



# Improving sensitivity of volunteers in palliative care for patients' spiritual stress

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## Introduction

Volunteers in care focused roles are definitely the persons in palliative care who spend the most time with patients. But are they sufficiently equipped to recognise signals of spiritual restlessness, stress or suffering? Often these appear to come hidden or masked, not well articulated.

The managers of a hospice took initiative, wrote a proposal and received a grant to develop a method to increase volunteers' sensibility for spiritual stress with patients in palliative care.

Several barriers for identification of spiritual needs and offering specialised help were analysed. For instance it was observed that

patients share existential and spiritual concerns with volunteers, who appear to consider this as private information, too personal to share with other volunteers or the coordinator/manager. Another barrier is a result of secularisation: common forms and rituals are not being used any more.

Many types of 'beliefs' or worldviews exist and often is not clear what type of expert can be of help in the case of existential suffering at the end of life.

The aim of this project was to develop a method that improves sensitivity of volunteers for spiritual stress with patients in palliative care.

A project of one year was started in which two researchers and two hospice managers worked together intensively in developing an observation method to improve recognition of spiritual needs in patients. We tried to improve the attention for hidden signals and encourage reflection on gut feelings of volunteers.

The project was monitored by a group of eight experts and a group of ten volunteers, providing feedback on the whole process. For dissemination purposes the national organisation for volunteers in palliative care (VPTZ Nederland) participated. Results were published as a small book in Dutch.

## Results

We used a development method based on three sources of knowledge: intensive literature research, critical case descriptions, and expert consultations.

In the first chapter of the book careful explanation was provided of different concepts like spirituality, religion, existentiality, philosophy, world views. We presented types of concerns that patients may experience in this life domain, without reference to a specific religion. For instance: Why do I have to suffer? Is there a life after death? Can I be forgiven? Cases were added in which spiritual suffering showed itself in an indirect way, for instance by asking more and more water.

As the core of the method to improve sensitivity a model from the Dutch guideline 'spiritual care in palliative care' was adopted that enables recognition of physical, psychological, social and spiritual concerns in patients. Volunteers were asked to fill out this model for each patient after their shift and evaluate if something extra was needed. The goal was not to have them diagnose spiritual stress in patients, but to generate more awareness for hidden signals of spiritual stress and needs in patients.

apply the forms and evaluate observations of patients after each shift.

The 7 steps were:

- 0) preparation: self observation, what is the quality of my attention?
- 1) becoming sensitive to recognizing and sharing own gut feelings, i.e. a 'sense of reassurance' or a 'sense of alarm',
- 2) being aware of the different position of the patient, facing end of life,
- 3) becoming silent, empty, open, listening,
- 4) refrain from doing, being there,
- 5) searching for concerns in the patient and offer responses,
- 6) writing observations down in a subjective way,
- 7) in case of not feeling reassured: evaluation of interpretations with other volunteers and manager.

The observation method was piloted in five hospices by ten volunteers, followed by an evaluation via in depth interviews (n=4) and focus groups (n=2). Respondents described that they had more attention, looked better, with more sensitivity when using the method. They questioned their observations and reflected more with other volunteers about how they understood the situation of a patient.

A book presentation was organised. Interested managers of volunteers were offered guidance to work with the method. They use the method for skill improvement of individual volunteers (to improve their sensitivity), for all volunteers in an organisation (to create a frame of reference), or at basic trainings for new volunteers entering the organisation. Special clues are included in the method for referral to further steps in care, including to asking assistance from spiritual counsellors.



## Literature

Goossensen, A., Hidding, A., De Kubber, S., Van de Vorst, M., Leget, C. (2016) Dorst of doodsangst? Het onderkennen van (spirituele) signalen van cliënten in de terminale fase. Utrecht: VPTZ Nederland. [Thirsty or anxiety for death? The recognition of (spiritual) signals in patients in the last phase of life.]

## More information

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Methods: The four in-depth interviews with volunteers were held by Sylvie de Kubber, junior researcher on this project. A river structure was used for the in-depth interviews with the central question: How did you experience working with the observation method? All interviews were typed out verbatim.

The focus group interview was held with 7 volunteers addressing comparable topics. The audiotape of 1 hour 53 minutes has been analysed together with the qualitative interviews. The analysis was based on general social sciences practices. Citations of the volunteers were added.