Training intervention for healthcare staff in the provision of existential support to patients with cancer: A randomised, controlled study

Running title: Training in provision of existential support

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Acknowledgements: Funding for this project has been gratefully received from the Royal Society of Arts and Sciences in Gothenburg, the Adlerbert Research Foundation, the Wilhelm and Martina Lundgren Fund and the Assar Gabrielsson Fund.

Number of tables: 2

Number of figures: 3

Number of references: 31

Word count in abstract: 248

Word count in manuscript: 3808
Abstract

Context: When a patient receives a cancer diagnosis, existential issues become more compelling. Throughout the illness trajectory, cancer patients could be cared for on oncology wards, by home care teams or in hospices. Nurses working with these patients are sometimes aware of the patients' existential needs but do not feel confident when discussing these issues.

Objectives: To determine the effects of a training intervention, where the focus is on existential issues and nurses' perceived confidence in communication and their attitude towards caring for dying patients.

Methods: This was a randomised, controlled trial with a training intervention consisting of theoretical training in existential issues combined with individual and group reflection. In total, 102 nurses on oncology wards and hospice wards and in palliative home care teams were randomised to a training group or non-training group. Primary outcomes, confidence in communication and attitude towards the care of dying patients were measured at baseline, immediately after the training and five to six months after.

Results: Confidence in communication improved significantly in the training group from baseline – before the training – to both the first and second follow-up, i.e. immediately after the training and five months after. The attitude towards caring for the dying did not improve in the training group.

Conclusion: This study shows that short-term training with reflection improves the confidence of healthcare staff when communicating, which is important for healthcare managers with limited resources. Further studies are needed to explore how patients experience the communication skills of healthcare staff after such training.

Keywords: existential support, palliative care, education, nurse
Background

Living with a life-threatening illness means living with the knowledge of a limited future and involves suffering and deterioration in quality of life (1). Existential issues refer to concerns about human life, such as meaning, freedom, loneliness and death (2). Challenges such as these arise when a person is facing death (3). These issues, including spirituality and religiosity, are well recognised as factors that affect patients' quality of life, quality of care and satisfaction (4), and need to be addressed by those close to the afflicted person, i.e. relatives or healthcare professionals.

In a study that explored hospice patients' suggestions regarding professionals' spiritual training, it was found that patients expect that healthcare professionals feel comfortable when discussing existential issues with patients and address these concerns sensitively (5). Affirmative relationships enable patients to identify their inner resources. The expectation among patients at the end of life that a good death includes open communication was also found in a qualitative study (6). Relationships and communication are key elements in dialogues dealing with existential issues. This is acknowledged in a metasynthesis, where spiritual care was synthesised to be relational, provided in a relationship with others and with a focus on presence, journeying together, listening, connecting, creating openings and engaging in reciprocal sharing (7). The importance of confirmation in communication has been acknowledged by Nåden and Saeteren (8), where outer confirmation was found to involve being understood and being taken seriously and inner confirmation involves maintaining human dignity and human worth. Although patients with cancer have a desire to discuss existential issues (9), healthcare staff found it difficult to respond to the patients' demands (10, 11). In a study of 355 oncology nurses (12), it was found that age, length of experience as a nurse and experience of caring for dying patients influenced the nurses' attitudes, where older and more experienced nurses had a more positive attitude. Besides age and previous experience, personality traits, such as a sense of coherence, could also influence the healthcare professionals' attitude to working in palliative care (13).
Interviews conducted with patients receiving palliative care and with palliative healthcare professionals addressed the question of optimal content of end-of-life discussions. Existential issues were found to be important although health professionals did not feel that it was their role to discuss such issues and preferred openness and being able to listen to the patients' concerns (14). Another study involving healthcare staff from a number of cancer care units showed that although staff is aware to some extent of which existential issues are important to cancer patients and how those issues should be approached, they often fail to take the initiative to discuss these issues (11).

A knowledge overview from the Swedish National Board of Health and Welfare states that there is an extensive need for training and support for healthcare staff in palliative care, including how to talk about death. The staff also requires support to satisfy existential needs as well as training to meet the general needs of dying patients (15).

The literature also indicates that training for healthcare staff in existential issues is insufficient and that there is a vagueness regarding their role (16, 17). A study involving healthcare staff at nursing homes found that they expressed a fear of death. They attempted to keep death at a distance by concentrating on practical tasks, avoiding elderly patients who were dying and not becoming involved on a deeper level in the life situations of the elderly (18). In an integrative review of the research literature in the existential area related to patients receiving palliative cancer care, few intervention studies were found. Those that do exist are characterised by long, repetitious group discussions in which spiritual/existential issues are discussed with physicians and psychologists as the moderators (19). Nor were specific studies found that were associated with the daily activities of the healthcare staff. Despite the lack of studies focusing on training in existential support, one study from Japan was found in which 40 nurses were randomised into three intervention groups that received the same training but at different times (20). The results showed significant effects of the intervention in terms of the nurses' attitude to helping patients with existential issues. This study was conducted in response to a lack of confidence among healthcare staff when discussing
existential issues in daily practice and the importance of acknowledging these issues in patients at the end of life [1]. The overall aim of the present study was to determine the effects of a training intervention where the focus is on existential issues, nurses' perceived communicative confidence and their attitude towards caring for dying patients.

The research questions were:

1. Can an intervention consisting of training and reflection increase nurses' perceived communicative confidence when discussing existential issues with patients with incurable cancer?
2. Can the intervention influence the attitude among healthcare staff towards caring for dying patients?
3. Is there any relationship between demographic variables and/or a sense of coherence and perceived communicative confidence among healthcare staff when discussing existential issues with patients?
4. How do the nurses assess their training?

**Methods**

The study was conducted in Sweden and was designed as a randomised, controlled trial involving a training intervention. It began at three hospices in 2010, continued on six oncology wards and ended in two palliative home care teams in early 2012. The questionnaires were completed longitudinally by registered nurses (RNs) and enrolled nurses (ENs) who had daily contact with patients with different cancer diagnoses. The patients were being cared for on oncology wards, at hospices and by hospital-affiliated palliative home care teams.

**Sample**

To ensure that all workplaces were represented in the training and non-training groups, the randomisation, which was done by the research team, took place following stratification of
workplaces (Figure 1). The hospice nurses were from three inpatient hospices, the oncology clinic staff were from six wards and the nurses in the palliative home care group were from two different teams. Due to the location of the hospices in different parts of the city, it was necessary to have one training group and one non-training group at each hospice and the nurses were then randomised within each hospice. At the oncology clinic, where only a few of the nurses were able to leave the ward at the same time, randomisation was performed at clinic level. The palliative home care teams (PHT) were based in a rural area, with a distance of about 500 km between the two teams. Consequently, one team was chosen to be the training group and another team was chosen to be the non-training group.

Please insert Figure 1 about here

**Intervention**

The intervention consisted of theoretical training in existential issues combined with group reflection to achieve greater understanding (21). The training group received training with reflection in five 90-minutes sessions over an eight-week period. The training sessions included both theoretical and practical elements. Between the training sessions, the participants were urged to read sections in the training material dealing with the various existential topics and to reflect on the questions for discussion posed in the material. All five sessions included group reflections, in which the participants applied theoretical knowledge to earlier or ongoing experiences of meeting severely diseased cancer patients and their families. The purpose was to deepen the participants' knowledge in this area and to provide opportunities to reflect on its usefulness in the daily care of the patients. Before the first session, each nurse wrote down a patient care situation in which existential issues arose. The training was run by three persons, all of whom were trained by the research team in this specific area.
The first session included training in basic conversational methods and the nurses were urged to be attentive when patients began talking about existential issues. The sessions involved theoretical training with an emphasis on existential topics, such as life and death, freedom, relationships, loneliness and meaning (2). These existential areas were also addressed in the training material that had been designed specifically for this intervention. The different sessions focused on the different areas, with additional training in communication skills. The material included sections based on theory and research (9, 11, 19) related to existential issues and was intended to expand and deepen the knowledge of the healthcare staff. The material included questions about existential concerns that could be used by the healthcare staff in conversations with patients and relatives. The intervention was tested in a pilot study in autumn 2009, after which the logistics were revised (22), resulting in the omission of some of the instruments used to evaluate the intervention.

**Data collection**

The participants in the training group completed questionnaires at baseline, i.e. prior to the training (T0), immediately after the training (T1), and five to six months after the training (T2). The participants in the non-training group completed the same questionnaires at the same times. The primary outcome was to determine confidence when communicating with patients at the end of life who said there was no reason to live, as well as attitudes to caring for dying patients.

**Instruments**

*Sense of Coherence* (SOC-13) is a questionnaire comprising 13 questions, divided into three scales relating to comprehensibility, manageability and meaningfulness (23), although only the total scale was used in the present study. The response alternatives are numbered 1-7, with possible responses ranging from 13 to 91.

*Attitudes Towards Caring for Patients Feeling Meaninglessness* was created in Japan. It has been translated into Swedish, with the adoption of recommended procedures for questionnaire translation (24, 25), and has been adapted to Swedish conditions. The reliability and validity of the
instrument have been tested and it has been used to assess different training courses for Japanese nurses in how to deal with existential issues (20). The instrument consists of fifty-nine questions covering the perceptions and feelings of healthcare staff involved in the care of terminally ill patients. In the present study, use was made of only one of the items that dealt with confidence in communicating with patients at the end of life who said that there was no reason to live. This was considered to be one of the primary outcomes, as we wanted to know if the participants felt that their communication skills had improved after the training. The response alternatives ranged from 1 (very uncertain) to 7 (very confident).

*Frommelt Attitude Towards Care of the Dying* (FATCOD) has been translated into Swedish and adapted to Swedish conditions (24, 25). FATCOD measures the participants' attitudes when caring for dying patients. Its reliability and validity have been tested and it consists of 30 assertions, 15 with negative wording and 15 with positive wording. Each assertion is graded on a five-point Likert scale (26). After negatively worded items are reversed, all items were summated, forming a scale ranging from 30 to 150, where 150 is a very positive attitude towards caring for dying patients and 30 is a very negative attitude. The applicability to Swedish conditions has been tested (27). The total FATCOD was considered to be one of the primary outcomes.

After the training, an *evaluation form* was handed out to the participants with four questions about the extent to which the training had been useful in the provision of existential care for patients, both in relation to the existing healthcare policy at the workplace and to their personal values. There were four response alternatives: Not useful at all; Useful to some extent; Useful; Very useful. The participants were also given an opportunity to propose changes in the training.

**Data analysis**

The distribution for continuous variables was given as mean, SD, median, minimum and maximum and for categorical variables as numbers and percentages. For comparison between two groups, the Mann-Whitney U-test was used with Fishers' exact test for dichotomous variables. The Chi-square
test was used for non-ordered categorical variables. Change over time within groups was analysed using the Wilcoxon signed rank test for continuous variables and signed test for non-ordered categorical variables. Spearman's correlation coefficient was used to explore the relationships between confidence in communication and attitude to care of the dying versus age, number of years in the profession, workplace and sense of coherence. All significance tests were two-sided and were conducted at the 0.05 significance level.

**Ethical considerations**

The study was approved by the Gothenburg Regional Research Ethics Committee (No. 426-08). The nurses were provided with verbal and written information and they gave their informed consent for participation.

**Results**

The demographic characteristics are presented in Table 1. Although the nurses in the non-training group were somewhat older (mean 44.4 vs 47.6 years) and had worked slightly longer in their profession (mean 16.8 vs 20.8 years), there were no statistically significant differences between the groups in terms of age, number of years in the profession, number of years at the workplace or sense of coherence.

Confidence in communicating with patients at the end of life who said that there was no reason to live increased significantly in the training group from baseline to both first (25 [48%] increased; 27 [52%] did not change) and second follow-up (23 [59%] increased; 15 [38%] did not change; 1 [2.5%] decreased), i.e. immediately after the training and five months later (Table 2 and Figure 2). There
was no similar increase in the non-training group and there were significant differences between the training and the non-training groups in both the first (median 6, range 4-7 vs median 5, range 3-6, \( p = 0.005 \)) and second follow-up (median 6, range 4-7 vs median 5, range 3-7, \( p = 0.005 \)). There were no significant differences between the groups at baseline. Communicative confidence over time in both groups is also shown in Figure 2.

Please insert Table 2 and Figure 2 about here.

The non-training group improved significantly in attitude towards care of the dying (FATCOD) (from 128.5, SD 6.8 to 130.2, SD 8.0), whilst the training group did not. There were no significant differences between the groups in either of the measurements of attitude towards care of the dying (Table 2). No significant differences were found between those who dropped out and the nurses who completed all the measurements.

There were no significant correlations between communicative confidence or attitude towards care of the dying (FATCOD) and age or any of the work-related variables. Nor was there a correlation with a sense of coherence (SOC-13).

The majority of the participants in the training group considered the training useful. Of the participants who completed the evaluation form, 49% considered the content of the training very useful and 34% considered it useful. Most of the participants (75%) considered it useful or very useful with regard to their personal values. The participants also considered the training useful with regard to the existing healthcare philosophy at their departments (84%) and when providing existential care to the patients (81%). The evaluation is presented in Figure 3. The responses to the open-ended question were mainly positive, although some respondents thought the groups should be smaller and some thought the training should go into greater depth with existential issues. Some
respondents working at the hospice thought the training was more like group counselling and compared it to the counselling that hospice staff receive on a regular basis.

Please insert Figure 3 about here.

Discussion

The present study showed that communicative confidence when caring for patients dying of cancer increased significantly in the training group but not in the non-training group. Communication is an essential part of nursing care and palliative care and consequently this training is important for all healthcare professionals. In the questionnaire Attitudes Towards Caring for Patients Feeling Meaninglessness, the item regarding communication relates to nurses' feelings when a patient at the end of life says there is no reason to live, i.e. an expression of meaninglessness close to death. The fact that death is imminent awakens a need to talk about existential issues. The most prevalent need among patients is to communicate about timeframes (28). When nurses encounter patients at the end of life, it is important to understand the patients' verbal or behavioural expressions regarding meaninglessness. Contributing factors often arise from changes in life, such as loss of career, loss of hope and loss of independence (29). When nurses encounter patients suffering at the end of life, it is important that the nurse supports the dying patients by listening willingly and actively (29, 30). Having the opportunity to talk about sad and difficult issues may help patients to understand illness, which creates hope, increases faith, alleviates suffering and allays the patient's fear of being abandoned (31). Greater knowledge of existential issues, both theoretically and through an exchange of experiences with colleagues in group discussions, seems to be a positive element in increasing communicative confidence among nurses. It also facilitates nurse-patient communication about life and death, thus helping patients to cope despite a difficult situation.
On the other hand, the study did not show any improvement in attitude towards care of the dying in the training group. Attitudes towards care of dying patients could be regarded as more complex, covering several aspects of care. Some of the items in the FATCOD scale include personal attitudes, fear of being present and getting close to a dying patient as well as attitudes to relatives and the relatives being close to the patient. These areas may not be influenced by training in discussing existential issues. Greater confidence when discussing existential issues with the patients might be a starting point in bringing about a change in attitude to the care of dying patients. A change in attitude to caring for dying patients could thus be a long-term effect, which was not measured in the present study. Furthermore, the FATCOD scale refers explicitly to dying patients and the nurses in the present study care for cancer patients at an earlier stage in the illness trajectory. This is the case in particular for nurses at the oncology clinic, who care for patients throughout the whole cancer trajectory. In the non-intervention group, the FATCOD score improved significantly, a fact that we cannot explain, since to our knowledge the staff did not receive any other training during this time.

The intervention in the present study comprised five 90-minute training sessions, making a total of 450 minutes. Because of limited resources and lack of time in a more complex and ‘slimmer’ healthcare reality, the training in the present study was optimal. In a short time, it gave healthcare professionals the opportunity to learn about existential areas that are important to patients as well as the opportunity to reflect individually and in a group on how these matters could be included in their own, everyday healthcare practice. Furthermore, the content of the training, based mainly on Yalom’s existential therapy (2), has been accepted by healthcare staff as being relevant to certain aspects of patients’ existential issues (12). The participants were positive to the form the training took, with a short reading exercise prior to the sessions, followed by some teaching by the course leader and then an opportunity for the participants to reflect on the relevance of the existential areas to their own working practice. Reflection was a way of integrating existential thinking among the nurses and we argue that it was a necessary part of the training. The training was well received by the participants, as shown in the positive evaluations.
The strength of the present study is that it was performed in different healthcare settings and involved nurses working with inpatients and outpatients with cancer who were at different stages of the illness trajectory. Moreover, it was conducted in different parts of the country. The hospices and the oncology clinic were located in a city with about half a million inhabitants and the home care teams worked in a sparsely populated rural area. This indicates that the training could be well received by a variety of participants. Since age, personality and previous experience have been found to influence attitudes towards the care of dying patients (12), we wanted to include these in the study. However, there were no significant correlations between any of our main outcomes and these factors. The non-training group was slightly older and had been at their workplace longer. We assumed, in accordance with the literature, that higher age and longer experience might influence our main outcomes. The fact that the non-training group was older and had longer experience further strengthens our results – the confidence of the training group in their communication improved significantly compared to the non-training group.

Morita et al. (20) adopted a workshop programme for nurses in Japan on how to deal with patients who express feelings of meaninglessness and found an increase in communicative confidence that was similar to our findings. Although they found an improved attitude towards caring for patients with a feeling of meaningless, we did not find any differences in attitude towards care of the dying (FATCOD). There could be different reasons for the disparity in results between the present study and the study by Morita et al. (20). Firstly, our training focused on communication dealing with existential issues in general, including meaning, as was the case in the Japanese study, but also death, freedom and loneliness. Secondly, we measured attitudes towards care of dying patients, which it could be assumed was more comprehensive than attitudes toward caring for patients experiencing a feeling of meaningless. We trained in communication dealing with existential issues and then measured communicative confidence and the attitude towards care of dying patients. The first is most appropriate although it could be argued that the latter was not distinct enough.
There are several limitations in the study. Firstly, the study measures only two outcomes, of which one was shown to be too unspecific to be influenced by the training. Secondly, we measured the nurses’ own reports of confidence and attitude. Further studies are needed to explore whether such training has any impact on patients’ experiences of the nurses’ communication capabilities. Thirdly, randomisation was carried out differently in the three settings, i.e. one of the PHTs was included in the intervention group and the other in the control group, whereas randomisation was carried out at the hospices and oncology wards. This could have influenced our results in that there was a risk of spill-over effects at the hospices and the oncology wards.

In conclusion, this study shows that short-term training with reflection improves the communicative confidence of healthcare staff, which is important for healthcare managers with limited resources. Further studies are needed to explore the patients’ experience of the communication skills of healthcare staff after undergoing training.

**Disclosure and acknowledgements**

Funding for this project has been gratefully received from the Royal Society of Arts and Sciences in Gothenburg, the Adlerbert Research Foundation, the Wilhelm and Martina Lundgren Fund and the Assar Gabrielsson Fund. There are no conflicts of interest.
References

### Tables

Table 1. Demographic and professional characteristics of intervention and control groups.

Mean (SD)/ Median (range) or n (%)

<table>
<thead>
<tr>
<th></th>
<th>Training group (n = 60)</th>
<th>Non-training group (n = 42)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>44.4 (11.4); 46 (24-64)</td>
<td>47.6 (10.5); 48 (26-64)</td>
<td>0.19</td>
</tr>
<tr>
<td>Number of years in the profession</td>
<td>16.8 (11.5); 14.5 (1-40)</td>
<td>20.8 (11.0); 18 (2-46)</td>
<td>0.090</td>
</tr>
<tr>
<td>Number of years at the workplace</td>
<td>6.2 (8.3); 3 (0-22)</td>
<td>7.5 (6.4); 6 (0-27)</td>
<td>0.17</td>
</tr>
<tr>
<td>Sense of coherence (SOC total)</td>
<td>66.23 (8.3); 68 (36-79)</td>
<td>68.3 (8.2); 69 (46-81)</td>
<td>0.20</td>
</tr>
<tr>
<td>Gender, women</td>
<td>59 (98.3%)</td>
<td>41 (97.6 %)</td>
<td>1.0</td>
</tr>
<tr>
<td>Place of work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice (n = 46)</td>
<td>25 (41.7 %)</td>
<td>21 (50.0 %)</td>
<td></td>
</tr>
<tr>
<td>Oncology (n = 39)</td>
<td>26 (43.3 %)</td>
<td>13 (31.0 %)</td>
<td></td>
</tr>
<tr>
<td>PHT (n = 17)</td>
<td>9 (15.0 %)</td>
<td>8 (19.0 %)</td>
<td></td>
</tr>
<tr>
<td>Professions, RNs</td>
<td>40 (66.7 %)</td>
<td>27 (64.3 %)</td>
<td>1.0</td>
</tr>
</tbody>
</table>

The Mann-Whitney U-test was used for continuous variables, chi-square test for non-ordered categorical variables and Fisher’s exact test for dichotomous variables
Table 2. Comparison of nurses' confidence when communicating and attitudes towards caring for the dying (FATCOD) within groups and between groups.

<table>
<thead>
<tr>
<th></th>
<th>Training group</th>
<th>Non-training group</th>
<th>Differences between the groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline 1st follow-up, after training</td>
<td>Change from baseline, p-value</td>
<td>Baseline 1st follow-up, after training</td>
</tr>
<tr>
<td></td>
<td>D: 0 NC: 27 (52%) I: 25 (48%) p&lt;0.001</td>
<td>6 (4;7) D: 1 (2.5%) NC: 15 (38%) I: 23 (59%) p&lt;0.001</td>
<td>5 (2;7) D: 8 (25%) NC: 15 (47%) I: 9 (28%) p=1.0</td>
</tr>
<tr>
<td>Confidence when communicating</td>
<td>5 (2;7) 6 (4;7)</td>
<td>132.3 (7.4) 1.5 (6.3)</td>
<td>128.5 (6.8) 131.5 (116;142) 2 (-10;14) p = 0.045</td>
</tr>
<tr>
<td>FATCOD</td>
<td>129.7 (6.7) 130.9 (8.4)</td>
<td>1.5 (6.3) 2 (-20;12) p = 0.112</td>
<td>2.0 (5.2) 2 (-10;14) p = 0.045</td>
</tr>
<tr>
<td></td>
<td>131 (104;138)</td>
<td>134 (113;143)</td>
<td>128.5 (6.8) 131.5 (116;142) 2 (-10;14) p = 0.045</td>
</tr>
</tbody>
</table>

Wilcoxon signed rank test was used for within-group comparisons in FATCOD and the Mann-Whitney U-test for between group comparisons. Sign test was used for non-ordered categorical variables.

Median (range) and n (%) of changes in confidence when communicating and Mean (SD)/ Median (range) of FATCOD is given in the table.

D = decrease, NC = no change, I = increase.
Figure 1. Randomisation into training and non-training group and measurements.

**Intervention group (n = 60)**
- Hospice: 25 (14 RNs and 11 ENs)
- Oncology: 26 (17 RNs and 9 ENs)
- Palliative home care teams (PHT): 9 (9 RNs)

**Control group (n = 42)**
- Hospice: 21 (11 RNs and 10 ENs)
- Oncology: 13 (8 RNs and 5 ENs)
- PHT: 8 (8 RNs)

- **Measurement 1**, baseline (n = 60)
- **Training, five sessions**
- **Measurement 2**, after training (n = 55)
- **Measurement 3**, at five months (n = 42)

- **Measurement 1**, baseline (n = 42)
- **Measurement 2**, 1st follow up (n = 34)
- **Measurement 3**, at five months (n = 29)
Figure 2. Level of confidence when communicating, training and non-training groups, from baseline, to the first (immediately after the training) and second follow-up (after five months).
Figure 3. The participants' evaluation of the training.