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Development of an existential support training program for healthcare professionals

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ABSTRACT

Objective: Our aim was to describe the developmental process of a training program for nurses to communicate existential issues with severely ill patients.

Method: The Medical Research Council (MRC) framework for the development and evaluation of complex interventions was used to develop a training program for nurses to communicate about existential issues with their patients. The steps in the framework were employed to describe the development of the training intervention, and the development, feasibility and piloting, evaluation, and implementation phases. The development and feasibility phases are described in the Methods section. The evaluation and implementation phases are described in the Results section.

Results: In the evaluation phase, the effectiveness of the intervention was shown as nurses' confidence in communication increased after training. The understanding of the change process was considered to be that the nurses could describe their way of communicating in terms of prerequisites, process, and content. Some efforts have been made to implement the training intervention, but these require further elaboration.

Significance of results: Existential and spiritual issues are very important to severely ill patients, and healthcare professionals need to be attentive to such questions. It is important that professionals be properly prepared when patients need this communication. An evidence-based training intervention could provide such preparation. Healthcare staff were able to identify situations where existential issues were apparent, and they reported that their confidence in communication about existential issues increased after attending a short-term training program that included reflection. In order to design a program that should be permanently implemented, more knowledge is needed of patients' perceptions of the quality of the healthcare staff's existential support.

KEYWORDS: Existential, Spirituality, Nurses, Training, Education, Medical Research Council framework

INTRODUCTION

Living with a life-threatening disease means living with the knowledge that the future may be limited, so that existential issues might become inevitable for the ill person and their family. The terms "existential issues" and "spiritual issues" are sometimes used interchangeably. Existential issues deal with questions on the basic conditions of being a human being, those that allow us to create a system of values and construct meaning in our lives. One of a great number of definitions of spirituality is "a dynamic and

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intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices" (Puchalski et al., 2014, p. 646). This definition is close to the meaning of existential issues, except that the religious dimension is not as significant in existential issues, and, accordingly, existential issues could be regarded as being a more comprehensive concept than the spiritual (Sessanna et al., 2007). La Cour and Hvidt (2010) posit that there is no consensus concerning definitions of the overlapping existential, spiritual, and religious concepts. They also do not define which concept is broader than the other. In addition, they hold that, while they all focus on meaning making, none should dominate the other.

Patients with incurable cancer have a desire to discuss existential issues (Strang, 2001), but studies indicate that healthcare staff seldom raise these issues with patients (Phelps et al., 2012; Balboni et al., 2013; Pearce et al., 2012), and when spiritual needs are unmet, patients are at risk for depression and a reduced sense of spiritual meaning and peace (Pearce et al., 2012). One explanation for the hesitation of healthcare staffs to raise existential issues in dialogue with patients might be a lack of training (Balboni et al., 2013).

An overview on the treatment of the elderly from the Swedish National Board of Health and Welfare notes that there is an extensive need for training and support of healthcare staff regarding how to talk about death, for meeting existential needs, and for training to be better able to meet the needs of dying patients (National Board of Health and Welfare, 2004). The literature also indicates that education of healthcare staff regarding existential issues is insufficient and that there is a vagueness concerning the staff's role (McSherry & Cash, 2004), which could result in the healthcare staff trying to keep death at a distance by concentrating on practical tasks and avoiding patients who are dying (Österlind et al., 2011). An analysis of supervision sessions with healthcare staff at a surgery clinic showed that staff were conscious about patients' feelings of despair and isolation but lacked strategies for dealing with them (Udo et al., 2011). However, research has shown that education can increase a staff's confidence in communication about existential issues (Morita et al., 2009). In an international survey of researchers' and clinicians' research priorities in spiritual care, one important area was found to be the development and evaluation of conversation models for spiritual conversations with patients (Selman et al., 2014). Because there is a paucity of conversation models and training, the intervention described in the present study was targeted toward an appropriate training program for healthcare staff. The aim of our study was thus to describe the development process of an existential support training program for nurses to facilitate conversations about existential issues with severely ill patients.

METHODS

Using the Medical Research Council (MRC) framework for the development and evaluation of complex interventions described by Campbell and colleagues and updated by Craig and coworkers, an intervention targeting existential issues in patients with cancer was developed and evaluated (Campbell et al., 2000; Craig et al., 2008). The framework consisted of four phases:

- development
- feasibility and piloting
- evaluation
- implementation

A detailed description of the steps and choices made throughout the development and feasibility phases of the educational intervention for healthcare professionals about existential issues will be described. The evaluation phase of the program will be described in the Results section, and the implementation phase will be described very briefly.

Development Phase

In the development phase, the aim was to identify existing evidence, identify or develop theory, and model the process of reaching the outcomes (Campbell et al., 2000; Craig et al., 2008). The existing evidence must first be explored in order to establish whether the intervention can be expected to have a worthwhile effect.

Identifying the Evidence Base

According to Craig et al. (2008), a key early task is to develop a theoretical understanding of the likely process of change by drawing on existing evidence and, if needed, supplemented by new primary research. To identify the evidence base, some explorative studies were conducted. The existing evidence was explored in two literature reviews, one encompassing existential issues in patients with cancer (Henoch & Danielson, 2009) and the other related to relatives of patients with chronic illness (Melin-Johansson et al., 2012). Neither review found any

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studies describing interventions that could be easily implemented in everyday healthcare practice (Henoch & Danielson, 2009; Melin-Johansson et al., 2012). Focus-group interviews were conducted with healthcare staff who work with cancer patients in different stages, that is, in surgical wards, oncology wards, palliative homecare teams, and inpatient hospices (Browall et al., 2010).

Identifying and Developing the Theory

The theoretical base for our intervention was existential psychotherapy, as described by Yalom (1980), who defined the main existential issues to be death, freedom, isolation, and meaninglessness. When analyzing the three studies described above, these concepts were confirmed in the studies. A further concept that is necessary to internalize the concepts identified by Yalom is reflection, which is needed to comprehend how death, meaning, freedom, and isolation can be included in conversations with palliative care patients.

Death

Yalom describes death as the most anxiety-provoking phenomenon, and this was confirmed by the literature review, where the struggle to maintain self-identity was one of the main themes (Henoch & Danielson, 2009). As long as a person is able to maintain self-identity, the self is sheltered and life maintained. The remedy for maintaining self-identity is the will to live. Self-identity is threatened when the person begins to despair about his or her continuing existence, that is to say, when death is nearing, when life is considered to be unpredictable and uncertain, and when one feels vulnerable (Henoch & Danielson, 2009). In the literature review of relatives' existential issues (Melin-Johansson et al., 2012), one important aspect was to be reminded about death in the environment and in the deterioration of the ill person. Death was also present for the relatives in that they lost their shared future with the ill person. In the focus-group interview study (Browall et al., 2010), the staff acknowledged that, while the awareness of death was imminent, there was also the joy of living. Although the studies described death as being present at the end of life, they also emphasized the importance of life. Therefore, the concepts of life and death were both considered to be important.

Meaning and Meaninglessness

According to Yalom (1980), to find meaning is an important human existential issue. In the literature review (Henoch & Danielson, 2009), meaning was described as being how patients use meaning and purpose in life, hope, and autonomy to maintain self-identity. In the literature review about relatives' existential issues (Melin-Johansson et al., 2012), hope, purpose in life, and meaningfulness were also present in the situation in that the relatives tried to find meaning in illness. The meaning had three dimensions: meaning in the past consisted of good memories; the current meaning concerned knowledge and daily routines; and meaning in the future was to pass on the skills and interests of the patient to the next generation. Experiencing hope was also important in terms of a feeling of future meaningfulness. In the focus-group interview study (Browall et al., 2010), meaning included acceptance, reevaluation of life, hope, and faith.

Freedom

Yalom (1980) describes freedom as giving the individual the choice in all situations, a choice for which one is responsible. Responsibility can, in some situations, evoke guilt and shame for one's past choices. In the literature review (Henoch & Danielson, 2009), guilt and unresolved issues were considered to be threats to self-identity. In the literature review about relatives (Melin-Johansson et al., 2012), it was found that they also felt a responsibility to help the patient, and they felt guilty if they did not, or as if they were not doing enough to help. Relatives could also experience survivor's guilt. In the focus-group interview study (Browall et al., 2010), the staff acknowledged that responsibility concerned feelings of guilt and reconciliation, about why things happened, and about the patients' responsibility for their situation.

Isolation

Existential isolation refers to an unbridgeable gulf between oneself and other beings (Yalom, 1980), and that humans have to face essential moments in life in isolation; alone. In the literature review (Henoch & Danielson, 2009), loss of relationships, isolation, aloneness, and loss of roles were threats to self-identity. In the literature review about relatives (Melin-Johansson et al., 2012), family members experienced that the former united lives were now separated, and they began psychological preparations for a changed but ongoing existence. In the focus-group interview study (Browall et al., 2010), the relationships were concerned with the notion that they were alleviating anxieties about loneliness if they were open and clear, and also that sometimes the patients became dependent on the relatives and staff, and that the patients experienced a loss of relationships when they were about to die. Because the isolation had its counterweight in developing new relationships, which the studies considered to be important, feelings of loneliness were eliminated.

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Reflection

In addition to the four domains identified by Yalom, reflection could also be a way to involve death, meaning, freedom, and loneliness into the healthcare professionals' own conceptualization of the world and to understand how to involve them in encounters with patients. Important to reflection is the experience and discovery of an affective reaction to the experience (Schön, 1987; Wong et al., 1997). Reflection in action redesigns thinking and acting during action. Thinking and action are complementary, and they nourish each other while at the same time limiting each other (Schön, 1987).

Modeling Process and Outcomes

Process

In the focus-group interviews (Browall et al., 2010), it was acknowledged by the staff that they lacked the training to converse with patients about existential issues; therefore, the components of the intervention consisted of an educational program for healthcare staff in relation to communicating about meaning, death, freedom, and loneliness. Because existential issues are present in everyone, reflection was considered to be an appropriate learning activity for the intervention. We decided that the most appropriate design to evaluate the intervention was a randomized controlled trial. The intervention was designed to be a training or education program and included a pamphlet providing short descriptions about the topic areas, questions for reflection and discussion during the training sessions, and suggestions for the types of questions that might apply to the topic areas that could be raised with patients. The teachers in the training groups ($n = 4$) were trained by the research staff about Yalom's theory and presented with results from previous research.

Because healthcare practice today is rather severely streamlined, it was assumed that managers in healthcare wards would be reluctant to let staff attend a long-term training program. Therefore, the intervention was designed to comprise five 90-minute sessions over an 8-week period, with theoretical training in existential issues combined with individual and group reflection sessions in order to achieve greater understanding. In the individual reflection sessions, the critical incident (CI) technique was employed (Flanagan, 1954; Bradbury-Jones & Tranter, 2008). The procedure for the training is presented in Table 1.

Outcomes

The effectiveness of the intervention was measured in the randomized controlled trial, with differences found between the intervention and control groups, and differences found in the intervention group before and after training. An increase in the staff's confidence in communication skills was determined to be the main outcome, as the training was intended to help staff raise existential concerns with patients. Another potential outcome could be that the staff's attitude toward caring for dying patients would be changed by the training. This resulted in the decision to use two instruments as outcome measures—The Attitudes Toward Caring for Patients Feeling Meaninglessness scale (Morita et al., 2009) and the Frommelt Attitude Toward Care of the Dying (FATCOD) tool (Frommelt, 1991; Henoch et al., 2013*a*)—both of which were translated into Swedish by the research team with the adoption of the recommended procedures for questionnaire translation (White & Elander, 1992; Maneesriwongul & Dixon, 2004). The instruments were distributed prior to the first session, right after the last session, and five months later. The control group did not receive any training but completed the questionnaires at the same time as the intervention group.

In order to understand the change process, two steps were taken. First, the individual reflections, using critical incidents (CI) technique prior to the first session, were collected and analyzed. Second, because reflection was considered to be an important part of the training, the training sessions were recorded and analyzed in order to understand the healthcare staff's reasoning about existential issues. The results from the evaluation phase are presented in the Results section.

Feasibility and Piloting Phase

Testing Procedures

According to Craig et al. (2008), evaluations of interventions are often undermined by problems that could have been predicted by thorough pilot testing. Therefore, the intervention was tested on a smaller scale in a surgery clinic at a county hospital (Udo et al., 2014). Some 42 nurses from three surgical wards were randomly assigned to an intervention or control group. Nurses in both groups completed a questionnaire at equivalent time intervals: at baseline before the educational intervention, directly after the intervention, and 3 and 6 months later. Some 11 face-to-face interviews were conducted with nurses directly after the intervention and 6 months later. In conjunction with the pilot study, work-related stress was also measured, and all nurses in all measurements rated themselves halfway between low and high burnout levels (Udo et al., 2013*b*). However, the intervention group's response indicated a long-term decrease in feelings of

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Table 1. *Overview of the training sessions*

Session	Topic	Content
Prior to first session	Your earlier experience of existential issues	Individual reflections: The participants described a situation with a patient where existential issues were raised, guided by the questions: What happened? What did you think? How did you feel?
1	Freedom	Lecture about communication techniques and about freedom, responsibility, guilt, and integrity. Reflections in group: What is freedom to you? How can you help a patient who is experiencing guilt? How can you respect a patient's integrity?
2	Relationships and loneliness	Lecture about alleviation, dependency, and losses. Reflections in group: How can you support a patient who has a limited network? How can you help a patient who suffers from his/her dependency? How can you support patients to cope with losses?
3	Life and death	Lecture about joy of living and thoughts of death Reflections in group: How do you feel about patients who are talking about a future, which you know that the patient will not experience? How do you feel when patients are targeting you with their anxiety and fear? What do you do when the patient's situation evokes unpleasant feelings of your own death?
4	Meaning	Lecture about acceptance, reevaluation, and hope Reflections in group: For whom should the patient accept his/her situation? How can you support a patient who is reevaluating his/her life? How can you strengthen the patient's hope? How does it feel to support a person who has a faith other than your own?
5	Your own experience	Reflections in group: What are your own existential issues? What support do you need?

work-related stress, decreased stress associated with workload, and less disappointment in their work.

During the pilot phase, the CI technique was also employed with the aim of gaining a deeper understanding of the nurses' experiences of existential care situations. Ten surgical nurses described existential care incidents by writing about their experiences. After 1 to 2 weeks, individual interviews were conducted with the same nurses about their written accounts. In the analysis, three themes were identified, each emphasizing the impact of integration between nurses' personal self and professional role in existential care situations (Udo et al., 2013*a*).

Estimating Recruitment and Retentions

In the pilot study, there was significant attrition, which was mostly related to high workload levels in the wards, which prevented the nurses from participating in training sessions. However, the design of the intervention to include five sessions was considered to be the minimum number to achieve a change in staff communications with patients.

Determining Sample Size

The sample was determined based on previous research that showed that, in the determination of sample size where the difference between groups is not known, one can use half the standard deviation as a measure of the expected difference (Sloan et al., 2005). With the significance level at 0.05 and with a power of 0.80, about 60 participants were needed for each group. Therefore, in the main study, the nursing staff was estimated to total 120, so that 60 participants were required.

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RESULTS

Evaluation Phase

The evaluation phase consisted of assessment of the effectiveness of the intervention, to understand the change process, and assessment of cost effectiveness (Craig et al., 2008). Cost effectiveness was not assessed, as a training intervention with five sessions was considered to be the minimum in order to achieve a change, and if this could lead to decreased work-related stress, this would be a cost-effective intervention, but this element must be further explored.

Assessing Effectiveness

The main intervention study was conducted as a randomized controlled trial with 102 registered nurses and enrolled nurses from hospices, oncology clinics, and a palliative homecare team, with 60 in the intervention group and 42 in the control group. The main outcome, that is, confidence in communication, increased significantly in the training group from baseline to both the first and second follow-ups, whereas attitudes toward care of dying patients did not change after the training program (Henoch et al., 2013*b*). There were no significant differences between intervention and control groups at baseline, but at both the first and second follow-ups there were significant differences between the groups. The attitudes toward care of dying patients did not change pre- and post-test, and there were no significant differences between the intervention and control groups (Henoch et al., 2013*b*).

Understanding the Change Process

We assumed that confidence in communication should increase after the interventions, and we also wanted to know how the participants reflected about existential issues, and so we recorded the training sessions in order to closely follow their reflections. In the sessions, the nurses reflected on how to communicate with severely diseased patients (Strang et al., 2014*c*). The reflections about nurses' communication were concerned with the themes of the conversations, which included living, dying, and relationships. The process of the conversations included how to open up conversations, being present and accommodating, being sensitive and confirming, and using both words and silence. The meaning of the conversations were concerned with feeling honored and professional, being burdened, and requiring external prerequisites (Strang et al., 2014*c*).

Prior to the start of the training, the staff wrote a critical incident report (CI) about a situation in which existential issues were brought up, and, of the 102 participants, 83 nurses wrote about 88 CIs. The nurses described such situations, which were mostly related to encounters with existential pain experiences, which were concerned with facing death and facing loss; and encountering experiences of hope, which were concerned with balancing honesty and the desire to live. The results from the analysis of the CIs concluded that healthcare professionals need to be aware of patients' feelings of abandonment in such exposed situations as patients' feelings of existential loneliness. There are some patients who express a desire to die, and this makes the nurses feel uncomfortable, and they find it difficult to confront these occurrences. Therefore, it is important to listen to patients' stories, regardless how care is organized, in order to gain access to patients' inner existential needs (Browall et al., 2014).

Implementation Phase

According to Craig et al. (2008), the implementation phase includes dissemination, surveillance, and monitoring, as well as long-term follow-up, and the effectiveness of the implementation is dependent on providing a clear description of each step of the intervention.

Some steps in the implementation of this intervention have been taken, but these have to be further evaluated. The assessment of effectiveness and understanding of the change process indicates that the theory of Yalom was an appropriate base for a discussion of existential issues (Yalom, 1980). Therefore, some studies were undertaken to confirm the appropriateness of the concepts in Yalom's theory for patients, relatives, and others. One interview study with patients with late-stage COPD about existential anxiety (Strang et al., 2013) showed that both life and death evoked existential anxiety for patients. But when facing death anxiety, they also tried to find counterweights to this by maintaining a defiant sense of joy, such as by celebrating good relationships and hobbies. The patients also experienced death anxiety as separation anxiety (Strang et al., 2013), which also has been acknowledged by Yalom (1980). In another interview study in patients with late-stage COPD about their experience of guilt (Strang et al., 2014*b*), the patients' own responsibility for the disease was highlighted. Despite the well-known association between smoking and COPD, only a minor percentage of patients expressed that they had experienced guilt that affected their daily lives (Strang et al., 2014*b*).

In a study where nursing students completed a questionnaire about their attitude toward the care of dying patients, the open-ended questions about their reasoning about their care of dying patients

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(Strang et al., 2014*a*) revealed that students acknowledged that the arrival of death could be very scary, but some expressed that they thought they ought to have the courage to stay with the patient. The students tried to find meaning in being present beside the dying patients, and they expressed that their responsibility extended to the expectation that nurses ought to be present with, listening to, confirming of, and supportive of patients (Strang et al., 2014*a*).

Yalom's (1980) theory was also used as a theoretical framework in a doctoral project about the experiences of relatives of persons with dementia (Hogsnes et al., 2014). In one of the interview studies, 11 spouses of persons with dementia described the existential life situations before and after relocation to a nursing home. Before relocation, the spouses described feelings of shame and guilt, and of being isolated in the nursing home. After the relocation, spouses described feelings of guilt and freedom, grief and thoughts of death, feelings of loneliness in the spousal relationship, and striving for acceptance (Hogsnes et al., 2014). These studies further confirmed that the inclusion of Yalom's (1980) concepts in the training was appropriate.

DISCUSSION

The knowledge gained from the project mainly concerns: (1) that healthcare staff recognize situations where existential issues are present and need to be taken care of; (2) that it is possible to implement a five-session training program about existential issues in different kinds of healthcare organizations; and (3) that it is possible to increase a healthcare staff's confidence in communication via a short training program.

The healthcare staff are well aware of situations where existential issues arise (Browall et al., 2014). Although nurses are aware of patients' existential issues and can describe situations where existential issues are brought up, it has also been acknowledged that nurses do not know what their responsibility is with respect to spiritual care (van Leeuwen et al., 2006). Because healthcare staff showed that they were aware of existential situations, the training could have been deepened in some aspects. In Norway, a project has been designed in which healthcare professionals in palliative care may reflect on their views about their own death (Hirsch & Röen, 2007). During the ten sessions, the staff reflected on the first time they experienced the death of someone close to them, how it was to see them die, how they wanted to say goodbye, their own funeral, beliefs about what happens after death, and what to do if you only had a year left to live. It also reflects on what work does to the body, sleep, family, and views of life, and what it is that takes and gives strength (Hirsch & Röen, 2007). This is a possible method for deepening reflections in the present training intervention.

Other ways to improve the intervention could involve other evidence-based elements, such as dignity therapy (Chochinov et al., 2005), where the patient's life story is used as a tool to help the patient find meaning. By telling a story, various pieces fall into place, and the story is often created in the storytelling. The aim of dignity therapy is to reduce suffering, improve quality of life, and strengthen a sense of purpose and dignity. Patients were offered the opportunity to take up important events or things they want to remember in a recorded conversation 30 to 60 minutes long. An edited transcript of these sessions was then returned to the patient, who could do what they wanted with the text, such as show it to their children and grandchildren (Chochinov et al., 2005). Listening to a patient's life story could be a part of a training program to increase nurses' ability to communicate with severely diseased patients.

In our project, confidence in communication significantly improved (Henoch et al., 2013*b*; Strang et al., 2014*c*), an outcome supported by other studies that found that communication skills can be improved by training (Morita et al., 2009; Moore et al., 2013). When comparing healthcare professionals who received communication skills training to control groups without training, the intervention group improved significantly in showing empathy and using open-ended questions. It was not clear whether the improvement in communication skills was sustained over time and which types of communication skills training were best (Moore et al., 2013). Because the present project was built on training in communication, the results showing that confidence in communication increased were expected. The training did not change healthcare staff's attitudes toward caring for dying patients. In other studies, education has been found to influence attitudes toward care of the dying (Mutto et al., 2010; Mallory, 2003; Frommelt, 1991); however, this outcome might be dependent on the focus of the education program.

During the implementation phase, our purpose was to examine the implementation of the intervention in practice (Craig et al., 2008) through dissemination, surveillance, and monitoring, as well as long-term follow-up. As described in the results, some minor steps to implementation have been taken, and some studies have confirmed the appropriateness of inclusion of Yalom's concepts (Strang et al., 2013; 2014a; 2014b). However, prior to implementation, the present system must be further tested

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in order to establish the stability of the intervention and to broaden the subject groups as well as explore possible extensions of the training. As the content of the training was built on literature and staff experiences, patients' perceptions of important existential issues must be explored, as well as staff's perceptions of the support given. Therefore, it would be appropriate to ask the patients if the healthcare staff's ability to communicate about existential issues had improved. To involve the patients in projects targeting their existential issues is compelling and needs to be explored further.

CONCLUSIONS

In our study, the Medical Research Council framework was used as a theoretical guide for intervention development, provided in a detailed description of the development process of a training intervention about existential issues for healthcare staff. This crucial element is often missing in reports of complex intervention trials (Campbell et al., 2000; Craig et al., 2008). To report the details of the elaboration process is essential to understand the different components of the intervention and enhance understanding of the trial results.

The present study shows that healthcare staff are able to identify situations where existential issues are raised, and that their confidence in communication about existential issues can increase with completion of a short-term training program that includes the element of reflection. In order to design a program that should be permanently implemented, more knowledge is needed of patients' perceptions about the quality of the healthcare staff's existential support.

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