

Describing Perceptions and Experiences of Undergraduate Nursing Students Regarding Death and Dying in Palliative Care Setting

Zohra Kurji¹, Jacqueline Dias¹, Salma Amin Rattani^{1*}, Amina Aijaz Khowaja¹ and Anila Naz AliSher²

1. School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan

2. Mayo Hospital, Lahore, Pakistan

Introduction

Palliative care is an approach that aims to improve the quality of life for patients with serious and terminal illnesses by providing holistic care. The care is not only limited to the patient, but also to their family members and the care covers a wide range of services, including physical, mental, psychosocial, emotional and spiritual aspects. Palliative care is recognized as a human right as an integral part of health, so it is the responsibility of the health system to develop palliative services. According to the World Health Organization 2018, about 40 million people need palliative care each year, 78% of whom are from low- and middle-income countries. In Pakistan, noncommunicable diseases, including cancer, have become the leading cause of morbidity and mortality, indicating a high need for palliative care. However, Pakistan's health system is not ready to consider it a priority program. In addition, Pakistan's health facility lacks qualified personnel and pain relievers such as opioids.

Methods

Design setting and participants

A descriptive research design was used to explore the perceptions and experiences of participants who were undergraduate nursing students (n = 41), caring for deceased and dying patients in the palliative course of the post RN BScN program. This program enrolls nurses with a minimum of two years of experience after completing three years of nursing diploma and one year of specialization diploma in any record. The course was offered from January 2018 to April 2018; the current study was conducted almost 3 months after the exposure of theory, simulation and clinic. During the course, practicing nurses shared their perceptions and experiences of providing palliative care to patients and their families.

Data collection, analysis, and rigor

The data was collected during group discussions using a semi-structured interview guide with the probes to deepen the exploration. Two group discussion experts were recruited to maintain the neutrality of the research. Field notes were taken and participants were observed for any non-verbal behavior, including silence, sighs, laughter, posture, etc., during the interviews. The focus group discussions were videotaped and verbatim were transcribed and analyzed; themes, sub-themes and categories were extracted. Participants were encouraged to express their experiences explicitly.

Ethical considerations

The study was launched after approval by the Aga Khan University ethics committee and permission from the dean of the school of nursing. Participants who agreed to participate have

received the consent form and have been advised that they will not be at risk if they refuse to participate. At the start of data collection, we announced that if someone felt emotionally unstable, they could leave the session. Few students have been observed to become emotional due to the recent loss of loved ones in their family. The discussions took place in a friendly environment so that the participants did not feel threatened by the presence of the researcher. Individuals have had the freedom to express their true thoughts, is also a requirement of this research. The confidentiality of individuals has been strictly preserved by concealing their names and using codes corresponding to the numbers of the newsgroups. All data was saved on a computer and access to the data was password protected. Individual consent forms signed by participants are stored in a lock and key.

Results

Through analysis of Six focus group discussions emerged the themes; attitudes of nurses, ethical dilemma, and readiness. Each theme with its sub-themes and categories are presented in Table 1 and supported through participants' verbatim.

Conclusion and Recommendation

Providing quality palliative care to dying patients is important for nurses. Therefore, it is important to be included in the nursing curriculum for achieving competency in palliative care for all graduates. Moreover, creating a supportive platform for nurses and patients' families to promote the culture of sharing ethical concerns in palliative care through ongoing dialogues is needed. Health care institutions need to develop infrastructure such as comprehensive policies for palliative patient and space such as providing a lounge with a counselor for the grieving process. Furthermore, administrative and institutional level decisions are required in governmental and nongovernmental institutions to support palliative care initiatives and the availability of opioids for pain management in context to Pakistan.