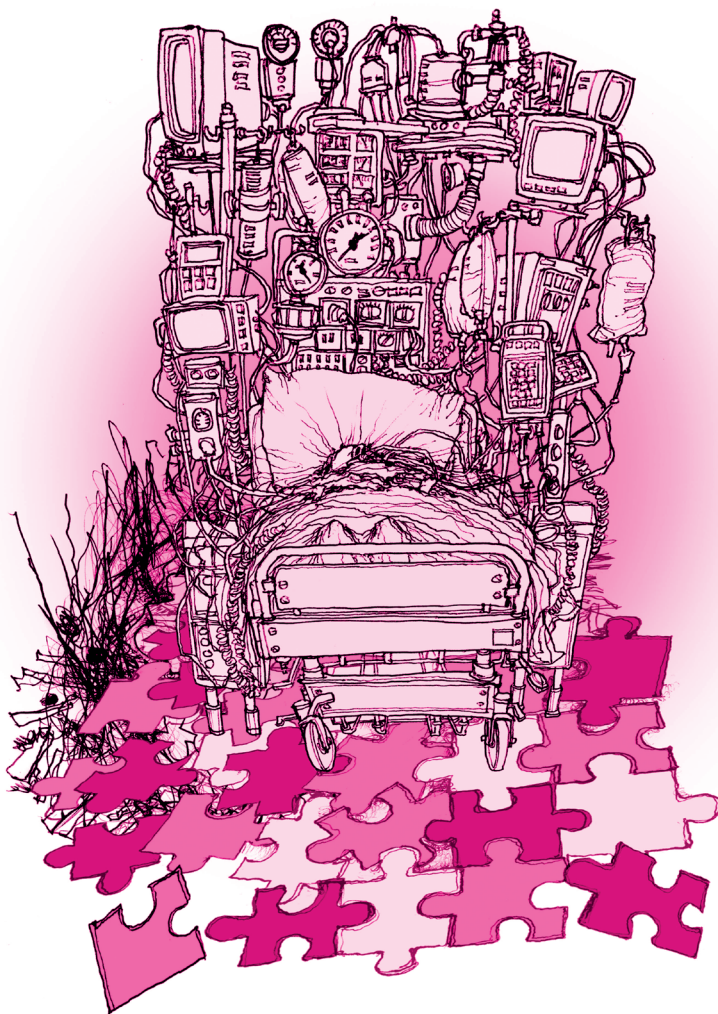


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GENERAL INTRODUCTION



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INTRODUCTION

Narrative meaning making of life events

Not having full control over our lives and the world is part of our human condition. In our daily lives, experiencing ourselves as free agents and succeeding in shaping our lives to a certain extent, we may not always be aware of this condition. But all human beings will at some point find themselves in situations that confront them with the boundaries of their capacities to engineer their own lives and forge their own destinies. Especially life events such as falling seriously ill, divorce, bereavement, losing a job, or falling victim to natural disasters, war or conflict, confront people with the “existential givens” of life [1]. These existential givens refer to our finitude and the fragility of our bodies, the vulnerability of what we deem valuable and the goals we strive for, as well as our freedom to find or make meaning in our lives [2].

“Meaning” as defined by Baumeister [3] is a “mental representation of possible relationships among things, events, and relationships. Thus, meaning *connects* things” (p. 15). The freedom to make meaning in our lives has been growing as the societal influence of religions as well as the explanatory power of their “grand narratives” has diminished [4, 5]. At least in our Western world, we have the freedom and possibilities to shape our own lives to a certain extent, but also have to create our own narratives about the events that befall us and disrupt our live stories. While in the past, traditions and grand narratives provided evident connections between our actions or experiences and our images of the good, the world and beyond, nowadays we largely have to create these connections ourselves [5, 6].

The connections we make often form narratives, as we tell stories that configure separate events into a meaningful whole. By constructing stories, we try to make sense of our experiences, providing a sense of overall meaning and purpose to our lives [3, 7-10]. The idea of narrative identity entails that people do not merely tell stories about their lives, but understand themselves and their lives in terms of a story. A person’s life narrative can be seen as a form of identity that both reflects and shapes who the person is [8, 11]. Thus, the process of narrative meaning may change a person’s identity. Therefore, **making meaning of life events can best be understood by taking into account people’s life narratives [12] including their worldview and life goals as parts of their identities.**

The “experience of contingency” as a “crisis of meaning”

Some life events challenge our ability to create meaningful connections between the event and our personal life narrative. Because of the connection between our identity

and life narrative, events that disrupt our life story may lead to a “crisis of meaning,” evoking existential questions. For example, falling seriously ill may raise questions like “What caused the disease? Why did it happen to *me*? What does it mean for my future, and for who I am?” Meaningful connections and expectations may be shattered and life goals frustrated, which necessitates reconstruction of the event and its meaning in the context of one’s life story [13, 14]. Moreover, disruptive life events such as falling seriously ill confront the limits of one’s control and of one’s ability to grasp the event and construct a meaningful story. That is why in religious studies, “crises of meaning” are often called “experiences of contingency” [15-17], the central concept of this dissertation. The concept was introduced by religious philosopher Kurt Wuchterl, building on the idea of religion as “dealing with contingency,” introduced by philosopher of religion Hermann Lübbe. “Experience of contingency” refers to a confrontation with the “randomness of life”.

“Contingent” originates from Aristotle’s “*endechomenon*,” referring to the realm of the possible: that what is “neither necessary nor impossible.” As explained by Vogt, Aristotle employs at least two definitions of *endechomenon* or “the possible,” one of them *including* the necessary as one form of the possible. Following Wuchterl, we use the more common, narrower definition of contingency as non-necessity and non-impossibility, as the experience of contingency is defined as a crisis of meaning due to the unintelligibility of a *non-necessary* event.

Since its translation to the Latin word “*contingens*” in the fourth century, the term “contingency” has been mainly associated with “chance,” although the concepts are slightly different. Following Aristotle, “contingent” is everything that is possible but has not yet come into being, as well as what befalls people but could also have been otherwise, often designated as “accidental” or “random.” Therefore, disruptive life events causing an experience of contingency are usually characterised by the inability to “grasp” and make meaning of the event and its randomness. The experience pertains not only to the cause and the consequences of the event for daily life, but also to the realization that such events can happen at any time and that everything we value is vulnerable. As will become clear later, **the two meanings of contingency connect the experience of contingency with the new possibilities that may result from the narrative integration of this experience.** See pages 25, 48 and Chapter 2 for further elaboration on the meaning and implications of the concept of contingency.

The relationship between meaning making and quality of life

The possibilities for finding or making meaning of contingent life events are sometimes visible in remarkable ways, in stories about people who have had to deal with a disrupt-

tive life event. For example, not uncommon are stories of people who almost died from a cardiac arrest and, as a result, have learned or realized what they find most important in life and how to live accordingly. While we may think that such a positive outcome is only within reach of people after recovering their health or after life events without permanent loss, myriad stories and studies suggest otherwise. For example, even patients with untreatable cancer have been found to relate in a positive way to the life event of falling terminally ill¹. In addition, some people with serious disabilities report a good or even excellent quality of life, known as “the disability paradox.”

These high levels of quality of life are not the result of denial of the consequences of disease and disability, but rather of finding meaning and purpose in life despite or even *as a result of* (learning to deal with) their condition. This form of human resilience is illustrated by well-known sayings such as “we cannot direct the wind, but we can adjust the sails,” “life isn’t about waiting for the storm to pass, it’s about learning to dance in the rain” and “what doesn’t kill you, makes you stronger.” These expressions reflect people’s capacity to adapt to new situations, to find meaning in adversity and see new possibilities, and to grow and learn from life’s struggles. We cannot always change the course of life, but in making meaning of this course of life, we may change ourselves, as Frankl’s quote at the start of this Introduction expresses. Apparently, disruptive life events that initially cannot be understood and integrated may nevertheless be integrated into one’s life narrative, eventually. The fact that this is not always easy is illustrated by the development of narrative interventions to deal with disruptive life events such as a cancer diagnosis.

A central question in this dissertation is how this narrative integration and identity change after an experience of contingency influences the quality of life that people experience. “Quality of life” (QoL) is a broad, multidimensional construct that can mean many different things, depending on the context and the aims of the research. It may refer to wellbeing in the broadest sense, but also to perceived health and functioning. The World Health Organization (WHO) defines QoL as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” For the context of our study, the emphasis on “perception” and the relationship with “goals, expectations,

¹ See for example the stories of cancer patients in the episode “Onvoorstelbaar gelukkig” (“Unbelievably happy”) of the Dutch tv program “Kruispunt” (“Crossroad”): https://www.npostart.nl/kruispunt/15-04-2018/KN_1698186 and the episode “Op de drempel” (“On the threshold”) of the interview program “Kijken in de ziel” (“Looking into the soul”): https://www.npostart.nl/kijken-in-de-ziel-op-de-drempel/04-01-2016/VPWON_1248779.

standards and concerns” is particularly relevant, as we have seen that making meaning of life events cannot be understood without regarding people’s life narratives, including their worldview and life goals.

As will become clear later, also relevant for this context is the more specific concept “health-related QoL” (HRQoL). In the health sciences, research into HRQoL is commonly restricted to patients’ subjective evaluation of the effects of diseases and treatments. The common characteristic in all definitions is that QoL refers to people’s *self-evaluation* of the QoL they experience. In other words, QoL pertains to the way people appraise and evaluate their own symptoms, limitations and abilities, overall health and overall quality of life, in the context of their own situation, goals, expectations and life story. This is why meaning making may significantly influence people’s QoL, as theoretical and empirical research in several disciplines suggests [18-23].

STATUS QUAESTIONIS, AIMS AND RESEARCH QUESTIONS

In this section, we will describe the research that has previously been done on the subject of this study, and the aims and research questions that remain and will be addressed in this dissertation. First, the focus and general objectives of this study will be specified. Next, the context of our study will be described, showing how it is embedded in both the humanities and psychology and medical sciences. Then, we will present the *status quaestionis* by describing the research on this subject that has been done so far in religious studies as well as in the social sciences.

Focus and objectives of this study

In this study, we focused on narrative meaning making of life events that evoke an experience of contingency, such as falling seriously ill. In addition, we aimed to improve our understanding of the way QoL is impacted by both experiences of contingency and different ways of making meaning of these experiences. To this aim, we propose an interdisciplinary approach, integrating perspectives and methods from humanities and social sciences into medical research and practice. To understand how people make meaning of experiences of contingency in the context of their life narratives and how this influences their QoL, we aim to integrate theories on contingency, narrative identity, life goals, worldview and QoL. In addition, we combine theoretical with both qualitative and quantitative research, in a first attempt to operationalize the concepts of narrative meaning making and integration into scales to be measured using a questionnaire.

Context of the research project

This study was conducted within the context of the IMPACT study², a research project aiming to improve the conceptualization and measurement of QoL. It was designed in response to a call for proposals by the Netherlands Organization for Scientific Research (NWO) as part of the Quality of Life and Health research program, in which researchers from the humanities and the medical sciences are brought together in interdisciplinary projects.³ The aim of this program was to improve our understanding of what QoL means, both in relation to health and to methodological and ethical issues associated with the collection and use of QoL data. In the call for proposals, researchers were invited to improve the measurement of QoL for a specific target group for which existing QoL measurement instruments were inadequate. The IMPACT study was devised to improve the conceptualization and measurement of QoL of patients with multiple chronic morbidities, exemplified by patients with cardiac disease undergoing cardiac intervention. As suggested by the part of the title distinguishing “conceptualization” and “measurement,” the study consisted of a theoretical part and a methodological part, each conducted by one PhD candidate, in close collaboration. This dissertation is the result of the theoretical part. The large-scale questionnaire study was prepared and carried out together with Justine Netjes, the first PhD candidate on the methodological part. The data collection and analysis were finalized together with Tom Oreel, who succeeded Justine as PhD candidate.

The IMPACT study was designed and performed with the collaboration of researchers from several disciplines, including medical psychology, empirical and practical religious studies, oncology, cardiology, cardiothoracic surgery, medical ethics, health economy, psychometrics, methodology and clinical psychology. Representatives of the Patient Society for Acquired Cardiac Diseases (Harteraad, formerly known as Hart & Vaatgroep) were also involved. The author of this dissertation, with a background in humanistic studies, ethics and medical philosophy, collaborated with (many of) the researchers mentioned above.

Theoretically, this thesis is mainly embedded in the thematic research group *Religion and the Crisis of Meaning* of the *Cognitive Humanities* program, based in the Depart-

2 The full title of the project is “Improving the conceptualization and measurement of quality of life of patients with multiple chronic morbidities, exemplified by patients with cardiac disease undergoing cardiac intervention.”

3 See <https://www.nwo.nl/en/research-and-results/programmes/quality+of+life+and+health> and www.nwo.nl/binaries/content/documents/nwo/algemeen/documentation/application/gw/kwaliteit-van-leven-en-gezondheid---call-for-proposals (Dutch) or <http://www.nwo.nl/binaries/content/documents/nwo-en/common/documentation/application/gw/quality-of-life-and-health---call-for-proposals> (English).

ment of Empirical and Practical Religious Studies of the Radboud University (Faculty of Philosophy, Theology and Religious Studies). In this department, religion in the broad sense is studied empirically, including non-religious worldviews, non-traditional forms of religions, spirituality, and meaning and understanding (*zingeven* in Dutch) in practices within institutional contexts such as healthcare institutions, schools, churches and government institutions. In the context of healthcare, this research focuses on the relationship between health and “experiences of contingency” and worldviews, as well as on the opportunities in spiritual care to support people with a crisis of meaning, i.e. an experience of contingency. See also page 25 and further.

In addition, the study was embedded (and conducted physically) at the Department of Medical Psychology of Amsterdam UMC, Academic Medical Center location in Amsterdam. In medical psychology as a discipline, theories, principles and methods from psychology are applied to gain insight into the interplay between mental and physical health, and to assess and improve the health and wellbeing of people with medical problems. This study was specifically embedded in the research line Quality of Life, which focuses on the theoretical, methodological, and clinically applied conundrums of “health-related quality of life” (see also page 21).

Lastly, this study was also informed by insights from the medical sciences, such as cardiology, internal medicine and oncology. Naturally, in these disciplines knowledge and experience is present on the impact of disease and treatment on people’s daily lives and the different ways in which people deal with this impact. The case descriptions and other examples of patient experiences in this dissertation were also provided by the oncologist and cardiologist in our team and thus informed by the knowledge and experience in these disciplines.

Previous research in empirical and practical religious studies

As an academic field rather than a discipline, empirical and practical religious studies can be seen as interdisciplinary in itself, drawing upon theories and methodologies from anthropology, theology, sociology, psychology, philosophy and history of religion. In the thematic research group Religion and the Crisis of Meaning of the Radboud University Nijmegen, “experiences of contingency” are always understood in connection with people’s worldview, and in the context of late modernity as an “age of contingency.” Below, this context will be explained further. Consequently, the research into experiences of contingency undertaken in empirical religious studies will be described and connected to our current project, thus working towards our research questions and defining the central concepts of our study.

Theories of contingency

At the Department of Empirical and Practical Religious Studies at the Radboud University, research into experiences of contingency draws upon theoretical notions of contingency from philosophy, sociology, social psychology, and theology. The philosophical notion of contingency in the sense of the Latin word “contingens” is part of modal logic: the study of reasoning about what is necessary and what is possible, and the validity of arguments. “Necessarily” and “possibly” are modals that qualify the truth of a statement. “Contingent” as a modal means that something is “neither necessary nor impossible.” Therefore, a statement is contingent if it is true in our world, but not true in all possible worlds [24].

Several sociologists have taken the modal-logic concept of contingency to a logic-ontological meaning. Ontology is the philosophical study of being, and encompasses all philosophical questions about existence and about the general features and relationships of the entities that exist [25]. Thus, in the logic-ontological meaning, contingency applies to what *is*, but could have been different. In sociology, this meaning of contingency is used to understand how life in late modern Western societies is different from life in premodern times, including the role of religion.

The social systems theorist Luhmann [26] calls contingency the “intrinsic value” of modern society. Following Lyotard, he states that in this sense, our times are to be understood as “postmodern” because of the rejection of all historical-philosophical meta-narratives. In a globalized, secularized, decentralized society in which traditional structures have lost their significance, no authority can consider its own culture the only or best way of life. Cultural narratives are contingent in the sense that they could have been different, or could even never have come into existence. As a result, without universal and transcendent truths, everything, including our personal narratives and thus self-understanding, has become contingent [26].

The sociologist Makropoulos, building on the works of the philosopher Bubner, emphasizes that contingency is a specific kind of uncertainty or indefiniteness. Contingent is not only what is available and intelligible (*Verfügbar*), and what befalls us coincidentally and cannot be grasped (*Unverfügbar*: unavailable) but also implies the possibility of human action. It is the possibility that everything could or can be different, that enables action [27]. This idea of “active contingency” or “contingency of action” brings into mind Aristotle’s concept of *endechomenon* or contingency as “the possible” (see page 20). Applied to late- or postmodern societies, Makropoulos uses the concept to describe how people are increasingly responsible for their own interpretations, life narrative, the development of their life goals and the way they strive to achieve these through their

actions [27]. It also applies to the interpretation of life events that no longer have a self-evident place in people's personal perspective on life. As a result, they have to find their own interpretations and reactions in accordance with their personal needs, desires and expectations. According to social psychologist Keupp, meaning making, especially of negative events that impact people's lives profoundly, is thus a challenge for individuals, requiring constant appraisal and accommodation.

Contingency and religion

Joas, a sociologist of religion, connects contingency to the role of religion in late modern societies. Nowadays, more and more people do not commit to one particular religious tradition but "select" elements from different religious traditions. In combining these in their own personal way, people create "patchwork identities" [6]. In addition, he connects contingency to the role of religion by describing the "power" of religion as helping people to be receptive to experiences of self-transcendence. With a religious frame of reference, these experiences may be understood as encounters with another reality. Philosophers of religion Dalferth and Stoellger characterize religion as a way to relate to and deal with the "uncontrollability" and "unavailabilities" of life in a controllable way [28]. "Uncontrollability" refers to what befalls us and is beyond our control, while "unavailabilities" are the things or events we cannot grasp or make sense of (which are often uncontrollable as well). Religious traditions have developed meaningful narratives, rituals, symbols and models for interpretation and action to relate to the (possibility of) meaninglessness experienced as a result of disruptive life events [29].

Experiences of contingency and the limits of reason

These ideas on the relationship between contingency and the religious relate to Wuchterl's religious-philosophical study on "the phenomenology of the experience of contingency." According to Wuchterl, every person will at some point in their lives be confronted with fundamental experiences of breaches in the order of things. These may be personal suffering, such as bereavement or serious illness, causing existential fear through confrontation with our finitude and the vulnerability of everything we value. But they may also include societal crises or situations of war and conflict, and even situations of "undeserved" luck⁴. Such events may be experienced as unavailable: outside the reach of our ability to understand and grasp them. Because they confront us with the boundaries of reason, Wuchterl also speaks of "boundary experiences", following Jaspers' philosophical concept of "boundary situations" as "situations that shake the foundations of a person's existence," such as fear, chance, guilt, suffering and death [30]. Resonating with the concept of "boundary awareness" by theologian Tillich

⁴ See the quote from Kundera's novel "The Unbearable Lightness of Being", at the end of this chapter.

[31], described as “becoming fundamentally conscious of the limitation of knowledge,” Wuchterl emphasizes the “crisis of meaning” that such events may cause. They raise questions of why these events are destined to befall *us* in particular, but also why our world is so opaque (*undurchschaubar*) and full of threats: why is the world not different, why not better? [15] Our inability to understand why the world is not different and why events befall us while they could also not have happened, confronts us with the limits of our reason.

Wuchterl’s “religious-philosophical contingency”

Building on the modal-logical and logic-ontological concepts of contingency as defined above, Wuchterl develops a specific, religious-philosophical concept of contingency. A personal conviction about a life event is religious-philosophically contingent, if:

1. ..the event is interpreted as ontologically contingent, resisting the person’s attempts to eliminate the ontological non-necessity;
2. ..the event has existential significance for the person;
3. ..the event triggers a reflective impulse to deal with it, argumentatively [15, 32].

In his endeavor to use the concept of contingency to clarify the boundaries between science, philosophy and religion, Wuchterl also distinguishes different forms of dealing with contingency. Some people do and some do not acknowledge the limits of reason and contemplate what may be beyond these limits: the “Other of Reason”. According to Wuchterl, naturalists do not recognize religious-philosophical contingencies. As a result of their belief in the self-organization of nature, there are only natural-law *necessities* and thus no contingencies. These types of explanations from the natural sciences are called “contingency management” and “coping with contingency” by Wuchterl. In addition, “immanent agnostics” appeal to universal autonomous reason, without boundaries that may be transcended and thus without acknowledging contingency in Wuchterl’s religious-philosophical definition [32]. Only nihilists, religious agnostics and adherents of religions acknowledge religious-philosophical contingency as defined by Wuchterl. Nihilists acknowledge the limits of reason, but believe that beyond these limits, there is nothing [32]. According to religious agnostics, nothing can be said about what is beyond the boundaries of reason, exactly because of the fact that it is beyond the reach of our reason. Nevertheless, this is a form of thinking *in terms of* (vertical) transcendence. In contrast, religious adherents are convinced of the possibility of access to the Other of Reason: encountering this Other as a place of possible truth which may reveal itself through metaphors and rituals (“revelation”).

Wuchterl: contingency acknowledgement and encounter

Wuchterl distinguishes two modes of dealing with religious-philosophical contingencies. The first mode is **acknowledging** contingency, which implies acknowledgement of the limits of reason and contemplating the *possibility* of an Other of Reason. In this mode of acknowledging, the content of this “Other” is left open. That is why Wuchterl states that religious agnostics may acknowledge contingency: although they insist that nothing can be known and said about this “Other,” and despite not being sure if there is anything beyond the limits of reason, they do consider the possibility. Acknowledging contingency does, however, require distantiation from naturalism and from the autonomy of reason [15, 32].

The second and last mode is **encountering** contingency, which is actually not described as an encounter with contingency but with the Other of Reason that becomes conceivable *by virtue of* religious-philosophical contingency [15]. An encounter goes further than mere acknowledgement, because the content is not left open: there is a conviction of the existence of something that reveals itself, but beyond reason, defying all human insight and availability. The Other of Reason is understood as “Totally Other” that can nevertheless be encountered. Because of the “unavailable character” of this encounter, it should not be understood as “religious coping” or “managing” contingency in the sense that definite answers or explanations are received that give the life event and the experience a certain necessity, thus removing contingency. According to Wuchterl, the realm of the religious is entered when talking about the “Totally Other”: a realm in which revelation is possible, and in which the inexpressible can be expressed through metaphors and parables. This religiousness may be institutionalized, but confessionless religiosity also encompasses the possibility of encountering the Totally Other. However, according to Wuchterl’s conceptualization, “contingency encounter” is inherently religious. For religious agnostics on the other hand, the encounter is not possible as they regard the Other of Reason as something that cannot be known or encountered [32].

The concept of contingency in our study

In the present study, the idea of contingency is the background against which we understand the way people make meaning of disruptive life events that befall them. Naturally, in human history, people have always struggled with disruptive life events. However, the increased complexity as well as the contingency of our own self-understanding and interpretations of the world resulting in personal responsibility have arguably changed the nature of experiences of contingency. Thus, we situate experiences of contingency in our West-European late modern society in which the significance of religious “grand narratives” and traditions have declined. In addition, we build on Wuchterl’s religious-philosophical study on experiences of contingency and the possibility of acknowledging

and encountering contingency. In his endeavor to take the logical-ontological meaning of contingency to *experiences* of contingency and how people deal with them, he paves the way for empirical research into these experiences. In the section about our theoretical model (page 47 and further), four “modes” of dealing with experiences of contingency will be distinguished under the concept of “narrative integration:” denying, acknowledging, accepting and receiving. The development of these concepts departed from Wuchterl’s theory and was informed by our empirical study described in Chapter 2. **In a few important aspects, our approach and conceptualization of dealing with experiences of contingency differ from Wuchterl’s theory.** Below, the differences are clarified. It must be noted that the conceptualizations we employ are working definitions that will be evaluated in our empirical research.

First, a broader definition of “experience of contingency” is used than Wuchterl’s specific religious-philosophical notion. In our study, “experience of contingency” refers to every experience of a disruption caused by a life event that is difficult to make sense of initially, and necessitates reinterpretation. Regardless of one’s worldview and of how one eventually deals with this experience, every confrontation with the vulnerability of what we value and the randomness of life that evokes existential questions is considered an experience of contingency. The question of whether the experience resists attempts to explain the event and eliminate the ontological non-necessity is regarded as considering the process of *dealing with* the experience of contingency instead of part of the definition of an experience of contingency itself. This broader definition enables us to empirically study the whole range of ways that people relate to contingency and deal with experiences of contingency, regardless of their worldview.

Second, related to the difference explained above, we use a different definition of “acknowledging contingency.” As explained earlier, Wuchterl defined it as not only acknowledging contingency, but also contemplating the possibility of an Other of Reason, as this is implied with the acknowledgement of the limits of reason. The difference with our definition is subtle: we define contingency acknowledgement as acknowledging both the contingency (non-necessity) and the existential relevance of a life event as a disruption of one’s life story. This may or may not be accompanied by contemplations on the possibility of an Other of Reason, as we hypothesize that in late modern Western societies, these explicit contemplations are not present in every person acknowledging the contingency and existential impact of a life event and asking existential questions. In addition, we added a worldview category, theistic determinism, that we hypothesize to be associated with less contingency acknowledgement. Theistic determinists do not acknowledge contingency if they consider everything, including human action, as the result of divine providence and thus as necessary: it *had* to happen.

Third, in our study “dealing with contingency” is regarded as a process rather than a fixed mode that stems directly from one’s worldview and latent philosophy. In this process people may move back and forth between modes, for example reinterpreting the life event, then finding explanations that may seem definite, and then asking existential questions again. One may *learn* to deal with experiences of contingency and to give these experiences a meaningful place in their personal life narrative, and still regard disruptive life events as contingent. Of course, this difference is connected with the difference between Wuchterl’s religious-philosophical concept “with which to understand the world” [32] and our aim to *empirically* investigate how people deal with experiences of contingencies and how their QoL is affected.

The fourth difference concerns the possibility of “narrative integration,” which is partly dependent on how the concepts of necessity and – as a consequence – contingency are defined. As Wuchterl suggests in his article published in 2019 (and thus after publication of most of the articles in this dissertation), some contingent events are integrated into one’s life story relatively easily, such as winning the lottery. In contrast, he states it is not possible to integrate religious-philosophical contingencies, such as “the consciousness of the finiteness of the human being” (p. 181), into one’s own identity. He refers to an article by Scherer-Rath, in which the latter proposes the idea of “narrative intelligence” as the faculty that enables people to perceive, acknowledge, accept and integrate contingencies [33]. Although Scherer-Rath emphasizes that narrative intelligence and narrative integration do not eliminate the disruptive and contingent character of life events, Wuchterl seems to discard them as “managing” or “coping with” contingency. Because he uses the concept of religious-philosophical contingencies as “absolute” and narrative integration as an act of reason that gives an event necessity, he places narrative intelligence in the realm of immanent agnostics. Narrative integration is thus seen as “managing” the existential threat of the event or of finitude consciousness, making it accessible to reason in a way that contingency is eliminated and no new contingencies will arise. In contrast, following Ricoeur [11] and Scherer-Rath [33], we conceptualize narrative integration as giving the contingent life event a meaningful place in one’s life story *as such*, without disregarding or removing its contingent, unintelligible and disruptive character. Although we hypothesize that the experience of contingency diminishes with the narrative integration of the event, the reinterpretation of the integrated life event does not have to be definite. The place of the event in one’s life narrative is not given necessity in the sense that contingency is eliminated and all existential questions have final answers. The answers and the meaning attributed may have “contingent certainty”, as Joas puts it: “a certainty felt in full awareness of its contingent foundations” [34]. See also the section on narrative identity and narrative integration below.

The final two differences regarding the concept of contingency both concern the conceptualization of contingency “encounter”, Wuchterl’s mode of dealing with religious-philosophical contingency on which our mode of “receiving” is based. The fifth is that in our study, contingency “receiving” is the last mode of narrative integration of a disruptive life event. For Wuchterl however, this mode of dealing with contingency is not a mode of narrative integration of a life event. Not only does he regard religious-philosophical contingencies as impossible to integrate into one’s identity; his concept of experiences of contingency also seems less connected to life events, as shown in his example of consciousness of one’s own finitude. Contingency encounter is described as an encounter with the “Other of Reason” in which a totally Other may reveal itself, but the implications for dealing with contingent life events are not clear. Wuchterl does state that this encounter may provide existential “personal security,” but does not develop an account of how such an encounter changes one’s interpretation of a disruptive life event in the context of one’s life narrative and how it influences one’s wellbeing. Developing such an account is one of the aims of the present study.

Sixth, Wuchterl states that contingency encounter is always religious, in the sense that a vertical movement of transcendence is made, towards a higher reality in which revelation may take place. Although religious and immanent agnostics may experience forms of horizontal transcendence or self-transcendence, contingency encounter is beyond their abilities. In our theoretical model, this religious encounter is not a separate category of dealing with contingency. It may be a form of “receiving,” the last mode of narrative integration of a life event that has evoked an experience of contingency. However, receiving is conceptualized as a transformation that implies receptivity for what cannot be rationally understood and for new possibilities and insights, not necessarily relating to a higher reality [35].

The concepts of (self)transcendence, religion and religious in our study

The differences with Wuchterl’s conceptualizations described above also relate to the way “transcendence” is defined in this dissertation. Considering experiences of contingency, Wuchterl focuses on “vertical” or “religious” transcendence, defined as transgression of the boundaries of reason towards a higher reality. In this dissertation we use a broader definition, following Joas [36]. Transcendence is defined as transgressing boundaries, which in the context of experiences of contingency are boundaries of reason, of what we are able to grasp and make sense of. However, the movement does not have to be directed towards a “higher” reality; it can also be conceived as something beyond, something deeper or greater than what we can understand and perceive [37]. This is not the same as what is denoted with the concept of “horizontal transcendence”, as this specifically refers to interpersonal forms of self-transcendence. With transcen-

dence we denote what is often referred to as the “more,” as in “what we see is not all there is”, which is often referred to with the word “spirituality” [38]. This is why in our theoretical model, the scope of the meaning of an event can be situational, existential and “spiritual,” instead of “religious.”

The “more” that spirituality refers to, does not have to be divine. It may be “more than human” or “more than mundane,” but also “more than temporary” or “more than we can see.” It may be envisioned as something personal (such as “God”) or impersonal (such as “a higher power” or “something higher”) (Bucher, 2014), but can also be experienced as something mysterious and inconceivable (“the mystery of life”), and even as something within the self. In congruence with this definition, we define self-transcendence (which is relevant for the mode of “receiving”) as a movement away from the self. This movement is the result of something “pulling” the self beyond its own boundaries (*Ergriffensein*) [36], which can be interpreted and articulated in a religious way but also in non-religious ways [36].

In this dissertation, following Joas [36], the term “religion” is reserved for systems of belief, systemizing experiences and ideas about the sacred and a higher reality. Through symbols, myths and rituals, it is possible to access, share and pass on these experiences and ideas. In addition, we use the adjective in relation to “religion” as a noun, although its meaning may be slightly broader than just referring to (institutionalized) religion. With “religious,” we refer to experiences or interpretations related to a higher reality or the sacred, which may or may not be systemized, institutionalized and embedded in traditions.

For Joas, self-transcendence is the starting point for all religious experience. However, his definition of religion goes further, encompassing both the notion of sacredness and a vertically transcendent reality. As we find the distinction between transcendence and religion meaningful, we use the term “spiritual” for non-religious references to the transcendent.

Joas’ definition of religion is functional rather than essential, emphasizing its ability to increase people’s receptiveness to contingency and experiences of transcendence. **Religion extends people’s frame of reference and subsequently their range of possible interpretations and experiences.** It does not merely help people to cope with the contingencies of life, but may change the way people perceive them and deal with them [34].

Narrative identity and narrative integration

In religious-scientific research on experiences of contingency, contingency theory is combined with philosophical theories on narrative identity, contributing to understanding why and how these experiences emerge and what kind of processes they evoke. These philosophical notions of identity also show kinship with the narrative approaches in psychology, as will be described in the next section.

According to the philosopher Ricoeur [39], people narratively interpret the world and their lives in three stages, called “mimesis:” the imitation of human action. The first stage is the prefiguration of our daily lives, already containing networks of structures that make storytelling possible, such as symbols and temporal structures. Thus, people’s lived experiences can be seen as stories that are not yet told. The second stage is the imaginative configuration of elements such as life events into a life narrative. Just as the plot of a story, this “narrative emplotment” brings order and coherence by connecting events, persons, and objects, as meaningful parts of a larger whole. Although this configuration endows the connections between the elements of the story with meaning and even with a certain necessity, this does not imply that contingency disappears or is not taken into account. The emplotment brings together heterogeneous elements into a tensive state of “concordant discordance:” a configuration of events that are still contingent and may still be disrupting the story, but with an internal coherence that gives them a meaningful place.

The third stage of mimesis, refiguration, is the integration of this imaginative perspective into people’s lived experience [39]. This means that people “read” their own life story, integrating their life events and experiences in the way they understand themselves. This integration is why narrative identity both reflects and shapes who the person is. Therefore, dealing with life events that disrupt people’s life story is often not merely a matter of coping and adaptation, but a process of meaning making that may ultimately change the identity of the person.

Connecting the concept of narrative identity to experiences of contingency as “crises of meaning,” the disruptive life event may be seen as disrupting the story line and endangering the unity of the narrative. Configuration and reconfiguration can mediate between the desire for concordance and accepting discordance. As a result, disruptive elements can be incorporated in the narrative without discarding their disruptive nature but taking on a meaning *within* the advancing story [11, 40]. As explained above, **we thus regard narrative integration as a result of meaning making that does not eliminate contingency.**

In addition, in narrative psychology as well as in philosophical theories on narrative identity, it is often proposed that constructing congruent stories is our way to provide a sense of overall meaning and purpose to our lives that is necessary for our wellbeing. This proposition raises the questions of whether experiences of contingency are detrimental to our wellbeing and QoL in the broad sense, and whether integrating these experiences may lead to higher levels of QoL. It is our aim to further explore these relationships empirically in this study. Moreover, theories on contingency and narrative identity propose that dealing with life events that disrupt people's life story is often not merely a matter of coping and adaptation.

As we already saw in the WHO definition, QoL is perceived and experienced in relation to people's goals, expectations, standards and concerns [41]. In religious studies, one's religious or non-religious worldview is added to this definition. One's worldview informs life goals, functions as the framework of interpretation, influencing how the life event is initially interpreted, but also determines if one relates to the immanent (human) world only or also to a transcendent (higher) reality, in the process of dealing with contingency and reconstructing one's life story. Thus, when a life event disrupts one's life and challenges or even shatters one's expectations, standards, life goals and sometimes even worldview, it necessitates reinterpretation of the event in the context of one's life story, and re-evaluations of what one may expect and strive for. And **because the pursuit of ultimate life goals and their integration into people's narrative identities are crucial for people's QoL, we hypothesize narrative integration to influence QoL positively** [16, 42].

Research into aspects and dimensions of contingent life-events

As a scholar in the thematic research group Religion and the Crisis of Meaning of the Radboud University Nijmegen, Michael Scherer-Rath was the first to use the concept of "experience of contingency" in a conceptual scheme for empirical research. In his research program "Narrative Reconstruction of Experience of Contingency," experiences of contingency are described as interpretation crises stemming from a situation of principal uncertainty, because a life event cannot be interpreted in the context of one's life narrative. In order to improve our understanding of experiences of contingency and eventually improve spiritual care for people dealing with these experiences, a scheme was developed to distinguish "Aspects and Dimensions of Contingent Experiences of life" (ADCL). The scheme enables researchers and spiritual counselors to place a respondent's interpretation of a life event in a matrix with the aspects positive versus negative, active versus passive, and the three dimensions situational, existential and spiritual or religious.

Moreover, the scheme offers “labels” for every combination of these aspects and dimensions [16] (see Table 1). For example, the label “gift” combines the aspects “positive” and “passive” with the dimension “existential” (having significance for one’s life as a whole). In interviews or interventions using this scheme, respondents are first invited to talk about their interpretation of the event (to “reconstruct” their interpretation), reflecting on which of the aspects and dimensions they attribute to it. Next, they may be offered the “labels” to choose the one that befits with their interpretation of a life event. These labels offer respondents potentially new language and perspectives, challenging them to view the event and their interpretation from a new perspective. This may evoke reconsiderations of their reconstruction of their interpretations, which is a form of “creative contingency:” interpretations of life events are not “necessary” but could also be otherwise [16]. In addition, the labels may help respondents to indicate if they attribute a situational, existential or religious meaning to the event. Indeed, labels such as “tragedy” or “achievement” may be easier to understand and more appealing than these three abstract notions.

Scherer-Rath’s ACDL scheme was the first step in the development of a structured interview guide to qualitatively assess people’s experiences of contingency. In several master’s theses and PhD studies, such as the studies by Van den Brand and Kruizinga (see below), this instrument was further developed.

Research into experiences of contingency of cancer patients

In the above-mentioned research group at the Radboud University Nijmegen, Egbert van Dalen recently conducted a qualitative PhD study into the experiences of people who are living with incurable cancer [43]. His study aimed to contribute to the development of a practice-oriented, religious-scientific theory of the interpretation crises of people with incurable cancer. Van Dalen studied the relationship between expectations and the crisis of meaning, in particular experiences of tragedy [44]. In addition, he focused on one particular aspect of experiences of contingency as defined by Wuchterl, namely that the event is judged to be ontologically contingent (neither necessary nor impossible). Therefore, he examined the ways people interpret and explain the cause of their disease.

Table 1. Aspects and dimensions of contingent experiences of Life (ADCL matrix) [16]

| | <i>Situational</i> | | <i>Existential</i> | | <i>Religious</i> | |
|----------------|--------------------|-----------------|--------------------|-----------------|------------------|-----------------|
| | <i>Positive</i> | <i>Negative</i> | <i>Positive</i> | <i>Negative</i> | <i>Positive</i> | <i>Negative</i> |
| <i>Active</i> | Achievement | Failure | Duty | Guilt | Calling | Sin |
| <i>Passive</i> | Good fortune | Misfortune | Gift | Tragedy | Grace | Desolation |

The interviews conducted by Van Dalen were used to explore whether Wuchterl's distinctions could be found in empirical data, precluding the qualitative analysis for the second chapter of this dissertation, about "modes of relating to contingency." While the Van Dalen and the present study both regard experiences of contingency, the present study's focus is extended to the process of narrative meaning making that follows this experience and on its relationship with QoL. In addition, we aim to explore these concepts quantitatively.

Research into experiences of contingency and ultimate life goals of teachers

In the same research group, an interview study based on the ADCL scheme and its theoretical framework was conducted by Jos van den Brand, whose dissertation was published in 2016 [45]. Van den Brand studied the role of worldview in the life narratives and interpretation of life events of teachers, and the relationship between these narratives and the intentionality of their pedagogical activity. He built on the assumption in Frijda's motivational theory that meaning making of existential events in the context of personal goals determines the intentionality of professional activity. The aim of his project was to empirically investigate the role of worldview in the interpretation of life events. To this aim, an "analytical model for reconstructing interpretation of life stories" was developed [46]. According to this model, existential events may conflict with ultimate life goals that are embedded in a person's foundational reality. "Foundational reality" refers to a specific part of one's worldview: one's conception of reality, which may be transcendent or immanent. By confronting the event with our personal goals, we attribute meaning to it, which is an interpretation that is itself contingent. The emotions that are evoked by the conflict between an event and personal goals influence the intentionality of our actions, which is usually directed towards striving for these personal goals [45].

An instrument for semi-structured interviews was constructed based on this analytical model. The instrument consisted of a topic list, an interview guide and instructions for respondents to draw a lifeline with life events as high and lows. The purpose of placing these life events on a lifeline was to help respondent recollect existential events and place them in the context of their whole lives, evoking reflection on their existential meaning. Next, respondents were presented a list of seventeen emotions and invited to choose the most apposite one for each life event. This was done in light of the aim to let respondents become aware of their interpretation of the event through reflection on the impact of the life events on their life goals. According to Frijda's motivational theory, positive emotions are evoked by life events that are perceived as contributing to striving for one's life goals, while negative emotions arise when striving for these life goals are frustrated [47].

Next, to explore people's interpretation of the life events and the possible experiences of contingency, respondents were invited to elaborate on what happened and when, and why the event was considered a high or low point (aspect: positive/negative). They were asked if the event was expected or unexpected, and who or what they considered responsible for the event (aspect: passive/active). Finally, the three series of labels as mentioned above (see Table 1) were presented, to let respondents indicate if they attributed a situational, existential or religious meaning to the event.

In our study, we used the analytical model and qualitative instrument of Van den Brand as a starting point for developing our theoretical model and quantitative instrument.

Research into an assisted reflection on experiences of contingency of cancer patients

Combining religious studies and medical science, Renske Kruizinga conducted a study on experiences of contingency in advanced cancer patients. In her PhD project, the qualitative instrument developed by Van den Brand was developed into an intervention with a narrative approach. Building on studies showing that spiritual interventions may benefit advanced cancer patients in terms of their QoL, the intervention aimed to improve the spiritual wellbeing and QoL of advanced cancer patients, by helping them to reflect on disruptive life events in relation to their life goals and world view [48]. The intervention could be characterized as an "assisted structured reflection:" a spiritual counsellor interviewed advanced cancer patients using the "Life In Sight application" (LISA) on a tablet computer. Respondents drew their life line with life events as ups and downs on the tablet, and spoke with the counsellor about their interpretation of three most important life events. Analyzing the respondent's answers after the first session, the counsellor categorized the life events using the aspects and dimensions of the ADCL scheme. The respondent's life goals were also categorized into different levels. In a second interview, the analysis was discussed with the respondent. This could be regarded as a "member check" to verify if the analyses did justice to the respondent's interpretations, but also as an intervention that could help respondents reconsider and reconstruct their interpretations and integrate disruptive life events into their life narratives [49].

To investigate whether this narrative intervention influenced the QoL as experienced by these patients, a randomized controlled trial was conducted with health-related QoL and spiritual wellbeing as outcomes [48]. Patients in the intervention group participated in two sessions with a spiritual counselor as described above, while patients in the control group received care as usual. Contrary to their expectations, Kruizinga et al. found no differences in QoL and spiritual wellbeing between the intervention and the control group. However, over eighty percent of the participants in the intervention group stated

that the intervention helped them get a clearer vision on their values and more insight into their lives [50]. This finding raises the question of whether health-related QoL and spiritual wellbeing are the only, or the most relevant, outcomes to consider when assessing the effects of an intervention aiming to facilitate narrative integration of experiences of contingency.

Kruizinga et al. were the first to use a quantitative approach to study experiences of contingency and narrative integration by relating qualitative data on experiences of contingency to quantitative measures of QoL. Our aim is to further this approach by developing quantitative assessments of experiences of contingency and narrative integration themselves. This may not only advance the development of theory on dealing with experiences of contingency, but also the development of more appropriate measures to evaluate the effects of interventions aiming at facilitating narrative integration of experiences of contingency.

As there is common ground between Kruizinga's and the present study, we conducted the research together for two co-authored articles, which are included in this dissertation. The first is on experiences of contingency in advanced cancer patients, presented in Chapter 2. The second is a systematic review and meta-analysis on the effect of spiritual interventions, using a narrative approach, on the QoL of cancer patients. This article is presented in Chapter 5.

Previous research in the social sciences

In (medical) sociology and several sub-disciplines within psychology, insights have been gained that are relevant for meaning making after disruptive life events and how meaning making influences people's wellbeing and QoL. Below, we will elaborate on these findings, as they fuel our aims and research questions .

Health sociology

In health sociology, building on the influential work *Chronic Illness and the Quality of Life* by Glaser and Strauss, scholars have aimed to understand the experience and meaning of chronic illness for patients as well as the people close to them [51]. Particularly the concept of "biographical disruption," coined by Bury [52], was taken forward in many theoretical and empirical studies. With this concept, he built on the sociological concept of "critical situation," defined as "a set of circumstances which (...) radically disrupts accustomed routines in daily life" [53]. "Biographical disruption" refers to the experience that illness, especially chronic illness, profoundly disrupts one's structures of life in many ways. Not only taken-for-granted behaviours and assumptions are disrupted, but also one's explanatory frameworks, leading to the existential questions mentioned

above [52]. In addition, this perspective was combined with narrative theory in the concept of “narrative reconstruction” of one’s changing relationship to the world, invoked by questions about the cause of one’s disease [54]. Increasingly striving to give voice to the experiences of lay people, the concept of biographical disruption guided ample empirical research into the meaning of falling ill [55, 56].

For our study, the concepts of biographical disruption and narrative reconstruction are important notions to build upon, emphasizing the disruptive nature of these experiences and the crisis of meaning that may follow. However, these concepts do not integrate the notion of the experience of contingency, which is a central focus of our study. Moreover, theories on biographical disruption within health sociology do not address the relationship between these experiences and QoL.

Health psychology

In contrast to health sociology, the relationships between meaning making of life events and wellbeing or QoL are studied in clinical-, health- and medical psychology. For example, the way cancer survivors interpret their illness was found to correlate with coping strategies and QoL [57], and meaning-focused coping was found to be associated with positive affect in people with chronic stress [58] and with positive affect and wellbeing in earthquake victims [58-61]. In psychology and (health) sociology, research has been performed on various aspects of meaning making and adaptation in the context of stressful life events, such as salutogenesis and sense of coherence⁵ [62], interpretation of illness [18, 57], meaning-focused coping [60], appraisal [63], coping and hope [59], self-determination [64, 65], meaning maintenance [66], situational and global meaning [67-69], posttraumatic growth [70] and narrative meaning making [71]. Important determinants in these processes have also been considered, including religion, worldview and spirituality [72-76], life goals [77-83] and dispositions [84-87].

As shown in an extensive review by health psychologist Park [21], myriad theoretical perspectives on meaning making exist in the field of psychology. The meaning making model proposed by Park and Folkman [67] and Park [21, 68] is based on several influential theories on meaning making in the context of highly stressful experiences. These theories have in common that they view stressful experiences as “disrupting,”

⁵ “Salutogenesis”, literally meaning “the origins of health”, is the interdisciplinary approach of health and disease developed by the medical sociologist Antonovsky, focusing on resources for health and wellbeing instead of health risks and disease. “Sense of coherence” is defined as “the extent to which an individual has a pervasive, enduring though dynamic, feeling of confidence that life is comprehensible, manageable, and meaningful” [76].

“shattering” meaning in the sense of connections, for example between the life event and life goals, beliefs, desires and expectations. Such disruptions are thought to lead to discrepancy in people’s orienting systems (“global meaning”) and the meaning they assign to the situation (“appraised meaning”), causing distress. The process of meaning making initiated by this distress is an attempt to restore meaning and, if successful, may lead to better adjustment to the stressful situation [21]. Park uses the term “meanings made” for the “products” of these processes of meaning making. Examples of these outcomes are acceptance, the sense of having “made sense,” reattributions of the cause of the event, restored or changed sense of meaning in life, changed global beliefs, and integration of the stressful experience into one’s (changed) identity. Every theoretical perspective emphasizes certain aspects of the impact of the event, the process of meaning making, and the “meanings made,” such as disruptions in life narratives, underlying cognitive structures, specific coping processes or outcomes such as benefit finding and posttraumatic growth. Since 2010, several empirical studies have been carried out that can be placed within the framework of Park’s model (e.g. by Davis and Novoa [88]; Dezutter et al. [89, 90], Park and George [69] and Rajandram et al. [91]).

The meaning-making framework by Park and other well-known psychological concepts, such as adaptation, acceptance and coping, clearly show kinship with the theoretical model we propose. For example, the concept of discrepancy in Park’s model resembles the conflict between the life event and worldview and/or ultimate life goals, and the coping process “cognitive re-appraisal” bears a resemblance to the concept “narrative meaning making” as the re-interpretation of the life event in the context of one’s life story. Furthermore, the concept of narrative integration could be related to “meanings made” such as acceptance, post-traumatic growth, changed identity, and changed global goals [21].

One could say that these psychological models and concepts illuminate the psychological dimension of the same process of meaning making. However, the psychological approach offers an explanatory and functional account of meaning making following an experience of contingency. With our religious-scientific approach that includes contingency theory, we aim to develop a more substantive account of meaning making. Our theoretical model facilitates the investigation of the meaning that life events have for people in the context of their personal life narrative, and the contents of ultimate life goals and worldviews that play a role in the construction of meaning and the experience of QoL.

Narrative psychology

In addition, as a perspective rather than a sub-discipline of psychology, narrative psychology provides relevant insights for the present study. Developed as a reaction to behavioral and cognitive psychology, in which humans were characterized using the metaphors of the animal and the computer respectively, narrative psychology considers human beings as storytellers [92]. In kinship with theories on narrative identity in philosophy, narrative psychology goes further than viewing storytelling as a means to make sense of oneself, others and the world. It proposes that human consciousness has an “order of meaning” that is temporal in its ground structure [93]. Human experience is always understood in terms of “activity” which incorporates both time and sequence: narrative is the organizing principle of human action. We think, perceive, imagine, interact and make moral choices according to narrative structures. And because we shape our life stories and understand ourselves in this narrative way, these stories shape us and thus form our narrative identities [94].

In health psychology, the narrative approach emphasizes how falling ill may disrupt our life narrative and sense of identity, and how storytelling can be helpful in rebuilding a sense of connection and coherence [95], integrating disrupting life events into one’s life narrative [96]. Qualitative approaches are used to reveal these stories, but also narrative interventions are developed, aimed at improving the wellbeing of specific groups such as people with a chronic disease, depression or dementia. For example, life review, life-review therapy and reminiscence interventions have been found to have positive effects on depression, purpose in life and mental health. They also help older adults finding meaning and coherence in their lives and enhance emotional wellbeing and life satisfaction [97].

In our study, we build on narrative psychology considering human beings as narrative beings who shape stories and at the same time are shaped by the stories they construct. In addition, our study is informed by the insights from qualitative research into narratives about disruptive life events. However, in narrative psychology, theories of contingency are not incorporated and quantitative research is not usually conducted to test hypothesized relationships between, for example, coherence and wellbeing.

Dispositions and response shifts or “shifts of meaning”

Another finding in health research relevant for the focus of our study is that, despite apparent changes in health, patients sometimes report surprisingly stable levels of QoL. Research suggests that QoL, as all patient self-reported data, may be subject to unmeasured influences. One of the key causes is disposition, already mentioned above as a determinant in processes of meaning making. Dispositions, or “traits,” are

relatively stable characteristics such as personality, and include generalized beliefs that may influence one’s conceptualization and consequently evaluation of QoL. Thus, the QoL reported by patients is not only the result of their (fluctuating) physical and mental wellbeing but is also influenced by their (stable) dispositions.

Another important cause is response shift, a phenomenon that may also be related to meaning making of disruptive life events and its influence on QoL. Response shift can occur in every type of self-evaluation, such as patient-reported outcomes (PROs), including QoL. The “shift” refers to a change in the meaning of the construct that is measured. **In health research, response shifts are changes in the meaning of one’s self-evaluation of QoL [98], often induced by a change in health due to disease or treatment.** These shifts of meaning may occur in people’s internal standards (“recalibration”), in the importance of certain values or goals (“reprioritization”) or in their conceptualization of QoL. For an example, see Figure 1.



Figure 1. An example of “response shift” in health research

Figure 1 shows a woman with stable coronary artery disease who rates her overall QoL a 4 out of 5. Then, she has a myocardial infarction (heart attack) and has to undergo emergency bypass surgery. Her recovery takes a long time, and six months after the surgery, her health state is not what it used to be before the infarction. Nevertheless, having adapted to the situation and having changed her ideas about QoL, she rates her overall QoL again a 4 out of 5. While her QoL scores have not changed, their meaning has, representing different health states.

In health research, for example in clinical trials, response shifts are usually not considered and thus may obfuscate changes in health. For example, response shift induced by health deterioration as a result of an invasive treatment to which a patient adapts, may result in higher levels of QoL than is expected based on the patient's actual health state. Over the past decades, response shift has been integrated in theories on the impact of health changes on QoL [98-100]. Several methods have been developed to detect response shifts, to enable distinguishing response shifts from changes in health state. In addition, research is done on the underlying processes leading to response shifts.

Although not much research is done into the existential dimension of response shift, some studies suggest a relationship with meaning making after disruptive life events. Rapkin and Schwartz state that people's goals and concerns continue to evolve during serious illness, which is associated with response shifts [99]. In the paper "Philosophical perspectives on response shifts," McClimans et al. propose that people's visions on "the good life," i.e. "substantive values," affect their self-evaluations and thus their answers about their QoL. Following Charles Taylor, they state that self-evaluations influenced by one's substantive values are "strong evaluations." In contrast, evaluations that are influenced by material conditions such as physical condition, environment and age, are called "weak evaluations." In health research, QoL evaluations are expected to be "weak evaluations," as they are intended to measure changes in health. However, they may in fact be (at least in part) "strong evaluations," because what we consider valuable determines how we conceptualize QoL. This makes QoL evaluations subject to changes in one's substantive values, and thus to response shifts [101].

Drawing on Frankl's quotation about having to change oneself when the situation cannot be changed, one may speculate that response shifts are more likely to happen when disruptive life events change a person's identity. More research into this existential dimension is needed, and may improve our understanding of response shifts, the circumstances in which they may occur, their meaning for patients and our interpretations in QoL research. Although response shift is not the main focus of this dissertation, we think that our study on meaning making in the context of serious illness may improve our understanding of the existential dimension of response shift, or "shifts of meaning," as it would be named in the vocabulary of the humanities.

In addition, the use of PROs such as QoL in medical decision-making raises questions, knowing that these outcomes may be influenced by patients' dispositions and shifts of meaning. Of course, response shifts are the result of meaningful change that is often adaptive and positively influencing patients' self-evaluations of QoL. The question is, however, if treatment decisions should be influenced by patients' response shifts or dis-

positions. For example, does a good QoL as a result of meaning shifts, despite disability or severe symptoms, mean that a patient needs less care than a patient with the same disability or symptoms but less response shift? Do these two patients have the same level of health, or is the person reporting higher QoL, due to shifts of meaning, healthier? In addition, decisions on the level of health policy may also be influenced, if clinical trials compare treatments that induce different levels of response shifts or response shifts in different outcomes and/or directions. So far, no research has been done to study the consequences of disposition and response shift on PROs and consequently medical decision making and healthcare.

Aims and research questions

In the previous sections, we described the research that has previously been conducted in religious studies and the social sciences, on the subject of narrative meaning making of life events that evoke an experience of contingency, and the way QoL is impacted by both experiences of contingency and different ways of making meaning of these experiences. Building on this knowledge, we are now able to formulate specific aims and research questions for this study.

Aims of this study

In this thesis, we propose an interdisciplinary approach to meaning making relating to QoL, integrating perspectives and methods from humanities and social sciences into medical research and practice. Our first aim is to develop a substantive theory on the way people make meaning of disruptive life events causing an experience of contingency and how this process influences their QoL, possibly also improving our understanding of response shift. This means that we focus on the kind of life events that may cause a crisis of meaning, what such a crisis means and how the process of meaning making may change people's life narratives and influence the QoL they experience. To these ends, we combine theory on QoL and response shift with theories on contingency and narrative identity, including the role of people's worldview and life goals in the context of late modern Western society. In addition, we aim to qualitatively investigate whether the theoretical concepts of narrative integration can be distinguished in the empirical reality and/or have to be refined based on empirical findings.

Our second aim is to take a first step in the operationalization of the theoretical concepts regarding experiences of contingency and narrative meaning making into a quantitative questionnaire, and to test this questionnaire among patients. As the humanities and religious sciences focus on understanding rather than measuring meanings and experiences, it is not a self-evident aim to develop a quantitative instrument regarding narrative meaning making and integration of experiences of contingency.

However, if we would be able to assess (dealing with) experiences of contingency and narrative meaning making quantitatively, it would allow us to carry out further research and increase our understanding. Not only research into narrative meaning making after disruptive life events and relationships with people's worldview, life goals and QoL would be valuable, but also into the effects of interventions aiming to help people who struggle with disruptive life events such as falling seriously ill.

The third aim of this study is to investigate the effects of meaning making interventions (often referred to as “spiritual” interventions) that use a narrative approach.

Reviewing studies investigating these effects may be indicative for the possible influence of narrative integration on QoL. Moreover, it may give an indication of the suitability for QoL as an outcome in assessing the effects of spiritual interventions using a narrative approach.

Lastly, **our fourth aim is to map how stable characteristics of people and shifts of meaning in the process of meaning making of one's illness may influence medical decision making, through their influence on patient-reported outcomes.** We aim to analyze these consequences from a medical-ethics perspective.

Research questions and interdisciplinary approach

From the aims of this study described above, the following research questions can be derived:

1. How do patients make meaning of their “experiences of contingency” after the life event of being diagnosed with incurable cancer? (Chapter 2)
2. How can we quantitatively assess (dealing with) experiences of contingency, narrative meaning making and narrative integration? (Chapter 3)
3. What are the relationships between disruptive life events, the experience of contingency, ultimate life goals, worldview, narrative meaning making, narrative integration and quality of life? (Chapter 4)
4. What are the effects of meaning making interventions (often referred to as “spiritual” interventions), using a narrative approach, on the quality of life of cancer patients? (Chapter 5)
5. How may dispositions and response shifts influence patient-reported outcomes and consequently medical decisions, and what are the ethical implications of these consequences? (Chapter 6)

The research questions are answered in a study with a mixed-method design, combining a theoretical, qualitative and quantitative approach. A theoretical model on narrative meaning making of contingent life events was developed based on literature research,

including an existing conceptual model on interpretation in life stories. Patients' experiences of contingency after being diagnosed with incurable cancer were explored using a qualitative analysis of in-depth interviews (Chapter 2), of which the results were integrated in the theoretical model. The theoretical model was operationalized in a quantitative questionnaire using an existing interview instrument that was based on the analytical model described under the heading "*Research into experiences of contingency and ultimate life goals of teachers.*" (page 36). This Reconstruction of Life Events questionnaire, RE-LIFE in short, was then tested in a large-scale study on QoL among cardiac patients, assessing the psychometric properties of the questionnaire (Chapter 3) as well as the relationships among the concepts of the model that were operationalized in questionnaire scales (Chapter 4). The fourth research question was addressed by conducting a systematic review and meta-analysis of clinical trials assessing the effects of spiritual interventions, addressing existential themes using a narrative approach, on the QoL of cancer patients (Chapter 5). To answer the fifth research question, we analyzed how dispositions and response shifts of patients may influence PROs and, consequently, medical decisions. In addition, we analyzed the possible consequences from a medical ethics perspective (Chapter 6). Details on the methods used to answer the separate research questions can be found in the method section of each chapter.

In the next section, we will elaborate on the methodology used to build the theoretical model that was the starting point for this study. Next, we will define the concepts of the theoretical model.

THEORETICAL MODEL: NARRATIVE MEANING MAKING AND INTEGRATION OF LIFE EVENTS

Methodological approach for developing the theoretical model

As a starting point, we used the conceptual model for reconstructing interpretation in life stories that was described and empirically tested previously [16, 17, 45, 46, 49, 102]. This model combines contingency theory [15] and narrative theory [10, 11], focusing on the role of narrative interpretation of life events in the construction of personal identity [46]. Since our aim is to improve our understanding of the way meaning making of illness experiences influences QoL, we carried out a literature search on meaning making, contingency, life goals, narrative identity, narrative integration, worldview, wellbeing and QoL, and refined and adapted the model.

The resulting theoretical model describes the dominant relationships between the following elements, as illustrated in Figure 2. **Falling ill, as a life event, conflicts with the person's worldview and/or with one or more ultimate life goals that are anchored in the worldview. The conflict can result in an experience of contingency. In the process of narrative meaning making that follows, the life event is re-interpreted in the context of one's own life narrative. Eventually, the event is integrated in the personal life story to a greater or lesser extent (narrative integration), affecting patients' QoL.**

The feedback loops in the model indicate that meaning making, resulting in narrative integration, may not be a linear but an iterative process. In the case of an experience of contingency, meaning making and narrative integration may not have taken place yet or may be unsuccessful, leading to a lower level of QoL. Narrative meaning making

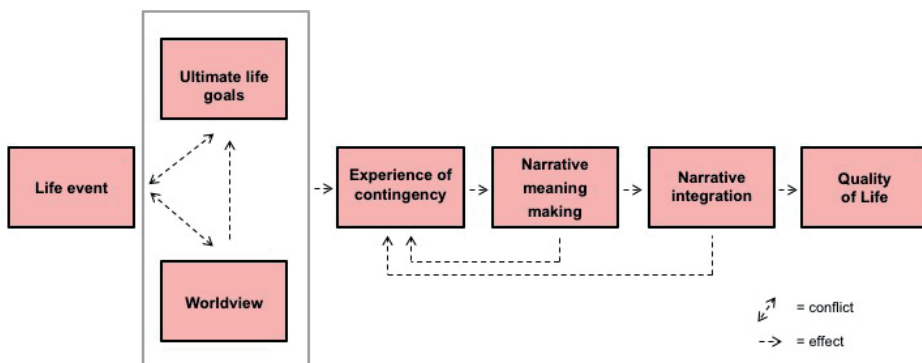


Figure 2. Theoretical model: *narrative meaning making of life events*. The dominant relationships and feedback loops are highlighted.

leading to narrative integration is expected to reduce the experience of contingency, thus increasing the level of QoL. It should be noted that this “reduction” of the experience of contingency refers to a reduction of the crisis of meaning at that moment. It does not “erase” the experience of contingency from the person’s life narrative, nor the existential significance of the life event. The life event remains a disruption in one’s life narrative, but is given a meaningful place. The meaning attributed to an event can continue to change, even after years, and may reduce but also increase the experience of contingency, affecting the person’s QoL. The elements of the theoretical model will be described below.

Life events

In narrative theory, events are defined as occurrences that the person interprets as meaningful in the context of her or his life story [11]. If a person considers an event as significant for his or her life as a whole, we speak of a *life* event [47]. Because we cannot fully control the course of most events, they can be considered contingent: they can happen, but do not necessarily have to happen [103].

This holds for both positive and negative events, unexpected as well as expected. Indeed, also expected events might *not* happen or might be inevitable while people may want to prevent them from happening. However, especially unexpected negative life events, such as illness, loss of beloved ones, and accidents, often conflict with life goals and/or the person’s worldview. These kinds of events may confront people with the “existential givens” of life, such as human mortality, making them realize that being alive implies being vulnerable, out of control, and unable to understand the world [1, 68, 104]. Shattering fundamental assumptions and disrupting people’s expected course of life, negative life events may not be integrated as easily in a person’s life story as positive life events [105].

Experiences of contingency

An experience of contingency is caused by a life event that conflicts with the person’s worldview and/or ultimate life goals and raises existential questions [16, 17, 49, 52, 102, 103, 106]. An experience of contingency can be seen as a biographical disruption: a “breach of trust” that urges the person to reinterpret one’s own life story, including the life event as a part of it [14, 107]. In religious studies, experience of contingency is also called “interpretation crisis” or “crisis of meaning” [13, 14, 102, 108], emphasizing the inability to understand and grasp the life event [103]. This inability to make sense and meaning of the life event conflicts with the fundamental human need for understanding, coherence, and meaning [3, 54, 66, 109-111].

Unexpected events, such as a train delay, getting the flu or falling in love, do not always result in an “experience of contingency.” It is the conflict with people’s worldview and/or the ultimate goals they strive for, which may “rupture” their life story and evoke existential questions. This can also happen as a result of a positive life event, such as winning the lottery or falling in love. Whereas such events may seem desirable, they can indeed conflict with one’s ultimate life goals and identity and can raise existential questions, challenging people’s outlook on life. Whether an event results in an experience of contingency or not will depend on a variety of factors, such as personality, experiences in the past, the context of the life story, and the moment of occurrence in the person’s life. For example, life events such as ending a relationship or losing one’s parents have a different meaning for the young, than for older people.

Falling seriously ill may lead to an experience of contingency, since illness often conflicts with life goals and confronts people with the randomness of life, the vulnerability of what they value, and their limits of control [1]. Such an event can also conflict with people’s worldview, thereby shattering their most fundamental assumptions about themselves, the world and the relationship between the two [105]. Falling seriously ill may, for example, conflict with one’s experience of control or with the belief in a benevolent, higher power.

Empirical research on the way people talk about experiences of contingency resulting from falling ill shows that these “interpretation crises” are often presented in two ways. First, in the use of metaphors that express the impact of the event on the person’s life. For example, cancer patients talk about their diagnosis as a “shock” or “blow,” or state that the event made “their world come crashing down” [17, 112]. These expressions are metaphors, having a symbolic rather than a literal, descriptive meaning. Metaphors may provide a rational bridge between the known and the unknown, in this case between the situation before and after the event [113, 114]. The second way is asking questions, trying to understand the event in the context of the person’s life story. Negative events such as a heart attack and cancer diagnosis may evoke questions about the cause of the event: who or what caused it, and would it not have happened if I had acted in other ways? Other possible questions are more existential, such as: why did it happen to *me*? What does this mean for my life, now and in the future?

Worldview

Worldview is also referred to as “outlook on life” or “philosophy of life.” We define worldview broadly, as people’s meaning system that informs the way they perceive the world, human life and death, and their own position and personal identity. A person’s worldview is always culturally embedded and serves as a framework of (implicit and

explicit) conceptions, beliefs, and attitudes by which people interpret reality [115, 116]. As such, worldview is also the framework by which people construct their values and goals and make meaning of life events in the context of their personal life narrative (cf. “Global meaning” in Park’s model [68]).

A person’s worldview can be religious or non-religious, but always contains structures referring to a *foundational reality* – the person’s conception of reality – that can be immanent or transcendent [31, 46]. This reality is *immanent* when it refers to fellow humans or nature, that is, the perceptible and intelligible world. It is *transcendent* when referring to something greater, higher, or deeper than ourselves and our perceptible world [37]. The transcendent dimension, also referred to as “the spiritual dimension,” offers people the opportunity to place and interpret life events in a framework that transcends our human world [16, 117].

When people believe that there is nothing beyond our human, perceivable world, we speak of “absolute immanence.” In contrast, when people believe that everything in our world and beyond is shaped and determined by a higher power, we speak of “absolute transcendence” [118]. In late modern societies, people’s foundational reality is usually characterized by a combination of immanence and transcendence. It can be “immanent transcendent,” meaning that a transcendent reality influences or permeates the perceivable world, but does not determine everything. The foundational reality can also be “transcendent immanent.” The immanent world is the starting point, from which people can transcend themselves and their actions to come into contact with that which transcends the perceivable world [118, 119].

Ultimate life goals

According to motivational theory, people’s worldview beliefs, encompassing – often implicit – visions on “the good,” give rise to their personal goals that motivate their actions [7]. Their worldview thus anchors and justifies their personal goals that determine the meaning attributed to a life event [3, 47]. As detailed by Emmons, people usually have many personal goals, which are not all equally important: they are hierarchically ranked [7, 120]. They can be distinguished in “ultimate life goals” and “instrumental life goals.” Ultimate life goals are the goals, or values, that give ultimate meaning to our lives – “ultimate” in the sense that this value cannot be replaced by something else. They are universal in the sense that they are shared by many people, and they are formulated in an abstract way. Because they are so central in people’s lives, an event that conflicts with these ultimate life goals may result in an experience of contingency.

In contrast, instrumental goals are more direct and concrete, often referring to actions. They are instrumental in the sense that they are directed toward fulfilling ultimate life goals that give them their meaning and direction [7, 45-47, 49, 121]. An example of an ultimate life goal is “taking care of my child,” anchoring the instrumental life goal “helping my daughter with her homework.”

Narrative meaning making

Narrative meaning making⁶ is the process that is hypothesized to follow the experience of contingency and serves to reinterpret the life event in the context of one's own life narrative, thus giving it a new meaning. As can be derived from the meaning of contingency as possibility (see page 20), narrative meaning making may be seen as creative contingency. Because narrative meaning making also gives us the possibility to relate to what befalls us in our own way, shape our own life story and construct our identity, it may also be understood as a creative and therefore contingent form of agency.

In our theoretical model, we highlight three aspects of narrative meaning making. First, *evaluation* is the attribution of a positive or negative meaning to the event, that is, whether the person sees the event as something positive or negative. This evaluation depends highly on the ultimate life goals that are obstructed or enhanced by the event [7, 49, 121]. Over time, while re-interpreting the event, the evaluation can change. Something perceived as negative at the moment of occurrence could eventually be interpreted as having a positive meaning for life as a whole. Even with a diagnosis of incurable cancer, some people were able to find a positive meaning [7, 18, 70, 122].

Second, *agency* refers to the perceived role of the person as active or passive. An active role implies that the person interprets the event as something that he or she caused or accomplished; a passive role implies that the event is seen as something that befell him or her [16, 49]. Asking questions about the cause of the event, people may arrive at conclusions such as “it was my own fault” and “it befell me.” However, people can also conclude that the exact cause cannot be known, for example in case of a disease of which the risk is increased by genetic predisposition as well as by an unhealthy lifestyle.

Third, *scope* refers to the scale or span of the meaning that the event has for the person. An *existential* scope means that the person recognizes the significance of the event for his or her life as a whole. The scope is *spiritual* if the interpretation of the life event refers

⁶ In contrast to several theories and following Baumeister (1991), we use the concept “meaning” in a neutral way, not as “meaningfulness” or “meanings made,” but as the meaning a person attributes to life events, which may be either positive, negative, or neutral.

to a transcendent dimension (for our definition of “transcendent,” see the description of “Worldview”). This is expected to be the case for people with a worldview referring to an absolute transcendent, immanent transcendent, or transcendent immanent foundational reality. In contrast, the scope can also be *situational*, i.e. having only meaning for a particular situation, but not for the person’s life as a whole. Since in such cases a conflict with ultimate life goals or worldview is not likely, we do not expect events with a situational meaning to result in an experience of contingency [16].

In expressions about the meaning of a life event, evaluation, agency, and scope are often encountered in combination, for example as the interpretation of an event as “bad luck.” The word “bad” refers to a negative evaluation. As for agency, the word “luck” implies that the person’s perceived role is passive. If the person interprets the event only as “bad luck” in a specific situation and not for life as a whole, the scope is situational.

Narrative integration

Narrative integration results from the process of narrative meaning making and refers to the extent to which the life event is integrated in the life narrative, given a new meaning and becoming a part of someone’s identity [14, 54]. Narrative integration can be seen as the human capacity to acknowledge contingency and integrate experiences into a meaningful whole, including life events that result in an experience of contingency [123]. Such life events are thus narratively “worked” to make them plausible but without disregarding their contingency [10, 124]. The event is still interpreted as a disruption of the life story, but is given a meaningful place [14].

Some people may be more able than others to integrate life events causing an experience of contingency into their life story, also depending on the type of event and the specific situation and life phase. Based on our qualitative study among cancer patients (see Chapter 2 [112]), we distinguish four modes of increasing narrative integration (see Figure 3).



Figure 3. Four modes of increasing narrative integration

First, in the mode of *denying*, the interpretation process is aborted rather than engaged in. There is no real confrontation with one's own vulnerability or the limits of one's own abilities to understand why the event has happened, and no attempts are made to integrate the event into the person's life story. We distinguish two types of denying. The first is ignoring the existential relevance of the event, leaving no questions about (the cause of) the event or the consequences for one's life. The second type is denying the contingency of the event, usually unconsciously, giving a definitive explanation for the event by stating that it *had* to happen, thus "removing" contingency. Such an explanation can result from a theocentric worldview – from which the cause of the event is interpreted as the absolute influence of a higher being – or from an interpretation of the event as a direct result from "absolute chance" or natural laws [15]. In this respect we partly follow Wuchterl's interpretation of the naturalist worldview as mentioned in *Previous research in empirical and practical religious studies* (page 24 and further), although he does not call it "denying" and considers it a "fixed" way of (not) relating to the contingency of the world rather than a mode of narrative integration the people may move through.

In all forms of denying the contingency of the event, the explanation is not the outcome of a search for an interpretation of the cause, but a way to "fix" contingency and end the interpretation process [15]. There is no need to search for a meaningful place for the event in one's life story, and the event is not described as a part of the person's life. In this mode, people may talk about the life event in terms of "necessity" or "moving on," such as "This was meant to be, all part of His plan for me" and "I just want to go on, so that's what I'm doing." However, it is difficult to be certain whether to interpret statements like this as denying or not. A statement about necessity alone may not signify actual denying of the contingency of the event, but may be part of tentative interpretations and conclusions that are still developing. In addition, statements about "just going on" do not necessarily mean that people are in the mode of "denying." They can also acknowledge the contingency and existential significance of the event but at the same time try to find comfort or distraction in going on with their daily activities.

Second, in the mode of *acknowledging*, the contingency of the event is taken seriously: the non-necessity and non-impossibility of the event are recognized and the event is seen as a disruption of the person's life story. No definitive explanation is given for the event, but a process of interpretation is put in motion, searching for the cause of the event and what it means for the person's life. In this mode, people often ask existential questions, which can be seen as first attempts to integrate the event in the life story. People may also talk about the event in terms of necessity ("ought" or "have to") and refer to the future, for example "I will have to accept it" or "I have to let go of so many things." These expressions indicate a willingness to acknowledge the significance for

one's life and engage in the process of narrative integration, without, however, accepting the event.

Third, in the mode of *accepting*, both the contingency of the life event and the new reality that comes with the consequences of the life event are acknowledged. The person actively searches for ways to integrate the event in the personal life narrative, re-interpreting the event. The initial meaning of the event often changes, and sometimes, the person sees new possibilities as a result of the event. Nevertheless, in this mode, the narrative reconstruction is still a struggle. The event is accepted but not fully integrated in the life story, and the new possibilities are not fully embraced. In this mode, people may talk about the event using verbs that indicate a process of re-interpretation, such as "At the moment, I can accept it more than in the beginning" or "It is a part of my life now."

Finally, in the mode of *receiving*, the contingency of the life event and the new reality are acknowledged and the integration of the event in the life story is completed. In terms of Ricoeur's stages of mimesis [39], the third stage (refiguration) allows for new perspectives on one's life narrative and consequently changes in one's self-understanding. A process of transformation and reshaping has taken place, as a result of embracing the "new possibilities" that emerge from the life event. These new possibilities can be concrete and caused directly by the life event, such as queue jumping and access to front rows in theaters due to a disability. They can also be new insights that the life event has brought, considering what people find important in life, or their perspective on human life as a whole. It does not necessarily mean that the event is re-interpreted as something positive, and grief or loss is not mitigated or played down, but new possibilities are part of the re-interpretation. People can arrive at the mode of receiving by relating to the immanent world, but also by relating the event or the self-transformation to a transcendent dimension. In both cases, the person is receptive for that which cannot be rationally understood and for the new possibilities that emerge from the life event [124]. This may be seen as a form of self-transcendence: the person is pulled away from the focus on him-/herself, which changes the relationship with his/her environment and makes way for (seeing and embracing) new possibilities.

In this mode, people often refer to values that have become more central in their life. Past participles are used to express a completed process and a certain passivity in the narrative reconstruction, for example, "I have learned a lot from it" or "It has made me realize what I find important in life." These changes are the reason we hypothesize narrative integration to play a role in the shifts of meaning that lead to "response shifts" in QOL research (see page 42). In the mode of receiving, new perspectives on one's life may

be developed that change people's values, goals and priorities. The conflict between the life event and one's ultimate life goals may disappear or be mitigated as a result of changing ultimate life goals, or replacing instrumental life goals for others that allow them to still strive for their ultimate life goals.

After some time, life events can be given a definite meaning. However, its meaning – and, therefore, the degree of integration in the life story – remains subject to change. Moreover, new experiences in life may urge for a reinterpretation of the event. It should also be noted that narrative meaning making and integration are part of life and of growing older. We constantly reinterpret events in the context of our life story and adapt our identity to accommodate changes to a lesser or greater extent, consciously or unconsciously.

As illustrated above with the example of denying, it may be difficult to label statements about respondents' interpretations to represent one of the four modes of narrative integration, that are dynamic and fluid. In qualitative analysis, the whole interview with the respondents needs to be used as context to help the researcher interpret the statements regarding narrative interpretation. Quantitative assessment of these nuanced concepts will be even more challenging, as this context is missing.

Quality of life

As mentioned on page 21, QoL may have different meanings, depending on the type and aims of the research. In our theoretical model the definition of the WHO [41] is used, because its integration of the context of people's value systems, goals, standards, and expectations concurs with our approach of the impact of meaning making of life events on QoL, which is best understood in relationship with people's life narratives, including their worldview and life goals. While the definition centers around people's "position in life" and does not explicitly mention health, people's perception of their own position does include their perceived health and functioning. In the vocabulary of our model, QoL pertains to the way people appraise and make meaning of their own symptoms, limitations and abilities, overall health and overall QoL, in the context of their own situation, goals, expectations and life story. This is why meaning making may significantly influence people's QoL, as theoretical and empirical research in several disciplines suggests. And **as narrative integration may decrease or remove the conflict between one's ultimate life goals and a disruptive life event, it is hypothesized to influence QoL positively.** This influence could be one of the explanations of "response shift" leading to higher QoL scores than would be expected in cases of deteriorating health.

To facilitate research on the relationship between narrative integration and QoL, an item assessing overall QoL was included in the RE-LIFE questionnaire. In addition, a health-related QoL questionnaire was used in our study, assessing domains such as vitality, physical functioning, general health perceptions, bodily pain, mental health and social role functioning.

Hypothesized relationships between the concepts of the theoretical model

Clearly, the process of narrative meaning making of life events is complex, multilayered, and dynamic. The proposed model is meant as a framework from which testable hypotheses can be derived. The dominant relationships and feedback loops as denoted in Figure 2 all represent hypotheses that are yet to be tested empirically.

The first hypothesis is that an experience of contingency implies a conflict between a life event and ultimate life goals or worldview. This hypothesis is partly addressed in Chapter 4, in which the mediating role of “negative impact of the life event on life goals” is investigated in the relationship between the experience of contingency and QoL.

The second hypothesis is that an experience of contingency impacts QoL adversely. As argued before, an experience of contingency indicates an inability to make sense and meaning of the life event, conflicting with the fundamental human need for understanding, coherence and meaning. Because narrative meaning making takes time, it is expected that shortly after an event leading to an experience of contingency, people may experience lower levels of QoL. This hypothesis is addressed in Chapters 3 and 4.

Third, we expect that after an experience of contingency, a process of meaning making starts, in which the person re-interprets the life event in the context of his or her life narrative. If the event is attributed a meaningful interpretation in the context of one’s life story, the experience of contingency is expected to be reduced (the upper feedback loop in Figure 2) and QoL to be increased, compared to the time shortly after the event. This meaningful interpretation does not necessarily mean that the event is attributed a positive meaning. It means that in contrast to the “crisis of meaning” during the experience of contingency, the person has come to a certain degree of understanding the meaning of the event for his or her life as a whole. As an iterative process, narrative meaning making is expected to continue, as long as the experience of contingency (the crisis of meaning) is not reduced significantly. This hypothesis is partly addressed in Chapters 3 and 4, in which the relationship between the experience of contingency, aspects of meaning making, narrative integration and QoL are investigated empirically.

Fourth, we expect narrative meaning making to lead to narrative integration: the process of meaning making in the context of the person's life as a whole may result in the integration of the life event in the life story. We hypothesize that a more complete narrative integration of the life event (i.e. receiving) as a result of meaning making is expected to reduce the experience of contingency (lower feedback loop) and enhance QoL. Theoretical and empirical research in psychology and religious studies suggests that wellbeing is associated with the ability to integrate positive as well as negative experiences into one's life story and perception of the self. Because this association suggests that a more complete integration of negative experiences results in higher levels of wellbeing, we expect that more narrative integration results leads to higher levels of QoL. This hypothesis is partly addressed in Chapter 3, in which QoL scores were compared between patients who did and did not indicate to have "received" contingency (indicating narrative integration).

THE RE-LIFE QUESTIONNAIRE

To allow for empirical testing of our theoretical model and make a first step towards quantitative research into narrative meaning making and integration after experiences of contingency, we developed a self-report questionnaire: The “Reconstruction of Life Events” Questionnaire (RE-LIFE), see Appendix 1 at the end of this dissertation. The RE-LIFE Questionnaire is a first operationalization of the concepts of the model, designed to assess narrative meaning making of all life events, including falling ill. In the context of our longitudinal study on QoL, it was adapted for cardiac patients with multiple morbidities. The results of this study, providing information about this questionnaire’s validity, are published in separate articles, incorporated in this dissertation as Chapters 3 and 4.

Development of the RE-LIFE Questionnaire

The structure and items of the RE-LIFE Questionnaire were developed using an existing qualitative instrument, based on the “Analytical model for reconstructing interpretation of life stories” mentioned before [14, 16, 17, 46, 49, 102, 125]. This instrument consists of a topic list for semi-structured interviews about experiences of contingency caused by life events. The items were further developed using transcriptions of in-depth interviews with advanced cancer patients that were held using the qualitative instrument mentioned above [17]. The “narrative integration” scale was developed in a qualitative study described previously [112]. The questionnaire was then refined and adapted after pilot tests with 8 healthy volunteers and 12 cardiac patients, and using peer feedback from researchers and practitioners in the fields of medical psychology, religious studies, medical ethics, oncology, and cardiology.

Structure of the RE-LIFE Questionnaire

In order to enable respondents to reflect on their most important life events in the context of their life as a whole, the questionnaire starts with the request to draw a lifeline, with positive and negative life events as ups and downs [46, 49]. Questions are then asked about the most unexpected negative life event (identified by the respondent) and the acquisition of the disease as the second life event. The questionnaire enquires about worldview, ultimate life goals, experience of contingency, narrative meaning making, narrative integration, and QoL.

Depending on the aims and target population, the questions about the disease may be removed or adjusted. See Appendix 1 at the end of this dissertation for the full RE-LIFE Questionnaire.

OUTLINE OF THE THESIS

In *Chapter two*, our qualitative study will be presented. In this study, patients' experiences of contingency after being diagnosed with incurable cancer were explored using a qualitative analysis of in-depth interviews. Working with an analytical model of "dealing with contingency" (which was called "narrative integration" later in this study) based on Wuchterl's theory, we tested if these theoretical distinctions could be found in our qualitative data and if they should be adapted and complemented.

Chapter three presents the psychometric properties of the RE-LIFE Questionnaire, which was tested in a large-scale study among patients with stable coronary artery disease, six months after revascularization. The scale structure of the questionnaire will be presented, as well as relationships with background characteristics and criterion measures, such as QoL.

In *Chapter four*, we will present the results of a multiple mediation analysis that assessed the relationships between the concepts of our theoretical model underlying the RE-LIFE Questionnaire. For this study, the data of the three-month-assessment were used.

Chapter five presents a systematic review and meta-analysis on the effects of spiritual interventions, using a narrative approach, on the QoL of cancer patients.

Chapter six presents possible consequences of patient dispositions and shifts of meaning that lead to "response shifts" in QOL research or in healthcare settings. We analyzed the possible consequences for medical decision making in individual patient care and policy making, from a medical ethics perspective.

In *Chapter seven*, the previous chapters will be summarized followed by a general discussion, in which the added value of this study is evaluated and a few overarching topics are discussed.

“They had been talking about his friend Z. when she announced, “If I hadn’t met you, I’d certainly have fallen in love with him.”

Even then, her words had left Tomas in a strange state of melancholy, and now he realized it was only a matter of chance that Tereza loved him and not his friend Z. Apart from her consummated love for Tomas, there were, **in the realm of possibility**, an infinite number of unconsummated loves for other men.

We all reject out of hand the idea that the love of our life may be something light or weightless; we presume our love is what must be, that without it our life would no longer be the same; we feel that Beethoven himself, gloomy and awe-inspiring, is playing the “Es muss sein!” to our own great love.

Tomas (...) came to the conclusion that the love story of his life exemplified not “Es muss sein!” (It must be so), but rather “Es konnte auch anders sein” (It could just as well be otherwise).”

— **Milan Kundera**, “The Unbearable Lightness of Being”

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