



UvA-DARE (Digital Academic Repository)

Out of the blue

Kruizinga, R.

[Link to publication](#)

Citation for published version (APA):

Kruizinga, R. (2017). Out of the blue: Experiences of contingency in advanced cancer patients

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: <http://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.

R C

elating to contingency I
hapter 6

This chapter is based on:

Kruizinga R, Hartog ID, Scherer-Rath M et al. Modes of relating to contingency: An exploration of experiences in advanced cancer patients. Palliat Support Care 2016:1-10.

Abstract

Objective

Throughout their lives, people are confronted with unexpected life events, which can be difficult to incorporate into their life narratives. Such a confrontation can result in an experience of contingency. Different ways of relating to contingency have been described by Wuchterl: denying, acknowledging, and “encounter with the Other.” In the present article, we aim to trace these theoretical distinctions in real-life experiences of patients.

Method

We analysed 45 interviews using the constant comparative method with a directed content analysis approach in the Atlas.ti coding program. The interviews originated from a randomised controlled trial evaluating an assisted reflection on life events and ultimate life goals. Seven spiritual counsellors from six hospitals in the Netherlands conducted the interviews from July of 2014 to March of 2016. All 45 patients had advanced cancer.

Results

We found four different modes into which relating to contingency can be classified: denying, acknowledging, accepting, and receiving. With denying, patients did not mention any impact of the life event on their lives. In acknowledging, the impact was recognized and a start was made to incorporate the event into their life. In accepting, patients went through a process of reinterpretation of the event. In receiving, patients talked about receiving insights from their illness and living a more conscious life.

Significance of results

Our study is the first to investigate the different ways of relating to contingency in clinical practice. The defined modes will improve our understanding of the various ways in which cancer patients relate to their disease, allowing caregivers to better target and shape individual care.

Introduction

Throughout their lives, people are invariably confronted with unexpected life events. These encounters can be positive or negative, but seriously negative experiences often affect people most profoundly. Life events with a profound impact are known to raise questions about life itself and can be difficult to incorporate into one's life. These experiences are called experiences of contingency. Contingency refers to the idea that everything—including one's own life—could have been different, and compared to one's plans and expectations could develop otherwise. In other words, the occurrence of the life event is a possibility, not a necessity [1, 2, 3]. Although in principle all life events can be considered as contingent events, contingency in practice will be experienced when an event is significant for the person's life as a whole, when it adversely affects personal life goals, and when the event cannot naturally be integrated into one's life [4]. A diagnosis of incurable cancer is often a tremendous shock and difficult to interpret in the context of one's personal life narrative [5, 6, 7, 8]. It may evoke such existential questions as "Why me?" "Why now?" "What will my future look like?" and "What is the value of life?" [9, 10].

In traditional communities of the 19th century, actions and choices were constrained because each individual was anchored within the binding structure of social, cultural, and political norms and values, so that the integration of adverse events was taken care of within the community [11]. In our current and more liquid modern times, the identity of people is not so clearly determined by these grounding structures [12, 13]. People define themselves less in social terms and increasingly construct and justify their lives in terms of narratives that support self-control [1, 14]. This allows them to create their own structure of plausibility from which they interpret daily life. The creation of such a structure requires the making of a story [15, 16]. A story creates a context in which events of the past, present, and future are fused into a plausible whole that serves the personal goals that one pursues. Thus, the activity of linking these events by describing what has happened enables people to understand the meaning of these events [17]. Construction of life narratives is an ongoing process that locates the narrator in the middle of his story, thereby maintaining a continuous process of self-interpretation [18, 19]. The need for these explanatory narratives is even stronger when specific life events force the development of a whole new storyline. Life crises can mark the start of reflection and evaluation of questions about who we are and where we go in life [18, 20].

According to the German philosopher Kurt Wuchterl, the contingency of the world is not always acknowledged. People are inclined to develop a theoretical explanation for every event, assuming that everything can and should be explained either in terms of human reason or the laws of nature [21, 22]. In explaining how the world works, people have often ignored or denied the contingency of events, even though contingency is inherent to the world itself [22]. Repudiating contingency is mostly done on the argument of an all-encompassing reason, by the laws of nature, or the will of a higher power, in which reference to unexpectedness—as is inherent in contingent events—is completely removed.

This notion of contingency as described by Wuchterl is not a general psychological notion, although it touches upon different concepts within (health) psychology. Much research has been carried out in the field of coping, describing how people deal with unexpected life events [23, 24, 25, 26, 27, 28]. Pargament and others have distinguished a specific form of coping—religious coping—which may positively or negatively contribute to dealing with severe life events [29, 30, 31, 32]. In addition, resilience research seeks to answer the

question of why some people cope more effectively than others with certain situations [27, 33]. The common denominators in all these approaches are that they are based on stress theory and that they deal with mechanisms of appraisal and adaptive behaviour, primarily focusing on how people function. Contingency theory, however, is a specific religious-philosophical approach that deals with the content of how people evaluate situations in relation to their world-view. This evaluation is crucial in the understanding of how people deal with critical situations. Contingency theory can be a valuable addition to the concepts and approaches within (health) psychology since it adds notions of purpose and intent to the functionalist approach of coping-based theories.

Not every unexpected event can be valued as being contingent from a religious-philosophical perspective. It has to meet certain criteria. According to Wuchterl, a personal issue is only religious-philosophical contingent when it (1) is judged within one's belief system as ontologically contingent, that is, not necessary to happen nor impossible; (2) resists every attempt by human actions to eliminate this non-necessity; (3) is accompanied by an existential interest; and (4) triggers a reflexive impulse to argumentatively deal with the contingent phenomenon [22].

He describes two ways in which people can relate to contingency, that is, narratively integrating these experiences into one's story of life. He describes these ways as "acknowledging" and "encounter with the Other." People who acknowledge that the world itself is ontologically contingent recognize the fact that unexpected things can happen that cannot always be explained. Questions remain open, and there is space to relate to something beyond our tangible world. An "encounter with the Other" refers to an encounter with something that is beyond human understanding and intelligibility. This possibility is called a "contingency encounter," although that which is encountered is the "Total Other." This encounter creates, as it were, the openness for new possibilities and opportunities. One is open to passively receive things that might happen or insights that might arise from this "new reality." The different ways of relating to contingency as distinguished by Wuchterl have not yet been examined in clinical practice. Here we aim to examine if we can trace these theoretical distinctions—denial of contingency, accepting contingency, encounter with the Other—empirically in the experiences of patients with advanced cancer.

Methods

To investigate differences in how patients relate to contingency in clinical practice, we analysed interviews that spiritual counsellors held with advanced cancer patients about their experiences of being ill and the existential meaning they attributed to it. In order to trace Wuchterl's conceptual distinction, we undertook our empirical research in two phases: development and validation.

Development Phase

As a conceptual starting point, we used Wuchterl's trichotomy (denying, accepting, encounter), where after 23 interviews with advanced cancer patients had been analysed. The interviews were conducted by spiritual counsellors using a semi-structured interview method exploring the patients' experiences with cancer, as described earlier [34]. The constant comparative method was employed with a directed content analysis approach, while our analyses started with a theory as guidance for the initial codes [35] and making use of the

Atlas.ti coding program [36]. We started with the formation of categories, subsequently establishing boundaries, and ended with summarizing the content of each category in a one-page document [37, 38]. Based on these analyses, we came to distinguish four modes of relating to contingency: denying, acknowledging, accepting, and receiving.

To improve the quality of the code descriptions, we organized a peer group meeting with eight researchers from Radboud University Nijmegen. These included two professors of pastoral theology and religious studies and six doctoral students working on different projects within practical and empirical religious studies. Using their feedback, we improved the code descriptions and defined more strict inclusion and exclusion criteria.

Context of the Study

The interviews used for validation of our model were conducted by seven spiritual counsellors working in different hospitals. Four of them had Roman Catholic backgrounds, two were Humanists, and one Protestant. All counsellors had more than seven years experience working in a hospital setting. Their experiences with the interview method and the study protocol of a randomised controlled trial (RCT) have been described elsewhere [34, 39]. In short, the spiritual counsellor asks the patient to draw a lifeline from birth until the present, with highs and lows indicating important life events. The patient chooses three important life events, which are discussed in more detail, and their expectations for the future and life goals are discussed. The spiritual counsellors were trained by our research team to examine the experiences of contingency caused by these life events. In the present analysis, we examined one of the three life events identified by all patients, namely, the life event of having incurable cancer.

Validation Phase

In the second phase, we used 45 interviews, originating from an RCT that evaluated an assisted structured reflection on life events and ultimate life goals to improve quality of life. To test the final code descriptions, an interrater reliability test (IRR) was performed with three coders (RK, IH, MSR) using fragments from eight RCT interviews. The other interviews (n=37) were coded by one researcher (RK) for reasons of efficiency, but in case of doubt (n=9) the interview fragments were coded and discussed by all three researchers (RK, IH, MSR) until consensus was reached.

Design of the Study

Patients were recruited from seven different hospitals: two academic hospitals, one categorical hospital, and four local hospitals. The Medical Ethics Review Committee of the Academic Medical Centre—Amsterdam confirmed that the Medical Research Involving Human Subjects Act (WMO) did not apply to our study and therefore an official approval of this study by the committee was not required (Letter June, 27th, 2012). The inclusion criteria for patients were as follows: 18 years of age with advanced cancer not amenable to curative treatment and with a life expectancy 6 months. Patients with a Karnofsky Performance Status score <60, insufficient command of the Dutch language, and a current psychiatric disease were excluded. Data were collected from July of 2014 until March of 2016. The interviews lasted for from 35 to 144 minutes.

Results

Patient demographics are provided in table 1. Twenty-one males and 24 females were included. All patients had Dutch nationality, and their mean age was 60. The four codes indicating the four different modes that resulted from our analysis are described below. All quotations are derived from the 45 analysed interviews that were held as part of an RCT.

Development Phase

In our analysis, we focused on the three conceptual distinctions proposed by Wuchterl: denying, accepting, and “encounter with the Other.”

In our data, we found a lot of statements that indicated acknowledgment of the contingency of the event, but without full acceptance. These statements did not fit the definition of “denying,” nor that of “acceptance.” Therefore, we defined the additional code of “acknowledging.” Also, for the description of Wuchterl’s “encounter,” we found that patients talked more about “receiving” something rather than “encountering” something, so we labelled this mode “receiving.”

Mode 1: Denying

In the analysed interviews, patients who talked about their experiences such that they were not engaging in an interpretation process were categorized as ‘denying’ the contingency. Most of the time, denial of contingency is seen in that which is absent, for instance, in a lack of existential questions, rather than clear statements of denial. We did find some statements of patients who did not want “it,” or did not want to talk about their cancer, pushed it aside, or emphasized their activeness to live on as they did before. *“Yes, but what is that diagnosis? It is a pure low point when you are told you have cancer, but I don’t want to have it. I want to keep going, I’ll fight for it too. I’m still very active in everything.”* (Male, 72, gastric cancer). In contingency denial, the patient has not started or has aborted the interpretation process; there is no real confrontation with one’s own vulnerability or the limits of one’s own abilities. *“I didn’t want to be written off or anything, I was very ill. And I still have that, I almost never tell people that I’m sick. Because then they think ‘oh I don’t have to invest in her because she’s going to die anyway’ or something like that. You know, that kind of feeling. So I just wanted to go on and that’s just what I did.”* (Female, 68, neuroendocrine tumour)

Sometimes a definitive explanation of the event is given or the existential meaning of the event is denied, leaving no questions about the event or its cause. This denial is associated with coping, as defined in medical psychology. Coping can be seen as a strategy to restore the balance in life as soon as possible, in order to be functional again and contin-

Table 1. *Patient Characteristics*

Sociodemographic characteristics		N	%
Age	Mean, SD	60	12
Gender	Male	21	47
	Female	24	53
Education	< Compulsory	11	24
	> Compulsory	34	76
Work	Working	17	38
	Not working	28	62
Living arrangement	Married	33	37
	Living with partner	6	13
	Living alone	6	13
Religious affiliation	Roman Catholic	8	18
	Protestant	8	18
	Other Christian	5	11
	Humanistic	6	13
	Atheistic	3	7
	Non-religious	15	33

ue with life, thereby avoiding an interpretation crisis. *"I: What are important life goals for you? P: Well to keep living for a while. That the cancer doesn't get the better of me. (...) I've arranged everything.(...) So it's all on the computer and if the computer crashes it's all on a USB stick. Everything is settled. (...) It doesn't dominate my life though, that wouldn't be good."*(Male, 64, kidney cancer) The phrases used in the case of contingency denial are often formulated as rationalizations or statements that express the respondent's lack of need to ask questions or need to understand the cause of an event. It most often reveals itself by that which is lacking, when no questions are asked and no process, ultimate meaning, or references to the existential domain are discussed *"Yes, when I heard I was sick. Then everything..., everything changed. (...) Your plans for the future, everything is uncertain."* (Female, 62, gynaecological cancer) .

Some patients talk about pure bad luck, but later on also talk about their struggles to incorporate this 'bad luck' into their lives. Therefore, statements that mention 'chance' or 'bad luck' should not automatically be linked to the code of denial. Statements about the existential meaning of this 'bad luck' indicate that the interpretation of 'bad luck' is the result of a search for a meaningful interpretation and not a definitive answer that immediately halts the interpretation process.

Mode 2: Acknowledging

When contingency is acknowledged, the experience of contingency is 'taken seriously', and it is recognized as an event that has an impact on one's life as a whole. *"If they had told me 'you are sick and it is, so to speak, lung cancer because you have smoked all your life and lived in the wrong way', then I would say okay. But in this case, I just think: well... (...) a low point, that is something you don't expect. Then you just think it's over. It's done."*(Male, 65, gastric cancer) No definitive explanation is given for the event, but a process of interpretation has been set in motion, searching for the cause and meaning of the life event. The event raises questions that cannot be answered immediately. Important in the acknowledgment of contingency is seeing the non-necessity and non-impossibility of the situation. It is recognized that it goes beyond one's understanding to grasp the cause of the event, but there is a need to relate to something that lies beyond one's capabilities. Asking questions about the cause of the event (e.g., 'Why me?' 'Why now?' 'Why did this happen?') is seen to be a key element in this mode of acknowledging. *"I just didn't understand it. I was really angry about it, yes. Well, don't get me wrong I don't blame the doctors. But you just think: 'why me again'? Why does this happen to me for the second time? Well, nobody can answer that question, neither can I.(...) So I let go of it, because it doesn't make sense trying to figure it out. (...) I just have to learn to deal with it."*(Male, 60, bone cancer)

Acknowledgment of contingency is only the first step in the narrative interpretation process, an attempt to place the event within one's life story. The experience of contingency is confronted, and the impact and significance of the event for one's life as a whole are recognized. However, the event is not accepted and not yet integrated into one's life story. *"That's a big cliché of course, but yeah, 'that's not possible, that can't happen to me. That counts for everyone else, but not for me'. I: it shouldn't? P: Well, shouldn't...but I accepted it pretty quickly. Really accepted. I thought: 'why should I complain, I'm already 62, such a nice husband, lovely children. (...) I have a beautiful life, had a beautiful childhood'. I wouldn't know what I could actually give as a reason for why I should be one of the lucky ones not to be affected by the disease."*(Female, 65, breast cancer) The phrases that are used to describe this can be formulated as verbs relating to how it should be or what they have to do.

Mode 3: Accepting

In the mode of accepting contingency, not only the contingency of a life event is acknowledged, but also the new reality that comes with it is recognized and accepted as a part of the person's life after the event. This acceptance is one step further toward an integration into the personal life story and in the direction of a new reality. *"But that's a whole process of letting go of everything. It doesn't happen automatically.(...) I've learned to go deep, really learned how to go deep. Just crying, weeping, shouting it out when I can't manage anymore. God has abandoned me, that kind of feeling. And yet still to pick yourself up again and fight when you have to fight. But you can't keep fighting and you can't keep going deep."*(Male, 35, brain cancer) In this mode, the statements are more passively formulated compared to the previous mode. The struggle to place the event into the whole life story is also part of acceptance. *"And I also knew it had helped me get a better understanding of myself. Through the disease, by being confronted with myself when lying on the couch for days in pain, during sleepless nights in agonizing pain, then you start thinking about yourself. Then you start changing things. You notice that some things are not good. And you also see things differently. You start seeing the world differently.(...) I really try to go with the flow now, it's difficult but I have learned from it. (...) I've done something with it, and it has brought me something too. Sometimes the lesson is hard."*(Female, 68, neuroendocrine tumour)

Accepting the contingent life event goes one step beyond acknowledging, because the event is now also an integrated part of one's life. Sometimes this is still a struggle, but in some cases new possibilities are seen and discovered. However, this is only the beginning of the learning process; full integration of this new opportunity is only completed in the mode of 'receiving'. In accepting, the patients are actively looking for a way in which the event can be integrated into their life. This is often expressed in the form of a process, with the use of verbs, for example, 'learning, accepting, seeing'. In this mode, the reinterpretation of the event and the significance for one's own life are clearly stated. *"I do believe that I have to go through this, I believe this, and that it happens for a reason. But that you have to learn something valuable from it. Or change your whole life. At least, do something with it. Not just go on like before."*(Female, 24, gynaecological cancer)

Mode 4: Receiving

In contrast to "encounter," as defined by Wuchterl, we observed an attitude of receiving: that what is received often concerns patients' ultimate life goals. In this mode of relating to contingency, there is full integration of the event into one's life story. The phrases that are used often denote transformation and deriving new insights, influencing the choices made in life. Patients refer to values that have become more important—for example, being more conscious or aware in life, taking more enjoyment from the here and now, having more meaningful relationships. Such phrases are mostly formulated in the past tense *"I'm natural now. I have a much more positive outlook on life and enjoy a lot more things. You know, things used to be just normal, you take everything for granted. (...) I think that what this whole thing of being ill has brought me is that I think a lot more about the spiritual side of things. Not that I am suddenly religious or anything. I don't believe in God. I always believed that there is something more but not really by definition a god. But I think about it a lot more now."*(Female, 24, gynaecological cancer)

Patients in the mode of receiving often talk about insights they have received from relating to the contingency of an event. They also talk about something that transcends our tangible world—for example, 'it happens for a reason' or 'someone/some power did

this'. This transcendence has a broad meaning. It can be something abstract, like 'the universe', 'the unknown', or the 'ultimate good', and some people call it 'a higher power/God'. *"A chance, yes I think so. To develop myself. To change myself.(...) I think in your life things happen to you so you can do something with them. So developing yourself in a better way or getting a different perspective on life or whatever. I: Different perspective, that means..? P: Uh yeah to do something with it what has happened to you. How I see it now. I can talk easily about my breast cancer and when I see how others react to it, I think yes. I am doing something with it, I'm trying to help other people with it."*(Female, 53, breast cancer) In the mode of receiving, 'new possibilities' are central, there is space in which to act, and it is preceded by a process of transformation and creation of new insights. There is not only the acknowledging of the world's ontological contingency, but it is a real encounter with 'the other side': that which we cannot know and cannot see.

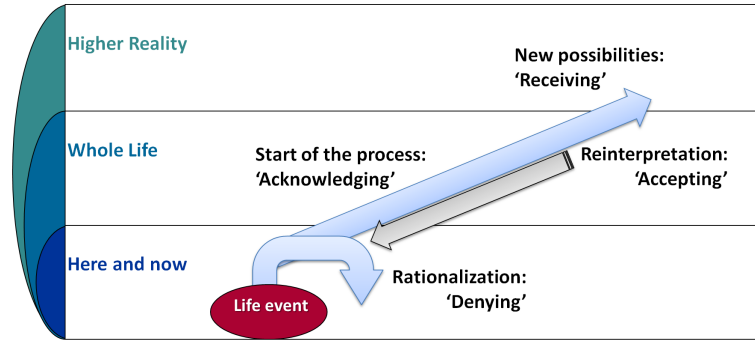
Table 2. Definitions of the four different modes of relating to contingency

Denial	1. No interpretation process is started to incorporate the event into one's life. No existential questions are being asked and no attempt is being made to understand the situation.
	2. The event is explained by stating that the event was necessary or destined to happen, due to 'absolute chance', the laws of nature or a very strict theocentric worldview. In this case the explanation is not an outcome of a search for interpretation, but it is a way to fix contingency and to end the interpretation process.
	3. 'Living a normal live or live on as before' is often mentioned in this mode, emphasizing their activeness.
Acknowledging	1. A person talks about the impact of the event on their entire life. The cause of the event can be rationalized but the impact is acknowledged.
	2. Questions are asked, such as: why did this happen, why me, did I do anything wrong, is it just chance, bad luck? These questions are often asked at the beginning of the process; they are the first attempts to include the event into one's own life story.
	3. People sometimes talk about accepting, but merely in the direction of 'should' or 'ought', as a necessity instead of a completed process. This mode only indicates the start of the process, it has not become a full part of their lives but they are working towards that inclusion.
Accepting	1. The impact of the life event on one's life as a whole is recognized and there is a difficult process going on of incorporating this event into the life story.
	2. This process can be at the beginning in only trying to integrate the event into a story, but it can also be more towards discovering the new possibilities.
	3. There are often signs of a reinterpretation of the event: a person looks back on the life event in a different way than at the outset. For example: at first the event can be interpreted as something bad, but in second instance it might have also a positive connotation.
Receiving	1. A person acknowledges the impact of the event on his/her life, has gone through a process of accepting and can now receive new possibilities from this new reality that which transcends our human framework, and to derive new insights from that encounter.
	2. It is a process of transformation, reshaping and creating new insights. The person is open to meet that which transcends our human framework, and to derive new insights from that encounter.
	3. More passive language is used, referring to the completed process of acceptance and integration, and the received insights and/or living a more conscious life.

Final Model

If we look at the four modes, their definitions (table 2) and their implications for different dimensions of life, we come to a schematic representation, see figure 1. The red circle at the bottom of the figure represents

Figure 1. Schematic representation of the four modes



a contingent life event. A life event can have a situational meaning for the person in the here and now. It can also have a more existential meaning for a person in terms of his/her life as a whole. Sometimes a life event can have a spiritual meaning for a person, regarding a higher reality. At the left, these three dimensions are specified. The first mode—denying—bends to the right because it represents not acknowledging the impact on one’s whole life. When an interpretation process is begun, it is the first step toward integration. This is the second mode—acknowledging. The blue arrow symbolizes a process moving toward full acceptance. In the mode of accepting, there is room for reinterpretation of a life event; hence the black arrow. At the end of the model, the mode of receiving is placed in the dimension of a higher reality, discovering the new possibilities and new insights.

Validation Phase

To test the final code descriptions, an IRR was performed and the calculated value of Cohen’s kappa was 0.83, which can be interpreted as a ‘very good agreement’ [40]. Of all the interviews (n=45) that have been encoded, only two were assigned the code of ‘denying’, and two were assigned the code of ‘receiving’. Most (n=24) were assigned the code of ‘recognizing’, and many were assigned the code of ‘accepting’ (n=17). We did not observe major differences between the four different modes and the socio-demographic characteristics (see table 3).

Table 3. Results of the validation phase

Sociodemographic characteristics		Denying n = 2	Acknowledging n = 24	Accepting n = 17	Receiving n = 2
Age	(mean)	68	61	60	39
Gender	Male	2	10	8	0
	Female	0	14	8	2
Education	< compulsory	0	3	3	0
	> compulsory	2	19	15	2
Work	Working	0	10	5	2
	Not working	2	14	12	0
Marital status	Married	2	17	13	1
	Living with partner	0	3	2	1
	Living alone	0	4	2	0
Religiosity	Religious	1	10	9	1
	Non-religious	1	14	8	1

Discussion

Our study is the first to investigate the theoretical distinctions put forward by Wuchterl regarding the experience of contingency in a clinical setting. The described modes of relating to contingency will make it possible to understand the experiences of cancer patients and allow caregivers to better target and shape individual care. Caring for the existential issues of patients is usually referred to as spiritual care. Spirituality can be an important element of the way patients face chronic illness, suffering, and loss. Spiritual care begins by truly listening to patients' hopes, their fears, and their beliefs and to incorporate these beliefs into the therapeutic plan [41]. This careful listening is a first step toward understanding and subsequently toward an accurate diagnosis of a patient's ability to relate to contingency. A proper diagnosis is a precondition for good counselling in dealing with a possible interpretation crisis. This is especially important when it comes to a severe interpretation crisis [42]. Unmet spiritual needs can lead to depression and a reduced sense of spiritual meaning and peace [43]. It is important to first recognize spiritual needs and to then understand those spiritual needs in all their forms and appearances. In contrast to Wuchterl, who reserved much space for the description of 'denial', we found indications of this mode of relating to contingency in only two interviews. This discrepancy can have different explanations.

First, our study only looked at the life event of having incurable cancer. In other cases, patients might be more inclined to ignore the contingency than in the case of our major event. Second, people who tend to ignore contingency might not be the people who are most likely to participate in studies on talking about their lives [44]. Therefore, the numbers in our study indicating the four different modes should not be used to draw conclusions about more general circumstances. Future studies in different patient populations and examining other life events could enhance our findings. It should be noted that an interview fragment only represents one particular moment during which the patient reflected on his or her experiences of contingency. Therefore, our findings should not be understood as fixed states, but as modes between which patients can pass back and forth. The different modes may necessitate different approaches to spiritual care. For instance, patients in the mode of denying contingency are more likely to be resistant to the kind of help that focuses on the meaning of a life event in their lives, as they do not recognize this line of thinking. In contrast, patients who are in the mode of receiving are less likely to benefit from help that gently tries to allow the patient to see that the event can have implications for their lives, as the patient has already discovered a new reality and new possibilities resulting from the event. Our finding of four different ways of relating to contingency gives insight into where a patient can be in terms of relating to existential questions and affords an opportunity to understand the questions that may arise in the different modes.

However, this is just the first step in understanding the experience of contingency in advanced cancer patients. We do not yet fully understand the relationship between the different modes, and we do not know whether patients can go through different modes and the direct implications for spiritual care. Future research is needed to investigate whether these different modes also correlate with the overall well-being of patients. Other studies have shown that negative religious coping is associated with poorer quality of life [45, 46], that existential and spiritual domains are related to suffering and quality of life [47] and that spiritual interventions addressing existential themes using a narrative approach can enhance quality of life [48].

Therefore, in addressing spirituality, we believe that an awareness of the contingency of life should gain more attention and be employed as a basic understanding when considering life itself. Furthermore, it is important to examine at what moment in the course of their disease that spiritual care can best be offered to cancer patients. Patients believe that professionals should know when and where to discuss spiritual concerns; however, much is still unknown about the timing of spiritual care [49]. Crucial to well-timed spiritual care is timely referral, which can be done by all healthcare professionals but is primarily done by the nursing staff, as they spend the most time with patients [50]. Spiritual care is generally seen as a domain of palliative and hospice care, but because patients need time to open up, rethink, and reshape their life stories, it might be argued that meeting with a spiritual care provider before the terminal phase is desirable [14, 49]. Therefore, the recommendations of the Spiritual Care Consensus Conference should be taken into account: patients should receive a simple and time-efficient spiritual screening at the point of entry into the healthcare system and be provided with appropriate referrals as needed [51]. Taking a spiritual history can be the first step in identifying potential spiritual issues and assessing the best time for referral to a board-certified chaplain [52]. However, to the best of our knowledge, no evidence-based research exists on the timing of spiritual care.

Strengths and limitations of the study

The results of our study stem from interviews conducted during a multicenter study involving academic as well as peripheral hospitals, which improves the generalizability of our results compared to single-center studies. Also, the sample size of 45 interviews increases the trustworthiness of our results compared to studies with smaller samples [53]. Nevertheless, the usability of our study is limited by its national context; a cross-cultural validation study is needed. Further qualitative research in other patient populations could provide more depth and a broader scope for our results. In addition, quantitative research could enrich our findings by examining whether these categories are related to patients' overall well-being and their self-reported spiritual well-being. Our findings were constrained by our patient population of advanced cancer patients, as well as by its focus on the life event of having cancer. In a different patient population or without the focus on the life event of having incurable cancer, this study could potentially have yielded different results. In conclusion, if we want to improve spiritual care in the healthcare setting, we must understand the existential needs and experiences of these patients. Our study provides insight into the essence of the experiences of advanced cancer patients by testing theoretical notions in practice.

Disclosures and acknowledgements

We want to express our gratitude to all the patients who were willing to participate in our study. Despite their severe illness, they were willing to make time for the interviews and to be very open in speaking about their personal experiences. The authors also wish to thank the spiritual counsellors who conducted the interviews and the oncologists and oncologist nurses who supervised patient inclusion. We also are grateful to Egbert van Dalen for the use of his interviews with advanced cancer patients on the topic of their experiences of contingency.

References

1. Zirfas J. Kontingenz und Tragik: Eine moderne Figur und ihre ästhetischen Konsequenzen. In: Liebau E, Zirfas J eds. *Drama der Moderne. Kontingenz und Tragik im Zeitalter der Freiheit*. Bielefeld: Transcript Verlag; 2010.
2. Makropoulos M. Kontingenz. Aspekte einer theoretischen Semantik der Moderne. *European Journal of Sociology* 2004;45(3):369-399.
3. Scherer-Rath M, van den Brand JAM, van Straten C et al. Experience of contingency and congruence of interpretation of life-events in clinical psychiatric settings: a qualitative pilot study. *J Empirical Theology* 2012;25:127-152.
4. Dalferth IU, Stoellger P. Religion zwischen Selbstverständlichkeit, Unselbstverständlichkeit und Unverständlichkeit. *Hermeneutik der Religion* 2007:1-21.
5. Benzein E, Norberg A, Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med* 2001;15(2):117-126.
6. Scherer-Rath M. Narrative reconstruction as creative contingency. In: Ganzevoort RR, de Haardt M. Scherer-Rath M eds. *Religious stories we live by. Narrative approaches in theology and religious studies*. Leiden: Brill; 2013. P. 131-142.
7. Kendall M, Murray SA. Tales of the unexpected: Patients' poetic accounts of the journey to a diagnosis of lung cancer. A prospective serial qualitative interview study. *Qual Inq* 2005;11(5):733-751.
8. Sarenmalm EK, Thorén-Jönsson AL, Gaston-Johansson F et al. Making sense of living under the shadow of death: Adjusting to a recurrent breast cancer illness. *Qual Health Res* 2009;19(8):1116-1130.
9. Fife RB. Are existential questions the norm for terminally ill patients? *J Palliat Med* 2002;5(6):815-817.
10. Houtepen R, Hendriks D. Nurses and the virtues of dealing with existential questions in terminal palliative care. *Nurs Ethics* 2003;10(4):377-387.
11. Keupp HI, Ahbe T, Gmür W et al. *Identitätskonstruktionen: Das Patchwork der Identitäten in der Spätmoderne*. Hamburg: Rowohlt Taschenbuch Verlag; 1999.
12. Bauman Z. *Liquid times: Living in an age of uncertainty*. New York City: John Wiley & Sons; 2013.
13. Taylor C. *A secular age*. Boston: Harvard University Press; 2007.
14. Ganzevoort RR, Bouwer J. Life story methods and care for the elderly. An empirical research project in practical theology. In: Ziebertz HG, Schweitzer F eds. *Dreaming the land, Theologies of resistance and hope*. Münster, LIT Verlag, 2007, pp 140-151.
15. Ricoeur P. *Zufall und Vernunft in der Geschichte*. Tübingen: Konkursbuch Verlag; 1986.
16. Straub J. Telling stories, Making History: Toward a Narrative Psychology of the Historical Construction of Meaning. In: *Narration, identity, and historical consciousness*. Oxford/New York: Berghahn Books; 2005. P. 44-98.
17. Olthof J, Vermetten HGJM. *De mens als verhaal, narratieve strategieën in psychotherapie voor kinderen en volwassenen*. Utrecht: De Tijdstroom; 1994.
18. Blitz I. *Crohngetauige: Een narratief onderzoek naar betekenisgeving bij jongeren met de ziekte van Crohn*. Doctoral dissertation. Utrecht: Utrecht University; 2008.
19. Murray M. The storied nature of health and illness. Qualitative health psychology. *Theories and methods* 1999:47-63.
20. Baart I. *Ziekte en zingeving: Een onderzoek naar chronische ziekte en subjectiviteit*. Assen: Uitgeverij Van Gorcum; 2002.
21. Richter HE. *All mighty: A study of the God complex in Western man*. Claremont: Hunter House; 1984.
22. Wuchterl K. *Kontingenz oder das Andere der Vernunft: zum Verhältnis von Philosophie, Naturwissenschaft und Religion*. Stuttgart: Franz Steiner Verlag; 2011.
23. Park CL, Folkman S. Meaning in the context of stress and coping. *Rev Gen Psychol* 1997;1(2):115-144.
24. Pearlman LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19:2-21.
25. Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer Science; 1984.
26. Bury M. Chronic illness as biographical disruption. *Social Health Illn* 1982;4(2):167-182.
27. Crenshaw DA, Brooks R, Goldstein S, eds. *Play therapy interventions to enhance resilience*. New York: Guilford Publications; 2015.
28. Cheng C, Lau HP, Chan MP. Coping flexibility and psychological adjustment to stressful life changes: A meta-analytic review. *Psychol Bull* 2014;140(6):1582.
29. Pargament KI, Ishler K, Dubow E et al. Methods of religious coping with the Gulf War: Cross-sectional and longitudinal analyses. *J Sci Study Relig* 1994;33:347-361.
30. Pargament KI, Smith BW, Koenig HG et al. Patterns of positive and negative religious coping with major life stressors. *J Sci Study Relig* 1998;37(4):710-724.
31. Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: development and initial validation of the RCOPE. *J Clin Psychol* 2000;56:519-543.

32. Körver J, Van Uden MHF, Pieper JZT. Post- or para-modern devotion in the Netherlands? In: Westerink H ed. *Constructs of Meaning and Religious Transformation. Current Issues in the Psychology of Religion*. Göttingen: Vandenhoeck & Ruprecht; 2013: 239–258.
33. Luthar SS. Resilience in development: A synthesis of research across five decades. In: Cicchetti D, Cohen DJ ed. *Developmental psychopathology: Risk, disorder, and adaptation*. New York City: John Wiley & Sons; 2006:739–795.
34. Kruizinga R, Helmich E, Schilderman JBAM et al. Professional identity at stake: A phenomenological analysis of spiritual counsellors' experiences working with a structured model to provide care to palliative cancer patients. *Support Care Cancer* 2016;24(7):3111–3118.
35. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277–1288.
36. Friesen S. *Qualitative data analysis with ATLAS.ti*. Thousand Oaks: Sage Publications; 2014.
37. Boeije H. A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Qual Quant* 2002;36(4):391–409.
38. Tesch R. *Qualitative analysis: Analysis types and software tools*. London: Falmer Press; 1990.
39. Kruizinga R, Scherer-Rath M, Schilderman JBAM et al. The life in sight application study (LISA): design of a randomised controlled trial to assess the role of an assisted structured reflection on life events and ultimate life goals to improve quality of life of cancer patients. *BMC Cancer* 2013;13(1):360.
40. Tinsley HEA, Weiss DJ. *Interrater reliability and agreement. Handbook of applied multivariate statistics and mathematical modeling*. New York: Academic Press; 2000:95–124.
41. Puchalski CM. The role of spirituality in health care. *Baylor University Medical Center Proceedings* 2001;14(4):352–357.
42. Van Dalen EJV, Scherer-Rath M, Hermans CAM et al. Breaking the bad news: Experiences of contingency in advanced cancer patients. *J Clin Oncol* 2012;30(15suppl_e19560).
43. Pearce MJ, Coan AD, Herndon JE et al. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. *Support Care Cancer* 2012;20(10):2269–2276.
44. Street Jr. RL, Gordon HS, Ward MM et al. Patient participation in medical consultations: Why some patients are more involved than others. *Medical Care* 2005;43(10):960–969.
45. Sherman AC, Simonton S, Latif U et al. Religious struggle and religious comfort in response to illness: Health outcomes among stem cell transplant patients. *J Behav Med* 2005;28(4):359–367.
46. Tarakeshwar N, Vanderwerker LC, Paulk E et al. Religious coping is associated with the quality of life of patients with advanced cancer. *J Palliat Med* 2006;9(3):646–657.
47. Mount BM, Boston PH, Cohen SR. Healing connections: On moving from suffering to a sense of well-being. *J Pain Symptom Manage* 2007;33(4):372–388.
48. Kruizinga R, Hartog ID, Jacobs M et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: A systematic review and meta-analysis. *Psychooncology* 2016;25(3):253–265.
49. Edwards A, Pang N, Shiu V et al. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliat Med* 2010;24(8):753–770.
50. Van Leeuwen R, Cusveller B. Nursing competencies for spiritual care. *J Adv Nurs* 2004;48(3):234–246.
51. Puchalski CM, Ferrell B, Virani R et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885–904.
52. Puchalski CM. The FICA Spiritual History Tool #274. *J Palliat Med* 2014;17(1):105–106.
53. Onwuegbuzie AJ, Leech NL. The role of sampling in qualitative research. *Academic Exchange Quarterly* 2005;9(3):280–285.