and Whisnant, 2012). Effective support has also been found to have been extended with the provision to patients of health education, behavioral training, and stress management programs (Kokavec, 2016) or with the inclusion of aerobic and flexibility exercises in a community-based exercise program (Cormie et al., 2017). Furthermore, it has been determined that participating in programs offered by cancer support centres can have a positive impact on patients in their coping journey, with patients feeling more satisfied that their needs have been met, such as experiencing relief from psychosocial distress and improvements in their functional well-being and level of

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**Table 1**  
Defining categories of focus group interviewees.

Patients	Volunteers	Professionals
Curative intent (CI) [2 groups]: <ul style="list-style-type: none"> <li>• Patients who were diagnosed early and being treated</li> </ul>	Befrienders (BF) [2 groups]: <ul style="list-style-type: none"> <li>• Past-patients or carers who had completed befriender training, regardless of the years of survivorship</li> <li>• A unique role in the Centre involving supporting other users socially and emotionally, or hosting activities that allowed for the sharing of experiences</li> </ul>	Nurses and social worker (N and SW) [1 group]: <ul style="list-style-type: none"> <li>• Nurses with training in oncology</li> </ul> Clinical psychologists (CP) [1 group]
Long-term survivorship (LS) [1 group]: <ul style="list-style-type: none"> <li>• Patients who had been diagnosed cancer for more than 5 years</li> </ul>		
Non-curative intent (NCI) [2 groups]: <ul style="list-style-type: none"> <li>• Patients who had experienced a recurrence of their cancer and were receiving palliative treatment</li> </ul>		

optimism (Edgar et al., 2003). Another study also reported that a cancer support centre located in a hospital brought comfort to users, allowing patients to make sense of their cancer experience and increasing their feeling of personal control (Williams et al., 2014). It was even described as an ‘oasis’ in the hospital, but just how the environment influenced the patients’ experience was not discussed. In addition, a model-based cancer support centre has been shown to increase patients’ satisfaction with the services that they received, to reduce barriers to accessing the available services, and to improve the patients’ understanding of cancer and its treatment (Corter et al., 2011). Given that how the interventions in cancer support centres and the environment in those centres work to achieve their effects has seldom been assessed in published studies (Cleary and Stanton, 2015), the personal experiences of stakeholders in the Centre merit our attention.

The aim of this study is hence to explore the essence of the psychosocial support provided in cancer support organizations in the community from the viewpoints of cancer patients, cancer survivors, volunteers and healthcare professionals.

## 2. Method

### 2.1. Design

A focused ethnographic approach was adopted, with an intensive study being conducted within a short period (Cruz and Higginbottom, 2013). The specifically defined cultural context was a cancer caring Centre for supporting cancer patients/users, and the focus was on the psychosocial support that it provides. A general picture of how the Centre operates was obtained through participant observations, which gave direction to the collecting of data in the subsequent in-depth interviews.

### 2.2. Setting

Different in design from a hospital, the cancer caring center in the current study (i.e. the Centre) is person-centered and provides free multi-professional services to both cancer patients, survivors and caregivers, for instance, counseling services, relaxation sessions, health and psycho-educational sessions, and support groups. The Centre is located next to a hospital. It is a single-story building, with a glass roof and walls. Entering the Centre, there are three main parts of the building where interactions usually occur: a red sofa at the entrance, a big round table, and an open kitchen. There are three activity rooms, each of a different color, namely orange, blue, and green. Various activities are held in the different rooms, for instance, relaxation and meditation activities are held in the blue room; meetings with psychologists are held in the orange room; and small information sessions are held in the green room. There is also a large mirrored room that can accommodate bigger groups, where support groups, psychoeducational workshops, medical or health talks, choir practices, meditative and

yoga classes, and other activities are held. Moreover, the Centre provides a great deal of free cancer-related information. There is a bookshelf filled with books on health and spiritual matters, which users can read in the Centre or borrow to take home. Outside of the building is a small garden with two ponds. Furthermore, there is a touch screen connected to the hospital system, allowing users while staying in the Centre to check where they are in the queue for the medical follow-up consultation at the oncology clinic of the hospital.

### 2.3. Participants

Purposive sampling was used to recruit participants for the focus groups. There are five types of participants under three mutually exclusive categories, i.e., 1. users as people living with cancer [i.e., curative intent (CI), long-term survivorship (LS), and non-curative intent (NCI)]; 2. volunteers as befrienders; and 3. professional staff [i.e., nurses (N), social workers (SW), and clinical psychologists (CP)] (Table 1). To promote a life-affirming identity, the Centre under study employs the term “users” to refer to patients, and the term “befrienders” to refer specifically to recovered patients who subsequently become volunteers at the Centre (Jencks, 1995). The notion of “befrienders” conjures up the sense of walking together with users, instead of simply volunteering to help them. The participants were recruited by the nurses in the Centre before being referred to the researchers. Focus groups were scheduled based on the availability of the participants. Each group consisted of five to seven participants. All five healthcare professionals (HCPs) were invited by the researcher to participate in the focus group interview representing the staff of the Centre. The recruitment of users continued until the point of data saturation. Written consent forms were obtained from all of the participants before the participant observations and focus groups were conducted.

### 2.4. Ethical considerations

The study was approved by the Human Subjects Ethics Application Review System of the university (Reference number: HSEARS20160212003). Permission to conduct the study was also obtained from the board of the cancer caring center. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committees and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

### 2.5. Data collection

To investigate the discrete culture in a cancer caring Centre, we followed the data collection strategies of ethnography – participant observations and focus groups (Cruz and Higginbottom, 2013).

Participant observations were conducted by the research assistant from June to September 2016. Assuming the attitude of not knowing

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