

Ways of Managing Palliative Care Needs of Adult Cancer Patients at Home in the Context of Pakistan: A Qualitative Approach

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ABSTRACT

Background: Cancer is a leading cause of global morbidity and mortality. Sufferings of the terminal stage, adult cancer patients can be alleviated through palliative care. Such patients prefer getting palliative care at home.

Aims: The objective of this study was to discover the ways by which palliative care needs of adult cancer patients are being managed at home, in the context of Pakistan.

Methods: For this qualitative study, data has been collected from 24 participants (patients n=12, family members n=12) via semi-structured, open-ended interviews.

Findings: The findings revealed that the palliative care needs of adult cancer patients are being met at home in four dimensions such as; physical, psychosocial, religious, and financial.

Conclusion: Family members were found as the strongest support for adult cancer patients in order to meet their palliative care needs at home.

Keywords: Cancer, palliative care, home, Pakistan, adult, qualitative.

INTRODUCTION

With an approximation of 19 million new cancer cases and 10 million cancer-related deaths in 2020, Cancer became the prominent cause of morbidity and mortality, worldwide [1]. In Pakistan, 178,388 new cancer cases and 117,149 cancer-related deaths occurred in 2020 [1].

“Palliative Care” was recognized as a crucial component of comprehensive cancer care by the 58th session of the World Health Assembly, in 2005 [2]. According to the World Health Organization; physical, psychosocial, and spiritual problems of greater than 90% of advanced-stage cancer patients can be alleviated by means of palliative care [3].

Additionally, due to the escalating cases of cancer patients globally, the demand for palliative care is also increasing speedily. Also, in Pakistan, approximately 80-90% of cancer patients show up in the healthcare setting at the terminal stage of cancer (stage III & IV) and in this situation, their requirement of receiving tender loving care at home, surges; when the curative care declines at the terminal stages of the disease; the role of palliative care rises [4]. In addition, these advanced-stage cancer patients wish for dying in their homes [5] and the situation in Pakistan is also identical in this regard [4, 6, 7].

Fortunately, the family and social support systems are highly strong in Pakistan. For this reason, mostly in

Pakistan, adult cancer patients receive palliative care at their homes from their informal caregivers such as; family members, relatives, neighbors and/or friends. Thus, for this reason, various ways are being used by informal caregivers for meeting the palliative care needs of adult cancer patients at home.

Research on the subject of palliative care is limited (n=4) in Pakistan [8-11], and has been conducted on the subjects of knowledge, attitude and practices of Pakistani physicians about palliative care and palliative medicine; palliative care needs of adult cancer patients; and on evaluating the impact of palliative care treatment on the self-esteem of cancer patients. However, as per the researcher’s knowledge, no research has been done in Pakistan for exploring the ways by which the palliative care needs of adult cancer patients are being fulfilled at home in Pakistan. Hence, this subject remains an under-researched theme in Pakistan. Therefore, the objective of this study was to explore the ways by which the palliative care needs of adult cancer patients are being managed at home in the context of Pakistan.

Research/Interview Question

- What are the ways by which the palliative care needs of adult cancer patients are being managed at home?

BACKGROUND REVIEW

Qualitative research conducted in Northern Ireland on the subject of assessing palliative care needs of adult cancer patients found that the core components

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of palliative care needs are; social and psychological support, financial support, and the necessity for choice and information [12]. Likewise, an investigation was carried out on advanced-stage, adult cancer patients (n=246) in Australia, in which most of the patients recognized their utmost needs as psychological support need; and the medical communication and information needs [13]. Similarly, secondary data analysis was done in North Carolina which discovered that assistance in daily living activities is the major palliative care need of cancer patients (n=4,980) ineligible for admission to hospice settings [14]. Also, a telephonic survey of advanced-stage cancer patients (n=169) was carried out in the United States in which their supreme palliative care needs to be emerged in psychological/emotional (62%) and symptoms (62%) domains [15]. Moreover, a Japanese study of cancer patients (n=807) concluded self-management as their highest concern impacting their quality of life, followed by other various needs affecting their quality of life [16]. Besides, a systematic review in which studies included were mostly from the western countries; uncovered that the largest unmet needs of the cancer patients were daily living activities followed by the psychological, information, psychosocial and physical domains [17]. Also, another systematic review revealed effective communication with healthcare professionals and the psychosocial domain as the most common unmet needs of cancer patients [18]. Recently, a qualitative inquiry realized the palliative care needs of adult cancer patients in Pakistan in the domains of physical, psychosocial, religious, financial, and healthcare system needs [11].

As, the above literature background discloses that no research has been conducted to identify and explore those approaches by which the palliative care needs of adult cancer patients are being managed at home in Pakistan; therefore, this condition determines the necessity of conducting a study in Pakistan on the above-stated matter.

METHODS

A total of 24 study participants including adult cancer patients (n=12) and their family members (n=12) were recruited from the community for this qualitative study by using the snowball sampling technique. The inclusion criteria for the participants included being adult cancer patients; having any stage, site, and treatment of cancer; family members providing most of the care to the patients; being willing to participate in the study; being willing to provide written consent, and can understand and communicate in English or Urdu language. However, patients having formal or paid caregivers were excluded from being recruited for this study. The data was obtained through in-depth, semi-structured, face-to-face interviews, with patients and their family members, at the participants' homes. No further information was gathered once the data attained saturation.

DATA ANALYSIS

According to Polit and Beck (2017) [19], as cited by Creswell (2013) [20], data collection and data analysis happen concurrently in qualitative research. For this reason, the data analysis for the study was initiated with the initial interview. The interview transcriptions were validated with the audio recordings of the interview. As in qualitative research, an accurate and deep understanding of the data cannot be secured until the researcher becomes acquainted with the data completely (Polit & Beck, 2017) [19], the researcher read and re-read the transcripts to become fully conversant with the data.

The analysis of the data began with the reporting of the main observations made by the researcher while interviewing the participants. After that, the interviews were transcribed. The transcription of the interviewer or the voice of the researcher was written in bold font, whereas the transcription of the patients' voice was underlined, and the transcription of the voice of the caregivers was written in an un-bold and un-underlined font. In addition, the voice of the researcher, patients, and caregivers was matched with the written transcriptions for verifying the accuracy of the written transcription.

After verification of the written transcriptions, the transcribed data was organized and indexed. Later on, the categories were developed and the data was coded according to the developed categories. As mentioned by Polit and Beck (2017) [19], there are no precise or specific rules to do this task. Researchers conducting descriptive studies, by nature, tend to form concrete categories of the data. Furthermore, the content analysis approach is used for analyzing the data, as this is used for analyzing the narrative data for discovering the major themes and patterns (Polit & Beck, 2017) [19].

The precision of data interpretation was supported and validated by the participants' narratives. Field notes were referred often to as the sources of data. During the study, the thesis supervisor and thesis co-supervisor were consulted for confirming the approach used in data analysis.

RIGOR OF THE STUDY

In qualitative research, it is the researcher's responsibility to confirm the trustworthiness of the study's findings. In this regard, Guba has proposed four criteria on which the truthfulness of the study findings can be analyzed. These four criteria include credibility, transferability, dependability and confirmability [21].

Credibility

Credibility or truthfulness deals with the internal validity of the study and can be achieved through different methods, such as triangulation, in-depth analysis, and getting thick descriptions of the phenomenon [22]. The triangulation in this study was achieved by obtaining information from more than one source; such as interviews taken with patients and the caregivers also,

to verify their responses. In addition, patients' medical records were also checked for assessing their grade of cancer. Moreover, skillful interview techniques were also applied while taking interviews, like asking open-ended questions to create descriptions, searching for meaningful insights, and asking questions in an organized manner to help the participants give deeper and richer responses. The researcher also probed to elicit in-depth information from the participants.

Transferability

Transferability is concerned with the external validity of the study [22]. The researcher ascertained the transferability of the study by reporting contextual and sufficient descriptions of the sample and setting, and the results of the study. This means the results of the study can be transferred to similar settings and contexts. However, the similarity of the results is not guaranteed in other settings and contexts.

Dependability

Dependability confirms the reliability of the study [22]. Lincoln and Guba (1985) [23] indicate a strong connection between credibility and dependability [21]. In order to obtain the dependability of the study findings, the researcher verified each transcription and made necessary changes where discrepancies were found between the interviews and the transcriptions. After reading the verified transcriptions, the researcher made preliminary categories of the findings. Then, these categories were refined after having detailed discussions with the research supervisors. After the refinement of the preliminarily formed categories, the number of categories was merged and reduced to form the basis of analysis.

Confirmability

To determine the confirmability of the study results, the categories of the findings were supported and validated by the words and quotations of the participants. The study findings and codes were verified, and the categories were formed in consultation with the research experts, such as the research supervisor and co-supervisor.

The ethical approval (Ref. #: 4568-SON-ERC-16) for this study was obtained from the Ethical Review Committee (ERC) of the Aga Khan University (AKU).

FINDINGS FROM THE INTERVIEWS

Findings from the interviews described that the palliative care needs of adult cancer patients are being managed at home in four dimensions; physical, psychosocial, religious, and financial.

1. Physical Dimension

On account of disease and/or its treatment, participants had to face limitations in meeting their physical needs of daily living activities and self-care, which they managed with the help of their family members as a patient verbalized, "My mother, sister, children, and husband supported me a lot.

They would hold my hand and take me inside the washroom [toilet]. They would stand there so that I do not fall, faint, or get dizzy" (Pt-12).

In addition to having family support, some patients organized things such that they facilitated them in performing self-care activities; as one of the patients described, "I keep a water thermos, a water glass, everything on my side table, close to my bed, for my easy access" (Pt-01).

Moreover, patients also modified the ways in which they used to carry out errands; like a caregiver explained, "My mother does those tasks which can be performed while sitting, such as folding clothes and cleaning the bedside table" (Cg-01).

A few participants also mentioned the role adjustment for fulfilling the physical needs at home. For instance, one caregiver (husband) stated, "After the job, when I come home, I cook, do housework and dishes. Earlier, my wife used to do all the chores but now she does not have the energy" (Cg-08).

2. Psychosocial Dimension

The disease, treatment, and its side effects affected socialization and psychological dimensions of the patients which they overcome by adapting alternative ways, like a female patient disclosed, "I used to tie a scarf on my head and went outside or attended weddings" (Pt-02).

Another patient mentioned, "I would go out everywhere. I attended all the weddings. I used to wear my wig and attended those weddings when I was bald" (Pt-12).

A caregiver illustrated, "She [wife] used to wear a mask while going outside. We would not go to dusty places where there could be dirt. We visited malls but we would not let her eat anything outside" (Cg-07).

Also, courage, self-motivation and the use of willpower by the patients helped them to maintain their emotional and social wellbeing; as one of the patients elaborated:

I had lost my hair so I got a wig to wear outside. I get ready in the same way as I used to do previously. It was not pleasing to see myself. My complexion turned dark, my head and eyebrows lost hair, and my face swelled up. But I never let it stress me. I visited temples, churches, parks, cinemas, hotels, and attended weddings also during chemotherapy sessions and that too; I did without wearing a mask. (Pt-09)

The family also played an important role in fulfilling the psychosocial needs of the patients; like a caregiver replied, "We gave him [father] support and made him understand that there are treatments for such

cases. He was in a bit of tension but we counseled him and supported him, so he eventually got better after that" (Cg-06). Another caregiver replied, "When chemotherapy started, we provided her [mother] with a wig to help her with the situation. There was a family wedding that we made her attend. We never made her feel that this is a problem" (Cg-24). Besides, engaging the patient actively, a caregiver explained; "We kept her [mother] busy always and did not treat her as a patient. We ensured that she went out and did small chores. We did not make her feel like a patient who could just sit around and rest" (Cg-03). Additionally, the family also encouraged patients to use social support organizations that existed in their neighborhood. For example, a caregiver mentioned, "She [mother] regularly visits the Senior Citizen Home where she exercises daily. So, we make sure that her physical and social activities continue" (Cg-22).

3. Religious Dimension

The patients modified their way of observing religious practices due to the disease process or the course of the therapy, as one of the caregivers stated, "He used to go to the mosque for offering prayers, but now he offers his Namaz [prayers] at home" (Cg-04). A caregiver explained, "She [patient] offers Salah [prayers] on a chair. She cannot offer Salah [prayers] standing or sitting or bending, because she gets stomach cramps when she does" (Cg-11). Similarly, a patient mentioned, "Now I am unable to attend Jamat Khana [mosque]. I am bedridden and cannot walk. So, I just sit on the bed and offer my prayers on the bed" (Pt-05).

Although patients continued with their religious practices in a modified way, they were not fully satisfied with it. A patient illustrated, "Offering Salah [prayers] as instructed and prostrating by putting one's head on the ground is different from offering Salah [prayers] on a chair. There is a great difference" (Pt-11). Another patient articulated, "It is about the comfort and peace that I have when I offer prayers in Jamat Khana [mosque]" (Pt-13).

4. Financial Dimension

Because of the higher diagnostic and treatment cost of the Cancer, participants tried to manage their financial challenges by different resources, such as, selling their assets and valuables, and taking help from close and extended family members, friends, unknown individuals, and welfare institutions. As one of the participants stated:

I sold my house, her [wife] gold, and now we are living on rent. My money was utilized in her treatment. Other than that, I went to a lady at Clifton. She used to give Rs.10,000/- for each chemotherapy session. So, I tried everything that was possible. (Cg-13)

Another participant expressed:

Financially I faced lots of crises. I got help from my brother, in-laws, and friends. My daughter works in a beauty parlour to meet her expenses. I got aid from the welfare department of the hospital and other organizations also. There are household expenses as well that have to be dealt with. So, I am living on help now. (Pt-07)

Also, family members of a few of the participants migrated to another country for managing the treatment and household expenditures, such as a participant revealed:

Other than those 50,000 rupees that my brother had to spend monthly for medications, he needed to have a certain amount to support his own family; wife and children and other household expenditures also. Therefore, he migrated to Africa for earning a good sum of money so that we could afford all these expenses. (Cg-03)

Some of the participants also changed the treatment place from one hospital to another hospital like a caregiver shared, "A doctor suggested to us to go to the hospital ### [name]. The hospital ### [name] performs the diagnostic tests itself, and we have to buy the medicines only" (Cg-01). Additionally, a patient also communicated:

I was prescribed to get 25 radiations, the cost of which was estimated as three lac rupees but I could not afford that amount. So, a doctor advised me to get it done from the hospital ### [name] and we followed it. (Pt-02)

DISCUSSION

The purpose of this descriptive exploratory study was to identify the ways by which the palliative care needs of adult cancer patients are being managed at home in the context of Pakistan, either by themselves or by their family members. The study findings revealed four important dimensions in which the palliative care needs of adult cancer patients are being managed at home, in Pakistan. These are; physical, psychosocial, religious and financial dimensions.

The findings revealed that in the Pakistani culture, family members of the patients facilitate them at their homes in performing their daily living and self-care activities, and in domestic tasks. Unlike the occupational therapy service in the developed countries [24, 25], in this study, family support was an important source of assistance for patients in managing their limitations in physical functioning. The relatives, including close and extended family members of the patients, in this study, did all household chores and helped patients in performing their daily activities, as the patients had reduced capabilities of self-care. This is because, in the Pakistani culture, family ties are strong between close and extended family members [26, 27].

This study also uncovered that patients received psychosocial support in their homes from their close and extended family members in times of trouble and tribulations. The answer for this finding lies again in the strong family value system present in the Pakistani culture where all the members of the family extend their support to each other [26, 27].

Although, in this study, no differences were found between the patients receiving their family support based on their sex, however; the results of a recently conducted study revealed that the male patients receive more support from their family members as compared to the female patients because a patriarchal family system is being followed in Pakistan where a male is regarded high due to his authority and power in the family [28].

Another different result reported in a study was related to the stages of the chronic disease and the level of support received by the patients from their family members [29]. According to that study, as the chronic disease progresses to the advanced stage, the family support received by the patients is declined due to the increasing demand for family support and fatigue experienced by the family members; as a result of the advancement of the disease [29]. However, the same study reported that the issue of reducing the level of familial support to patients could be addressed successfully in a family that has more number of family members as compared to those having less number of members in the family [29].

STRENGTHS

Following are the strengths of the current study:

- It is probably the first cancer-based palliative care study, conducted in-home healthcare settings in Pakistan.
- Not only were the patients included in the study, but their family members (as informal caregivers) also participated in this study.
- This study was not limited to the patients having only one or specific site of cancer, rather it included patients having different sites of cancer.

LIMITATION

As the interviews were conducted in the native language, so, a few cultural things may have been lost while translating the information from the native to another language.

RECOMMENDATIONS

For the purpose of breadth and depth of understanding of the way the family system works in managing the palliative care needs of adult cancer patients at home, mix-method studies should be conducted in the future.

STUDY IMPLICATIONS

For Practice

The findings suggested that healthcare professionals can improve the quality of care provided to the adult cancer patients at home, in the following ways:

- A cancer-support group can be initiated in which success stories of participants positively managing their needs at home, should be shared with other cancer patients for encouraging and motivating them.
- Patients should be encouraged to live an active life as much as possible by modifying their activities according to their condition.
- Healthcare professionals should provide timely, accurate, and practical guidance or information to the family members regarding managing patients effectively at home.

For Healthcare System

The findings suggested that the following improvements are required in the structure and processes of the existing healthcare systems to support cancer patients receiving palliative care at home:

- Home-based healthcare services should be provided to cancer patients.
- Rehabilitation services for such patients should be initiated, comprising customized physical activities, sports and exercise classes, psychotherapy sessions, and social get-to-gather or outings.
- Where applicable; smart-phone-based health care services should be launched to benefit patients, their family members and healthcare organization.

CONCLUSION

The findings of this study highlight the importance of having strong family values and the strong family system, that are existing in Pakistan; by which the adult cancer patients were able to manage their palliative care needs in their homes.

ETHICS APPROVAL

The ethical approval (Ref. #: 4568-SON-ERC-16) for this study was obtained from the Ethical Review Committee (ERC) of the Aga Khan University (AKU).

CONSENT FOR PUBLICATION

Informed consent was taken from the participants.

AVAILABILITY OF DATA

Not Applicable

FUNDING

No funding was received to conduct this study.

CONFLICT OF INTEREST

There is no conflict of interest.

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