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Out of the blue

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hapter 1

General introduction

“It just comes out of nowhere” (female, 51, breast cancer).

“This was a real shock to me, it was completely out of the blue” (male, 74, bone cancer).

When patients describe the moment they received the diagnosis of incurable cancer, they usually emphasize the unexpectedness of the event and its impact on their life as a whole. It often evokes existential questions like ‘Why me, why this, why now?’ and requires an adaptation of one’s life story. These experiences can be called experiences of contingency.

Experiences of contingency

Contingency means that everything – including one’s own life – could have been different, and according to one’s plans and expectations could have developed differently [1-3]. Every day people are confronted with experiences of contingency, which can be either positive or negative. The negative experiences, however, affect people most profoundly. These can differ in type – illness, loss, accident... – and their impact may depend on personal characteristics and attitudes and on social situations or support [1, 3]. Contingency is mostly experienced when an event is profound, when it undermines personal life goals and when it cannot be integrated naturally into one’s own life [4]. A diagnosis of incurable cancer is often an experience of contingency. The double negative of the term contingency (not necessary, not impossible) contains two opposing experiences. On the one hand there is the unforeseen, referring to the accidental, random, unexpected and futile. On the other it refers to a field of creativity: it provides a place to act and make decisions [2, 5].

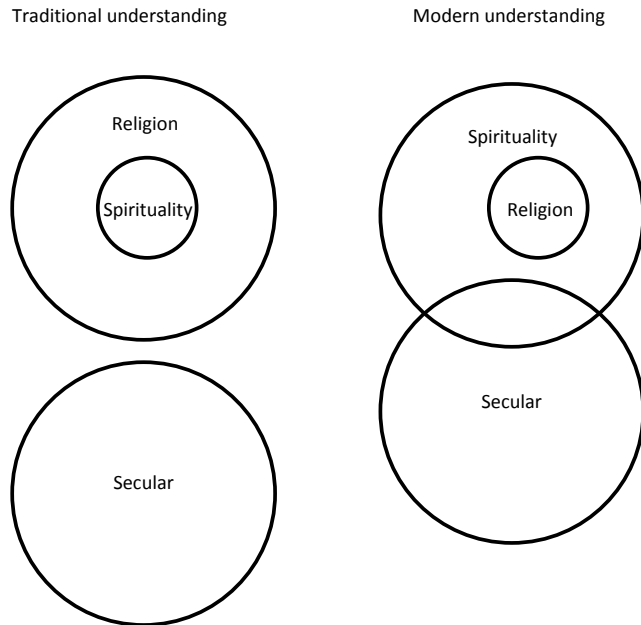
While in traditional societies individual life stories were embedded in binding structures, values and norms, in our late modern society people’s identities are no longer clearly defined by these basic structures [6, 7]. Nowadays, people have to create their own reaction and interpretation in accordance with their life view. According to Luhmann, dangerous situations are no longer – as they were in older forms of society – regarded as results of nature, god or destiny, but as the result of decisions [8]. So the concept of contingency makes people aware of the increased number of options for their choices and actions, and even more so to the possible consequences these individual options may have [9]. Contingency, therefore, enables people to create a meaningful relationship with the situation they are faced with in their own context – with “meaningful” implying acting in a way that shows a natural connection to the past and includes desires, wishes and needs for the future [10, 11].

The creation of an interpretation framework requires a creative process of narrative reconstruction [12]. Experiences of contingency create a possibility for the individual to reflect and create meaning. This is where the notion of spirituality comes in, by attributing meaning to something that cannot naturally be understood. Herein, contingency is directly associated with the concept of spirituality through the possibility whereby people can create their own interpretation. Spirituality may therefore be the opportunity for people to attribute meaning, thus helping them to reflect on experiences of contingency by using a narrative reconstruction of the situation which can be shaped and constructed in order to integrate the event into their lives [4,7].

Spirituality

One of the patients participating in a validation study on the measurement of spiritual well-being, replied to me, “*What is spiritualism anyway, something vague with believing in aliens and stuff?*” This reaction illustrates how the term ‘spirituality’ can be vague and misinterpreted, particularly in a Dutch context where it used to have a different connotation. Spirituality used to be understood as a smaller, specific part of religion, reserved for religious people who had mystical spiritual experiences [13]. Over the years, spirituality has shifted away from this particular connection to faith and religion to become a broader term including everything that transcends our tangible world. People who describe themselves as being secular can also have spiritual experiences, and the term ‘secular spirituality’ has even appeared [14]. A simplified representation of the traditional and modern understandings of spirituality is shown in figure 1.

Figure 1. Traditional and modern understanding of spirituality



As a result of this shift, there is now a need for a more inclusive definition of spirituality, encompassing both the religious and the secular linguistic fields to describe a dimension of human experience [15]. Sheldrake describes three aspects of spirituality which are key to our modern understanding of the term. In the first place, spirituality is an holistic notion, understood as the integrating factor in life. Secondly, it is concerned with a quest for the “sacred”, which can be broadly interpreted (nature, arts, god, cosmos). Lastly, spirituality is often understood as a quest for meaning which derives from a decline in traditional religious views, especially in Western Europe [13]. In this thesis we use the definition of spirituality agreed upon in a 2009 Consensus Conference: “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” [16]. In this understanding of spirituality, secular and religious elements are combined and the emphasis is on meaning, purpose and being connected. When performing research in the domain of spiritual care it is important to use an inclusive and broad definition of spirituality, combining the religious and secular linguistic fields, so as to ensure that spiritual care is provided to a broad patient population who may benefit from it. This is especially true for Western Europe, where fewer people characterize themselves as being religious [17].

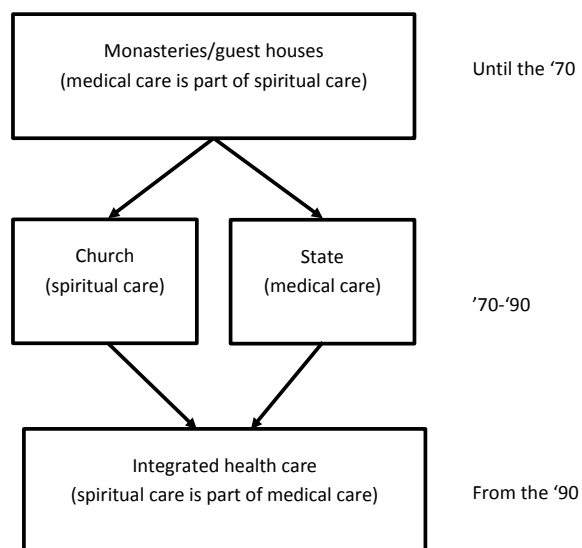
Spiritual care

When time is limited by an incurable disease, moments of reflection and reprioritising can be of ultimate value. Spiritual care can create time and space and can empower patients to reflect on what really matters. Two patients interviewed for this thesis perfectly illustrated the core of what spiritual care can do: *“It was a very good experience, especially drawing my life line. That was very enlightening to me, as was formulating my expectations of the future. To think about what is really important to me, what I should be investing my energy in”* (male, 35, brain cancer). *“What specifically lingered were the life goals that I formulated for the future. I’ve thought a lot about it and it keeps coming back. Do I dare to look this far into the future? Well, sometimes I do and then those are the reference points you strive for”* (female, 64, oesophageal cancer). Evidence of its positive effects has led over the years to more and more acceptance of spiritual care as an important part of health care. In 2002 the WHO included spiritual care as an aspect of palliative care, because it can offer patients a sense of comfort, meaning, control and personal growth [18]. Despite the fact that spiritual needs are now part of the WHO definition of palliative care, however, spiritual issues are still poorly addressed and underdeveloped [19, 20]. Physicians tend to underrate or ignore spirituality and patients indicate that their spiritual needs are neglected in standard clinical environments [20-23]. Moreover, there are still concerns about the concepts of quality of life and response shift in relation to spirituality.

The problems with the role of spiritual care in a clinical setting can be understood from the history of medicine and spiritual care. What we today call hospitals descend from the monastic tradition whereby nuns, for the most part, took care of the ill and the church sent missionaries to remote areas to help people with their spiritual and medical needs [24, 25]. During the ‘pillarization’ of Dutch society, the churches and the state became more independent of one another and, consequently, spirituality was relegated to the ecclesiastical domain [26]. From 1970s, however, as secularization increased, spiritual care shifted from the churches back to hospitals. Over several decades, spiritual care professionals working in healthcare have moved from being emissaries of local religious communities to members of the healthcare team [27-29]. Nowadays, spiritual care is no longer strictly a domain of the church but is gradually becoming an essential part of healthcare once again [24, 30-32]; see figure 2.

This new situation entails all kind of questions and challenges: who is responsible for the soul, the spiritual counsellor or the doctor? And what are the interdisciplinary opportunities and risks? [33]. Another shift can be noticed in the profession of spiritual care, which has to do with the training of spiritual care professionals. In the America of

Figure 2. Simplified Scheme of Transitions in Spiritual Care



the 1930s there were two different views on how to shape pastoral care and how to train the student, known as the New England and the New York group. The New England group was convinced that the use of underlying concepts and methodological research helps to improve pastoral care. The New York group focused on experiences of the counsellors and designed peer-reviewed and supervision training. The latter was strongly influenced by the work of Sigmund Freud and William James and their interests in personal competence, rather than work content. The ideas of the New York school were adopted by Dutch theologians who designed the training for spiritual care professionals in the Netherlands and started Clinical Pastoral Education (CPE) [34]. From the 1970s, the question 'Who must I be to be of help?' became more central in the education of pastoral carers. The focus on their personal, professional and spiritual background implied that methods and underlying concepts had shifted to the background. The personal competence of 'being present' and being able to listen carefully without an agenda was central in many curricula [35]. Nowadays, there is an increasing interest in evidence-based research and in the use of different methods in spiritual care, although personal competences also remain part of the curriculum. In this thesis we aim to contribute to the scientific foundation of the field of spiritual care through empirical evidence-based research and the theory of experiences of contingency.

Advanced cancer patients

Amongst those people who are expected to benefit from spiritual care those who are confronted with the finitude of life. For many patients, receiving the diagnosis of cancer is a direct confrontation with the possibility of death. Cancer is a leading cause of death, with an estimated 8.2 million people worldwide dying from it each year – a number which is expected to increase because of the ageing population and the adoption of behaviours and lifestyle factors known to cause cancer [18]. Patients with cancer have to cope with loss of control over their lives, with anxiety or depression and with the fear of recurrence [36]. Knowing that their time is limited can bring an urgent need to deal with existential questions, and therefore engender a need for spiritual care. This thesis will focus on advanced cancer patients, not limited to a particular type of tumour.

Rationale of the study

Studies have shown that advanced cancer patients benefit from spiritual interventions in terms of quality of life and overall well-being [37-39]. Various scientific studies and health-care protocols, especially in the United States, have contributed to the idea that spiritual care is of ultimate value to advanced cancer patients. However, studies in the field of spirituality still have important issues to resolve regarding validity, conceptualization and scientific accountability. Since spirituality is a broad, multifaceted term and different definitions of spirituality and spiritual care are used, the operationalisation of the term is difficult. Also, there is no consensus as to who should provide spiritual care to patients. When looking at spirituality studies, we see a wide range of spiritual care providers, from doctors, nurses, spiritual counsellors and psychologists to less clearly defined professions such as spiritual healers [40]. The main concern, however, is that most researchers in this field do not use a thorough, grounded theory on which to base their studies. Consequently, a large number of studies may be considered as 'spiritual care studies' but all have different underlying theories, ideas and assumptions, which in many cases are not explicitly mentioned. We might speak of a gap in the field of spirituality research, illustrated by a lack of knowledge and by discrepancies between spiritual care as a theoretical value and as it is practised in a

healthcare setting [41, 42].

Considering the current knowledge gaps in spirituality research, in this thesis we aim to contribute to the scientific foundation and evidence of spiritual care research in a healthcare setting. The studies we designed use a narrative approach, because we believe this is the most suitable one when dealing with the existential questions patients are confronted with. Advanced cancer patients often use narratives to construct their own meaningful framework. A narrative creates coherence by linking past, present, future and personal goals into an intelligible whole [2, 43]. In confrontation with experiences of contingency, an extra narrative effort is required to construct a new meaningful framework of interpretation [5]. In order to get a grip on other studies that used a narrative approach in providing spiritual care to cancer patients and to evaluate the effect of those studies on patients' quality of life, we set up a systematic review and meta-analysis. In this study we systematically address the question of whether spiritual interventions with a narrative approach improve quality of life of cancer patients.

Subsequently, we designed an intervention to address the spiritual concerns of cancer patients using a narrative approach and the assumptions of the contingency theory. The intervention is designed to be assisted by spiritual counsellors working in a hospital setting, as they are experts in the field of the existential needs of patients facing the finitude of life. We will evaluate the effects of the intervention by conducting a randomised controlled trial, in which one group receives the intervention and the other receives care as usual. By conducting evidence-based intervention studies, the professionalisation of spiritual care will further be improved and as a result of this study spiritual counsellors may become more structurally involved in the care of cancer patients.

Furthermore, the relationship between quality of life, spirituality and spiritual well-being needs more investigation. Studies have shown a direct relationship between quality of life and spiritual well-being, although the nature of this relationship is still rather fuzzy. It is not clear which factors influence it, making it harder to shape and target spiritual care interventions. Some previous studies in advanced cancer patients have shown that images of God and attitudes towards death are directly or indirectly associated with quality of life, depression and hopelessness [44, 45]. Some other studies found a relationship between specific concepts of religiousness and spiritual well-being [46-48]. We will therefore conduct an exploratory study on possible influencing factors, such as images of God, attitudes towards death and specific religious concepts, and how they affect the spiritual well-being and quality of life of cancer patients. The identification of such factors is an important step towards the development of interventions to improve spiritual well-being and to provide insights into this complex concept.

Since the spiritual care provider is the main person carrying out the intervention we have designed, assessment of his/her experiences with the intervention is of crucial importance for its further improvement and implementation. In many hospitals, spiritual counsellors are the designated professionals to provide care when patients indicate that they have spiritual needs. The professional identity of a spiritual counsellor is in general identified mainly by the ability to listen carefully, without an agenda, rather than by the use of more structural approaches. With the aim of professionalizing and substantiating spiritual care, it is important to have more evidence-based studies which include spiritual counsellors who apply a certain structure in their work. To understand the experiences of spiritual counsellors working with a new structured method in offering spiritual care to palliative patients in relation to a multidisciplinary healthcare team, we will carry out an interpretive

analysis of in-depth interviews. Understanding the difficulties that spiritual counsellors experience in using more structured approaches will help by shaping intervention studies and incorporating such counsellors in a way that is in line with their professional identity.

Many studies have been conducted in the field of coping, focusing on how cancer patients deal with their condition as an unexpected life event, but these have concentrated primarily on functional aspects. In order to understand how people actually evaluate these unexpected life events in relation to their own world view, however, a more religious-philosophical approach is desirable. A functionalistic approach focuses only on the way cancer patients display how they are dealing with the event, whereas a religious-philosophical approach allows us to unravel their underlying beliefs and so provides an insight into how they interpret the situation and attribute meaning to it. We believe that focusing on how patients relate to a situation that is an existential given and looking into their interpretative framework is a valuable perspective in understanding the depth of their experiences. Opting for this religious-philosophical approach also allows us to better shape and target spiritual care. Starting with the experiences of contingency, we studied the content of the interviews from our randomised controlled trial with advanced cancer patients in the Netherlands. In addition, we conducted a small interview study with American patients.

Research questions

The central questions we answer in order to provide insight into experiences of contingency in advanced cancer patients and to improve the clinical practice of spiritual care are as follows.

1. How can we assess the effect of a structured reflection on life events and ultimate life goals of cancer patients to improve their quality of life and spiritual well-being? (chapter 2)
2. Do spiritual intervention studies that use a narrative approach improve the quality of life of cancer patients? (chapter 3)
3. Is there a relationship between spiritual well-being and specific images of God and attitudes towards death and afterlife? (chapter 4)
4. How do spiritual care professionals experience and give meaning to their experiences in learning to work with a structured model in offering spiritual care? (chapter 5)
5. How do advanced cancer patients relate to the experience of contingency in having incurable cancer in a Dutch patient population (chapter 6) and in a North American patient population. (chapter 7)
6. What is the effect of a structured reflection on life events and ultimate life goals of cancer patients in improving quality of life and spiritual well-being? (chapter 8)

The research questions are answered by using a mixed-method study design. A qualitative approach was chosen when analysing the interview data, but a quantitative approach was used when assessing factors that influence spiritual well-being, the effects of spiritual interventions and the effects of our randomised controlled trial. Both quantitative and qualitative strategies were included so as to approach the topic from different angles and make

the most of different research methods. The contingency theory was used as a theoretical foundation to this thesis. Details about the specific method used in the various studies is provided in each chapter.

Outline

In outline, this thesis follows the four basic questions of journalism: how, where, who and what [49]? Beginning with the first question, in chapter 2 we explain how we are going to evaluate the role of a semi-structured interview model in providing spiritual care to cancer patients. The design of the randomised controlled trial is set out, the underlying theories are described and the operationalisation is explained. The inclusion of a study protocol increases the transparency of the research, enabling the reader to compare what was originally intended with what was actually done.

The third and fourth chapters answer the question of where our research can be placed in relation to other research fields. First, we present a meta-analysis of all spiritual intervention studies with a narrative approach that have been conducted in advanced cancer patients to measure quality of life. The outcomes of this study helps to gain an overview of what other studies have done and what their findings are, so that we can relate our study to this wider field of research. Second, the field of spirituality and spiritual well-being is examined in relation to images of God and attitudes towards death. Because the field of spiritual well-being is relatively new, it is important to understand what factors can possibly be influential in unravelling the concept of spiritual well-being. Other studies have shown that there is a connection between quality of life and images of God and attitudes towards death in advanced cancer patients in the Netherlands.

Chapter five answers the question of 'who' provides spiritual care. A phenomenological analysis of spiritual counsellors' experiences in using a structured model is conducted to deepen our understanding of their professional roles. We asked the spiritual counsellors participating in our randomised controlled trial how they experienced working with the structured model and the e-application. This aspect of the study deepens our understanding of the professional roles and identities of spiritual counsellors in an inter-professional team.

The question at the heart of our study, and that most frequently asked by people around us, was: what is the role of a structured interview model on the quality of life and spiritual well-being of cancer patients? We can now finally answer this question, over three chapters. The qualitative analysis of the structured interviews is presented in chapter six. We describe how patients relate to the experience of contingency in having incurable cancer. Then, in chapter seven, we look beyond the Dutch borders to find out if our model of describing these experiences of contingency is also applicable to an American cancer patient population. The quantitative results of our study are described in chapter eight. Here we outline the different results of the intervention study and interpret them in relation to other studies.

Finally, we end with a summary and general discussion reflecting on spiritual care in a healthcare setting. We describe current problems in the field and ways to achieve a fully-fledged integration of spiritual and medical care.

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