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## Felt Needs of Cancer Palliative Care Professionals Working in India: A Qualitative Study

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### ABSTRACT

**Objectives:** Cancer palliative care professionals face a plethora of challenges related to death, dying and suffering apart from limited workforce and other resources in India. However, the grief held by them is underappreciated and psychological needs are under explored. The aim of the present study was to explore felt needs of cancer palliative care professionals working in India.

**Materials and Methods:** The study was cross-sectional, qualitative and in-depth in nature. It was conducted across four cancer palliative care centers in Bengaluru city of India. sample consisted of 15 professionals (mean age = 42 years and standard deviation = 8.41) with at least six months of experience, involved in direct patient care who gave an additional consent for audio-recording. The tools used were sociodemographic and professional datasheet and semi-structured interview guide, which were developed for the present study and validated from five experts. Thematic analysis was used to generate and analyze patterns within the qualitative data.

**Results:** Five themes were identified, namely, death and grief; challenges in practice; strategies for self-care; positive professional experiences; and vision for palliative care.

**Conclusion:** The cancer palliative care professionals need regular support in coping with death and grief, regular trainings and supervision across workplace to deal with occupational challenges, and to address their self-care and spiritual needs. The study highlights need to introduce more specialized training courses in handling pediatric patients, increase palliative care workforce, and hospice units. This can have implications in future research and training with development of innovative interventions to address these needs and challenges.

**Keywords:** Cancer, Challenges, Death, Felt needs, Grief, Palliative care professionals.

### INTRODUCTION

Death can easily evoke different psychological reactions within humans. Witnessing and handling death and dying as a professional in a palliative care setting is challenging as it can arouse death related anxiety, reminds one about his/her own or significant others' mortality. The challenges are plethoric for cancer palliative care professionals which makes it different from other medical set-ups.

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With limited health-care resources and scarcity of trained and experienced professionals in palliative care (oncologists, nurses, counselors, and other allied health professionals), the field is challenging in providing access to the needy patients in India.<sup>[1-4]</sup>

Research suggests that (a) cancer palliative care professionals experience high levels of burnout, compassion fatigue and psychosocial distress,<sup>[5,6]</sup> (b) grief held by oncology staff is underappreciated and underestimated,<sup>[7]</sup> (c) devastating consequences for quality of patient care,<sup>[8]</sup> and (d) close encounters with death leads to reflections of life and death.<sup>[9]</sup>

There have been a few qualitative studies<sup>[3,10-12]</sup> conducted in India with an intention of understanding professional care providers' views and experiences working in a palliative care setting. However, to improve the patient care, organizational services, and personal and professional fulfillment of professionals, it's important to explore and address the psychological and emotional needs as experienced by the cancer palliative care professionals. The aim of the present study was to explore felt needs of cancer palliative care professionals working in India.

## MATERIALS AND METHODS

### Sample

The study was cross-sectional, qualitative and in-depth in nature. A total of 26 cancer palliative care professionals were contacted with the help of coordinators from each of the four centers. They gave consent to be contacted again for audio-recordings of face-to-face semi-structured interviews. The sample consisted of 15 professional care providers (7 Nurses, 6 Doctors, 1 Counselor, and 1 Social Worker) working in four cancer palliative care settings in Bengaluru city (one hospice and three hospitals). Participants were recruited purposively based on following inclusion criteria: (1) Professionals involved in direct patient care, (2) professionals with work experience in palliative care for at least 6 months (to be able to share experiences and challenges of working in the field), (3) professionals able to speak/read in English or Hindi languages, and (4) who gave written informed consent for the in-depth interview and audio-recording. The data collection was carried out during October 2016 to January 2017 based on availability of the professionals and till theme saturation.

### Procedure

Ethical approval for the study was taken from the Institute's Ethical Committee Board of NIMHANS, Bengaluru and permissions were taken from all four cancer palliative care centers. The interviews were conducted at the professionals' workplace in a quiet room as per their availability and at mutually convenient time and place. The duration of interviews

ranged from about 40 min to 1 h 15 min. All the interviews were audio-recorded, and it ensured no data was lost while transcribing verbatims. Furthermore, field diary was maintained by the researcher to note down observations, reflections, and other details during and after completion of each interview.

### Tools

The tools used were developed specifically for the study: (i) socio-demographic and professional datasheet to collect socio-demographic and professional details, information about personal experiences and self-care practices; and (ii) semi-structured interview guide for palliative care professionals.

The draft of the semi-structured interview guide was developed for the present study to examine the emotional and psychological aspects of felt needs based on existing literature. It was then given to five experts working actively in the area of cancer palliative care to evaluate the domains, clarity and adequacy of items, contents of probes, and suggest modifications. These five experts were not a part of the sample being studied. Based on feedback and suggestions given by the experts, the domains and items were rephrased for more systematic elicitation of relevant information. After making the required modifications, the final draft of semi-structured interview guide was given to same experts for the final approval. Apart from the guidelines for the interviewer and prelude for the respondents; various sub-domains of the interview guide included: (a) Initial experiences, (b) working with patients, (c) working with care providers of patients, (d) death and dying, (e) psychological experiences, (f) physical health, (g) effect on personal life, (h) spiritual and religious strategies, (i) job satisfaction, and (j) reflections.

### Data analysis

The qualitative data obtained were analyzed using thematic analysis as recommended by Braun and Clarke.<sup>[13,14]</sup> The following procedure was adopted in analysis of qualitative data: (a) Familiarizing with the data, (b) generating initial codes, (c) search for themes, (d) reviewing themes, and (e) defining and naming themes.

All the transcripts were repeatedly read to familiarize the researchers (AK and MPS) with the data. The coding was done for each transcript and the codes were derived from the data rather than being theory driven. It was ensured that the qualitative data analysis was done systematically in a step by step procedure. After the initial coding of the data, an exhaustive list of the different codes across data set was prepared. The list was examined to see how some of these codes could be sorted or grouped into potential themes. At this stage, some initial codes were used to form main themes, whereas others formed the sub-themes. Some of the sub-themes that were overlapping or interrelated were

collapsed to form broader themes. Appropriate care was taken to ensure that clear distinctions between themes were preserved. The grouping of various codes and categories into sub-themes and themes were developed based on discussions and consensus between two researchers.

## RESULTS

### Profile of the sample characteristics

The age range of the sample was 25–55 years with a mean age of 42 years (SD = 8.41). Seven participants had completed their Graduation (47%), six participants (40%) had completed their Diploma in Nursing while two had done postgraduation (13%). Number of patients seen by these participants per week varied from 12 to 87 depending on the setting with a mean number of cases per week as 40 (SD = 20.40). Eight participants had a personal experience with a family member having cancer (53%), out of which six had shared having been affected by the experience. Majority of them followed self-care practices (13; 87%), religious practices (12; 80%) while more than half of them did not engage in any spiritual practices (8; 53%). Table 1 shows demographic and work-related characteristics of the participants.

### Themes with relevant excerpts from the transcripts

The themes, sub-themes, and relevant excerpts from the transcripts of interviews are presented under following headings: (1) Death and Grief, (2) challenges in practice, (3) strategies for self-care, (4) positive professional experiences, and (5) vision for palliative care.

#### Death and grief

This includes sub-themes related to young untimely deaths, beliefs about death, paradox of death and grief reactions, which was prominently seen across all interviews [Table 2].

All the participants spoke about their challenging experiences related to death, dying and grief, specifically dealing with pediatric patients, “I cannot overcome death of patients who have not even seen life...those young patients (tearful)”; “Facing death is a challenge till date...specially when family with 6 or 5 or 4 years old children come...under 20-or 22 patients are here...to be able to see them suffer is a big challenge.”

Participants believed that suffering is bad, deaths should be sudden and without suffering, “I think such suffering should not be given to anyone”; “Why innocent people should suffer with no bad habits?”

Many of them reported mixed feelings of relief and helplessness at the same time whenever their patients passed away, “It’s really sad but at the same time we feel we have done our part for giving relief”; “After 8 hours he died....I felt good

**Table 1:** Socio-demographic and work-related characteristics of the participants (n=15).

Variables	n (%)
Age (years), n (%)	
25–40	6 (40)
41–60	9 (60)
Gender, n (%)	
Female	13 (87)
Male	2 (13)
Marital status, n (%)	
Married	12 (80)
Not married	3 (20)
Religion, n (%)	
Hindu	7 (47)
Christian	8 (53)
Income per month, n (%)	
15,000–30,000/-	5 (33)
30,001–50,000/-	6 (40)
>50,000/-	4 (27)
Workplace type, n (%)	
Hospice	5 (33)
Hospital	10 (67)
Profession at workplace, n (%)	
Nurses	7 (47)
Doctors	6 (40)
Social worker and counselor	2 (13)
Additional training taken in palliative care, n (%)	
Yes	14 (93)
No	1 (7)

**Table 2:** Themes and sub-themes extracted from the interview data (n=15).

S. No.	Theme	Sub-themes
1.	Death and Grief	a. Young Untimely Deaths b. Beliefs about Death c. Paradox of death d. Grief Reactions
2.	Challenges in Practice	a. Challenges in beginning of career b. Challenges with Patients and their Families c. Challenges with Seniors & Colleagues d. Challenges at Organizational level e. Physical & Mental Exhaustion
3.	Strategies for Self-Care	a. Personal Strategies for self-care b. Social strategies for self-care c. Religious/ Spiritual Strategies for self-care
4.	Positive Professional Experiences	a. Professional Satisfaction b. Service to humanity c. Perceived changes in ‘self’
5.	Vision for Palliative Care	a. Professional Attributes Required b. Future Expectations c. Training & Supervision

for him that he would not have to suffer now but it was so.so horrible to witness that...and I was really upset as well.”

There were range of reactions explained by the participants, which were nothing but grief, such as “*I feel sad and helpless and sometimes I cry in front of my patients only... and sometimes I just can't take it...I sit somewhere and cry*”; and “*I have lost my mood...I sometimes feel I am going into depression...by seeing such people everyday.*”

### **Challenges in palliative care**

This includes sub-themes related to challenges in beginning of career, challenges faced with patients and their families, challenges with seniors and colleagues, challenges faced at organizational level, and physical and mental exhaustion experienced by the participants [Table 2].

Participants shared their challenges faced with patients and their families with respect to handling poor awareness and knowledge about cancer and palliative care amongst the community. They also expressed how challenging giving psychological support, handling questions related to life and death, and spirituality is. One participant shared, “*Families want us to postpone the death.those things are very challenging...they keep asking how's the patient, how's the patient, indirectly they want to know how much time the patient will live...every single day...same question,*” while other participant said, “*Their spiritual needs which I feel I can't handle, it is so challenging when the patients come and ask such questions about life and death.*”

Most reported challenges faced when they had started their careers in the field of palliative care, “*I was not ready to face dying people because as a youngster we wouldn't want to deal with death and dying...that was a huge challenge...I felt helpless...with no formal training and I felt ill equipped with knowledge and I didn't want to do it that time.*” While other participants shared that they were mostly disturbed at the start of their careers with loss of sleep and thoughts of quitting the job.

With regard to challenges faced with seniors and colleagues, participants reported not being respected and understood by different professionals within the same team. One participant reported, “*sometimes we have to manage everything, especially at night time we get lot of emergency calls, no doctors or counsellor are available and so many responsibilities are there on my head, alone.*”

While the other shared hierarchy issues within the same department, “*Since I'm alone, I cannot always tell my problems to the doctor. They are anyways in higher level. I don't have a colleague to share my problem. So, that's what. So if any problem for palliative medicine, I have to run around. No support.*”

At organizational level there were challenges experienced such as income earned per month, infrastructure, respect

for the profession, workload, and scarcity of employed professionals. Few quotes from the transcripts - “*Pay wise, space wise, respect wise, we have fought with the management and even the government since beginning...its unfair for the amount of work we do and that is not even considered...so that causes frustration...they say that palliative is not an important area and we should not be so demanding*”; “*We don't have social workers or counselors as a regular team member and we can only make referrals, it increases my stress levels as I have to manage everything alone.*” One participant mentioned how other departments look down upon palliative care, “*Other departments call us 'angels of death', the minute they see us, they are scared that some patient might die or something like that referral has been made.*”

Many of them were experiencing physical and mental exhaustion reportedly as a result of their workload at workplace, which they described using terms such as tiredness, giddiness, exhaustion, irritability, and no personal time. One professional looked disturbed while explaining her duties and how it leaves her with no time, “*I don't have any free time...I have to study for my course, do my household work, then duty here whole day...no time is left to think about myself.*” Another person mentioned “*I do generally get mentally exhausted and there are really tough days when I become irritable easily on anybody...I drink lots of coffee and don't want to exercise towards the end of the day. I want to just go home and sleep.*”

### **Strategies for self-care**

This includes sub-themes related to personal strategies, social strategies, and religious/spiritual strategies used by professionals as part of their self-care [Table 2].

Professionals were asked what different types of helpful self-care strategies they indulge in on a regular basis, to which some described using personal strategies such as playing with kids, spending time at home, distracting from workplace and detachment from their feelings. “*Once I go home, I will not totally forget about patients, I will think of some other instances, and suddenly will try to come out of it by being busy in housework.*”

Some expressed social support from colleagues and seniors was helpful as one participant shared, “*I share with my friends, my colleagues...with them I try to discuss it so as to how to overcome it, if necessary I call up my seniors who are retired now and see what best way I can get out of my emotions to self-counsel myself...self-reflection on my practices also helps*”; another participant said, “*My colleagues are very supportive and cooperative. If I am sad, they are always around to help me out.*”

And many reportedly engage in prayers and retreats on a regular basis, for example, “*My religion has given me moral*

support...I think there is some power in it...some positive power and energy. And I have adapted dhyana and meditation too in my routine, I think it helps me to accept and let go.”; and “Prayer helps me a lot...I have fellow colleagues who have the same faith and we pray together as a team...we remember our patients after coming to department from rounds and pray for them.”

### **Positive professional experiences**

This includes sub-themes related to professional satisfaction, service to humanity, and perceived changes in self [Table 2] after joining work as a cancer palliative care professional.

The interview data were not limited to challenges or difficulties, participants also expressed how they have changed over time because of their profession with inculcation of acceptance, courage and compassion for others. Few excerpts shared are, “It has made me little stronger...now I feel it’s a part of life and you need to move on...it takes time but acceptance has come;” “I have more courage now and I have started appreciating life more than before.”; and “I think we are much more compassionate now...we have become more caring.”

Some participants shared positive experiences while helping others and called it a “noble service” and “service to humanity.” Majority mentioned the satisfaction their job provided, example, “I feel satisfied at the end of it...when I do this I feel satisfied...and feel a kind of happiness...I feel some kind of worth...regarding what I am doing.” A few participants also shared how positive feedback from their patients and their families is reassuring and motivating. One participant shared, “When my patients and my superiors thank me and appreciate me that I am working well, that gives me so much motivation.” They also described their job as a service to mankind, “Serving the people, who are suffering, is a great service in itself;” and “My job is to help other people. I am happy to work for them and I feel it’s God’s work and we should help people.”

### **Vision for palliative care**

This includes sub-themes related to professional attributes required for being palliative care professional, future expectations from the field, and training and supervision related aspects [Table 2]. As per the participants, one needs to be equipped well and be aware about the field of palliative care before their joining. For example, one participant shared “One needs to mentally prepare first and then come here,” other participant said, “Emotional involvement in work is required.” while another one felt without compassion one couldn’t survive, “Passion, training, commitment, and faithfulness is required to be in this job. Without compassionate touch you can’t survive.”

There were expectations related to increase in workforce, more facilities for relaxation at workplace and more hospice to be set up in the country. “More hospices need to come up or at least palliative care services to be made available for the public”; “More staff, more equipment, more social workers and trained counselors are required here. And we need more extra-curricular activities for the staff here.”

Majority strongly expressed how training and supervision was important to be able deal with the unique challenges of palliative care. For example, “To witness wounds, deaths and handle all these...a proper training is required...palliative care is a difficult job;”

“We need to have palliative care training and only then you can provide exact training to the trainers. There are not many trained physicians or nurses in palliative care in India...so you can imagine the quality of existing training courses.”

## **DISCUSSION**

The impact of death and dying on participants’ personal lives has many implications, both within and beyond palliative care.<sup>[15]</sup> Some participants also conveyed their mixed feelings of relief and sadness when confronting death of their patients which was explained as paradox of death, the similar theme was found previously in a study<sup>[3]</sup> where the health workers reported conflicting feelings of relief and sadness when confronted with the death of their patients. Furthermore, the connections made with the patients in confronting death can involve both suffering and meaning.<sup>[16]</sup>

Impact of personal experiences with cancer on joining the cancer palliative care field was acknowledged by six out of the eight participants who reported having had the personal experiences with cancer. This could be understood in terms of explanations given about early life experiences with death to be a common and prominent feature as a major motivator in participants’ career path of end-of-life care.<sup>[15]</sup>

Psychological reactions to grief could range from remembering the patients, repeated thoughts, images or memories of the time spent with the patients, sadness and feeling very helpless, crying, guilt or regret, having dreams about them, sleep and appetite disturbances and not getting enough time to grieve. A total of 63% of staff in a study<sup>[17]</sup> reported experiencing “a great deal” of stress at work, which was predicted by greater perceived workload and insufficient time to grieve for patients’ death, while it has also been suggested that highest sources of stress were the factors of work load and patient death and dying.<sup>[18]</sup> Ruminations about one’s own mortality or death of own children or family member (identification) triggered by daily deaths at workplace and feeling helpless about the same were also seen as sub-themes in another study where rumination on oneself or one’s family and sense of powerlessness over cancer was noted.<sup>[19]</sup>

Most participants shared their initial challenges which were difficult and traumatic as a beginner in the field of palliative care. In India, large number of patients contact the medical team when the disease has reached the advanced stage.<sup>[1,3]</sup> There are already issues with infrastructure, staff shortage and other facilities in the field of palliative care in India<sup>[2,4,20]</sup> and then added stressors come from interpersonal communications at various levels with seniors, colleagues, and authorities.

There are qualitative<sup>[21,22]</sup> and quantitative studies<sup>[23-25]</sup> done earlier which suggest that support from team members, colleagues, and supervision provisions could be helpful factors against burnout, compassion fatigue and further may positively impact overall job satisfaction.

Spirituality has been suggested as essential for palliative care practitioners and have an appreciation of different religious perspectives and rituals to meet the unique needs of their patients and families.<sup>[26]</sup> Similarly, it has been indicated that spirituality is complex and challenging to implement into clinical actions.<sup>[27]</sup> In a series of studies,<sup>[28-30]</sup> self-care has been explained as physical, social, and inner self-care which could be seen as equivalent to personal, social and spiritual self-care in the present study findings. The present study participants' self-care strategies and practices ranged from physical activity, exercises, dance, and daily walk to spending quality time with family and kids, while some shared crying and going aloof at working hours to deal with the emotional distress as they could not cry in front of patients and others. Practices of self-care have been studied extensively across the globe for its effects on lower burnout and enhanced satisfaction levels,<sup>[23,28-30]</sup> and for improved well-being.<sup>[7,23]</sup>

The participants in the present study had described how they feel they have changed as a person because of their work in a positive way. Different stages to undergo a unifying process was described earlier, which was called 'transformation or metamorphosis' in palliative care professionals, such as initial phase of pre-palliative care to honeymoon to frustration to maturation, and which is influenced throughout by several factors.<sup>[31]</sup>

The participants have expressed the need for better infrastructure, appointment of more staff members, recognition as a separate department, more hospice to come up and services to be made available to the rural areas too. The literature also supports these expectations as development of services have been inadequate as some of the areas are well covered while most are not with only 1% been able to get palliative care services.<sup>[2,32]</sup> India's large growing population and the noteworthy rise of advanced stage illnesses diagnoses like cancer are presenting significant demands on existing palliative care services.<sup>[3]</sup> Majority of the participants reported being not satisfied with current opportunities in training and supervision, which can have an

impact on the quality of patient care and well-being of the professionals. It has been observed in a quantitative study that specialized additional training has lot of significance in enhancing compassion satisfaction.<sup>[33]</sup> Furthermore, it has been suggested to include establishment of mentoring programs to guide junior staff, continuing education classes to bolster self-care and well-being, staff retreats to promote teambuilding, and sabbaticals based on productivity to enhance commitment and professional development<sup>[34]</sup> which could be utilized as part of training programs in palliative care in India.

There have been qualitative studies done with volunteers in palliative care settings which observed the perceived need for extensive training in handling grief and bereavement for children and elderly, spiritual aspects, self-care, and regular refresher training programs.<sup>[35,36]</sup> In the present study, all participants mentioned difficulties in dealing with death of pediatric patients which highlights the need for specialized training for this aspect. Similar difficult experiences caring for dying children have been seen to be related to professional's referenced personal pain and inadequate support.<sup>[37,38]</sup>

In the present study, theme saturation was reached by the 12<sup>th</sup> interview and interviews were carried out with a sample of 15 participants. Thus, the sample size was sufficient for obtaining qualitative data however more sample size could have added to generalizability of the results with respect to different professionals (more counselors/social workers) as their needs could have been different. A systematic procedure was followed for qualitative data analysis; however, independent raters were not used in the present study.

Similar in-depth studies could be carried out in other regions within India to explore the consistencies and differences across various palliative care units. Future studies could include bigger sample size with proportionate sampling from each professional category considering each could have unique needs. The findings provide directions to formulate contents of a psychological intervention specially addressing the grief, beliefs related to death, suffering and young deaths, compassion, and self-care strategies. The findings suggest that cancer palliative care professionals need organizational support, intensive specialized training and resources for dealing with grief, death of children, occupational challenges, and emotional exhaustion. Regular supervision, staff support, and innovative resilience building workshops or programs could also be beneficial.

## CONCLUSION

Cancer palliative care professionals need support and help for handling death of young patients, grief and dying at workplace, regular training and supervision are needed across centers to help deal with occupational challenges,

and their self-care and spiritual needs need to be addressed as well. Most professionals draw strength from their positive professional experiences; however, improvements could be made at the centers to gear them with better coping skills. There is an urgent need for more workforce, specialized training courses, hospice units, and better preparation. It is important to address needs and challenges faced by the cancer palliative care professionals for better patient care and professional fulfillment.

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### Conflicts of interest

There are no conflicts of interest.

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