

Knowledge of Palliative Care: An Indian's Perspective

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Abstract Background: Globally, the demand for palliative care services is markedly increased for the past decade due to emerging chronic diseases and ageing population. As a result, the health system needs to recognise and meet the needs of the people with life limiting illness. Palliative care is a specialised discipline of health care with the aim of providing care for the patient with terminal illness. Furthermore, there is evidence that minority ethnic groups have lack of knowledge on palliative care services in Australia. Purpose: To explore the issues in accessing palliative care services in Australia and provide recommendations to improve access. Methods & design: The research design chosen was constructivist grounded theory approach. Ethics approval was obtained from the study setting and from the university. Data collection was carried out in two phases. Semi-structured interview guide was used to collect the data. An in-depth interview was conducted and each interview lasts for 45 min to one and half hours. Snow ball sampling technique was done to recruit the participants. The inclusion criteria were: first generation Indian migrants; who understands, read and write English; Indian people receiving or already received palliative care services. Data was analysed by using grounded theory analytic technique. Findings: After analysing the data, two major themes were identified: knowledge about health care services, and knowledge on palliative care services. Conclusion: Although palliative care services are delivered effectively across Australia, still there are issues in accessing palliative care services among minority ethnic groups. Therefore, identifying these gaps and fulfilling these needs are the major focus in the Australia health care system.

Keywords Palliative Care, Family Caregivers, Indians, Terminal Illness

1. Introduction

While palliative care for patients with terminal illness in Australia has been progressed rapidly in the past decade, but many issues still need to be addressed and rectified [7]. To improve quality care for patients with terminal illness, the Commonwealth Government of Australia established

specialty palliative care services across Australia [21]. Despite the successful implementation of palliative care services, minority ethnic groups still have problem in accessing these services [14]. Although the reasons are not exactly known, it is predicted that it could be due to lack of knowledge and lack of information about the existing services [15].

Australia is a very diverse multicultural country with immigrants from countries including the United Kingdom, Europe, Russia, China, India, Middle East and Vietnam [10]. Indians form the second largest migrant group [9]. In Australia, all health care, including palliative care services, are available for everyone irrespective of ethnic background. However, the literature shows that minority groups of people living in Western countries such as the United Kingdom (UK), United States (US) and Australia have less access to the local health care system, particularly palliative care services [4]. It is, therefore, important to understand how palliative care is delivered to minority populations. The purpose of this study was to explore the knowledge of palliative care services of the families of terminally ill migrant Indian people, whose relatives were receiving palliative care services, in either inpatient or home-based settings. It is noted in the literature [15] [19] that family members' knowledge on palliative care services have received little research attention to date.

2. Materials and Methods

The constructivist grounded theory method is one of the most dominant qualitative research approaches used in nursing and the social sciences and grounded theory researchers need to be familiar with grounded theory in all its major forms, in order to be able to understand how they might adapt it in use or revise it into new forms and variations [2].

The constructivist-interpretivist approach [6] adapted as CGTM [2] guided the research. A constructivist research paradigm 'assumes a relativist ontology (there are many realities) and a subjectivist epistemology (participant and researcher co-create understandings)' [8]. Charmaz [1] argues that a constructivist approach to the 'interactive nature of both data collection and analysis resolves the

criticisms of the methods and reconciles positivist assumptions and postmodernist critiques' (p.62). The major elements and assumptions of constructivist into this research are that: individuals seek understanding of their world and that they develop meanings of their experiences through interaction with others; participant meanings are multiple and layered; and reality is co-created by the participants and the researcher and that the researcher is a part of the world they study and the data they collect [8].

Constructivist grounded theory, underpinned by a symbolic interactionist perspective, assumes 'reality, society and self are constructed through interaction and that interaction is inherently dynamic and interpretive' [2]. In CGTM, the researcher is the part of the world of study and the theoretical renderings are an 'interpretive portrayal of the studied world, not an extract picture of it' [2]. Constructivist grounded theories are constructed through the researcher's 'past and present involvements and interactions with people, perspectives, and research practices' [2].

Constructivist grounded theory retains the rigour of the traditional grounded theory method, whilst it fosters openness and reflexivity and encourages empathetic understanding of the participants' meanings, actions and worlds. According to Charmaz [2], CGTM adopts the tools of grounded theory, but it does not support the objectivist, positivist assumptions of the more traditional methods. The result is that theoretical analyses in CGTM are interpretive accounts of an experienced reality, rather than objective reports of it.

2.1. Setting of the Study

The study was conducted in the south-eastern metropolitan areas of Melbourne, Australia, where a large proportion of the Indian population reside. A wide range of health services offering aspects of palliative care are available in the area, ranging from services for people with specific diseases (e.g. cancer, motor neurone disease, HIV/AIDS) to those providing both generalist and specialist services for terminally ill patients. The services available include specialist inpatient palliative care units in the major hospitals in the area, standalone hospices, day hospices, home-based services and consultation in aged care facilities.

2.2. Participant Recruitment and Sample Selection

Three strategies were used to recruit participants into the study. The first and main strategy was to ask the palliative care nurse consultants from Service 1 and the palliative care nurses from Service 2 to identify Indian patients, who had received or were currently receiving care for a terminal illness, and to distribute letters of invitation to them to participate in the study. The second strategy was to ask local General Practitioners (GPs) to forward a letter of invitation on behalf of the research team to the family of current or past patients of Indian descent, who required terminal care. The final strategy was to use a snowball sampling technique by

which families who agreed to participate in the study were asked if they knew other Indian families who would fit the criteria and if so, to pass on a copy of the letter of invitation to them.

2.3. Inclusion Criteria

The inclusion criteria were that the family member was over 18 years of age, could understand, speak and read English, and in the event the patient had died, the death had occurred less than 12 months ago. Of 13 family members who met the inclusion criteria, six agreed to participate in the study. These comprised two with relatives receiving inpatient palliative care, two with relatives receiving home care services, one with a relative receiving outpatient care, and one where the relative was deceased after receiving inpatient palliative care. For most of the ill relatives the primary diagnosis was cancer. Of the seven family members who declined to participate, two did so because their ill relative was too ill and for the other five no reason was given.

2.4. Ethical Considerations

Before commencing the study primary ethics approval was obtained from the Southern Health Human Research Ethics Committee and the Monash University Standing Committee on Research Involving Humans. The application was also sent to South East Palliative Care (SEPC) for approval for permission to undertake the research, although the organisation did not have an ethics committee.

As required by the ethics committees, all participants were provided with a Plain Language Explanatory Statement that detailed the purpose of the study and what it entailed; and provided assurances that all information provided would be held in strict confidence and that they would not be personally identified in any reports arising from the study. All data collected from participants were de-identified and pseudonyms used to ensure participant anonymity. Participants were also informed that they could withdraw from the project at any stage without prejudice. Written consent was obtained prior to commencing the interviews. During the course of the study all documents and audiotapes were kept in a locked filing cabinet in the researcher's office and electronic information stored on a password protected computer. Only the researcher and supervisors had access to this information.

2.5. Data Collection Procedure

Before commencing the study, ethics approval from the relevant study site were obtained. This study utilised an in-depth interview process and a semi-structured interview schedule to elicit each participant's interpretation of his or her experience. The interview questions asked the participant to describe and reflect upon his or her experiences [1] of how interventions existed currently and how they could be improved in the future.

The interview schedule was developed in two parts. The first part was designed to obtain two sets of data: descriptive demographic details of the ill relative (e.g. relationship to the patient, age, marital status, length of time in Australia, occupation, income, religion, language and dietary habits); and demographic details and medical history of the ill relative, who required or had received palliative care (gender, age, diagnosis, other conditions/health problems, duration of current or past illness, type of health care e.g. inpatient, home care).

The second part of the interview was semi-structured and incorporated a set of broad open-ended questions designed to explore the experiences of family members in accessing palliative care services in Australia, their understanding of palliative care, and the problems and issues they encountered relating to their cultural background.

2.6. Data Analysis

2.6.1. Quantitative Analysis

The main purpose of the quantitative analysis in the first part of this project was to obtain a detailed demographic description of the sample characteristics of family members and the patients who were receiving or had received palliative care. Responses to the structured questionnaire were coded and entered on to a computer for analysis using MS Excel. Descriptive statistics were used to analyse the demographic data, using frequency distributions and summary statistics.

2.6.2. Qualitative Analysis

Data analysis in qualitative research consists of preparing and organising the data for analysis, then reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in figures, tables, or a discussion [5]. Approaches to qualitative analysis vary, for example, Madison [17] uses a critical ethnographic approach, Miles and Huberman [20] adopt a broad, systematic approach to analysis, and Wolcott [23] uses ethnographic and case study analysis procedures. Even though these researchers vary to some degree within their qualitative data analysis methods they agree on the basic steps of coding the data, combining the codes into broader categories or themes, and displaying and making comparisons in the data graphs, tables, and charts. Therefore, the aim of this analysis was to identify the codes and categories, and to develop broad themes and subthemes, influenced by a CGTM analysis approach [2].

The CGTM analysis approach suggested by Charmaz [3] influenced the analysis method for this study, by: 'comparing data with data; labelling data with active, specific codes; selecting focused codes; comparing and sorting data with focused codes; raising telling focused codes to tentative analytic categories; comparing data and codes with analytic categories; constructing theoretical concepts from abstract categories; comparing category with concept;

and comparing concept and concept'.

Before undertaking the data analysis, a series of preliminary steps were conducted. Grounded theory is not a linear process. Rather, the approach is 'concurrent, iterative and integrative as data collection, analysis and conceptual theorising occur simultaneously and from the beginning of the research process' [2]. This CGTM process is continued until the grounded theory is developed.

Grounded theory methods utilise constant comparative analysis to 'establish analytic distinctions and to determine if the data supports and continues to support the categories that are emerging' [13]. The constant comparison method required that the author continually return to the data, and the transcribed words of the family members, using the previous data analysis to influence future collection and analysis. The process of constant comparison involved comparing incidents to establish uniformities and varying conditions that could be identified. It also involved comparing emerging concepts to more incidents for the purpose of 'theoretical elaboration, saturation and densification of concepts' as well as the comparison of emergent concepts with each other [13].

2.7. Findings

2.7.1. Knowledge about Australian Healthcare System

All those who participated in this study perceived they knew something about the Australian health care system. However, a few caregivers stated that they did not know where to go for treatment or which hospital to choose for speciality care, particularly for cancer.

Caregiver-1 said because he had been living in Melbourne for a long time he knew where to seek medical assistance if any problem occurred. He said:

I have been living in Australia for the past 25 years and it was not difficult for me to access the services. Because, hospital was close to my home, I decided to go there.

Conversely, Caregiver-3 said that:

When my mother in-law had a fall I did not know which hospital I have to take her.

Caregivers' comments indicated some knowledge of the Australian health system generally and palliative care services in particular, but others like Caregiver-1 only knew about services because of living close to a hospital. Some caregivers had approached Indian cultural groups and associations, who seemed unaware of health system resources and other related systems. Caregiver-3 was angry and expressed her feelings that because Indian cultural groups only undertake recreational activities, they do not help people who are in need and who are then left alone without support. Other caregivers described using family members, especially children, to get the information they required. For example, Caregiver-5 stated:

It all suddenly happened for my husband. Because my daughter is a nursing student she took my husband to the hospital immediately.

2.7.2. Knowledge Regarding Palliative Care Services

Based on the caregivers' accounts, some caregivers faced many issues when they accessed palliative care services. Most of them did not know about the availability of palliative care services, explaining that they came to know about them only when the patient was admitted to the institutional settings or required services. Confusion remained, however, about what exactly palliative care services could provide. Caregiver-4 stated that:

We do not know what they exactly do in palliative care but, whatever problems the patient has, the doctors come and attend the patient immediately and resolve the problems like pain, breathing difficulty and urinary infection.

Most caregivers noted that they did not know the term 'palliative care' prior to needing these services and they had not heard about the available services. They had some idea of the meaning of palliative care, especially in supporting a person's quality of life. Caregiver-2 said that:

About palliative care what I know is, it is the care given to the people with terminal illness, and maintaining and keeping quality of life. That's all I know.

Caregiver-1's thoughts add to this, however, his view was that palliative care was for people in the final stages of life:

It is the care given to the patients who are terminally ill. This is the care given to the patients who are dying and who have no hope for the future.

Caregiver-5 also saw palliative care as being only for the dying:

Palliative care is given....um... to the patient....um... with dying stage.

Another caregiver reflected that palliative care is difficult to define, especially in the aged care setting:

I have no idea about palliative care. My mother-in-law is in nursing home. I know that much.

The other two caregivers said they did not know meaning of palliative care and they had not heard of it. All caregivers felt that lack of general awareness of the services available resulted in them taking on additional roles.

Most caregivers suggested that issues of rights, privacy and consent are not at the forefront within Indian culture. However, they all knew that everyone has a right to their choice of treatment. One caregiver mentioned that autonomy and independence in treatment choices is a basic human right. Another said that she was unaware of their rights and the benefits of palliative care services.

One caregiver stated:

My mother-in-law was in pain from a leg fracture and it is a basic human right that she asks for pain medications.

Caregiver-4's mother-in-law was hesitant to ask the

nurses for medication and this prevented her from receiving what she required and resulted in poor quality care at the end of her life. Caregiver-4 went on to describe how she challenged a nurse to provide pain relief for her mother-in-law:

She was on regular pain relief tablets every four hours. When the nurse turns her on her side she screams with the pain. I asked the nurse whether she can have any other strong pain killer. But the nurse said no because she was already using pain patch.

This is an example of the lack of confidence that a number of caregivers expressed. They lacked assertiveness to insist on treatment and maximum information from the health service.

2.8. Discussion

This study raised a number of concerns relating to service delivery for migrant Indian people with terminal illness. Delivering appropriate health services to needy people is assumed to be a vital role for all health organisations. Organisations' structural issues seemed to be the first concern for family members and their ill relatives. Most of the study participants received palliative care services either from an inpatient palliative care unit or in residential aged care. The study's Indian participants perceived that these palliative care institutions were geared towards the needs of Christians, leading to people of other religious backgrounds, such as Hindus, Sikhs and Muslims, being hesitant to use these services.

Generally, Indians believe that if an ill person is admitted to the palliative care unit, he or she will not return home and will die there. They assume that the person will not recover from the illness in a palliative care unit. Some caregivers assumed that if the specialist palliative care service had a Christian image their ill relative may be reluctant to be admitted. This view is supported by literature [16].

Karim et al [16] research in St Mary's hospice, UK identified that, compared to white Europeans; there was an underutilisation of day care and in-patient hospice services by members of black/minority ethnic populations. Doctors did, however, refer their black/minority ethnic patients for hospice home care services: 8.5% of referrals received by the hospice were non-white patients. This referral rate increased to 19.3% in specific postcode areas known to have significant black/minority ethnic communities. Karim et al [16] concluded that further research is needed to establish awareness, explore attitudes towards palliative care services and assess the demand for specific services within various black/minority ethnic communities. Some caregivers believed it brought bad luck if their ill relatives were admitted to a unit, or placed in a bed where a previous patient had died. Hence, health care professionals need to discuss family members' religious beliefs with them and try to meet their needs accordingly.

Lack of reliable data in the health care system is a

contributing factor that inhibits culturally appropriate care for minority ethnic groups. Research [15], [18], has been undertaken in Australia involving minority ethnic populations such as Asian (Chinese, Vietnamese and Sri Lankan) and European immigrants, however, in a study of cancer in Indian families in Western Australia it was reported that there were no published studies of the Indian population and no reliable statistics regarding the incidence of cancer among Indians in Australia [22]. There is insufficient information available on the epidemiology of disease, and the burden of terminal illness and cancer for this population group, which might result in poor service provision. Systems need to be developed to gather information about the health status of people from cultural minorities in order to facilitate the delivery of appropriate palliative care.

In addition, it is possible that insufficient numbers of doctors and nurses with knowledge and experience in palliative care in residential aged care facilities and hospitals may have resulted in poor quality patient care. For example, in a report published in US, Cohen and Salsberg [4] identified the common barriers of quality palliative care. These includes low numbers of physicians and lack of trained health professionals in palliative care; low numbers of community hospitals that offered palliative care services; and limited financing for palliative care services [4].

3. Conclusions

It provides empirical evidence that there are still issues in accessing health care services for minority ethnic groups across the world. It is, therefore, a great challenge for policy makers, health care organisations and other legislative managers to deliver equitable services to all populations irrespective of their cultural background. While planning health care they need to consider minority populations to meet their needs. Constructivist grounded theory is a research method that can provide increased understandings of how family members experience when their ill relative receive palliative care services. This study provides a theory of family member's experiences of terminally ill Indian patients receiving palliative care services from the family member's perspectives themselves.

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