Out of the blue
Experiences of contingency in advanced cancer patients
Kruizinga, R.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Experiences of spiritual counsellors

Chapter 5

This chapter is based on:
Abstract

Background
Good palliative care requires excellent inter-professional collaboration; however, working in inter-professional teams may be challenging and difficult.

Aim
The aim of the study is to understand the lived experience of spiritual counsellors working with a new structured method in offering spiritual care to palliative patients in relation to a multidisciplinary health care team. Design Interpretive phenomenological analysis of in-depth interviews, was done using template analysis to structure the data. We included nine spiritual counsellors who are trained in using the new structured method to provide spiritual care for advanced cancer patients.

Results
Although the spiritual counsellors were experiencing struggles with structure and iPad, they were immediately willing to work with the new structured method as they expected the visibility and professionalisation of their profession to improve. In this process, they experienced a need to adapt to a certain role while working with the new method and described how the identities of the profession were challenged.

Conclusions
There is a need to concretise, professionalise, and substantiate the work of spiritual counsellors in a health care setting, to enhance visibility for patients and improve inter-professional collaboration with other health care workers. However, introducing new methods to spiritual counsellors is not easy, as this may challenge or jeopardize their current professional identities. Therefore, we recommend to engage spiritual counsellors early in processes of change to ensure that the core of who they are as professionals remains reflected in their work.
Introduction

Good palliative care is aimed at improving the quality of life of patients by addressing physical, psychosocial, and existential or spiritual needs. It requires a multidisciplinary approach which requires excellent collaboration. Working in inter-professional teams, however, may be challenging and difficult [1]. Misconceptions or stereotypes can hamper a fruitful working relationship [2], and failures in inter-professional teamwork lead to compromised patient care [3, 4]. For inter-professional collaboration to be effective, shared mental models, enabling a common understanding of the situation, the plan for treatment, and the roles and tasks of the different health care professionals are needed [5].

A common understanding of one’s professional role requires a strong sense of professional identity: before others can understand your role, one must be aware of one’s own role and hence of one’s own identity [6–8]. For doctors and nurses, roles and identities may be self-evident, based on clearly defined protocols and evidence-based practice [9, 10]. However, this may not hold true for professionals addressing the spiritual domain of care. Often, care for spiritual needs is poorly articulated, and methods are hardly ever evidence-based [11]. Central to the professional identity of spiritual counsellors is the competence of listening carefully without agenda, rather than conceptual or more structured approaches [12]. As a result, the role of a spiritual counsellor in a palliative care setting may be unclear or ambiguous to the rest of the multidisciplinary team [13].

From a constructivist perspective, professional identity is considered to be an ongoing developmental process; it needs to be (re)created in the act of performing and in relation to others, being influenced by values, and expectations within the profession [14, 15]. Thus, spiritual counsellors working in the field of palliative care need to negotiate different competing forces. For them, as members of the inter-professional care team, they have to accommodate a more structured approach and evidence base for their work as is required from other medical professionals as well [16]. However, following their current professional identity in which “being present” is a central goal, more than having structured conversations, this may be a challenge [12, 17, 18].

The aim of this current study was to explore how spiritual counsellors learned to use a new, more structured, approach to the provision of spiritual counselling, as part of a randomised controlled trial [19]. Our research question was: how do spiritual counsellors experience and give meaning to their experiences in learning to work with a structured model in offering spiritual care? We investigate the practice of spiritual counsellors in hospitals to deepen our understanding of the professional roles and identities they bring to the inter-professional team. Therefore, the insights of this study will not only be helpful for the spiritual counsellors themselves but also for all professionals working in interdisciplinary health care settings.
Methods

Context of the study
The current study is part of a larger randomised controlled trial (RCT) to examine the effect on quality of life of palliative cancer patients of an intervention consisting of two specific structured consultations led by a spiritual counsellor [19]. Details of the professional intervention have been described elsewhere [20]. In brief, making use of an e-application, specifically designed for the purpose of this study and running on an iPad, the spiritual counsellor asks a patient to draw a life line to indicate important life events on this line and formulate life goals. Then, the (dis)coherence between life events and life goals is explored in a structured way and discussed with the patient. Nine spiritual counsellors were purposefully selected for the RCT and were also invited to take part in the current study. All accepted the invitation. The selection was based on the following criteria: both men and women, with different religious backgrounds and with at least 5 years of work experience. The number of participating spiritual counsellors was based on the calculated sample size of patients needed for the RCT (n=153), of which half would be seen by a spiritual counsellor [19]. To limit the workload for the spiritual counsellors participating in the RCT while allowing for sufficient experience with the intervention, we decided to allocate a minimum of eight and a maximum of 10 patients to one spiritual counsellor.

Prior to the RCT, the spiritual counsellors were trained in using the structured model with an e-application. The training period consisted of two plenary training sessions, supported by a written manual, and an individual pilot study. The pilot study consisted of two interviews in which the spiritual counsellors were asked to use the model, first with a student and, thereafter, with a palliative cancer patient. The interviews conducted by the spiritual counsellors during the pilot study were recorded, transcribed, and examined. The research team evaluated the interviews separately with each spiritual counsellor by giving oral and written feedback on a practical level e.g., “you can help the patient with the iPad when it is too hard” and on a more theoretical level e.g., “you could have asked here what do you mean with a good life?.” During the training period, one spiritual counsellor quit the process because of a change of workload; yet, also, this spiritual counsellor was interviewed for this qualitative study. After the training was finished and before the RCT was started, we carried out a single face-to-face interview with the spiritual counsellors in which we addressed their experiences.

Research team
The first author (RK) interviewed the spiritual counsellors. She already knew the spiritual counsellors, as they all participated in the training that was part of the RCT. Within the whole research team, there was a broad range of expertise, both clinical (EH, HvL), spiritual (MSR, HS, HvL), educational (EH), and methodological (EH, MSR).

Phenomenological approach
In order to investigate and understand the experiences of the spiritual counsellors, we used an interpretive phenomenological approach. The goal of phenomenology is to enlarge and deepen the understanding of the range of immediate experiences [21], and a phenomenologist tends to employ qualitative methods that put the experiences of the participants at focus [22]. In our study, we regard the lived experiences of the spiritual counsellors as a phenomenon and used the interviews to enlarge and deepen our understanding.
Data collection
The interviews were conducted between November 2013 and January 2015 by one researcher (RK). Using a topic list (Fig. 1), we explicitly asked our participants to reflect on the new structured method in comparison to their usual work, asking for their motivation for participation in the RCT, their expectations and experiences in using the structured method and iPad application in the interaction with patients, and their thoughts about the development of the profession and evidence-based spiritual care. The interviews varied between 30 and 60 min and were audio recorded and transcribed verbatim.

Analysis
We used template analysis to order the data and to discover the most important and recurring themes [23, 24]. A template consists of a list of codes and is organized in overarching themes. The codes and themes on the template are derived from the individual interviews. As a first step, two researchers (RK, EH) familiarized themselves with the data, by reading and rereading the transcripts. They identified units of meaning and labelled them with a summarising code. After having coded the first three interviews, they started with the development of the template using sticky notes to group the codes and identify overarching themes. This template was revised and refined every time a new interview was coded, new codes were added, and other codes were combined. Adjustment and development of the template was regularly presented to a third researcher (HvL) to see if there was recognition, to make the main researchers aware of any biases and to deepen our understanding.

Involving researchers with different backgrounds (medicine, educational sciences, and religious studies) was important to improve the breadth and depth of the analysis. Following the constructivist paradigm, we did not look for coding disagreements. Within a constructivist research paradigm, knowledge and interpretations are considered to be constructed in the interaction between the interviewer and participants and between the researchers and the data. Therefore, the involvement of multiple coders was not intended to increase objectivity, but to reach a deeper understanding, building on different perspectives.

In the process of making the template, we regularly presented adjustments to a third researcher (HvL). RK used a diary to note all personal findings while working on this article, we used this reflective research to record all the decisions we made regarding coding, the development of the template, and the final writing-up of the results.
Chapter 5

Results

Participants

All spiritual counsellors participating in the RCT [9] were willing to make time in order to take part in the interviews. The characteristics of the participating spiritual counsellors are displayed in Table 1. The age of the spiritual counsellors ranged from 44 to 61 years. All but one had an academic training and were very familiar with the practice of providing spiritual care in a hospital setting (mean 12.5 years).

Table 1. Respondents’ characteristics

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Age</th>
<th>Birth country</th>
<th>Work experience</th>
<th>Clinical Pastoral</th>
<th>Life orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resp. 1</td>
<td>Male</td>
<td>55</td>
<td>The Netherlands</td>
<td>23 years</td>
<td>no</td>
<td>Humanist</td>
</tr>
<tr>
<td>Resp. 2</td>
<td>Female</td>
<td>44</td>
<td>The Netherlands</td>
<td>7 years</td>
<td>yes</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Resp. 3</td>
<td>Female</td>
<td>44</td>
<td>South Africa</td>
<td>8 years</td>
<td>yes</td>
<td>Protestant</td>
</tr>
<tr>
<td>Resp. 4</td>
<td>Male</td>
<td>54</td>
<td>The Netherlands</td>
<td>18 years</td>
<td>yes</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Resp. 5</td>
<td>Male</td>
<td>61</td>
<td>The Netherlands</td>
<td>7 years</td>
<td>yes</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Resp. 6</td>
<td>Female</td>
<td>45</td>
<td>The Netherlands</td>
<td>8 years</td>
<td>no</td>
<td>Humanist</td>
</tr>
<tr>
<td>Resp. 7</td>
<td>Male</td>
<td>54</td>
<td>The Netherlands</td>
<td>21 years</td>
<td>yes</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Resp. 8</td>
<td>Male</td>
<td>58</td>
<td>The Netherlands</td>
<td>14 years</td>
<td>yes</td>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Resp. 9</td>
<td>Female</td>
<td>46</td>
<td>The Netherlands</td>
<td>6,5 years</td>
<td>no</td>
<td>Buddhist</td>
</tr>
</tbody>
</table>

Template

From the interview data, we designed a template (Fig. 2). The template shows two overarching themes: negotiating experiences (1, 2, 3) and conceptions of professional identity (4).

Figure 2. Template showing overarching themes
Experiences of Spiritual Counsellors

Negotiating experiences relates to experiences during training and practicing (first heading of the template), experiences with the new, structured model (heading 2), and experiences while working with the iPad and e-application (heading 3). The fourth heading in the template includes experiences with developing a new professional identity. In this study, we were interested in how spiritual counsellors experience and give meaning to their experiences while learning to work with a new, structured model in offering spiritual care and how this influences identity development. As the first heading of the template is mostly capturing practical experiences during training, in the description of our results, we will focus on headings two, three, and four of the template. First, we will discuss the experiences of the spiritual counsellors with the model. Second, we will address the experiences with the iPad and e-application and finally we present our findings regarding the spiritual counsellors’ conceptions on their profession and professional identity.

Experiences with a new method: struggles with structure

The participating spiritual counsellors all reported both positive and negative experiences with the model. Most importantly, they were struggling with the need to follow the fixed structure of the model. They reported that the model was too decisive and that it sometimes hampered the conversation, which led to a resistance against the predefined structure. Some were even to the patient, when adhering to the model, ultimately leading to refraining from responsibility. The model was associated with wearing a straight-jacket. “What I find difficult is to be in a straitjacket of a model when it suddenly appears to be very constraining (...) but that is just my creative urge for freedom because I think there is more than this model, the patient is always more and I force her into a framework.”(resp.1) All counsellors also reported positive experiences with the model. They discovered the value of the model in addressing life events and emotions, the search for consistency and focusing on the future. Even the structure of the model was eventually appreciated. According to the spiritual counsellors, the value of the structure was that it helps patients to reflect and that there is no opportunity to escape from the topic. They stated that this may be of particular help to a specific type of patient, for instance, patients who do not normally express themselves easily. Some spiritual counsellors mentioned that the model requires to make everything explicit while in ordinary conversations things can remain implicit.

The relationship with the patient was experienced as different from the normal situation, due to the setting of this study design. Some reported that the relationship was more clinical, and the patients were entering the room with a clear goal, to participate in a scientific study. Spiritual counsellors referred to setting the agenda and leading the patients in a very structured way as a completely new approach. “It is valuable not to linger with the very first topic (...) but to carry on and really use the method, because eventually you will reach something good.(...) But I need to repress my first feelings, uh... I have a tendency to explore that what lies on top, things someone starts talking about.”(resp.4)

Experiences with a new method: the influence of an iPad

Using an e-application that runs on an iPad is also completely different from the normal work setting of hospital spiritual counsellors. In the beginning of the training, almost all counsellors struggled with the use of the iPad. “Well, if I am honest, I have not once really liked it, because there was always a kind of tension in me whether the technique would work.”(resp.8) They talked about the iPad in strong terms such as “it is an awful digital thing,” and they experienced technical problems related to the iPad. Some counsellors emphasized that the
iPad does not belong to spiritual care in general. Once the spiritual counsellors got more acquainted with the iPad and there were less technical problems, they all mentioned positive perceptions too “I first thought we are going to do interviews using such a nasty digital thing, that does not belong to my profession, and now I see that it is a very nice tool and also very helpful because you are sitting next to each other, bending over it together.”(resp.6).

Experiences with the iPad were often reported in terms of metaphors, maybe to describe the special role of the iPad that cannot easily be explained in normal words, using phrases such as “the iPad is a tool, a coat rack, a small shop.” One counsellor reported that working with the iPad had the same effect as when a patient is showing photos. He experienced it as helpful to look at something together instead of looking at each other. Others reported on the new dimension that came along by working with an iPad: “the iPad is doing something together, like doing the dishes, puzzling or playing a board game.” Another dimension that emerged was the effect of visualizing part of the conversation, which many counsellors described as helpful in staying focused. “Then it doesn’t all play in my head, but it is, it kind of becomes externalized. Yes, and also it keeps my head together, because otherwise I swerve off topic. (...) I was also afraid that the fact that the device is out there would work alienating, but I manage to continue a dialogue with the patient and to use the device just as a tool.”(resp.4)

Conceptions on professional identity: adapting to a certain role
Almost all spiritual counsellors reported that in order to conduct these structured conversations they intentionally changed roles, from acting as a counsellor into being a researcher, an interviewer or a research assistant. “It has to do with my education, that we really learned not to be directive (...) but instead connect with the story of the other who sets the agenda and I do not have a clear agenda. So I need to make a switch I am not sitting here as spiritual counsellor giving support, but I am doing this in the context of a research project.”(resp.6) They referred to their previous education, in which they had learned what a spiritual counsellor should be like, which is different from the requirements of this study. “The patient should be leading and determining what we are talking about. And occasionally I ask a question, but, well, the patient decides whether or not to talk about it and where we are going. (...) When I have a conversation with a patient and, at one point, the conversation falls silent, because the patient is just sitting there, having internal conversations, (...) I am perfectly satisfied! (...) I’ve done my job. But now I have to do everything. I have to pull out everything, everything must be explicitly stated.”(resp.2)

From not having an agenda to completely leading the patient is a big shift and requires behavioural changes. One way of dealing with this different way of performing their work was deliberately changing roles or wearing different ‘hats’. “The ‘researcher hat’ is actually needed to facilitate the discussion, to adhere to the model.”(resp.3) Working with the model requires a specific mindset. “I think the difficulty for me is, but that is very personal, that I need to get the right mindset, that I have to prepare well, and know, ok now I am working with this, that is your tool and these are the rules, these are the frames and within this you can move. But that is a matter of practice. (...) I should be aware that the patient does not run off with a story and takes control.”(resp.5)

Conceptions of professional identity: changing identities of the profession
Some spiritual counsellors explicitly reported that this model is beyond ordinary spiritual care because it is too structured, leading to the question what exactly entails spiritual care in the context of health care. “The core of my profession is (...) to help people to enter into
dialogue with themselves or listen to themselves, (...) around the themes that are important, when they are falling ill, that you help them to get close to what is important to them, what has meaning, what carries them and gives strength.”(resp.2) Spiritual counsellors mentioned that this notion on the core of spiritual care is currently changing, as are the views on the position of spiritual care within the hospital infrastructure. Furthermore, the financial constraints health care in general is facing also stimulate counsellors to rethink about their profession. “You do see that a shift occurs (...) out there they transferred the spiritual care into the department of occupational therapy. (...) a very odd move that you entitle spiritual care as an activity that anyone could perform.”(resp.5)

All spiritual counsellors emphasized that spiritual care is an important part of health care, which certainly belongs there. Spiritual care is seen as creating space for existential issues and may serve as a safe haven, a free place, especially compared to doctors, who usually have limited time and attention for patients. How to emphasize this unique position seemed to be a matter of debate. “You can highlight the sanctuary position as something that is unique to you or your profession (...). We must indeed continue to do so, but that does not mean that you should not do other things. (...) Not clinging (...) Then you take on a defensive mode of ‘you take everything from us, but we are very unique in it!’ (...) I do think this is changing. (...) Many young spiritual counsellors (...) are very open-minded to this. (...) They also combine the other parts. The science part is not dirty or anything. It is no blaspheme to make things evidence-based. There is nothing wrong with that.”(resp.9) There is at this moment very little research done on the effects of spiritual care, while the professional background of hospital spiritual counsellors is academic. “The added value [of the RCT] is that you show to the oncologists (...) here is an example, this is what it looks like and this is what it contributes, making it visible.”(resp.3)

Spiritual counsellors, however, have difficulties with making their work visible. “Chaplains are not trained for that. They come from very strong internally oriented worlds.”(resp.7) All counsellors emphasized the importance of visibility, underpinning, and professionalisation of their work, as one of the main reasons to participate in the RCT, illustrating how the identity of the profession is changing.

**Discussion**

**Statement of main results**

The objectives of our study were to understand how spiritual counsellors experienced working with a structured method in offering spiritual care and to discover how they gave meaning to their experiences. Central to their accounts was the experience of their professional identities being challenged. Using the structured method leads to both negative and positive experiences. Negative experiences with the model were related to its highly structured way of relating with patients, which sometimes hampered the interactions with patients, and therefore, could be experienced as too constraining. Positive experiences also pertained to the structure, now facilitating the conversation with patients who do not easily reflect on their feelings and providing a tool to focus on core topics. Although initially perceived as an awful digital thing, the iPad finally was also accepted as a helpful tool, enhancing different ways of interacting with patients. Despite their positive experiences, all spiritual counsellors referred to their professional identities as being at stake.
Many spiritual counsellors reported that they needed to intentionally change their roles, from being a counsellor into acting as a researcher, raising the question what the core of being a spiritual counsellor implies. All spiritual counsellors reported on the importance of visibility, underpinning, and professionalisation of their work.

**Strengths and limitations of this study**
All the interviews were conducted by one researcher (RK) who was also responsible for designing the training period and for providing support and feedback. An advantage of this study design was that RK had already a relationship with the participants and knew the context, so the spiritual counsellors could immediately report their experiences without the need for further explanation. A disadvantage may be that the researcher was too much biased or that the spiritual counsellors gave socially acceptable answers. However, in the interviews, the spiritual counsellors did report a substantial amount of negative feelings, experiences, and views.

To develop a broad understanding, the interview study was mainly conducted in collaboration with another researcher (EH) who was not part of the project before and had no previous contact with counsellors. This enabled EH to have an external look at the study and study results. The wide range of expertise within the research team could be regarded as a strength enriching our analysis. Our study findings may be limited by the large homogeneity of our sample. Most of our participants had a Roman Catholic background, were white, middle-aged, and Dutch. It could be that colleagues who are younger, with other religious backgrounds, and working in other parts of the world would have had different experiences. Younger spiritual counsellors for instance might have experienced less struggles with technique and structure because they are less rooted in their profession.

The inclusion of mostly Dutch spiritual counsellors also influenced the outcomes, as the issues of visibility and professionalism could be less relevant in countries where spiritual counsellors are still sent from the church. Nevertheless, insights of this study could be of substantial value when spiritual care is shifting towards a more integral part of health care, as this shift is noticed in different countries [25–27].

**Interpretation of findings in relation to other studies**
Other studies show that the profession of spiritual care is in transformation, evolving from a denominationally bound profession into a specific kind of healthcare profession [28]. These developments ask for more validity, evidence, professionalisation, and collaboration in the profession of spiritual care [16, 25]. While our research question focussed on the lived experiences of the spiritual counsellors in working with a new structured method, as a result, we identified struggles with professional roles and the identity of the profession. This finding may have to do with the fact that spiritual counselling is a relatively young profession in a changing environment. Previously, spiritual counsellors were sent by the church, while in our sample, all were employed by the hospital.

Many spiritual counsellors oppose a more structured way of working because standards seem to conflict with their sanctuary position as well as with the concept of “presence” in client-centered therapy [29]. This concept from Rogers has profoundly influenced the development of spiritual counselling and underscored the value of just being present as a spiritual counsellor and not intervening too much [30]. By using this new structured method, spiritual counsellors were forced into an “action mode” by having to lead the patient through the questions [31]. A shift from the mode of “being present” to an “action mode”
could be an additional explanation for the struggles the spiritual counsellors experienced.

**Meaning of this study: implications and future research**

Within the biopsychosocial paradigm, existential or spiritual needs may receive little attention, and non-medical input in inter-professional team discussions tends to be undervalued by medically educated team members [32, 33]. This issue becomes even more pressing in palliative care, when in the face of death, the relevance of the search for meaning and purpose in life is intensified [34]. Policymakers should be aware of the important role spiritual counsellors can play in the palliative care setting, but also consider their professional identity when introducing new methods for delivering spiritual care. Spiritual interventions can have a complex nature and sometimes special clinical training is necessary to engage in them.

An appropriate recommendation is therefore that these interventions should be done only by a board-certified chaplain or an equivalently prepared spiritual care provider [35]. When a change in work content offers a threat to the professional role, professionals will not readily adapt to the new routines, which could reduce the effectiveness of inter-professional teams [36]. Therefore, in processes of change, attention should not only be paid to an explanation and teaching of practical methods but also to the role and position of a spiritual counsellor. It would be helpful to engage spiritual counsellors early in the processes of change. Future research should focus on the effect that increased visibility of spiritual counsellors in palliative teams may have on the professional identity of other team members and which may ultimately contribute to delivering better quality palliative care.
Chapter 5

References


