Training Spiritual Care in Palliative Care in Teaching Hospitals in the Netherlands: A Multicentre Trial

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Abstract

Background: In the Netherlands, the spiritual dimension in healthcare became marginal in the second part of the twentieth century. In the Dutch healthcare system, palliative care is not a medical specialization and teaching hospitals do not have specialist palliative care units with specialized palliative care teams. Palliative care in these hospitals is delivered by healthcare professionals in general departments (mainly curative focused ones), and is based on multidisciplinary guidelines supported by palliative care consultation teams. A national multidisciplinary guideline on spiritual care is included, but standardized training based on this guideline still lacks. Implementation of this guideline is expected to have a positive effect on quality of care but is in an early state, the role of the specialists in this field—the healthcare chaplains—is developing. The objective of this article is to present the protocol of this study and stimulate discussion about methods of research on spirituality and spiritual care.

Methods and Findings: This action research study is planned as an explorative multicentre trial. Healthcare chaplains of ten teaching hospitals will offer training on spiritual care in palliative care for healthcare professionals. What is the effect of this intervention on the competences of clinical teams? What is the effect on the perceived care and treatment as experienced by patients?

The effects of the intervention on the competences of the clinicians will be measured once pre-study and twice post-study. Effects on patients’ physical symptoms and spiritual distress, and the perceived focus of caregivers on their spiritual needs or existential questions will also be measured pre- and post-study.

Keywords: Multidisciplinary team; Spiritual care; Chaplaincy; Education; Palliative care

Introduction

The development of palliative care (PC) based on the definition of the World Health Organisation (WHO) [1] challenges healthcare professionals to react not only to the physical symptoms and the psychological and social problems of dying patients and their proxies, but also to the spiritual needs of patients and families confronted with a life-threatening disease. A growing number of publications shows consensus on the definition of spirituality in healthcare and how to implement this dimension in palliative care [2-5]. The publication of the Oxford Textbook of Spirituality in Healthcare [6] was a milestone in this development. A recent pan-European survey [7] on spiritual care research priorities by the European Association for Palliative Care (EAPC)
Multidisciplinary Spiritual Care Training

van de Geer, Zock, Leget, Veeger, Prins, Groot, & Vissers

Taskforce on Spiritual Care in Palliative Care [8] illustrates a high need for training and education.

In the Netherlands, the spiritual dimension in professional healthcare discussions became marginal from the second part of the twentieth century. The nomination of two chairs on palliative care in 2005 increased attention on the spiritual dimension in palliative care, and identified it as one of the challenges facing the Dutch healthcare system in the next decade [9,10]. From that moment on, an inspiring process led to a consensus-based, multidisciplinary guideline on spiritual care within palliative care in the Netherlands, as part of the national Dutch multidisciplinary guidelines on palliative care for healthcare professionals [11-13]. It is translated in English [14] and German [15]. Since Dutch teaching hospitals do not have specialist PC units with specialized PC teams, PC in these hospitals is delivered by healthcare professionals in general (mainly curative focused) departments. The guideline on spiritual care (SC) recommends that it is delivered by all members of multidisciplinary teams, and expects them to be supported and trained by healthcare chaplains as the specialists on the spiritual dimension.

Since a multidisciplinary guideline does not automatically change clinical practice, research on specific educational approaches is necessary to increase the knowledge on how to implement the spiritual dimension in palliative care [16]. Furthermore chaplains’ knowledge regarding staff education in spiritual care, as well as chaplains’ knowledge regarding staff preferences for spiritual assessment tools, is still too limited to formulate quality indicators for training in spiritual care on a national level [17]. Therefore a multicentre action research study, called “Improvement of spiritual care in palliative care by training professional caregivers,” was planned for different wards in ten large, non-academic teaching hospitals where patients in a palliative trajectory are admitted regularly.

Aims and objectives
The aim of this action research project is to start the implementation of the new method of delivering multidisciplinary spiritual care as described in the national guideline on palliative care [13]. It is crucial to this new method that professional caregivers are able to assess and respond to the spiritual needs of palliative patients and their families, appropriate to their role as physician or nurse, as well as provide adequate referrals to specialized disciplines on the spiritual dimension in the case of complex care needs and crises.

The main research questions are: how to train doctors and nurses in assessing and responding to the spiritual and existential needs of their patients and proxies? What is the effect of hospital chaplains training multidisciplinary clinical teams in these competencies? What is the effect on the perceived care and treatment as experienced by patients?

Our hypothesis is that training in spiritual care contributes to the development of spiritual care competencies and leads to higher quality of care.

The objective of this article is to present the protocol of this study for international exchange and discussion about implementation, education, and research on spiritual care.
Methods

Ethical approval and cooperation

This study is designed and will be conducted according to the World Health Organization (WHO) Good Clinical Practice Guidelines. The medical ethical committee in Leeuwarden, Netherlands gave it ethical approval on July 4, 2013 (nWMO22). This study is registered at the Dutch Trial Register: NTR4559.

The project was initiated in the chaplaincy department of the Medical Center Leeuwarden (MCL). It is supported by Agora (the Dutch national organization for palliative care), the Comprehensive Cancer Centre The Netherlands (IKNL), and the Dutch Association of Spiritual Caregivers in Health Care Institutions (VGVZ), and includes the cooperation of the University of Groningen, the Radboud University Nijmegen Medical Centre, and the University of Humanistic Studies in Utrecht. From 2013 onward, the MCL Academy has taken responsibility for the operational progress of the project.

Design of the study

This action research study is planned as an explorative multicentre trial, in which dedicated teams of healthcare chaplains of ten non-academic teaching hospitals will perform the intervention: pilot training in spiritual care in palliative care (SCPC) for healthcare professionals.

Action research is defined by Elizabeth Koshy, Valsa Koshy, and Heather Waterman as “an approach employed by practitioners for improving practice as part of the process of change. The research is context-bound and participative. It is a continuous learning process in which the researcher learns and also shares the newly generated knowledge with those who may benefit from it. … The key concepts include a better understanding, participation, improvement, reform, problem finding, problem solving, a step-by-step process, modification and theory building.” [18, p. 9-10].

Influencing professionals to develop spiritual care as a multidisciplinary team can only be successful when it builds on local-specific resources that are connected with the unique culture of each participating institution/hospital/department. Therefore the intervention in our study had to be open to local variety. We chose an explorative prospective action research design, combining qualitative and quantitative methods.

Both Michelle Campbell [19] and Richard Grol [16] consider influencing professionals' behaviour to be a complex intervention. Situated on the continuum of increasing evidence according to the Medical Research Council (MRC) framework for the evaluation of complex interventions, this study combines elements of the first three phases of increasing evidence in a phase II trial. (Figure 1).

In our study data will be collected on three levels:

- Patients' perspective: to explore self-reported and proxy spiritual distress, the perceived quality of spiritual care, and the effect of the intervention.
- Healthcare professionals: to explore barriers for spiritual care, preferences in training spiritual care, use of diagnostic tools for needs in
spiritual care, and the effect of the intervention.

- Healthcare chaplains: to explore spiritual care training methods, healthcare professionals’ preferences, and quality indicators for spiritual care training.

The intervention

To establish a consensus-based framework of ten requirements for the intervention, pilot training in SCPC (see Table 1), the researchers invited 33 professionals and researchers with expert knowledge on PC and SC to discuss the requirements at a conference in Enschede, The Netherlands on November 4, 2013 (see Table 2).

This prototype of the pilot training in SCPC is based on: the EAPC consensus definition of spirituality [8], the Dutch guideline on spiritual care [13], and an additional literature review on diagnostic tools and education of spiritual care [23].

The pilot training in SCPC is expected to vary due to local differences and contextual factors, such as the local culture and identity of the hospital, personal competences of the teacher(s), and the specific needs of the multidisciplinary team. During the action research process, the pilot training in SCPC can develop based on the experience, learning process, and new knowledge arising from the cooperation between the participating chaplains/teachers.

In the participating hospitals, the chaplains/teachers performing the pilot training in SCPC will have the status of co-researcher in this study, and will be responsible for organizing active support of the palliative care consultation team; raising support by hospital management and approval by the local scientific and ethical committees;
identifying departments open for the intervention (multidisciplinary teams of any clinical department interested in the improvement of SCPC by means of the pilot training in spiritual care); selecting control departments not receiving the intervention; planning, organizing, and teaching the pilot training in SCPC; and organizing cooperation with the palliative care consultation team for the inclusion of and interviews with patients in the pilot departments and the control departments.

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### Table 1. Requirements for the pilot training in spiritual care in palliative care (SCPC)

<table>
<thead>
<tr>
<th>Target group</th>
<th>Multidisciplinary clinical teams of physicians, nurses, and other health care professionals of departments in teaching hospitals (not including: specialized palliative care teams or units).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competencies</td>
<td>Aim is to develop basic competencies for multidisciplinary spiritual care: recognizing, referring, self-reflexivity, and an open attitude toward patient spirituality, as formulated by Annemieke Kuin [20] based on the work of René Van Leeuwen [21].</td>
</tr>
<tr>
<td>Preparation</td>
<td>A Dutch e-learning module on SCPC based on the guideline is considered to be ideal preparation for local training. An electronic learning environment with a selection of reading material and video fragments on SC considered to be compatible with the guideline will be made available to participants who want to prepare themselves before the pilot training on SCPC [22].</td>
</tr>
<tr>
<td>Planning</td>
<td>Implementation of the training is considered ideal when planned as two lessons of 90-120 minutes with an interval of at least three weeks. Minimum is one lesson of 90 minutes with follow-up teaching methods (coaching on the job, bedside teaching).</td>
</tr>
<tr>
<td>Structure</td>
<td>The local format of the training has to be designed with the aim to (1) sensitize participants for the spiritual dimension of palliative care and (2) make participants realize the importance of their own spiritual and existential dimensions, in order to (3) integrate it into professional practice.</td>
</tr>
<tr>
<td>Tools</td>
<td>No screening tools for spiritual care or spiritual care models proposed by Roland Pennaertz [23] are admitted to the pilot training on SCPC. Because of a lack of validated translations, the choice is limited to those already mentioned and translated in the Dutch guideline: symbolic listening according to Erhard Weiher [24], the translation of the three screening questions developed by the Mount Vernon Cancer Network [25], and the Dutch spiritual care model Ars Moriendi [26].</td>
</tr>
<tr>
<td>Practice-based learning</td>
<td>Teaching has to be practice oriented and practice based. Participants should be stimulated to deliver case descriptions and receive feedback on these descriptions from the teacher/chaplain.</td>
</tr>
<tr>
<td>Freedom for local adjustments</td>
<td>Given the local diversity in teaching hospitals and the nature of teaching spiritual care, the pilot training in SCPC is not possible without any diversity in tone, language, and methods. The local teachers/chaplains receive relative freedom in methodology and planning. Educational aims and goals as mentioned above are to be considered. Teaching to only one discipline of the multidisciplinary clinical team is not an option.</td>
</tr>
<tr>
<td>Teaching methods</td>
<td>No mandatory teaching methods. Selected core concepts and definitions of the guideline will be delivered on slides. Basic knowledge of Kolb’s experiential learning model [27] will be taught to the group of teachers/chaplains, preferred methods of teaching spiritual care will be exchanged by the group during the study.</td>
</tr>
<tr>
<td>Accreditation</td>
<td>The intervention needs approval by professional organizations of physicians and nurses, so participants can score the training to meet their professional registration requirements.</td>
</tr>
</tbody>
</table>
Hospital inclusion criteria:

- Fulfilling the criteria of a non-academic teaching hospital in the Stichting Topklinische Ziekenhuizen (Association of Tertiary Medical Teaching Hospitals),
- Being actively involved in developing palliative care by means of a specialist consultation team, and
- Implementing palliative care quality improvement programs.

Chaplaincy team inclusion criteria:

- Being actively involved in the PC improvement program in the hospital,
- Being responsible for the way SC is developed in that program,
- Having at least one member of the team specialized in SC in PC (mandatory specialized training program: five-day master class on spirituality in palliative care organized by Leerhuizen Palliatieve Zorg Rotterdam) [28],
- Participating chaplains will have to be experienced teachers and have their own learning style assessed using the Kolb Learning Style Inventory 3.1 [27].

The selected teachers will be prepared with one and a half days of education on learning styles and methods. In order to collect/gather practical and experiential knowledge, they will be asked to keep a log during the process of organizing, teaching, and following-up with the multidisciplinary teams they educate.

### Table 2. Participants at invitational conference Enschede, Netherlands

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care chaplains (spiritual care experts)</td>
<td>5</td>
</tr>
<tr>
<td>Health care chaplains (candidate teachers with pilot training in SCPC)</td>
<td>11</td>
</tr>
<tr>
<td>Registered nurses (palliative and/or spiritual care experts)</td>
<td>3</td>
</tr>
<tr>
<td>Medical doctors (palliative and/or spiritual care experts)</td>
<td>3</td>
</tr>
<tr>
<td>Psychologists (palliative and/or spiritual care experts)</td>
<td>2</td>
</tr>
<tr>
<td>Researchers</td>
<td>4</td>
</tr>
<tr>
<td>Educational consultants</td>
<td>2</td>
</tr>
<tr>
<td>Palliative care policy advisor</td>
<td>1</td>
</tr>
<tr>
<td>Health care academy manager</td>
<td>1</td>
</tr>
<tr>
<td>Project assistant</td>
<td>1</td>
</tr>
</tbody>
</table>
According to the action research perspective and the explorative character of this trial, an extra training day based on first experiences is planned between the first group of four participants and the second group of six participants, for possible improvement of the intervention.

**Planning of the intervention**

All interventions will have to be planned within the period of one year. A minimum of at least ten is targeted to reach consistent data. The pilot training in SCPC can be given to any clinical team of curative departments in the hospital that also treats palliative patients. See Figure 2.
**Standardized evaluation of the intervention**

Effects of the intervention on the competences of the professional caregivers will be measured pre-intervention (one month before training) and twice post-intervention (one month and six months after training).

The effects on patients’ physical, psychosocial, and spiritual distress are measured one month before and one month after the caregivers participate in the educational program. Patients’ physical symptoms, spiritual distress, and the perceived focus of caregivers on their spiritual needs, quest for meaning, or existential questions will be measured.

**Patient-inclusion criteria**

For the inclusion of palliative care patients from the hospital departments where clinicians participate in the pilot training in SCPC and the control group of departments that do not participate, a Dutch translation of the Supportive and Palliative Care Indicators Tool [29], called Ondersteunende en Palliatieve Zorg Indicatoren Set (OPZIS), was developed in cooperation with the University Medical Center Groningen to identify palliative patients. The OPZIS [30] (see Appendix 1) seems feasible in the context of this study.

The target is to include five to ten patients from each pilot and control department following Good Clinical Practice (GCP) guidelines on informed consent, privacy, and processing of collected data.

**Measuring the effect of the pilot training in SCPC on consumer quality of care**

After informed written consent, questionnaires will be given by specialist palliative care nurses or ward nurses with additional palliative care training that function as palliative care ambassadors in their department. The questionnaire contains items on age, gender, demographical data; 15 items on physical and psychosocial symptoms using the Utrecht Symptom Diary [31]; four spiritual items using adapted items of the Distress Thermometer [32] (see Appendix 2); 26 items using the Spiritual Attitude and Interests List [33]; and six items related to spiritual care from the NIVEL report on consumer quality indicators of palliative care [34]. Patient data will be coded referring to hospital, department, and numerical order of inclusion.

**Measuring the effect of the pilot training in SCPC on professional caregivers competencies**

Based on the methods used by Maria Wasner, Christine Longaker, Martin Johannes Fegg, and Gian Domenico Borasio [35], Katrien Cornette and Jenny Put [36], and René van Leeuwen [21] to assess spiritual care competencies of healthcare professionals/students and the effect of training in spiritual care, an online questionnaire has been developed. This questionnaire is divided into nine items on demographical data, ten items on work experience and attitude, 11 items on perceived barriers for providing spiritual care, 26 items of the Spiritual Attitude and Involvement List (SAIL), and 27 items on Spiritual Care Competence Scale (SCCS).
Expected outcome

We expect the following dimensions to emerge due to the effect of this training:

- Decrease of perceived barriers to spiritual care, according to caregivers compared with baseline;
- Development of caregivers competencies compared with baseline,
- Higher consumer quality of care compared with baseline on pilot departments, no difference on control departments;
- (For chaplains:) understanding of/knowledge concerning the needs of primary caregivers in the application of spiritual care after training; understanding of/knowledge concerning the possibilities of the integration of spiritual care in the working process of the multidisciplinary team; and knowledge concerning the education of spiritual care.

Our target is to collect data from ten multidisciplinary teams (approximately 330 caregivers) and from 110 to 180 palliative patients treated in hospital settings.

Data analysis

Earlier studies were based on different definitions of spirituality, and validated instruments in Dutch that are based on international consensus definitions still lack in this rather new—for the Netherlands—field of multidisciplinary spiritual care. Therefore this trial is explorative (phase one) and a power analysis is not possible.

For this pilot study, the target number of multidisciplinary teams \( (n = 10) \), as well as the target number of patients \( (n = 18 \text{ per site}) \) is not based on a formal sample size calculation. With the planned study size, this pilot will generate valuable data for an exploratory evaluation of the introduction of the new method of delivering multidisciplinary spiritual care, from the perspectives of the caregivers and the patients. In both settings, summary statistics (point estimates and standard deviation range) will be used to evaluate the respective effects of the new method. Any hypothesis testing on observed changes in professional caregivers’ competencies and perceived barriers for spiritual care will be performed using paired samples, \( t \)-tests, and Wilcoxon Sign Rank Tests. Patients’ spiritual distress and perceived quality of care will be interpreted within the setting of an exploratory study rather than a confirmative one.

Qualitative data from the semi-structured interviews with the teachers/hospital chaplains will be transcribed verbatim and analysed. Subsequently a qualitative thematic analysis will be done using ATLAS-TI in two rounds: immediately after all pre-intervention interviews with the pilot teachers are conducted and after all post-intervention interviews are conducted.

Strength and limitations discussion

This study has several strengths:

- It is a first systematic implementation of the multidisciplinary guideline on SC, monitoring its effect on healthcare professionals’ competences and patients’ spiritual well-being at the same time.
The strength of designing this study as a multicentre trial at the threshold of its implementation process is that it stimulates almost 36 percent of the teaching hospitals in our country to start the implementation of the guideline on SC.

This pilot study opens new, multidisciplinary territory combining quantitative and qualitative research methods from different research paradigms.

It is able to create bottom-up commitment from and local multidisciplinary cooperation between medical, nursing, and spiritual disciplines.

It can contribute to developing the guideline from consensus based to practice based.

It will develop knowledge about the use of diagnostic tools for the screening or assessment of the spiritual dimension by professional caregivers.

This knowledge can be used for a first revision of the guideline.

Together with the quantitative evaluation, this action research approach aims for developing bottom-up quality indicators for spiritual care. Learning together about the spiritual needs and resources of our patients, their proxies, and ourselves can invoke local renewals of the multidisciplinary cooperation between doctors, nurses, and healthcare chaplains.

The strength of this study lies in the attempt to combine the very different academic paradigms of medical, nursing, and chaplaincy disciplines; however, this also might complicate its evaluation.

Studying at the threshold of a national implementation process on spiritual care creates some important limitations:

To measure patients’ spiritual symptoms and spiritual needs in Dutch, only two tools were validated and are considered for application: the Spiritual Attitude and Interests List (SAIL) [33] and the spiritual items of the Lastmeter, a measurement tool recommended by the Dutch oncology guideline for detection of psychosocial needs [37].

SAIL is not developed to measure spiritual symptoms and the needs of clinical patients, and the tool is not based on an inclusive/consensus definition of spirituality. It is based on a specifically non-theistic definition of spirituality [33, p. 142]. However, as it might be able to generate data on patients’ spirituality and needs that are relevant in the context of developing training in spiritual care, the research team decided to use SAIL. Adaptation of SAIL to the broader national and international consensus definitions of spirituality would enhance its relevance.

The spiritual items of the Lastmeter were developed before the new consensus definitions of spirituality were published. The research team considered these items not to be compatible with the directives
of the multidisciplinary guideline on spiritual care. We used the official suggested items of the Dutch professional organization for healthcare chaplains (VGVZ) on the concept oncology Guideline Detection of psychosocial needs. The research team proposed a combination of the suggestions by the VGVZ, relevant spiritual care items of the national quality indicator set for palliative care, and basic items on religion and religious or spiritual practices, and this was accepted by the experts in the invitational conference on November 4, 2013. (See Appendix 2: Adapted Spiritual Items of the Distress Thermometer.) To the best of our knowledge these are the optimal questions to use; however, formal validation has not yet been performed.

In June 2014, the Dutch professional organization of healthcare chaplains (VGVZ) showed its appreciation for this design of healthcare chaplains’ research by awarding the first VGVZ Research Award to a Dutch abstract of this protocol.

**Abbreviations**

OPZIS *ondersteunende en palliatieve zorg indicatoren set* is a translation of the Supportive and Palliative Care Indicators Tool (SPICT)

SAIL Spiritual Attitude and Involvement List

SCCS Spiritual Care Competence Scale

SCPC Spiritual Care in Palliative Care

SPICT Supportive and Palliative Care Indicators Tool

STZ Stichting Topklinische Ziekenhuizen (Association of Tertiary Medical Teaching Hospitals)

**References**


28. Leeghwa Ren Palliatieve Zorg. URL: http://www.leeghuizenpalliatievezorg.nl/ [February 29, 2016].


30. Medical Centre Leeuwarden. Ondersteunende en Palliatieve Zorg Indicatoren Set. URL: https://www.mcl.nl/_library/44790/OPZIS%20MCL%202014.pdf/ [February 29, 2016].


Appendix 1

Supportive and Palliative Care Indicators Tool (SPICT™)

Use the SPICT™ to identify people with any advanced, progressive, incurable condition(s).

1. Look for two or more general clinical indicators of deteriorating health

- Performance status poor or deteriorating. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- At risk of dying from a sudden, acute deterioration.
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

2. Now look for any clinical indicators of advanced conditions

<table>
<thead>
<tr>
<th>Advanced heart/vascular disease</th>
<th>Advanced kidney disease</th>
<th>Advanced cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA Class III/IV heart failure, or extensive coronary artery disease: • breathlessness or chest pain at rest or on minimal exertion.</td>
<td>Stage 4 or 5 chronic kidney disease (eGFR &lt; 30ml/min) with deteriorating health.</td>
<td>Functional ability deteriorating due to progressive metastatic cancer.</td>
</tr>
<tr>
<td>Severe, inoperable peripheral vascular disease.</td>
<td>Kidney failure due to another life limiting condition or its treatment.</td>
<td>Too frail for oncology treatment due to advanced multimorbidity or advanced cancer.</td>
</tr>
<tr>
<td>Advanced respiratory disease</td>
<td>Stopping dialysis.</td>
<td>Advanced neurological disease</td>
</tr>
<tr>
<td>Severe chronic obstructive pulmonary disease or severe pulmonary fibrosis • breathless at rest or on minimal exertion between exacerbations.</td>
<td>Serum albumin &lt; 25g/l, INR prolonged (INR &gt; 2).</td>
<td>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</td>
</tr>
<tr>
<td>Meets criteria for long term oxygen therapy (PaO2 &lt; 7.3 kPa).</td>
<td>Liver transplant is contraindicated.</td>
<td>Speech problems with increasing difficulty communicating and/or progressive dysphagia.</td>
</tr>
<tr>
<td>Has needed ventilation for respiratory failure.</td>
<td>Advanced liver disease</td>
<td>Recurrent aspiration pneumonia; breathess or respiratory failure.</td>
</tr>
<tr>
<td>Advanced cirrhosis with one or more complications in past year: • diuretic resistant ascites • hepatic encephalopathy • hepatorenal syndrome • bacterial peritonitis • recurrent variceal bleeds</td>
<td></td>
<td>Advanced dementia/ frailty</td>
</tr>
<tr>
<td></td>
<td>Serum albumin &lt; 25g/l, INR prolonged (INR &gt; 2).</td>
<td>Unable to dress, walk or eat without help.</td>
</tr>
<tr>
<td></td>
<td>Liver transplant is contraindicated.</td>
<td>Eating less; difficulty maintaining nutrition.</td>
</tr>
</tbody>
</table>

3. Ask

Would it surprise you if this patient died in the next 12 months? **No**

4. Plan supportive and palliative care

- Review current treatment / care plan, and medication.
- Refer for specialist palliative care assessment if symptoms or needs are complex and difficult to manage.
- Agree future care goals/ plan with the patient & family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care using the GP/ primary care register.

Advanced kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure due to another life limiting condition or its treatment.
- Stopping dialysis.

Advanced liver disease

- Serum albumin < 25g/l, INR prolonged (INR > 2).
- Liver transplant is contraindicated.

Advanced neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathess or respiratory failure.

Advanced dementia/ frailty

- Unable to dress, walk or eat without help.
- Eating less; difficulty maintaining nutrition.
- Urinary and faecal incontinence.
- Progressive weakness, fatigue, inactivity.
- Unable to communicate meaningfully; little social interaction.
- Fractured femur; multiple falls.
- Recurrent febrile episodes or infections; aspiration pneumonia.
Appendix 2:
Adapted spiritual items of the Distress Thermometer

View of life, life questions, existential questions

View of life, life questions, or existential questions have to do with: what you believe life means, what the value of it is to you and how it should be lived. It can also be linked to a particular religion. Here are a few questions about your beliefs. Cross the option that always best describes your situation. We realize that you may find it difficult to answer some questions, perhaps because you are using other words to describe your beliefs or that you have not given it much thought. Yet it is important that you complete all the questions.

Please consider the following points when completing the questions:

- Circle the answer that always best suits you (one mark per question).
- There are no “right” or “wrong” answers.
- Often, your first impulse is the best; do not think too long about your answers.

1. Please indicate whether you experienced difficulties or problems last week (including today) in the field regarding views of life/life questions, such as:

- coping with loss
- questions about the end of life/death
- loss of confidence
- questions about the fulfillment/meaning of my life
- guilt
- questions about the purpose of the treatment
- need for rituals

<table>
<thead>
<tr>
<th>No distress</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>A lot of distress</th>
</tr>
</thead>
</table>

2. Please indicate whether your proxies experienced any difficulties or problems last week (including today) in the field regarding views of life/life questions, such as:

- coping with loss
- questions about the end of life/death
- loss of confidence
- questions about the fulfillment/meaning of my life
- guilt
- questions about the purpose of the treatment
- need for rituals

<table>
<thead>
<tr>
<th>No distress</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>A lot of distress</th>
</tr>
</thead>
</table>
3. Do you think it is important that healthcare professionals (doctors, nurses, other health care professionals) on this ward pay attention to difficulties or problems related to the above topics or questions?

<table>
<thead>
<tr>
<th>Not important</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Very important</th>
</tr>
</thead>
</table>

4. How do you rate the attention of healthcare professionals (doctors, nurses, other health care professionals) to difficulties or problems related to the above topics or questions?

<table>
<thead>
<tr>
<th>No attention</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>A lot of attention</th>
</tr>
</thead>
</table>