European Journal of Oncology Nursing 18 (2014) 492–498

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Truth-telling to patients' terminal illness: What makes oncology nurses act individually?☆

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Keywords:
Oncology nurse
Terminal cancer
Truth telling
Attitude
Experience

A B S T R A C T

Purpose: Nurses encounter the challenge of truth-telling to patients' terminal illness (TTPTI) in their daily care activities, particularly for nurses working in the pervasive culture of family protectiveness and medical paternalism. This study aims to investigate oncology nurses' major responses to handling this issue and to explore what factors might explain oncology nurses' various actions.
Methods: A pilot quantitative study was designed to describe full-time nurses' ($n = 70$) truth-telling experiences at an oncology centre in Taipei. The potential influencing factors of nurses' demographic data, clinical characteristics, and truth-telling attitudes were also explored.
Results: Most nurses expressed that truth-telling was a physician's responsibility. Nevertheless, 70.6% of nurses responded that they had performed truth-telling, and 20 nurses (29.4%) reported no experience. The reasons for inaction were "Truth-telling is not my duty", "Families required me to conceal the truth", and "Truth-telling is difficult for me". Based on a stepwise regression analysis, nurses' truth-telling acts can be predicted based on less perceived difficulty of talking about "Do not resuscitate" with patients, a higher perceived authorisation from the unit, and more oncology work experience (adjusted $R^2 = 24.1\%$).
Conclusions: Oncology care experience, perceived comfort in communication with terminal patients, and unit authorisation are important factors for cultivating nurses' professional accountability in truth-telling. Nursing leaders and educators should consider reducing nursing barriers for truth-telling, improving oncology nurses' professional accountability, and facilitating better quality care environments for terminal patients.

Introduction

Through clinical observation, we often found notes that stated "Do not tell the patient's diagnosis" or an order for "Do not resuscitate (DNR)" taped inside the first page of a patient's chart …

Terminal cancer is defined as incurable (Begley and Blackwood, 2000), and death is expected for people in this situation. Handling the issue of "truth-telling to patients' terminal illness (TTPTI)" is a challenge for health professionals to reveal the truth to patients and their significant others. Being diagnosed with a terminal illness is also a critical time for patients to know their illness, because they have less survival time, and an appropriate dying process becomes

☆ This study was supported by a grant from the Ministry of Health & Welfare Taiwan, R.O.C. (DOH 92-HP-1507), and the Ministry of Science & Technology Taiwan, R.O.C. (NSC 96-2411-H-010-001-), the authors thank all of the participants in this study.

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http://dx.doi.org/10.1016/j.ejon.2014.04.010
1462-3889/

one of most significant events in their mortal lives (Konishi and Davis, 1999; Lorensen et al., 2003). For many years, western health care systems have considered a patient's autonomy to be an important ethical principle in directing clinical decisions. This principle forced the shift from nondisclosure to disclosure during the late 1960s and the 1970s (Mystakidou et al., 2004). In contrast, people in family-oriented countries are more inclined to maintain a paternalistic relationship (Costantini et al., 2006) and advocate nondisclosure. Some studies have indicated that not disclosing the truth could help patients live with less anxiety and preserve more hope and better quality of life (Begley and Blackwood, 2000; Hu et al., 2002), consistent with the ethical principles of non-maleficence and beneficence. The disclosure patterns between western and eastern cultures regarding TTPTI are drastically different.

In Italy, Repetto et al. (2009) interviewed 622 older patients with various stages of cancer, and the results showed that 412 (66.2%) patients were informed about their illness condition, whereas 210 (33.8%) were not informed. The authors concluded that illness truth disclosure can enhance patients' involvement in their cancer care and facilitate disease treatment, prognosis, and more positive expectations. In another study conducted in China, attitudes toward truth disclosure varied based on the patient's cancer stage, and nearly half of patients (49.7%, $n = 75$) and family members (56%, $n = 177$) believed that not disclosing the truth about terminal illness was useful for maintaining patients' quality of life (Jiang et al., 2007). People may have a stereotyped impression that physicians always perform TTPTI in the US; however, one article posited that physicians might not communicate all of the TTPTI, except if patients demand the truth about their illness (Daugherty and Hlubocky, 2008). Several studies revealed that patients who were older and female and had a lower expected survival time experienced a higher frequency of non-disclosure (Back and Huak, 2005; Dahlstrand et al., 2008; Wang et al., 2004).

Although nurses are not the main health professionals in charge of truth-telling in clinics, they are inescapably involved in TTPTI events (Hancock et al., 2007). Most nurses express that the physician caring for the patient should inform patients of the truth about their terminal illness (Georges and Grypdonck, 2002; Li et al., 2008; Lorensen et al., 2003; Sasahara et al., 2003). However, physicians may not believe that honest disclosure is beneficial in establishing satisfactory relationships between health care providers, patients, and families. Furthermore, patients or family members might think that physicians are too authoritative or too busy (Hu et al., 2002; Sasahara et al., 2003) and would occasionally prefer to ask nurses about the truth of their illness (Sasahara et al., 2003). This causes nurses must face a great ethical dilemma of whether to tell and how to reveal the truth about a terminal illness to the patients (Fowler, 2004; Hancock et al., 2007). In a study by Li et al. (2008), 55.8% of Chinese nurses ($n = 111$) thought that a terminal diagnosis should not be announced, and nurses with a higher education level and more working experience agreed that TTPTI would make patients feel hopeless and helpless and reduce the quality of life.

Based on these studies, we need to determine the best judgement and actions for nurses to handle TTPTI in clinics in various cultural and medical environments. Additionally, we need to explore whether nurses have sufficient educational and supportive systems to ethically cope with TTPTI. In the literature, accountability is defined as being answerable for one's decisions, which is also a basis for building a trusting relationship with a client and is a way to deliver ethical quality care. Accountability is also an interrelationship between responsibility, autonomy, and authority (Milton, 2008; Snowdon and Rajacich, 1993). Nurses are in a good position to know or explore the attitudes of patients and their family members towards TTPTI (Mystakidou et al., 2004; Vivian, 2006). Considering nurses' advocacy role for patients, TTPTI-related nursing knowledge is implicit in the current role of a nurse specialist. Various approaches should be designed for nurses to cope with this issue in their clinical work.

Taiwan's oncology nurses encounter challenges in their role of accountability and power in TTPTI. The medical laws and cultural environment tend to be paternalistic and patriarchal. Physicians have the primary responsibility to make a diagnosis (Legislative-Yuan, Dec. 04, 2012b). The truth-telling principle is identified in the 8th rule of the "Hospice Palliative Care Act", which is entitled "Physicians should inform the terminal patients or family members about the medical care plans … ." (Legislative-Yuan, Jan. 26, 2012a). The law is meant to protect patients' rights but not necessarily to inform patients about their illness, and patients may receive insufficient information. A direct legal role for nurses in TTPTI is not described in Taiwan's "Nursing Personnel Act" (Legislative-Yuan, Dec. 21, 2011). Nurses are under physicians' orders to execute medical assistance, and the role of providing nursing advice and counselling can be found in the 24th rule. In this social context, patients with terminal cancer are mostly unaware of the details of their illness and might ask nurses the truth about their diagnosis or prognosis, either directly or indirectly. Therefore, oncology nurses indisputably face the tremendous dilemma of TTPTI in their daily bedside care (Luhanga et al., 2010).

Based on the above literature, clinical oncology nurses are in a critical position to affect truth-telling, and nurses working in paternalistic countries may have very limited power to address and cope with TTPTI issues (Konishi, 1998; Zuzelo, 2007). Taiwan's oncology nurses face many contemporary types of TTPTI challenges in their daily clinical practice, such as protecting patients' autonomy, accepting the paternalistic culture, maintaining or breaking the role boundary between physicians and families, and following or negotiating with the hospital's guidelines or its authorisation of truth-telling (Hu et al., 2002; Li et al., 2008). In some hospital units, obtaining DNR permission from patients or families was the nurses' responsibility. They needed to remind the patient's physician to complete DNR orders, and some of them learned or were encouraged to explain the meaning of the order to the patient (Hu et al., 2002; Konishi, 1998; Zuzelo, 2007). Most current studies have emphasised physicians' truth-telling behaviour or have only focused on nurses' general attitudes or opinions about truth-telling. In this study, we considered clinical oncology nurses' TTPTI performance as a potential form of professional accountability, which may provide significant explanations of the degree of oncology nurses' participation or disengagement in the nurse-patient TTPTI interaction. Currently, no study has empirically explored oncology nurses' actual TTPTI behaviours, the reasons and factors that might explain nurses' individual TTPTI performance, and how their background and related ethical-psychological attitudes contribute to their clinical TTPTI performance. The empirical relationship between performing and avoiding TTPTI has not been clearly established in previous research.

Therefore, this study attempts to investigate the concrete details of Taiwan's oncology nurses' TTPTI performance, compare characteristics of nurses who are TTPTI-experienced versus nurses who are TTPTI-inexperienced and discover the predictors of nurses who have TTPTI behaviours. This study intends to discover the differences in oncology nurses' learning and adaptation in clinical situations of TTPTI and what makes oncology nurses act individually using a pilot study of Taiwanese oncology nurses, which may reveal important lessons for nursing professionals and educators in other countries.