



Importance Of Pediatric Palliative Care (Ppc) For Child's Parents With Pediatric End-Of-Life Issues In India And Its Challenge

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Abstract

Palliative care also encompasses psychological support to assist the patient in managing his physical condition. This provides an enhanced quality of life by offering a multi-arm supporting system that aids in combating the patient's illness and fulfilling certain requirements beyond those that are medically necessary. Data analysis and field discoveries have led researchers to PC for the patient who having care from their parents. to reach the conclusion researcher has developed a questionnaire for PC of sick child management numerous metrics are formulated which will show the data connected to the process of PC management and various factors associated with PC of sick child management. Studied showed that the significant proportion of participants (81%) have indicated that the primary challenge they encounter while providing patient care is self-inflicted physical discomfort. A considerable proportion of participants (79%) have identified income loss as an additional element contributing to the challenges associated with patient care.

Keywords: *parents, child, pediatric, palliative care*

Introduction

The World Health Organisation termed PC “an approach that improves the quality of life of patients and their families who are coping with the challenges associated with a life-threatening illness through the early detection and treatment of pain brought about by early detection and treatment of pain and other issues, as well as their precise identification, assessment, and management. What sets PC apart from other types of treatment is its focus on the patient's physical, emotional, and spiritual well-being. Palliative care is different from curative treatment in that it focuses on the patient rather than the disease. Palliative care aims to improve the quality of life of both families and patients as a response to discomfort caused by pain and other symptoms, most of which are of a physical origin, by providing psychological, social, and spiritual assistance in addition to medical and nursing treatment. This doesn't involve costly and cumbersome procedures, sophisticated gadgets, or complicated therapeutic protocols.

In India, the other problems faced by palliative patients are those arising out of their poverty, which can entail a lack of access to safe drinking water, good food, and/or healthcare. dwellings that are clean and have at least the most basic sanitation amenities. In addition to this, if any of the individuals with a disease of such a serious kind were to be hit, it would be a big tragedy for the individual himself as well. as members of his or her own family. The impending death is a concern for the majority of the patients and their relatives. The required assistance goes beyond that of medical care. Hence, on account of this, there is a critical need for a home care system that might be established through community commitment to offer complete care to the patient and their family as part of the treatment plan.

Method

Researcher has developed a questionnaire for PC of sick child management numerous metrics are formulated which will show the data connected to the process of PC management and various factors associated with PC of sick child management. After the objectives of the topic have been set, researcher has prepared a questionnaire for PC management. The researcher will pass over the questionnaire to the seven different components, which will comprise various parameters such as the relevance of the roles played by ayurvedic medicine and its integration with modern medical management in relation to PC management. The definitions of the variables that were used in the study can be found in the various sections of chapter five.

Data from the primary sources, which include questionnaires, interviews, and group discussions.

Field surveys are going to be done in order to obtain the primary data that is needed for this objective. In order to accomplish this goal, we will be preparing seven questionnaires, which the respondents will then complete out. In addition to open and honest thoughts from a chosen group of respondents, this study will also incorporate important material on the management of PC and the Observation technique.

Result and discussion

In relation to the gender composition of the care providers, males predominated by 24% compared to 76% females among those interviewed. With respect to the caregivers' relationship with the patient, the researcher discovered that a significant plurality of 62% are the spouses of the patient. In relation to the responses, the offspring of the patients constitute the second-largest segment, following the spouses. Approximately 24% of the caregivers are the patients' offspring.

Infrequently, siblings, other relatives, or friends assisted in the care of the patients. A significant proportion of the participants (48%) indicated that they have been providing patient care for a duration of one to five years. A minority of the participants (21%) indicated that they have been providing patient care for over a decade.

A majority of the patients, according to the researcher, suffered from severe disabilities as a result of the malignancy. A total of 39% of the patients were undergoing cancer treatment. Second, a sizable percentage of patients (30%) had age-related disabilities, or impairments brought on by advanced age. 11% lost limbs, 7% had blindness or deafness, and 3% had a psychiatric illness. None of the patients included in the selected samples exhibited a coma or were afflicted with HIV. A significant proportion of the carers (73%) lacked any form of training in patient care. According to the carers, they were not given any formal training regarding the proper way to care for the patients, the precautions and barriers that must be considered during treatment, and other relevant information. A significant proportion of carers (80%) reported providing the service of nourishing patients. Only a minority of carers (20%) made reference to the fact that they administer wound care to patients. A significant proportion of parents of sick children (89%) reported providing assistance to patients during the execution of movements. A significant proportion (87%) of the carers additionally stated that they administer oral medications to the patients. In addition to the aforementioned services, the parents of sick children stated that their involvement in administering injections, caring for catheters, managing colostomies, and bolstering patients' morale was minimal. The researcher observed that a significant proportion of the respondents (81%) identified physical ailments of the carers as the primary obstacle they encounter while providing patient care. A considerable proportion of participants (79%) have identified income loss as an additional element contributing to the challenges associated with patient care. Additionally, the researcher observed that a significant proportion (74%) of the participants cited the increased expense of treatment as the second factor contributing to challenges in patient care. Significant proportions of the respondents (60%) have indicated that the parents of sick children are encountering emotional challenges while providing care for the patients. A minority of the respondents (21%) indicated that they encounter challenges in patient care due to their inability to transport the patient to the hospital. Nevertheless, 79% of the participants indicated that this does not pose a significant obstacle when providing patient care. A majority of the participants (56%) indicated that they would also be inclined to seek assistance from external agencies that could aid in the provision of patient care. The majority of respondents (79%) indicate that government organisations provide the majority of the assistance. The researcher observed that a significant proportion of the participants (77%) reported not receiving any form of aid or financial assistance. Conversely, a mere 23% of the respondents indicated that they do receive some form of financial assistance.

Table 1: Respondents of trained

Sr. No.	Options	Responses	%
1	Yes	27	27
2	No	73	73
Total		100	100

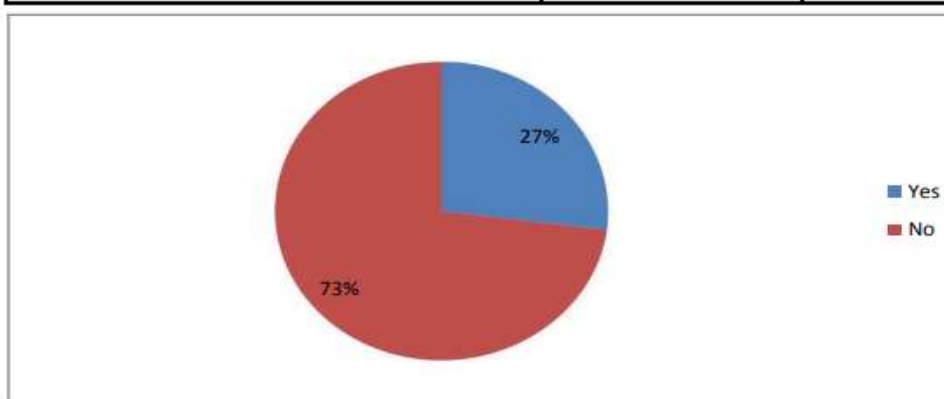


Figure 1: whether respondents are trained

Interpretation

In relation to the gender composition of the care giver respondents, among the entire sampled care giver population, 24% identify as male and 76% identify as female.

Table 2: Duration of caring their patient

Sr. No.	Options	Responses	%
1	Less than one year	9	9
2	1-5 year	48	48
3	5-10 year	22	22
5	More than 10 years	21	21
Total		100	100

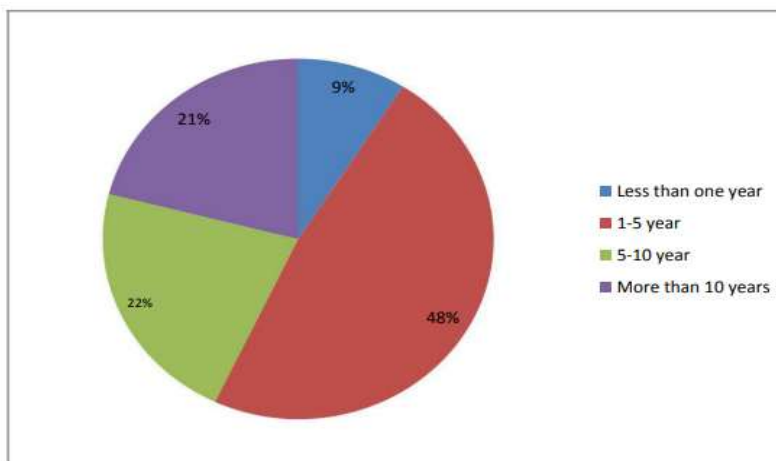


Figure 2: Duration of caring their patient

Interpretation

With regards to the length of time spent providing care for the patient, the following percentages of care givers from the total sample: 9% have been providing care for the patient for less than one year, 48% have been providing care for one to five years, 22% have been providing care for five to ten years, and the remaining 21% have been providing care for more than ten years.

Table 3: Service offered by parents of sick child

Sr.	Options	Yes	No	Total			
No.		Res	%	Res.	%	Res.	%
1	feeding of the patient	80	80	20	20	100	100
2	wound care	20	20	80	80	100	100
3	Assisting movements	89	89	11	11	100	100
4	Giving oral medicines	87	87	13	13	100	100
5	Giving injections	5	5	95	95	100	100
6	Catheter care	2	2	98	98	100	100
7	Colostomy care	7	7	93	93	100	100
8	Morale boosting	31	31	69	69	100	100

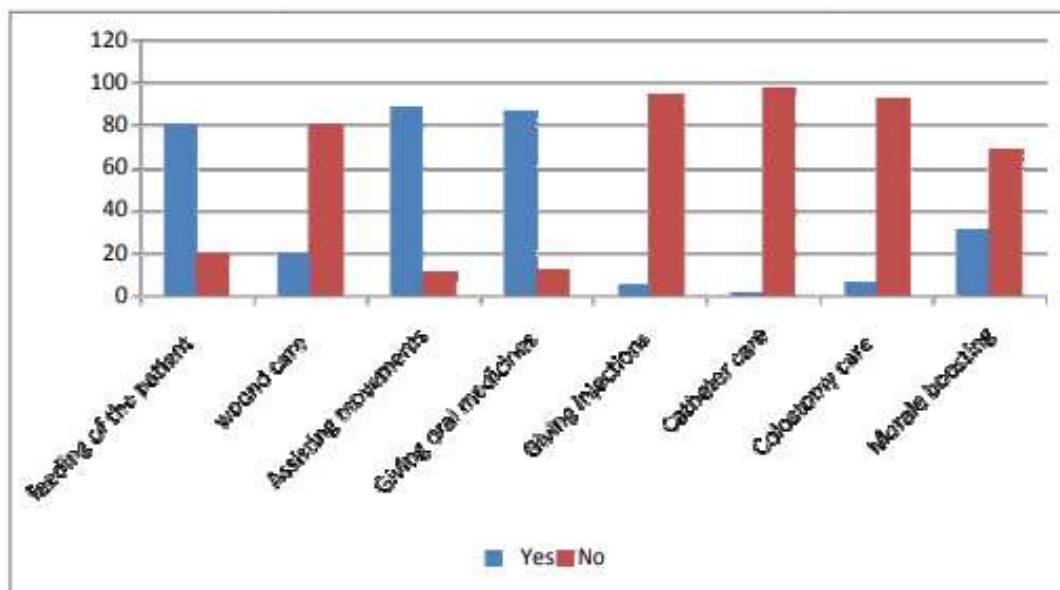


Figure 3: Service by parents of sick child

Interpretation

In relation to the various services provided by care attendants, it was found that 80% of the respondents provide feeding for the patient, while 20% of the respondents do not provide this service. When considering wound care, 20% of the caretakers in the sample offer this service, while the remaining 80% do not. A total of 89% of the caretakers included in the sample aid patients in their movements, while the remaining 11% of respondents in the caretakers category do not offer this service.

Table 4: Patient care burden share by family member

Sr. No.	Options	Responses	%
1	Yes	73	73
2	No	17	17
Total		100	100

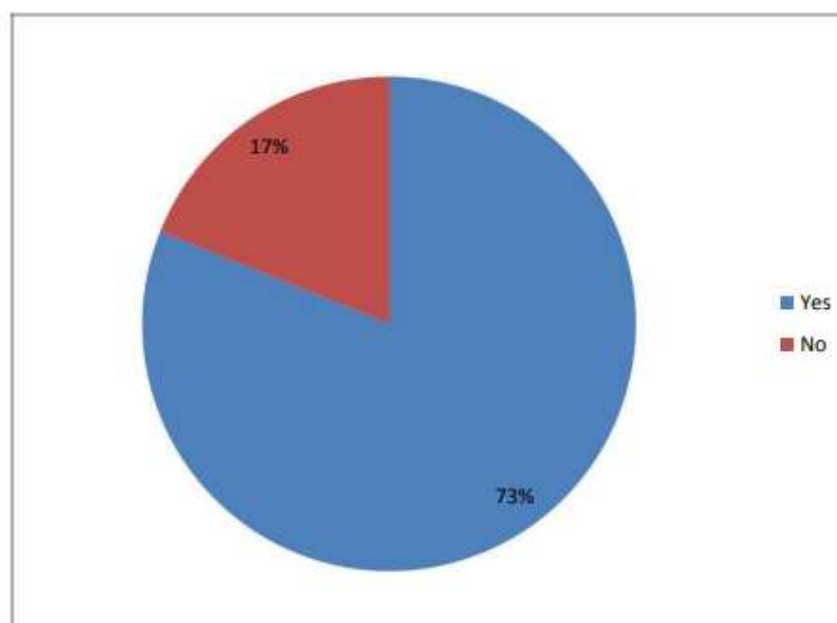


Figure 4: Patient care burden share by family member

Interpretation

As far as receiving financial assistance is concerned, out of the total sampled carers, 77% of the respondents say that they do not receive financial assistance, and the remaining 23% say that they receive some financial assistance.

Concerning the gender of the respondents in the category of parents of sick child, out of the total number of parents of sick child who were sampled, 24% are males and 76% are females. This finding relates to the overall population of caregivers. In terms of the relationship between caregivers and patients, one hundred percent of those who were polled provided positive ratings. 14% of the respondents are the patient's parents, 62% of the respondents are the patient's spouse, and 24% of the respondents are the patient's son or daughter. Caregivers make up the majority of the respondents. calm and unruffled.

Conclusion

The current study is distinctive in that it is the first research in the field of palliative care systems to examine the significance of parents of sick child role in promoting patient well-being. For the purposes of this research, parents of sick child are the individuals who bear the primary responsibility for the patient. A researcher has endeavoured to comprehend the sources from which these participants will obtain information regarding parents of sick child. In the absence of a diagnosis, the patient in order to obtain consent, the parents of sick child must provide assent for all decisions concerning the care of the patient. Frequently, family members assume the role of parents of sick child. A research endeavour has been undertaken to comprehend, analyse, and evaluate diverse facets of parents of sick child who spend the day at the residences of patients. Depression, anxiety, hostility, withdrawal from the job, loss of concentration, alterations in eating patterns, insomnia, fatigue, excessive drinking or smoking, and other health complications are all indicators of stress among caretakers.

References

1. Swit, C. S., & Breen, R. (2023). Parenting during a pandemic: Predictors of parental burnout. *Journal of Family Issues*, 44(7), 1817-1837.
2. Wolfe, J., Friebert, S., and Hilden, J. (2002). 'Caring for children with advanced cancer Integrating palliative care', *Pediatric Clinics of North America*, 49, 1043-1062.
3. Woźniak-Prus, M., Gambin, M., Sekowski, M., Cudo, A., Pisula, E., Kiepusa, E., ... & Kmita, G. (2020). Positive experiences in the parent-child relationship during the COVID-19 lockdown in Poland: the role of emotion regulation, empathy, parenting self-efficacy, and social support.
4. Wright, M., Wood, J., Lynch, T., and Clark, D. (2008). 'Mapping Levels of Palliative Care Development: A Global View', *Journal of pain and symptom management*, 35(5), 469-485.
5. Young, B., Dixon-Woods, M., and Heney, D. (2002). 'Identity and role in parenting a child with cancer', *Pediatric Rehabilitation*, 5(4), 209-214.
6. Vrijmoet-Wiersma, C. M., van Klink, J.M.M., Kolk, A.M., Koopman, H.M., Ball, L.M., and Egeler, R. (2008). 'Assessment of Parental Psychological Stress in Pediatric Cancer: A Review', *Journal of Pediatric Psychology*, 33(7), 694-706
7. Seth, T. (2010). 'Communication to pediatric cancer patients and their families: A cultural perspective', *Indian Journal of Palliative Care*, 16(1), 26-29.
8. Benini, F., Papadatou, D., Bernad , M., Craig, F., De Zen, L., Downing, J., ... & Wolfe, J. (2022). International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *Journal of pain and symptom management*, 63(5), e529-e543.
9. Khalid, K., Saad, S. K. M., Abd Ghani, N. A., & Kadher, A. N. M. A. (2019). Religious and cultural challenges in paediatrics palliative care: a review of literature. *Pediatric Hematology Oncology Journal*, 4(3), 67-73.
10. Ul-Ain, R., Faizan, M., & Mohamed, A. (2021). Pediatric palliative care: Competency and educational needs assessment in pediatricians of a developing country. *Pediatric Hematology Oncology Journal*, 6(3), 118-122.
11. Chelazzi, C., Villa, G., Lanini, I., Romagnoli, S., & Latronico, N. (2023). The adult and pediatric palliative care: differences and shared issues. *Journal of Anesthesia, Analgesia and Critical Care*, 3(1), 1-8.
12. Postier, A. C., Wolfe, J., Hauser, J., Remke, S. S., Baker, J. N., Kolste, A., ... & Friedrichsdorf, S. J. (2022). Education in palliative and end-of-life care-pediatrics: Curriculum use and dissemination. *Journal of Pain and Symptom Management*, 63(3), 349-358.