



A conversation approach based on shared goal-setting and shared decision-making for nurses in cancer aftercare: A developmental study

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ABSTRACT

Purpose: This study aimed to develop and pretest a systematic conversation approach for nurses to tailor aftercare to oncology patient's goals, unmet needs and wishes.

Methods: We used an iterative developmental process for complex interventions: 1. Identifying problems 2. Identifying overall objectives 3. Designing the intervention 4. Pretesting and adapting the intervention.

Results: The main results of the problem identification were: non-systematic and incomplete screening of potential issues, caveats in providing information, and shared decision-making. The overall objective formulated was: To develop a model for aftercare conversations based on shared goal-setting and decision-making. The conversation approach consists of four phases: 1. Preparation of the consultation including a questionnaire, 2. Shared goal-setting by means of a tool visualizing domains of life, and 3. Shared care planning by means of an overview of possible choices in aftercare, a database with health care professionals and a cancer survivorship care plan. 4. Evaluation. The results of the pretest revealed that the conversation approach needs to be flexible and tailored to the patient and practice setting, and embedded in the care processes. The conversation approach was perceived as enhancing patient-centeredness and leading to more in-depth consultations.

Conclusion: The conversation approach was developed in co-creation with stakeholders. The results of the pretest revealed important implications and suggestions for implementation in routine care. The aftercare conversation approach can be used by nurses to provide tailored patient-centered evidence-based aftercare. Tailored aftercare should support oncology patient's goals, unmet needs and wishes. Further tailoring is needed.

1. Introduction

Cancer survival rates have improved due to advances in early detection and treatment (American Cancer Society, 2015; European Society for Medical Oncology (ESMO), 2014). In conjunction with rising global cancer incidence rates (Torre et al., 2016), this has led to a rapid increase in the number of individuals living with and beyond cancer. In 2012, the estimated global 5-year prevalence for all cancers combined was 15,296 per 100,000 persons, equivalent to 32.6 million people living with a cancer history (within 5 years of diagnosis) (Corsini et al., 2017; Ferlay et al., 2015).

Cancer and its treatment are often associated with long-term physical and psychosocial issues such as fatigue, pain, reduced muscle mass and strength, problems in daily functioning, fear, anxiety, sleep

disturbances, reduced self-esteem and problems with returning to work (Aaronson et al., 2014; ESMO, 2014; Integraal Kankercentrum Nederland (IKNL), 2011a; Simard et al., 2013). As such, cancer survivors often face the imposing task of rebuilding their physical and psychological health, which requires evidence-based aftercare (The Health Council of the Netherlands, 2007; Hewitt et al., 2005). Oncology nurses and advanced practice nurses may play a crucial role in the development and delivery of coordinated aftercare (Klemp, 2015).

Aftercare is often intertwined with clinical follow-up, as these terms are not always clearly distinguished. In this study, aftercare and follow-up are defined in accordance with the Dutch Health Council (The Health Council of the Netherlands, 2007) as follows: aftercare includes interventions such as education, physical training and psychosocial support that helps patients to deal with potential issues of cancer and its

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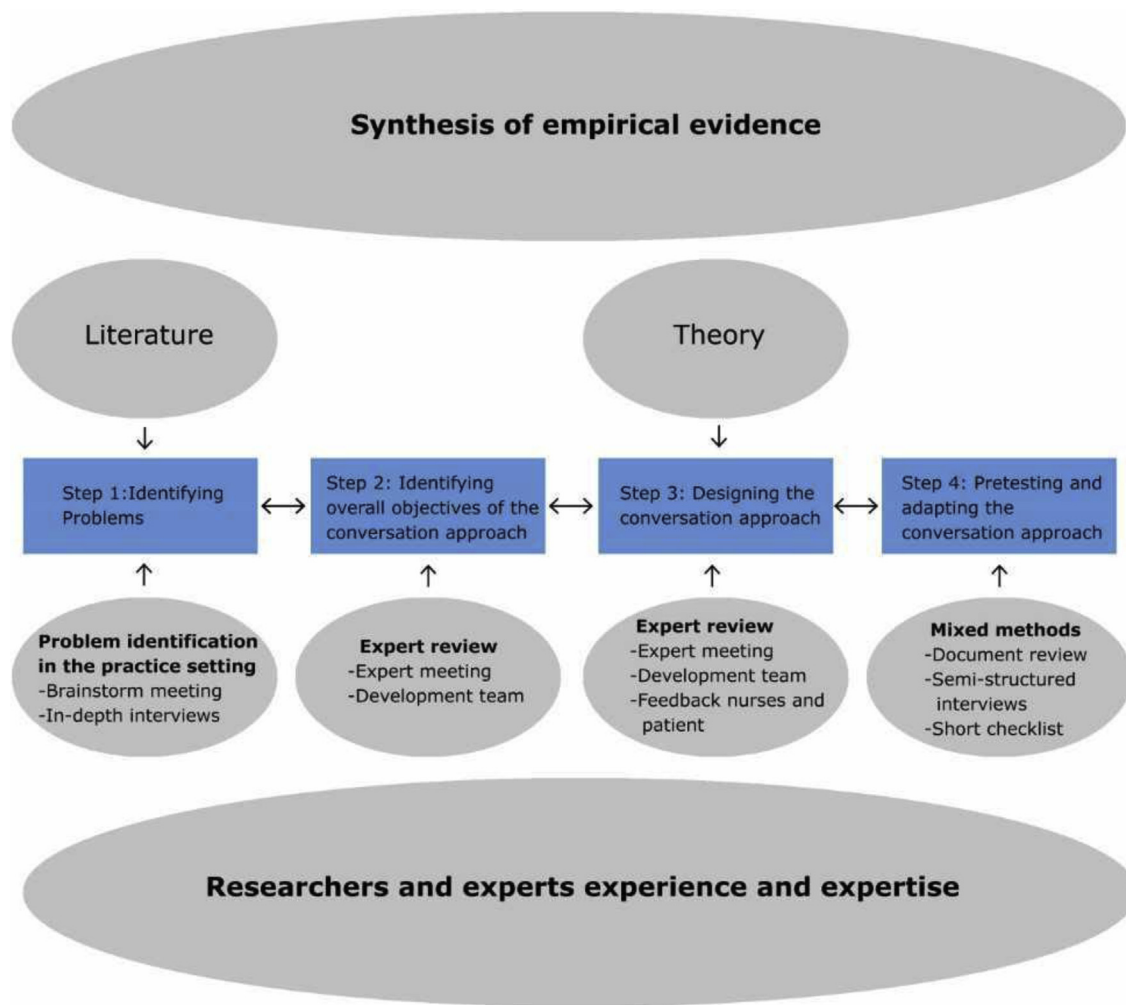


Fig. 1. Development process for a conversation approach in cancer aftercare in nursing (Corry et al., 2013).

treatment. Follow-up is the programmatic approach to prevent cancer recurrence.

According to Dutch's evidence-based clinical practice guidelines, aftercare should address the personal goals of the patient and stimulate his or her self-management (IKNL, 2011a; Visserman et al., 2014). Guidelines recommend a systematic approach for aftercare based on shared decision-making, in which problems, goals, and wishes are systematically screened, shared, and integrated in a cancer survivorship plan (IKNL, 2011a, b) Shared decision-making (SDM) actively involves patients in making health care choices based on the best available evidence, clinical expertise, and the values or goals of the informed patient (Charles et al., 1997; Friesen-Storms et al., 2015; Légaré et al., 2014; Weston, 2001). In chronic care, it is always important to include patients in making shared decisions about their health care management, which may, in turn, have positive effects on health and self-management (Coulter et al., 2015; Friesen-Storms et al., 2015).

Very few cancer survivors receive any comprehensive aftercare, although a number of potential issues and needs have been identified for which evidence-based guidelines exist. These evidence-based guidelines do not seem to be consistently implemented (Klemp, 2015) and a majority of survivors report having unmet information and support needs (Kotronoulas et al., 2017; Paterson et al., 2015; Rowlands et al., 2015; Willems et al., 2016). Patient advocacy groups, expert consensus panels, and governmental reports have recommended improvements in the quality of aftercare (ESMO, 2014; Hewitt et al., 2005; The Health Council of the Netherlands, 2007).

Registered oncology nurses and advanced practice nurses can

significantly contribute to the quality of aftercare (Corcoran et al., 2015). Nurses focus on teaching and control of potential issues, whereas physicians concentrate on medical diagnostics and therapy. Nurses also focus on personal goals and needs and are often more available than physicians to patients and families who call with problems associated with symptom management or home care support (Schulman, 2013).

Although the relevance of goal-setting and shared decision-making in aftercare is acknowledged, nurses do not always know how to implement them in daily practice (Bekelman et al., 2017; Friesen-Storms et al., 2015; Marsland and Bowman, 2010; Revello and Fields, 2015). In the literature, various models of how shared decision-making can be applied in daily practice have been developed (Elwyn et al., 2012; Makoul and Clayman, 2006; O'Connor et al., 2007). In addition, several authors describe models or guides for goal-setting (Bekelman et al., 2017; Lenzen et al., 2015; Scobbie et al., 2011). These models, however, have not been specifically adjusted for cancer aftercare. It is important to develop a specific model or systematic conversation approach to facilitate shared goal-setting and shared decision-making in daily practice for cancer aftercare (The Health Council of the Netherlands, 2007; IKNL, 2011a).

The aim of this study was to develop and pretest a systematic conversation approach for nurses to tailor aftercare to the oncology patients' goals, unmet needs, and wishes.

2. Methods

We applied an iterative development process for complex

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