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ORIGINAL ARTICLE

Understanding context: A qualitative analysis of the roles of family caregivers of people living with cancer in Vietnam and the implications for service development in low-income settings

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Abstract

Objectives: Research on the needs of family caregivers of people living with cancer remains disproportionately focused in high income contexts. This research gap adds to the critical challenge on global equitable delivery of cancer care. This study describes the roles of family caregivers of people living with cancer in Vietnam and possible implications for intervention development.

Methods: Semi-structured interviews and focus groups with family caregivers (n = 20) and health care providers (n = 22) were conducted in two national oncology hospitals. Findings were verified via workshops with carers (n = 11) and health care professionals (n = 28) in five oncology hospitals representing different regions of Vietnam. Data was analyzed collaboratively by an international team of researchers according to thematic analysis.

Results: Family caregivers in Vietnam provide an integral role in the delivery of inpatient cancer care. In the hospital environment families are responsible for multiple roles including feeding, hydration, changing, washing, moving, wound care and security of personal belongings. Central to this role is primary decision making in terms of treatment and end-of-life care; relaying information, providing nutritional, emotional and financial support. Families are forced to manage severe complications and health care needs with minimal health literacy and limited health care professional input.

Conclusions: Understanding context and the unique roles of family caregivers of people living with cancer is critical in the development of supportive services. As psycho-oncology develops in low and middle income contexts, it is essential that family caregiver roles are of significant importance.

KEYWORDS
cancer, cancer patients, carers, caregivers, family care, LMICs, NCD, oncology, Vietnam

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1 | BACKGROUND

Sustainable Development Goals outline the need to reduce premature mortality from non-communicable diseases (NCDs) in low and middle income countries (LMICs). Essential to this is the development of culturally specific supportive care services which seek to support patients and families to live with and beyond disease. For interventions and services to be appropriately designed, it is necessary to understand context and culture regarding the role of the family, and how the roles of family caregivers are understood.

In Vietnam, an estimated 165,000 people are diagnosed with cancer annually. The majority of these cases present at a late to advanced stage and an estimated 115,000 people die from cancer per year. There are significant challenges in providing timely and effective cancer services, as well as significant barriers that create challenges in accessing services. Caregiver care research indicates that when someone is diagnosed with cancer, informal care is often provided by close family relatives. Caregivers are defined as any family members such as spouse, children or grandchildren who provide caring tasks. Providing informal care can have sustained impact on caregivers physical and mental health compromising their ability to carry out their cancer caring role.

This, in turn, can often impact on patient outcomes. This link demonstrates the need to understand the roles of family caregivers and their caring burden in order to support families and promote their health and wellbeing, as well as to optimize outcomes for patients. This is of critical importance in settings with limited resources. In a low middle income context, many families are forced to manage severe complications and health care needs, with minimal health literacy and limited health care professional input.

Understanding the roles of family caregivers and how care in LMICs like Vietnam is conceptualized is of significant importance in effectively developing interventions to address challenges faced by caregivers. No studies exist in Vietnam describing the roles of family caregivers specifically in specialized, central cancer hospital settings. The objective of this study was to understand how care is conceptualized within the Vietnamese context and to use this information to guide the development of interventions for cancer patients and their families.

2 | METHODOLOGY

Ethical Statement: Ethical approval was received from the Institutional Review Board in Vietnam of Hanoi University of Public Health in Vietnam (ref: 442/2018/YTCC-HD3).

The study employed a descriptive qualitative research design. Family caregivers and health care providers (HCPs) were sampled from two central oncology hospitals in Hanoi and Ho Chi Minh City and invited to participate in either a focus group or an in-depth interview (IDI). Convenience sampling was used to recruit both family caregivers and HCP. A selected HCP in each hospital identified family caregivers from current inpatient lists representative of multiple departments and cancer types. Commonly, Vietnamese family caregivers stay in the hospital with the in-patient. Family caregivers and patients were approached by HCP and informed about the study and caregivers were invited to take part.

No participants invited refused to take part in the study. Inclusion criteria for family caregivers were that they were currently caring for cancer inpatients at the hospital and were over the age 18. HCP were purposively sampled from different departments (internal medicine, radiotherapy, chemotherapy, surgery, palliative care, nutrition, and social work departments) in each hospital and invited to participate via email. Inclusion criteria for HCPs were that they were employed as a HCP at our study sites. All participants were fully informed about the study and provided informed consent to participate.

Prior to data collection, the team conducted consultations with caregivers (n = 12) and HCP (n = 23) to inform our methodological design and interview guide development. These individuals were not included within the study presented. This process allowed the team to design a data collection process with minimal disruption to caregivers and HCP. Semi-structured interview guides were developed by the research team based on key literature, and caregiver and professional feedback. The interview guide contained key questions regarding caregiver roles and experiences and needs for support.

IDI with HCP and separate focus group discussions (FGDs) with caregivers and HCP were then conducted in meeting and conference rooms within the hospitals in order to minimize disruption to routines of both caregivers and HCPs. The separation of caregivers and HCP during data collection was guided by our initial consultation phase to reduce power differentials and promote open discussion. Participants were offered IDI to accommodate schedules.

IDI/focus groups were conducted in Vietnamese and audio-recorded. Each IDI/focus group lasted on average 1 h and 15 min. Two Vietnamese female researchers who have extensive experiences in health qualitative research conducted all IDI and focus groups. Partial simultaneous translation (summaries and key points of discussion) into English was conducted by one of the Vietnamese researchers to allow the English-language team members (one female, and one male) to follow conversations and if appropriate input questions or probes without breaking the flow of discussion. Interviews were audio recorded and transcribed verbatim. The study has been reported according to Consolidated criteria for reporting qualitative research guidelines.

2.1 | Data analysis

Recordings were transcribed in Vietnamese and translated into English. Translations were checked by the Vietnamese research team, and nuances in language were discussed in data analysis meetings. Data was analyzed manually and inductively using thematic content analysis. IDI and focus groups were analyzed separately and combined together following identification of identical themes and codes. Codes and themes were collaboratively identified after reading and re-reading transcripts (in Vietnamese and English).
Analysis occurred face to face with the Vietnamese research team members traveling to the UK to conduct analysis. This allowed greater discussion of themes, implications, translational interrogation and discussion of nuance within transcripts. Field notes taken by all the researchers were also used to corroborate and deepen analysis.

Following completion of analysis, results were shared with both HCPs and caregivers at five oncology hospitals throughout Vietnam in Hanoi, Ho Chi Minh City, Da Nang, Hue and Can Tho, in order to validate and verify data and assess the geographic generalizability of our findings. The research team met HCPs ($n = 28$) and carers ($n = 11$) at each site to discuss the findings of the study in-depth. This allowed triangulation of data, allowing the team to establish that saturation had been achieved, and increased rigor and confidence in results.

### 3 | RESULTS

This study highlighted that family caregivers in Vietnam experienced significant burden in fulfilling five critical roles in the care for cancer patients. Roles included \(^1\) making decisions regarding treatment and care of the patient, \(^2\) taking responsibility in relaying information to patients, \(^3\) supporting the provision of basic needs and nutrition, \(^4\) providing emotional support, and \(^5\) providing financial support. Caregivers are almost exclusively family members, and caring is considered an integral family responsibility. Care is often provided collectively by multiple members of the family. These different roles and expectations offer both opportunities and challenges in providing effective care for people diagnosed with cancer, especially in a context in which the health system has limited capacity.

#### 3.1 | Characteristics of family carers in hospital settings in Vietnam

Family caregivers participating in our study ($n = 20$) were predominately female (65%) and aged between 29 and 72 years old. Carers (with one exception) were direct family members of the patient (e.g., spouses, parents, siblings, and children). Family caregivers were caring for family with breast, colorectal, esophageal, stomach, and ovarian cancer diagnoses. HCPs ($n = 22$) participants included staff in both senior and junior positions. HCPs represented different departments within hospitals including internal medicine, radiotherapy, chemotherapy, surgery, palliative care, nutrition, and social work departments.

Informal caregivers (the literal translation being: người chăm sóc không chính thức) are often referred to as "family persons" or "người nhà". Participants viewed the term "carer" as redundant in Vietnam as the role is synonymous with being a family member. At times the role of primary carer is conducted by elderly spouses who also have health issues. Despite the collectivist nature of caring, the primary burden at times falls upon elderly members of the family.

It was reported that, in general, personal and supportive care in Vietnam is not provided by health staff. All supportive care is conducted by family members who describe themselves as unskilled and lacking knowledge about health and health care. Caregivers reported having no prior medical knowledge or experience, leaving them unequipped to provide the multiplicity of caring roles required. It was noted that, for a minority of patients from affluent backgrounds, a "carer" may be employed to stay with the person requiring treatment in hospital. In these rare cases, such hired carers might have professional training.

Caring roles are often shared by multiple family members, meaning that the caregiver staying in the hospital often rotates among family members. This can create difficulties and challenges in providing continuity of care. It was noted that communication of information between doctors and multiple family caregivers was a challenge. Notably, despite the crucial roles that family caregivers provide for patients, there is often a lack of recognition or supportive resources for them within the health system, meaning that their needs are unmet.

Each day there is a different carer. In some case a patient’s family has eight children. They each take turns to look after the patient (FGD 2, nursing staff, hospital 1).

In Vietnam the family members take care of everything (FGD 4, doctors, hospital 2).

#### 3.2 | Making decisions about treatment and care

Participants indicated that medical decision making when a patient is diagnosed with cancer is the responsibility of the family caregivers and not only that of the patient. Decisions are often taken collectively, however with little information. Final decisions often rest on the oldest son or male in the family, especially if disagreements need to be resolved. Decision making is viewed as a significant responsibility, with family caregivers making choices regarding the selection of health care facilities, treatments, and/or whether to pursue treatment and giving consent for treatment. This decision making extends to the advanced stage regarding death and dying.

When I discovered that my mother was diagnosed with late stage cancer we had psychological problems (we were worried). The family is large (and had many opinions). People have little knowledge. Basically our family became united (in the decision) not to have surgery because it was too late and she was likely to die (FGD 1, caregiver, hospital 1).

Both the sick person and the family are worried of cancer, and they are not equipped with the knowledge, so they could not make right decisions with a clear mind (FGD 2, nursing staff, hospital 1).
3.3 | Responsibility to relay information

Family caregivers and HCP professionals noted that caregivers often act as mediators between doctors and the patients, deciding what information should be shared with the patients and what questions are the priority. HCPs reported that they often provide information about diagnosis, care and treatment directly to caregivers, and not patients. HCP expressed concerns that information was sometimes withheld from patients. Family caregivers often described taking paternalistic roles and shielding patients from difficult information about their diagnosis or prognosis. This responsibility of relaying information is often taken without any prior medical knowledge, and can be stressful and challenging.

There will be some cases where the patient’s family says that they do not want their mother to know. In that case I still examine the patient as usual but the disease prognosis was exchanged with the patient’s family (IDI 9, doctor, hospital 1).

The constant change of family members was described as frustrating by HCPs as they worried regimes of treatment were not shared or may be miscommunicated between family members. Consequently, the medications sometimes were taken inappropriately or incorrectly.

For example, (caregivers) are told to give the three day course of medications for patients. But they didn’t tell the other caregiver, they swap medications between the first day and last day, so that’s the wrong treatment (FGD 2, nursing staff, hospital 1).

3.4 | Supporting the provision of basic needs and nutrition

Family caregivers, especially from outside the major cities, often stay in or beside hospitals providing constant care and support for patients. Family caregivers often spend long periods of time away from other family and employment, sleeping in the hospitals (often on the floor) or in nearby motels. Family caregivers noted that they often assume responsibility for washing, feeding, dressing, hydration, moving, administering medications, and wound care. In addition to these basic needs, family caregivers played an important role in providing security for their family’s belongings. Notably, at times, family caregivers are ordered to leave the wards by HCPs at specific times, despite providing these essential needs.

When my wife came back from her operation she couldn’t move, so for three days after the operation I had to help her with the bedpan and feed her (FDG 1, family caregiver, hospital 1).

I learned all of that but I provide very little care in practice. I almost just follow doctor’s prescription rather than caring. We don’t bathe them or help them with washing hair or haircuts. For feeding, I just show the family members how to do it (FGD 2, nursing staff, hospital 1).

The role of providing nutrition and making nutrition related decisions was viewed as a major role of family caregivers. Within Vietnamese hospitals, meals are not commonly provided and therefore it is the responsibility of the family to provide all meals for the patients, with exception of some meals provided by charities. Family caregivers highlighted that the meals provided for patients should be nutritious and assist the patients’ recovery however because of either lack of finance or lack of knowledge or nutritional advice they were unable to provide nutritious meals.

3.5 | Providing emotional support

Family caregivers describe that providing emotional support for patients as well as other family members as an integral role. Family caregivers and HCPs reported that assisting with improving the mood of patients or increasing their motivation is a daily task. There was a common belief among participants that supporting carers in this role would help patients in their recovery. Family caregivers viewed themselves as best placed to understand their family member’s mood and feelings, and to know how to motivate them. However, this role put great strain on the caregiver particularly when they are managing their own emotional difficulties.

Usually we advise patients and encourage them to reduce the depression and comfort patients and families. Families are the most important to support and encourage the patient (FGD 3, nursing staff, hospital 2).

It was noted that when family caregivers cannot fulfill this role, when the caregivers own mood is negative, or in instances where families might abandon patients, this can create negative feelings for the person diagnosed with cancer.

Family members are very important in motivating and comforting the patient so the patient relieves depression. Usually, in the late stages, the patient is afraid of being abandoned because there are many caregivers in his time (Because caring takes a long time), they are depressed and not able to afford (treatment) anymore. They might abandon the patient. Patients are afraid of that (FGD 3, nursing staff, hospital 2).

Generally, HCPs only intervened to support the emotional health of both patients and family caregivers for those patients with
the most severe mental health issues and who required psychiatric care.

Most of the patients initially are very worried about their illness. When explaining to the patient they will worry more because they are worried or anxious. If I’m not sure how to treat, I have to transfer psychiatric examination. Here we don’t have psychologists (IDI 4, doctor, hospital 1).

### 3.6 Providing financial support

The long-term chronic nature of cancer means a prolonged and often expensive treatment process. Family caregivers play significant roles in paying for treatment, and out-of-pocket expenditure. While insurance supports some costs, it often only covers a proportion of some treatments, and does not cover out-of-pocket expenditure. Out-of-pocket expenditure includes transportation costs, cost for buying extra medicine (traditional medicine, supplementary food and drugs) and paying for accommodation close to the hospital.

The expectation that family caregivers stay with their family in the hospital means that for many they will lose income. Given the lengthy nature of cancer treatment, this can mean extended periods of time with lost income. The financial burden of providing informal care caused extreme worry and pressure for family caregivers.

The first time, I spent up to 10 million on rent. In the early days (of hospitalization), I did not know where to find popular motels, I went to one with very bad quality. I wished there was information on the accommodation nearby in the Internet so that people like me don’t have to suffer that much (FGD 1, family caregiver, hospital 1).

### 4 DISCUSSION

The needs and challenges for family caregivers in Vietnam have been documented in other studies, as have the wider systemic challenges for patients accessing, using, and paying for cancer services. To date, however, the specific roles of family caregivers have not been well described. This is an important gap, as how families perceive their roles and how they conceptualize “care” has significant implications for the design, content, messaging and delivery of future supportive resources and interventions.

Family caregivers in Vietnam play multiple highly important roles in the care of people diagnosed with cancer, and often those roles are conceptualized as an integral part of family life. Unlike peers in high income contexts, caregivers lack visibility, recognition, and explicit support especially in medical system. The lack of terminology to describe family caregivers reflects this intrinsic nature of caring within Vietnamese families and how this limits the development of support.

The roles and experiences of family caregivers are not universal but are driven by context and culture. Notably, this study showed five critical roles fulfilled by family caregivers in Vietnam, including, making decisions regarding treatment and care of the patient, taking responsibility in relaying information to patients, supporting the provision of basic needs and nutrition, providing emotional support, and providing financial support. Vietnamese families have a strong sense of obligation as traditional Vietnamese family values is one of cultural characteristics rooted in the triple teachings of Buddhism, Confucianism and Taoism. In relation to health, families are often involved in health-related decisions for individuals. Often relatives have to be in agreement before their family member can start or continue a therapeutic program. This finding is of particular importance in the development of supportive care as often the evidence in high income countries has focused on the development of interventions for the patient or a dyad. This approach may not be appropriate in other contexts.

Findings from this study indicated that in a hospital setting, families act as “mediator”, taking responsibility for what information should be relayed to the patient. This role is in contrast to those family caregivers in western contexts with many reporting being excluded and ill-informed in decisions. Importantly, service development must recognize the family caregiver as decision maker and include assistance for them to make fully informed decisions.

Often decisions are made by the eldest man in the family, especially when disagreement occurs. Elderly parents usually live with their sons, especially the oldest son, who is expected to take responsibility for their parents when they are old. Future interventions should recognize these gender and family dynamics and be shaped appropriately.

Due to the lack of psycho-oncology provision, families assume the role of counselor and emotional support. HCP lack formal psychological training. There is a need for further psychological training particularly in the area of oncology for health staff, as well as guidance for family caregivers in how to share bad news on diagnosis and treatment effects. Previous studies suggested that, despite the need for psychological support, there is an absence of high-quality studies to support the use of interventions to support cancer caregivers and to assist in the development of supports in LMICs.

#### 4.1 Study limitations

Due to the qualitative nature, this study was unable to explore the difference in caregivers group in relation to gender, geographical areas (urban vs. rural), age (young vs. elderly) and relationship of family caregivers to patients. It may be the case that caring roles and support provided for family caregivers are varied among different subgroups. A quantitative survey exploring caregivers with different characteristics may be beneficial to develop a comprehensive...
understanding of caregivers roles and identify measures to provide effective support.

4.2 | Clinical implications

The nature of care for someone diagnosed with cancer brings significant new challenges for many family caregivers throughout Vietnam. As cancer incidence increases steadily in the country, this burden is expected to grow as is the need for specialized supportive oncology care. The nature of informal cancer care is typically long-term within a hospitalized context which in turn creates great financial, time and emotional burdens. While the current model and perceptions of care in Vietnam in which family caregivers spend extended time with patients and care for a multitude of different needs, may have been feasible for short-term illness; the long-term, complex and hospital-based nature of cancer care may require different approaches.

There is an urgent need for new supportive resources for family caregivers of people diagnosed with cancer. Such a resource needs to be cognizant of how caregivers perceive their roles and the role of family, as well as their needs. Researchers from high income contexts looking to support Vietnamese collaborators in the development of interventions in this area, should appreciate the collectivist, family-centric approach to care, and the multiple roles played by families in taking decisions, relaying information, and providing basic needs. In response to needs identified, the team are currently developing an online supportive intervention for family caregivers which recognizes and responds to the unique and multiple roles conducted by caregivers providing support for a patient with cancer in Vietnam.

5 | CONCLUSIONS

Family caregivers play a vital and central role in the delivery of cancer care in Vietnam. This role however comes with great burden and with no formal support. Culturally and contextually appropriate interventions or resources that are cognizant of how care is conceptualized in Vietnam, and how the roles of family caregivers are perceived, should be developed.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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