Family Perspectives on Communication With Healthcare Providers During End-of-Life Cancer Care

Renee Royak-Schaler, PhD, MEd, Shahinaz M. Gadalla, MD, MS, Jeanne P. Lemkau, PhD, Douglas D. Ross, MD, PhD, Carla Alexander, MD, and Deborah Scott, MEd

Purpose/Objectives: To assess healthcare provider communication about end-of-life (EOL) and hospice care with patients with terminal cancer and their families, from the perspective of the family members.

Design: Exploratory, qualitative study using focus group discussion.

Setting: University of Maryland Greenebaum Cancer Center.

Sample: 24 spouses and first-degree relatives of deceased patients with cancer who had been treated at the cancer center from 2000–2002.

Methods: Family members participated in one of two focus group discussions and completed a short questionnaire regarding their sociodemographic characteristics and the type of EOL care their deceased relatives had received. Qualitative data were analyzed using descriptive statistics. Qualitative data were audiorecorded and analyzed by comparing, contrasting, and summarizing content themes from the focus groups using NUD*IST S(N) software.

Main Research Variables: Family perceptions of communication with the healthcare team in EOL cancer care.

Findings: Participants associated the information, content, style, language, and timing of communication about EOL and hospice care from healthcare professionals with patient age, attitudes, and compliance with medical decisions. Informed decisions about EOL care by patients and their family members, including the use of hospice services, appeared to be compromised by these types of communication biases.

Conclusions: Satisfaction with EOL care was associated with the perceived quality of communication among patients, family members, and the healthcare team.

Implications for Nursing: Study findings highlight the importance of training healthcare professionals in the content, timing, and potential biases associated with information delivery to facilitate informed decisions about EOL and hospice care to dying patients and their families.

Key Points . . .

➤ Communication about hospice and end-of-life (EOL) care can be less than optimal, leaving patients and their families struggling to get the information they need to make informed decisions.

➤ Families stress the importance of receiving timely and accurate information about EOL care options to assist in making informed decisions and obtaining the best quality of care for patients.

➤ The training of healthcare professionals in the content, timing, and potential biases associated with information delivery about EOL and hospice care can promote a peaceful transition for dying patients and their families.

Renee Royak-Schaler, PhD, MEd, is an associate professor and Shahinaz M. Gadalla, MD, MS, is a doctoral candidate, both in the Department of Epidemiology and Preventive Medicine in the School of Medicine at the University of Maryland in Baltimore; Jeanne P. Lemkau, PhD, is professor emerita in the Departments of Family Medicine and Community Health at Wright State University in Dayton, OH; and Douglas D. Ross, MD, PhD, is a professor in the Experimental Therapeutics Program. Carla Alexander, MD, is an assistant professor in the Institute for Human Virology, and Deborah Scott, MEd, is a research associate, all in the School of Medicine at the University of Maryland. This study was funded by a grant from the University of Maryland Greenebaum Cancer Center in Baltimore. (Submitted September 2005. Accepted for publication November 22, 2005.)