Exploration of the end of life care preferences and effectiveness of the intervention package on selected psychosocial variables among the terminally ill patients and their family members in selected settings of Tamil Nadu

Dr. E. Devakirubai

ABSTRACT

Background of the Study: In today’s social climate, death is viewed as something to be avoided at all costs. There is a significant shift in the nature of disease worldwide, with a significant increase in the Non-Communicable Diseases (NCDs). These diseases are the world’s main killer and it accounts for nearly half of all deaths in India. This disease transition had led to an increase in patients with terminal illness who require quality end-of-life care. End-of-life requires dealing with challenging issues along various dimensions- physical, psychological, social and cultural. Attending to psychosocial factors is a crucial aspect of end-of-life care. As the largest group of health care professionals, and those most connected with the comprehensive needs of the terminally ill and their families, nurses play a vital role in humane and dignified care at the end-of-life. Aim: The aim of the study was to explore the end-of-life care preferences and to evaluate the effectiveness of the intervention package on death anxiety, hope and dignity of the terminally ill patients. Methodology: Mixed- Method- Embedded Intervention Model was adopted for the study. In the quantitative approach, non-equivalent pretest-posttest control group design, a type of quasi intervention design was used concurrently. The study was conducted at Jeevodaya Hospice, Chennai. A total of 120 terminally ill patients were selected purposively, out of which 60 were in the intervention group and control group each. Tools used were semi-structured questionnaire on end-of-life care preferences, Modified Death Anxiety Scale, Modified Hope Scale and Modified Patient Dignity Inventory. Interview technique was used to collect the data. Data was analyzed using descriptive and inferential statistics. The Intervention for the study structured empathy oriented end-of-life counseling was administered over 6 sessions on an average of 7 hours spanning over 8 days to solve the issues related to death and dying. Eight patients were studied qualitatively using a semi structured interview guide. The tape
recorded interviews were transcribed, translated and analyzed using the principles of qualitative content analysis. **Results:** Majority (69.16%) had not communicated about their end-of-life care preferences. Terminally ill patients preferred to medicines to control pain (82.5%) but did not prefer life prolonging treatment options. Home was the preferred place for EOL care (40%) and majority (77.5%) preferred to die at home. Nearly 74% preferred to incorporate their spiritual beliefs into EOL care and 71.66% preferred to write a living will. A more or less similar attitude prevailed with 40.83% and 37.5% agreeing for Euthanasia and PAS to be made legally available. The structured empathy oriented end-of-life counseling was effective in allaying death anxiety \(t=9.09, p=0.00\), increasing hope \(t=16.65, p=0.00\) and improving the sense of dignity \(t=14.70, p=0.00\) of the terminally ill patients. There was a significant relationship between death anxiety and hop \(r=-0.5\), death anxiety and dignity \(r=0.7\) and dignity and hope \(r=-0.6\). The themes that emerged out of qualitative analysis triangulated the quantitative findings.

**Conclusion:** Quality EOL care is synonymous with holistic compassionate EOL care. Study findings conclude that nurses may be utilized in a more formalized and systematic way to deal with the psychosocial existential issues during the end-of-life care. Continuous and sustained effort to improve EOL research will definitely be a stepping stone for quality EOL care in India.

**[Key Words:]** Non Communicable Disease- end-of-life, end-of-life care preferences, terminally ill patients, structured empathy oriented end-of-life counseling.