

Original Article

Knowledge on Prevention of Pressure Ulcers Among Caregivers of Patients Receiving Home-based Palliative Care

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ABSTRACT

Objectives: Pressure Ulcer (PUs) remains one of the most crucial aspects of any home-based palliative care setting. The objective of this need assessment study was to assess caregivers' knowledge regarding the prevention of pressure ulcers (PUs) among home-based palliative care patients.

Materials and Methods: Study design: This study was a quantitative cross-sectional survey. Setting: The study was conducted among caregivers of home-based palliative care patients residing in Olavanna Panchayath, Kozhikode. Population: Caregivers of home-based palliative care patients at risk of developing bedsores. Sample and sample size: Using the purposive sampling technique, the need assessment was conducted among 20 caregivers of home-based palliative care patients. Data were collected using a structured knowledge interview schedule. Data analysis: The obtained data were analyzed using descriptive statistics.

Results: Knowledge assessment among care providers reveals that 10% had good knowledge, 40% had average knowledge, 50% had poor knowledge, and none had very good or very poor knowledge.

Conclusion: Providing evidence-based clinical practice guidelines and structured teaching programs can improve the knowledge of caregivers. Measures to improve the availability of helping hands at home through volunteer training, ensuring the necessary equipment and regular supervision are crucial for contributing to patient comfort and safety, which will enhance the quality of life of palliative care patients

Keywords: Knowledge, Home-based palliative care, Caregivers, Prevention of pressure ulcers

INTRODUCTION

Pressure ulcer (PU) is defined as a 'localised' injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear' by the National Pressure Ulcer Advisory Panel (NPUAP).^[1] It is an essential health concern in those receiving palliative care. Most patients receiving palliative care might have an increased risk for PUs^[2,3] due to their clinical condition and decreased functional status. Their vulnerability increases as they become less active and their immobility increases as the disease progress. Other factors that predispose people to PU formation are poor nutrition, poor sensation, urinary and faecal incontinence, and poor overall physical and mental health.^[2,3]

PUs remains one of the most neglected aspects of health-care provision in India. A large proportion of home care patients present with PUs and many more patients are at risk. Pressure sore prevention in palliative care is considered an essential element of holistic care, with the primary goal of promoting quality of life for patients and families.^[4] Identifying their associated risk factors at an early stage may go a long way in preventing their occurrence.^[5]

PUs can decrease quality of life physically, emotionally, socially, and mentally and lead to increased mortality and morbidity. Due to the increased prevalence of PUs in home-care settings, the treatment and prevention of PUs in the community have become a health-care burden.^[3] If a PU is developed, problems exist from the availability

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Received: 23 September 2021 Accepted: 03 January 2022 EPub Ahead of Print: 09 February 2022 Published: 24 March 2022 DOI: 10.25259/IJPC_84_2021

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of suitable dressings to balancing life expectancy with PUs. The emotional and social distress that these patients experience is a significant and possibly under-recognised issue and this is directly attributed to their wounds. All these problems must be recognised early and addressed promptly to manage wounds effectively in this patient population.^[6]

Palliative care has been recognised as essential healthcare which should be comprehensive, accessible, and appropriate to the community. Family is the most valued social institution in India. During the last years of anyone's life, the majority of time is being spent at home, with family members providing much of the informal care.^[5] Thus, the involvement of family caregivers is essential for optimal care of palliative care patients in ensuring treatment compliance, continuity of care, and social support, which urges the home care nurses to stress more on educating the family. Family caregivers are guided to care for patients at home by the palliative care team. Caregivers play a key role in preventing PUs. If caregivers are knowledgeable about PU prevention, they can assist patients in achieving the best possible quality of life and spending their final days peacefully and comfortably with dignity.^[7]

A systematic review of 31 studies found that PUs significantly limit many aspects of an individual's well-being, including general health physical, social, financial, and psychological quality of life.^[8] Thus, the caregivers should have adequate knowledge of preventive practices of bedsores. Palliative care nurses must evaluate the caregiver's knowledge on PU prevention because PUs cause not only increased healthcare costs but also loss of life. A need assessment study which is a systematic process for determining and addressing needs, or gaps between current conditions and desired conditions, was undertaken to assess the caregivers' knowledge regarding the prevention of PUs among palliative care patients. This study aimed to determine the need for developing evidence-based clinical practice guidelines for caregivers of palliative care patients on PU prevention in the home care setting.

Objective

The objective of the need assessment is to assess caregivers' knowledge regarding the prevention of PUs among palliative care patients residing in Olavanna Panchayath, Kozhikode, Kerala.

MATERIALS AND METHODS

Setting

The need assessment was conducted among caregivers of palliative care patients residing in Olavanna Panchayath, Kozhikode, Kerala.

Population

Caregivers of palliative care patients at risk of developing bedsores residing in Olavanna Panchayath, Kozhikode, Kerala.

Sample and sample size

The need assessment was conducted among 20 caregivers of palliative care patients residing in Olavanna Panchayath, Kozhikode, Kerala.

Sampling criteria

Caregivers of patients on palliative care who had been providing palliative care at home for at least 1 month were included in the study. Paid caregivers and distant relatives who came for short durations and caregivers who cannot understand either English or Malayalam (the local language) were excluded from the study.

Tool for data collection

A structured knowledge interview schedule consisting of 25 multiple choice questions was developed by referring to various literature from foundations of nursing and medical-surgical nursing textbooks, guidelines from National Institute for Health and Care Excellence,^[9] NPUAP^[10] and European PU Advisory Panel^[11] guidelines. Expert opinion and suggestions were taken from nursing and palliative care in determining the essential areas to be included. [Table 1] Depicts the Blue print-of structured knowledge interview schedule regarding knowledge on prevention of bed sore. The tool to collect data was first prepared in English then translated to Malayalam. To establish content validity, the structured knowledge interview schedule was given to seven experts in the field of palliative nursing, medical surgical nursing, palliative medicine, and community health nursing. The validators were requested to give their opinion and suggestions regarding the adequacy, relevance, and appropriateness of the item. Modifications were done as per the suggestions. Criteria were developed for validating the tool. There was a 100% agreement for 20 items. Three items had 85% agreement and one item had 71% agreement. Modifications were done as per suggestions. With the corrections and suggestions given by all validators, the individual item had ICVI = 1, and the SCVI was = 0.963. To ascertain the reliability of a structured knowledge interview schedule, the split-half method was used. The tool was divided into two equivalent halves and correlation for the half test was calculated, using Karl Pearson correlation coefficient formula. The significance of the correlation was tested using Spearman Brown prophesy formula. The r-value was 0.83 and the tool was found reliable.

Data collection

The data were collected by administering the structured knowledge interview schedule to caregivers of palliative care patients by purposive sampling technique. The administrative permission was obtained from Panchayath president Olavanna and Medical Officer In Charge, Community Health Centre (CHC), Olavanna.

The investigator visited the families during regular home care and collected the data. After explaining the study's purpose and objectives, informed consent was taken from all the participants who agreed to participate in the study. The participants were also informed that their answers would be kept confidential. The sample consisted of 20 caregivers. The data were collected from each participant in person and recorded systematically. Approximately 10–12 min was taken to complete the interview schedule. The collected data were organised on the master data sheet.

Data analysis

To find out the level of knowledge of care providers, a 5 point scale was used. The scales were graded arbitrarily as follows: Very good knowledge – >80%; good Knowledge 60–80%; average knowledge – 40–60%; poor Knowledge - 20–40% and very poor knowledge <20%. The obtained data were analysed in terms of descriptive statistics.

RESULTS

The assessment of knowledge among caregivers reveals that 10% of them had good knowledge, 40% had average knowledge, and 50% had poor knowledge, whereas none had very good or very poor knowledge. [Table 2] depicts the level of knowledge of caregivers on the prevention of pressure ulcers among palliative care clients.

DISCUSSION

The home care service model delivered in the present data collection setting is derived from the Kerala model of home-based palliative care services.^[12] In low- and middle-income countries like India, there is a triple combination of high patient load, lack of trained nursing workforce, and poor financial status, so this model was born out of necessity. A study conducted in 2015 to assess the prevalence of PUs in a home care unit reported that almost 20% of patients with advanced cancer taken up for home-care services suffer from PU in Kerala.^[13] From the need assessment, it was found that most care providers do not have adequate knowledge regarding the prevention of PUs among patients receiving palliative care. The lack of knowledge among the caregivers can also be a reason for such a high prevalence of PUs in patients with palliative care needs receiving home care. It was also noticed that all the patients could not be kept on air mattresses or water mattresses due to issues on power supply, lack of adequate beddings, problems of affordability and feasibility. It was also reported that the inability to lie flat because of shortness of breath, the presence of a catheter, ostomy, a reduced ability to perform activities of daily living could also increase the risk of PUs.^[14] In the present study, about half of the caregivers had poor knowledge of preventive measures for PUs. All the participants were educated on preventive practices of PUs and the doubts were cleared in their local language.

This may not be feasible during regular home care due to the high load of patients covered by a small team. The need assessment gave a clear indication for developing evidence-based guidelines for caregivers of palliative care patients on PU prevention.

Nurses working at homecare have the opportunity to manipulate certain environmental factors that can prevent PUs and develop effective treatment plans for PUs if they occur.^[14] Thus, the role of the home care team/nurse is to educate and empower the caregiver by teaching them simple and cost-effective methods which can prevent the occurrence of PUs. Awareness programmes and hands-on training workshops should be encouraged for home care teams, other health-care professionals, grass-root level health workers such as ASHAs, volunteers, and caregivers of patients receiving palliative care on prevention and management of PUs. Such cost-effective interventions may help in reducing the incidence of PUs in the home care setting.

It was identified that there were no written guidelines present in the study setting for caregivers of palliative care patients on PU prevention. Research is needed to scientifically identify the patient's characteristics of palliative care and what makes a PU unlikely to heal while not limiting the quality of life in the home care settings. A standardised guideline on adverse events in the home-care setting is needed to be used in home-care programmes. Prospective cohort studies are needed to improve estimates of PU in larger populations and intervention studies should be undertaken to reduce the risk that home-care patients experience. Future research should be conducted to identify protective behaviours and risk factors associated with the development of PUs in patients receiving palliative care. Due to resource limitations, we could only include caregivers who resided within 10 km of the PHC during the data collection. Further research is recommended to systematically identify quality measures and the evidence to support quality assessment and improvement in the palliative care of patients at risk of developing pressure sores in the home care setting. Having culturally sensitive evidence-based practices in a home-care setting is the need of the hour.

The findings of the study have been used to guide clinical practice. Thus, similar studies not only generate scope to develop nursing interventions built on caregivers' needs and circumstances but also policy formation. Future research is necessary to elucidate the effectiveness of such cost-effective interventions and develop evidence-based protocols and clinical practice guidelines for caregivers of patients receiving palliative care in the home care setting.

Recommendations

- PU prevention policies and evidence-based clinical practice guidelines are gaining prominence in the face

Table 1: Blue print-structured knowledge interview schedule regarding knowledge on prevention of bedsore.

Knowledge	Items			Number of questions	%
Content area	Knowledge	Comprehension	Applications		
Skin assessment	1, 2, 3, 4, 5, 7	8, 9	6	9	36
Preventive skincare	-	11, 12, 13	10, 14	5	20
Repositioning and mobilisation	-	16, 19	15, 17, 18, 20	6	24
Nutrition and hydration	22, 23, 24	21	25	5	20
Total	9	8	8	25	100

Table 2: Level of knowledge of caregivers on prevention of pressure ulcers among palliative care patients.

n=20			
S. No.	Knowledge score	Frequency	Percentage
1.	Very good	Nil	-
2.	Good	2	10
3.	Average	8	40
4.	Poor	10	50
5.	Very Poor	-	-

of rising costs, especially in the existing condition of the post-COVID-19 pandemic. Health-care organisations have a responsibility and a role in developing PU prevention strategies to alleviate the suffering and resource demands caused by PUs.

- Evidence-based clinical practice guidelines should be developed and provided to all caregivers of palliative care patients to minimise the incidence of PUs.
- Policymakers should prepare policies and clinical practice guidelines to prevent PUs in the home-care setting.
- Further researches can be done in the area of health education to the general population for the prevention of PUs among bedridden patients.
- Those organisations providing palliative care services should give special emphasis on prevention practices during training for volunteers and caregivers
- Palliative care nurses need to enhance their attitude and knowledge on PU prevention to improve further and supervise the caregivers to ensure quality care.
- Palliative care nurses should also provide incidental teaching to the respective caregivers. The latter know or practice deficits to improve patients' comfort and quality of life.
- Health service organisations should identify the perceived barriers of care and then minimise these barriers as much as possible to prevent PUs.
- They also should recruit more nurse educators to balance their numbers with the respective patients and caregivers to provide interventions such as PU prevention.

CONCLUSION

In the home setting, we must also be mindful that sometimes the primary goal of preventing PU development is displaced by a greater need for comfort. The home care team, patients, and family caregivers must balance the patient's comfort with PU prevention and treatment. If comfort measures supersede over prevention, both PU prevention and treatment can be painful for palliative care patients. When considering PU management interventions in a similar population, the home care team should be able to address the overall goal of patient care and patient quality of life. Thus, the findings of this need assessment study support the need to focus attention on PUs prevention for patients receiving home care and define further specific guidelines aimed at patients' comfort and quality of life.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Position Statements-National Pressure Ulcer Advisory Panel; 2021. Available from: <https://www.npiap.com/page/positionstatements> [Last accessed on 2021 Sep 08].
2. Bluestein D, Javaheri A. Pressure ulcers: Prevention, evaluation, and management. *Am Fam Physician* 2008;78:1186-94.
3. Langemo DK, Black J, National Pressure Ulcer Advisory Panel. Pressure ulcers in individuals receiving palliative care: A national pressure ulcer advisory panel white paper. *Adv Skin Wound Care* 2010;23:59-72.
4. Chaplin J. Pressure sore risk assessment in palliative care. *J Tissue Viability* 2000;10:27-31.
5. Hughes RG, editor. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality; 2008.
6. Naylor WA. A guide to wound management in palliative care. *Int J Palliat Nurs* 2005;11:572, 574-9; discussion 579.
7. Etafa W, Argaw Z, Gemechu E, Melese B. Nurses' attitude and perceived barriers to pressure ulcer prevention. *BMC Nurs* 2018;17:14.
8. Overview, Pressure Ulcers: Prevention and Management, Guidance, NICE; 2021. Available from: <https://www.nice.org.uk/guidance/cg179> [Last accessed on 2021 Sep 08].

- accessed on 2021 Sep 11].
9. Guidelines-National Pressure Ulcer Advisory Panel; 2021. Available from: <https://www.npiap.com/page/guidelines> [Last accessed on 2021 Sep 11].
 10. PU Guidelines, EPUAP; 2021. Available from: <http://www.epuap.org/pu-guidelines> [Last accessed on 2021 Sep 11].
 11. Bollini P, Venkateswaran C, Sureshkumar K. Palliative care in Kerala, India: A model for resource-poor settings. *Oncol Res Treat* 2004;27:138-42.
 12. Sankaran BM, Chakraborty S, Patil VM, Raghavan SN, Thomas S, Sen S. Burden and outcomes of pressure ulcers in cancer patients receiving the Kerala model of home based palliative care in India: Results from a prospective. *Indian J Palliat Care* 2015;21:152-7.
 13. Brink P, Smith TE, Linkewich B. Factors associated with pressure ulcers in palliative home care. *J Palliat Med* 2006;9:1369-75.
 14. Maklebust J. Preventing pressure ulcers in home care patients. *Home Healthc Nurse* 1999;17:229-37; quiz 237-8.

How to cite this article: Antony L, Thelly AS. Knowledge on prevention of pressure ulcers among caregivers of patients receiving home-based palliative care. *Indian J Palliat Care* 2022;28:75-9.