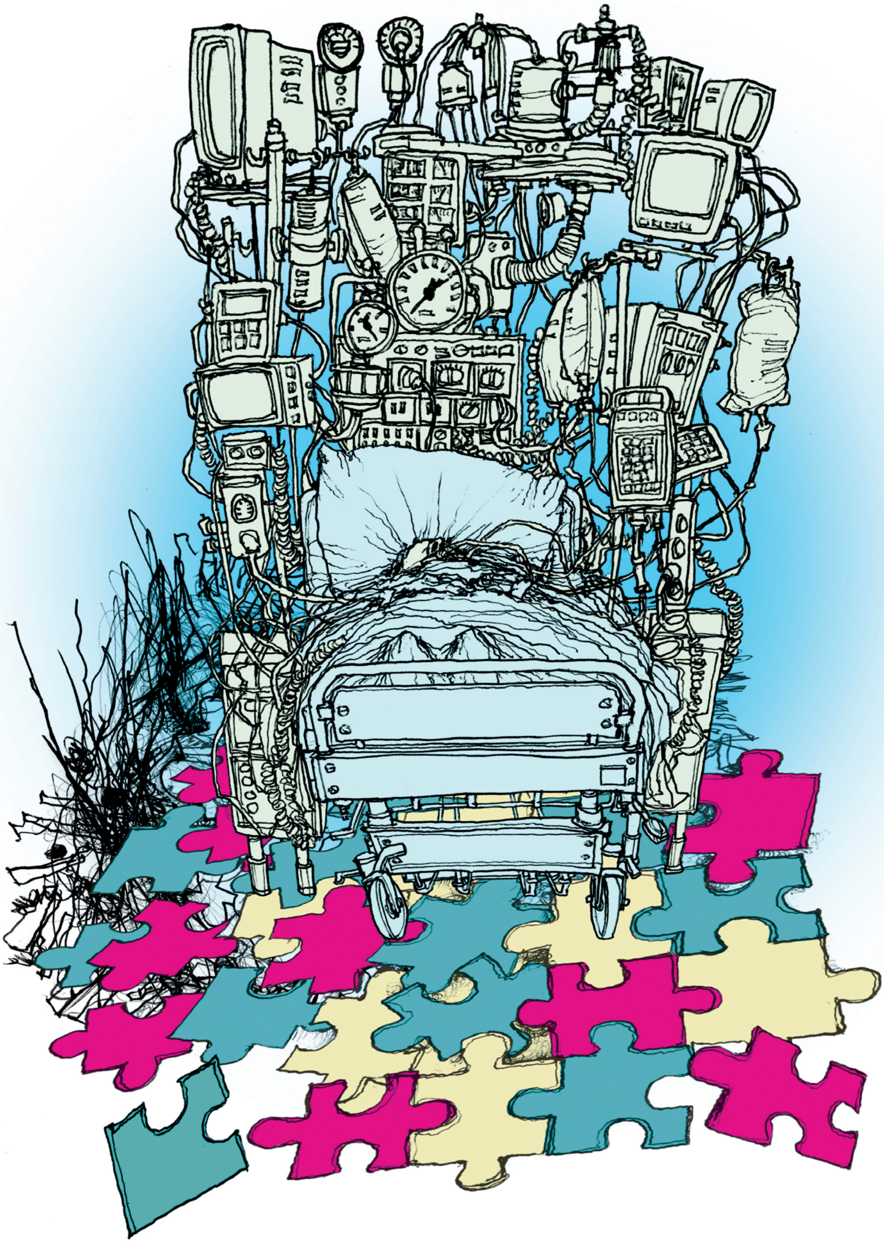
SHATTERED WORLDS AND NEW POSSIBILITIES

HOW NARRATIVE INTEGRATION OF CONTINGENT LIFE EVENTS INFLUENCES PEOPLE'S QUALITY OF LIFE



IRIS HARTOG

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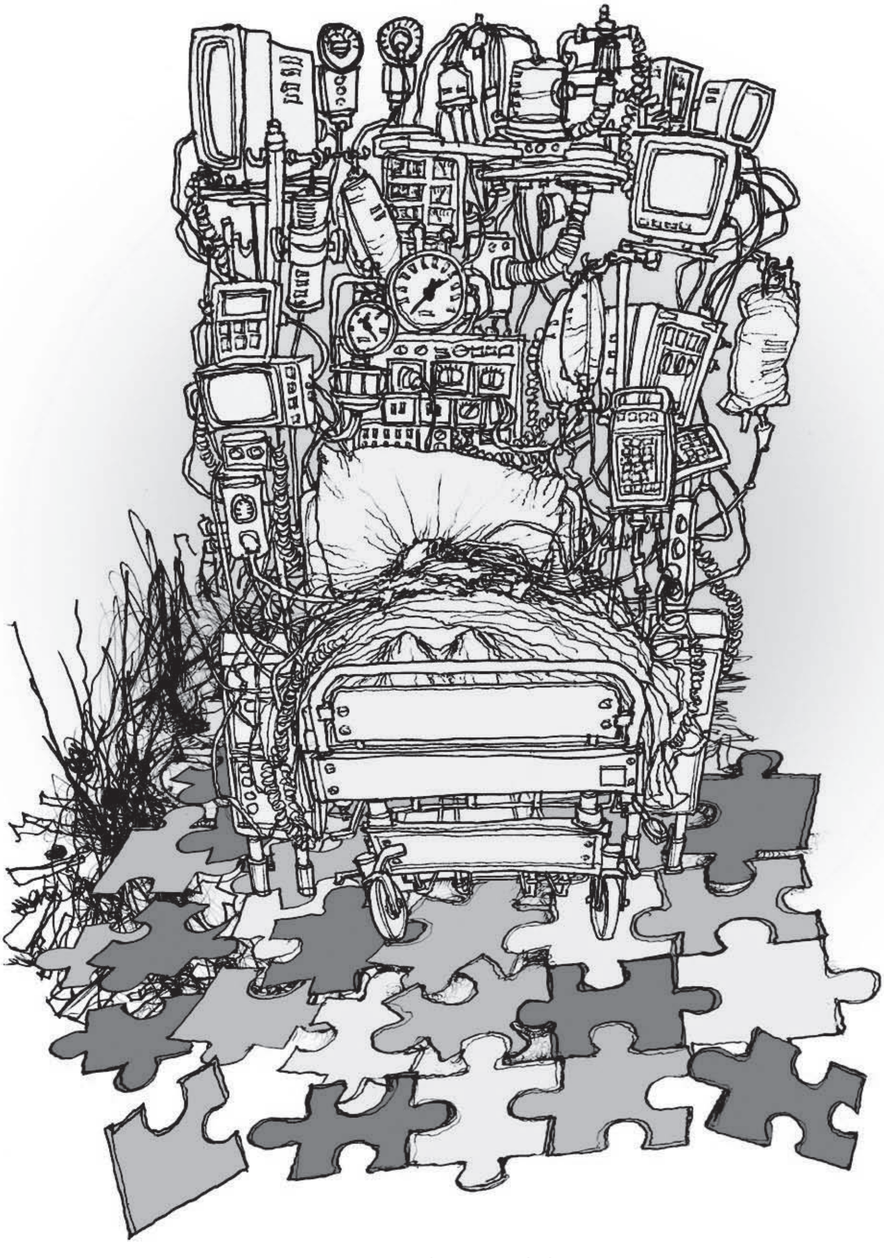

IRIS HARTOG

Shattered worlds and new possibilities. How narrative integration of contingent life events influences people's quality of life

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Shattered worlds and new possibilities

How narrative integration of contingent life events influences people's quality of life

Proefschrift ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
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“*When we are no longer able to change a situation –*
we are challenged to change ourselves.”

Viktor E. Frankl

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SAMENVATTING *(SUMMARY)*

Dit proefschrift gaat over ingrijpende levensgebeurtenissen die een "ervaring van contingentie" veroorzaken, en over de manier waarop mensen betekenis geven aan zulke gebeurtenissen en deze een plaats geven in hun levensverhaal. Sommige levensgebeurtenissen, zoals het krijgen van een ernstige ziekte, zijn moeilijk op een zinvolle manier te verbinden met de eerdere gebeurtenissen in ons persoonlijke levensverhaal en met de waarden en doelen die daarin centraal staan. Door de verbinding tussen onze identiteit en dat levensverhaal kunnen zulke gebeurtenissen, die tot een "breuk" in ons levensverhaal leiden, een "betekeniscrisis" veroorzaken en existentiele vragen oproepen. In de religiewetenschappen worden dit ook wel "ervaringen van contingentie" genoemd, die ons bewust maken van onze kwetsbaarheid en eindigheid, en ons confronteren met de willekeur van het leven. "Contingentie" verwijst naar deze willekeur van de wereld van alles dat daarin gebeurt. Het vertrekpunt van deze studie is het concept van "ervaring van contingentie" zoals ontwikkeld door religiefilosoof Kurt Wuchterl, die het omschrijft als het onvermogen om ingrijpende gebeurtenissen en hun toevalligheid te (be)grijpen, te plaatsen en er betekenis aan te geven. Volgens Wuchterl kunnen mensen op verschillende manieren omgaan met contingentie, afhankelijk van hun levensbeschouwing. Het concept "narratieve integratie" dat wij hebben ontwikkeld vanuit zijn theoretische onderscheidingen en ons empirisch onderzoek, brengt de twee betekenissen van contingentie samen die een centrale plaats hebben in deze dissertatie: 1) de willekeurigheid van levensgebeurtenissen die ons overkomen; en 2) de nieuwe mogelijkheden die zich kunnen openbaren in het proces van betekenisgeving en narratieve integratie.

Hoewel vele onderzoeken en verhalen laten zien dat negatieve levensgebeurtenissen zoals het krijgen van een ernstige ziekte een negatieve invloed hebben op KvL, blijken sommige mensen op opmerkelijk positieve manieren met zulke gebeurtenissen om te gaan, en een betere KvL te ervaren dan verwacht. Deze hoge niveaus van KvL worden niet veroorzaakt door het ontkennen van de gevolgen van ziekte en beperkingen, maar door zingeving en het vinden van nieuwe levensdoelen en perspectieven ondanks –of zelfs dankzij– de nieuwe levensomstandigheden en het leren omgaan daarmee. Een bevinding die hiermee samenhangt is dat in onderzoek naar gezondheidsgerelateerde KvL, dat verwijst naar de subjectieve waardering van de impact van ziekte en behandeling, patiënten soms verrassend stabiele niveaus van KvL rapporteren, ondanks duidelijke veranderingen in hun gezondheidstoestand. In dit proefschrift worden twee oorzaken hiervan besproken: 1) de relatief stabiele eigenschappen van mensen ("disposities"); en 2) verschuivingen in betekenisgeving, ook wel "response shifts" genoemd. Deze betekenisverschuivingen, bijvoorbeeld in het belang dat iemand hecht aan bepaalde levensdoelen (“herprioritering”), worden vaak in gang gezet door een gezondheidsverandering als gevolg van ziekte of behandeling. Hierdoor kunnen gezondheidsveranderingen aan het zicht worden onttrokken in studies die deze veranderingen juist in beeld willen brengen.

In dit proefschrift wordt een interdisciplinaire benadering voorgesteld van betekenisgeving in relatie tot KvL, waarin perspectieven en methoden van zowel de geesteswetenschappen als de medische wetenschappen worden geïntegreerd.

Het **eerste doel** van dit onderzoek was het ontwikkelen van een theoretisch model over betekenisverlening aan ingrijpende gebeurtenissen die een ervaring van contingentie veroorzaken, en hoe dit proces van invloed is op de ervaren kwaliteit van leven – een model dat tevens ons begrip van response shift zou kunnen vergroten. **Om dit doel te bereiken, wordt theorie over KvL en response shift gecombineerd met theorieën over contingentie en narratieve identiteit, inclusief de rol van levensbeschouwing en levensdoelen in de context van onze laatmoderne Westerse samenleving.** Daarnaast was het doel om kwalitatief te onderzoeken of de aan Wuchterl ontleende theoretische concepten van narratieve integratie kunnen worden onderscheiden in de empirie, en/of aangepast zouden moeten worden naar aanleiding van onze empirische bevindingen. Ons **tweede doel** was het zetten van een eerste stap in het operationaliseren van de theoretische concepten met betrekking tot ervaringen van contingentie en narratieve betekenisgeving in een kwantitatieve vragenlijst, en het testen daarvan onder patiënten. Het **derde doel** was het onderzoeken van de effecten van betekenisgeving-interventies (ook wel “spirituele interventies” genoemd) die een narratieve benadering hanteren. Het **vierde doel** was in kaart brengen hoe stabiele eigenschappen en betekenisverschuivingen in het proces van betekenisverlening aan ziekte van invloed kunnen zijn op medische besluitvorming, via hun invloed op patiëntgerapporteerde data (zoals KvL). De consequenties van deze invloeden werden vervolgens geanalyseerd vanuit een medisch-ethisch perspectief.

In **Hoofdstuk 1** wordt het theoretische model “Narratieve betekenisgeving en integratie van levensgebeurtenissen” gepresenteerd: Het krijgen van een ernstige ziekte is een *levensgebeurtenis* die conflicteert met iemands *levensbeschouwing* en/of met één of meerdere *ultieme levensdoelen*, die zijn verankerd in de levensbeschouwing. Dit conflict kan resulteren in een *ervaring van contingentie*. In het proces van *narratieve betekenisgeving* dat hierop volgt, wordt de gebeurtenis geherinterpreteerd in de context van het eigen levensverhaal. Uiteindelijk wordt de gebeurtenis in meerdere of mindere mate geïntegreerd in het levensverhaal *(narratieve integratie)*, wat invloed heeft op de ervaren *KvL*. Gebaseerd op dit model werd de Reconstruction of Life Events-vragenlijst (RE-LIFE) ontwikkeld (zie Appendix 1 aan het eind van dit proefschrift).

Hoofdstuk 2 gaat in op de vraag hoe patiënten betekenis geven aan hun “ervaringen van contingentie” na de diagnose van ongeneeslijke kanker. Hierin presenteren we de resultaten van ons kwalitatieve onderzoek naar de omgang met contingentie door mensen met uitgezaaide kanker. In een ontwikkel- en validatie-fase werden respectievelijk 23 en 45 diepte-interviews geanalyseerd, resulterend in vier modi van omgaan met contingentie: “ontkennen”, “erkennen”, “accepteren” en “ontvangen”.

In de modus van **ontkennen** is er geen sprake van een interpretatieproces dat wordt aangegaan. De contingentie en/of existentiële relevantie van de gebeurtenis wordt ontkend, waardoor er geen vragen opkomen of onbeantwoord blijven over (de oorzaak van) de gebeurtenis of de gevolgen ervan voor iemands leven. In de modus van **erkennen** wordt de contingentie van de gebeurtenis serieus genomen en geïnterpreteerd als een ontwrichting of “breuk” in iemands levensverhaal. Een interpretatieproces komt op gang waarin wordt gezocht naar de oorzaak van de gebeurtenis en de betekenis ervan voor iemands leven. In de modus van **accepteren** wordt actief gezocht naar manieren om de gebeurtenis te integreren in iemands persoonlijke levensverhaal, en krijgt de gebeurtenis een nieuwe betekenis. De narratieve reconstructie blijft in deze modus echter nog een worsteling. In de laatste modus, **ontvangen**, is de integratie van de gebeurtenis in het levensverhaal compleet. “Nieuwe mogelijkheden” die ontstaan door de gebeurtenis en/of door de herinterpretatie worden omarmd, zoals nieuwe inzichten als gevolg van de gebeurtenis.

Onze studie is de eerste die Wuchterl’s theoretische concepten met betrekking tot omgaan met contingentie empirisch heeft onderzocht, in een klinische context. De modi van omgaan met contingentie zoals gevonden in deze studie dragen bij aan ons begrip van narratieve betekenisgeving en integratie van ervaringen van contingentie, veroorzaakt door ontwrichtende levensgebeurtenissen zoals het krijgen van een ongeneeslijke ziekte. Onze bevindingen kunnen zorgverleners helpen om gerichter zorg te verlenen aan patiënten met ervaringen van contingentie, en deze zorg beter vorm te geven. Ook maken onze resultaten het mogelijk om de theoretische onderscheidingen te operationaliseren in een kwantitatief meetinstrument, om toekomstig onderzoek naar narratieve betekenisgeving en integratie van ingrijpende gebeurtenissen mogelijk te maken.

In **Hoofdstuk 3** wordt de tweede onderzoeksvraag beantwoord: Hoe kunnen we (omgaan met) ervaringen van contingentie en narratieve betekenisgeving en integratie kwantitatief onderzoeken? In dit hoofdstuk worden de psychometrische eigenschappen van de RE-LIFE-vragenlijst gepresenteerd, waaronder de schaalstructuur, de interne consistentie en betrouwbaarheid van de schalen, en de convergente validiteit van de twee belangrijkste schalen van de vragenlijst: “ervaring van contingentie” en “narratieve integratie”.

De RE-LIFE werd ingevuld door 237 patiënten met een hartaandoening, zes maanden na een behandeling aan het hart (“revascularisatie”). Principale factoranalyse resulteerde in zeven multi-item-schalen die vanuit de theorie geduid konden worden. Voor het concept “levensbeschouwing” werden twee in plaats van drie schalen geïdentificeerd: “transcendentie” en “absolute immanentie”. Eén schaal werd gevonden voor “ervaring van contingentie”, volgens verwachting. Voor “narratieve betekenisgeving” werden twee van de zes veronderstelde schalen onderscheiden, behorend tot het subconcept “reikwijdte” (“scope”) van de betekenis: “spiritueel” en “existentieel”. Ten slotte werden twee van de vier veronderstelde schalen voor “narratieve integratie” gevonden: “erkennen” en “ontvangen”. De interne consistentie van de schalen bestaande uit meer dan twee items was acceptabel tot betrouwbaar. Zoals verwacht, rapporteerden patiënten met een ervaring van contingentie lagere niveaus van KvL. Patiënten die aangaven contingentie te hebben “ontvangen”, wat duidt op narratieve integratie, rapporteerden meer posttraumatische groei.

Deze studie is een eerste stap in het operationaliseren theoretische concepten van narratieve betekenisgeving uit de religiewetenschap (“ervaring van contingentie” en “narratieve integratie”) in een kwantitatieve vragenlijst. De RE-LIFE is een veelbelovend instrument dat kwantitatief onderzoek op dit gebied mogelijk kan maken en dat geestelijk verzorgers kan ondersteunen in het helpen van mensen bij het integreren van ervaringen van contingentie in hun levensverhaal.

In **Hoofdstuk 4** wordt ingegaan op de derde onderzoeksvraag: Wat zijn de relaties tussen ontwrichtende levensgebeurtenissen, de ervaring van contingentie, ultieme levensdoelen, levensbeschouwing, narratieve betekenisgeving, narratieve integratie en KvL? We presenteren hierin de resultaten van een multiple mediatie-analyse waarmee de relaties werden onderzocht tussen de concepten van het theoretisch model dat ten grondslag ligt aan de RE-LIFE-vragenlijst. Hiervoor werden de data gebruikt va de vragenlijsten die drie maanden na de revascularisatie waren ingevuld. Met behulp van correlaties en bivariate regressiecoefficiënten werd bekeken welke variabelen voldeden aan de criteria voor mogelijke mediatie. Dit leidde tot twee modellen voor mogelijke mediatie met “ervaring van contingentie” als de onafhankelijke variabele, die vervolgens werden getoetst met regressie-gebaseerde seriële multiple mediatie-analyse.

De invloed van “ervaring van contingentie” op “erkennen” (geen narratieve integratie) bleek gedeeltelijk te lopen via de invloed ervan op “negatieve impact op levensdoelen” en “existentiële betekenis”, waarmee de veronderstelde relaties van Model 1 werden bevestigd. De invloed van “ervaring van contingentie” op KvL werd zelfs geheel verklaard door de invloed ervan op “negatieve impact op levensdoelen”, “existentiële betekenis” en “erkennen”, waarmee ook de veronderstelde relaties van Model 2 werden bevestigd.

Concluderend werden verschillende veronderstelde relaties binnen het theoretische model bevestigd. Onze resultaten suggereren dat ervaringen van contingentie leiden tot een worsteling om de gebeurtenis op een betekenisvolle manier in het eigen levensverhaal te integreren, wat een negatieve invloed heeft op de ervaren KvL. Ook blijkt dat narratieve betekenisgeving en integratie een significante invloed hebben op KvL. Op basis van deze resultaten is onze suggestie voor geestelijke verzorging, psychologische behandeling en psychotherapie om in te gaan op de existentiële kwesties die cliënten ter sprake brengen en om contingentie expliciet te benoemen en te bespreken. Mogelijke onderwerpen zijn bijvoorbeeld het ontwrichtende karakter van de gebeurtenis, en de onmogelijkheid om de (oorzaak van) gebeurtenis te begrijpen.

In **Hoofdstuk 5** staat de vierde onderzoeksvraag centraal: Wat zijn de effecten van interventies gericht op betekenisgeving (vaak “spirituele” interventies genoemd), die een narratieve benadering hanteren, op de KvL van patiënten met kanker? Om deze vraag te beantwoorden werd systematisch gezocht naar gerandomiseerde, gecontroleerde klinische studies (RCT’s) waarin spirituele interventies (gericht op existentiële thema’s en met een narratieve benadering) vergeleken werden met “standaardzorg”. De studies moesten KvL of “subjectief welbevinden” als uitkomstmaat rapporteren.

In totaal werden 4972 studies geïdentificeerd, waarvan 12 trials (1878 patiënten) konden worden geïncludeerd in de meta-analyse. De gebruikte uitkomstmaten in de studies varieerden, en het algehele risico op *bias* werd beoordeeld als hoog. Meta-analyse van de twaalf studies liet een gematigd positief effect zien op de algehele KvL 0-2 weken na de interventie, ten faveure van de spirituele interventies. Voor de meetmomenten tussen de 3 en 6 maanden na de interventie was dit effect echter klein en niet-significant. Subgroep-analyse van alleen de westerse studies liet een klein maar significant effect zien van de spirituele interventies vergeleken met de controlegroepen. Inclusie van enkel studies die voldeden aan het criterium van blindering van de randomisatie liet geen significant verschil zien tussen de interventie- en controlegroep. Ten slotte werd onderscheid gemaakt tussen levensloop-interventies (“life review”), multidisciplinaire interventies en interventies gericht op betekenisgeving, waarbij het grootste verschil in effect op KvL tussen de interventie- en controlegroep werd gezien bij de interventies gericht op betekenisgeving.

Concluderend kunnen we stellen dat spirituele interventies gericht op existentiële thema's met een narratieve benadering direct na de interventie een gematigd positief effect hebben op de KvL van kankerpatiënten, in vergelijking met een controlegroep. Er werd geen bewijs gevonden voor een blijvend positief effect na 3 tot 6 maanden. Gezien de aard van de interventies en de uitkomstmaten is het voorstelbaar dat spirituele interventies met een narratieve benadering effectiever zijn wanneer niet één sessie wordt aangeboden, maar een serie sessies. Nader onderzoek is nodig om beter te begrijpen hoe spirituele interventies zouden kunnen bijdrage aan een meer langdurig positief effect op KvL.

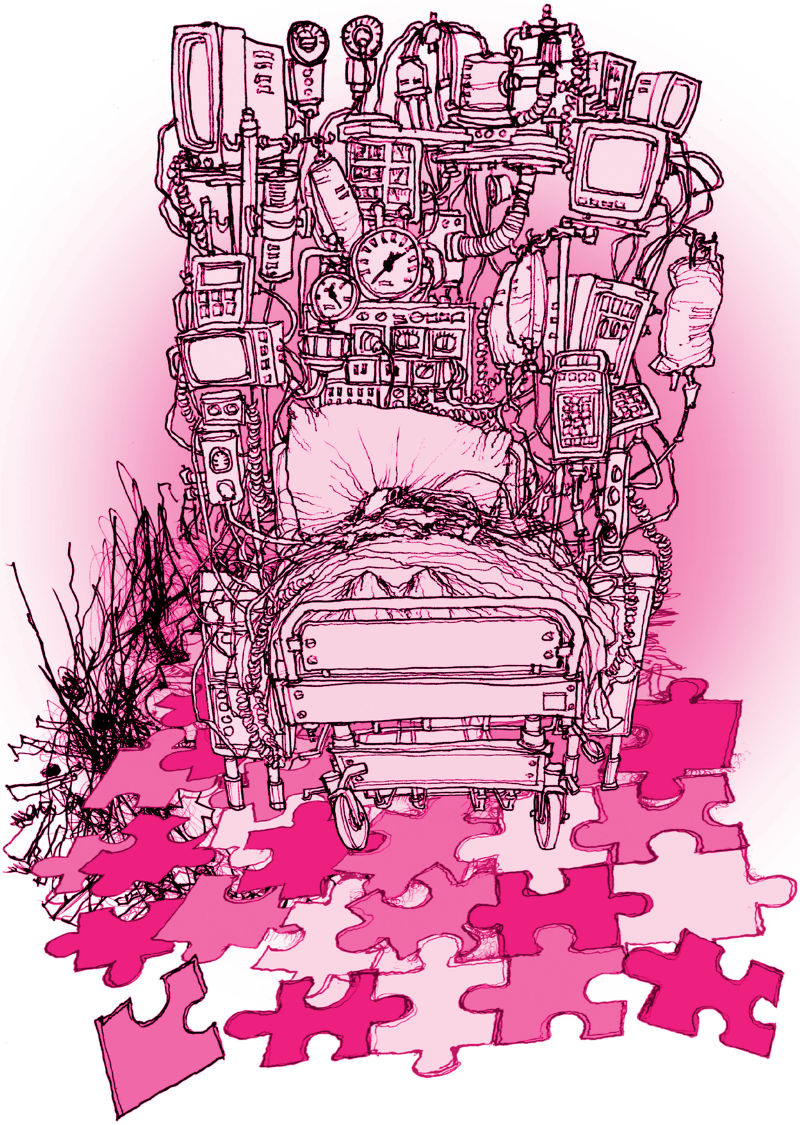
Hoofdstuk 6 beantwoordt de vijfde en laatste onderzoeksvraag: Hoe kunnen disposities en betekenisverschuivingen ("response shifts") patiëntgerapporteerde uitkomsten (PRO's) en als gevolg medische beslissingen beïnvloeden, en wat zijn de ethische implicaties van die invloed? PRO's worden veel gebruikt in medische besluitvorming, zowel op het niveau van individuele patiëntenzorg als op het niveau van gezondheidsbeleid. Steeds meer onderzoek toont aan dat PRO-data beïnvloed kunnen worden door response shifts (verschuivingen in interpretaties) en disposities (stabiele eigenschappen) van patiënten. In dit hoofdstuk worden de mogelijke, onbedoelde gevolgen voor medische besluitvorming voor individuele patiëntenzorg en voor de totstandkoming van zorgbeleid in kaart gebracht. Verschillende voorbeelden van deze gevolgen worden geanalyseerd vanuit een medisch-ethisch perspectief.

Op het microniveau worden drie *soorten invloed* van response shift of dispositie op gezamenlijke besluitvorming onderscheiden. De eerste soort is hun mogelijke invloed op PRO-data (van klinische trials) die worden gebruikt in het proces van besluitvorming. De tweede soort is hun invloed op de formele of informele zelfrapportages van de patiënt zelf. De derde soort is hun invloed op de voorkeuren van patiënten voor bepaalde behandelingen (of het afzien van behandeling). Deze invloeden kunnen als gevolg hebben dat individuele patiënten niet de meest optimale behandeling krijgen.

Op het macroniveau worden twee *soorten beleidsbeslissingen* onderscheiden die kunnen worden beïnvloed door response shift en dispositie. De eerste soort is het opstellen van behandelrichtlijnen voor specifieke aandoeningen, die aangeven welke behandeling de voorkeur heeft, gebaseerd op gegevens van klinische trials. Invloeden van response shift of dispositie op deze gegevens kunnen resulteren in suboptimale richtlijnen, bijvoorbeeld het aanbevelen van een behandeling die meer invasief is dan het alternatief, maar door response shift desondanks tot hogere niveaus van KvL leidt. De tweede soort betreft kosteneffectiviteitsanalyses gebaseerd op data van klinische trials, om te bepalen welke behandelingen wel en niet vergoed worden vanuit de basisverzekering voor gezondheidszorg. Voor deze beslissingen worden PRO-data gecombineerd met "utiliteitstarieven", om de utiliteit van een behandeling te bepalen in termen van QALY's (voor kwaliteit gecorrigeerde levensjaren). Deze tarieven geven weer hoe het algemene publiek bepaalde gezondheidstoestanden waardeert die door patiënten zijn beschreven. Als gevolg kunnen zulke kosteneffectiviteitsanalyses tot andere conclusies leiden dan wanneer de utiliteitsscores van patiënten zelf zouden worden gebruikt. Scores van patiënten zelf zouden namelijk beïnvloed kunnen zijn door response shift, geïnduceerd door hun ziekte-ervaring.

Wanneer er geen rekening wordt gehouden met invloeden van response shift en dispositie op PRO-data en vervolgens op medische beslissingen, is het mogelijk dat patiënten hierdoor niet de meest optimale behandeling krijgen. Ook worden hierdoor mogelijk niet de meest effectieve of kosteneffectieve behandelingen opgenomen in de vergoedingen vanuit de basisverzekering voor gezondheidszorg. Zorgverleners, onderzoekers, beleidsmakers, zorgverzekeraars en andere belanghebbenden dienen kritisch te kijken naar de redenen om patiënt-rapportages te gebruiken en naar de manieren waarop zij worden gebruikt.

In **Hoofdstuk 7** komt een aantal algemene discussiepunten aan bod. Hierin wordt onder andere besproken hoe geestelijk verzorgers en therapeuten "contingentiecompetentie" kunnen inzetten om hun cliënten te helpen nieuwe mogelijkheden te zien, en de vraag besproken of alle mensen (in gelijke mate) "narratieve wezens" zijn. Ook wordt de mogelijke relatie besproken tussen response shifts en levensdoelen, en de vraag opgeworpen of we "kwaliteit van leven" narratief zouden moeten conceptualiseren, bijvoorbeeld als "narratieve integratie". Tot slot worden mogelijke richtingen voor toekomstig onderzoek geschetst, waarbij onder andere narratieve integratie wordt voorgesteld als relevant concept voor onderzoek op het gebied van "narrative foreclosure", het zelfgekozen levenseinde en "voltooid leven".



1

GENERAL INTRODUCTION

This chapter is an expanded version of:

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Contribution of the author of this dissertation:

The author designed and wrote the first draft of the article and revised several versions of the chapter based on feedback of all co-authors. The extended version was also designed, written and revised by the author, based on feedback of MS-R, MS, HvL and PN.

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 disruptive 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 ill[1]. 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,

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[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 study[2], 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-

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[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 (*zingeving* 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 also include societal crises or situations of war and conflict, and even situations of "undeserved" luck[4]. 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

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[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 transcendence 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 framwork 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]

	Situational		***Existential***		***Religious***	
	Positive	*Negative*	*Positive*	*Negative*	*Positive*	*Negative*
Active	Achievement	Failure	Duty	Guilt	Calling	Sin
Passive	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 reseach 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 coherence[5] [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,”

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[5] “Salotugenesis”, 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, depresion 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 reseach 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 mentionned 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 dispositions. 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

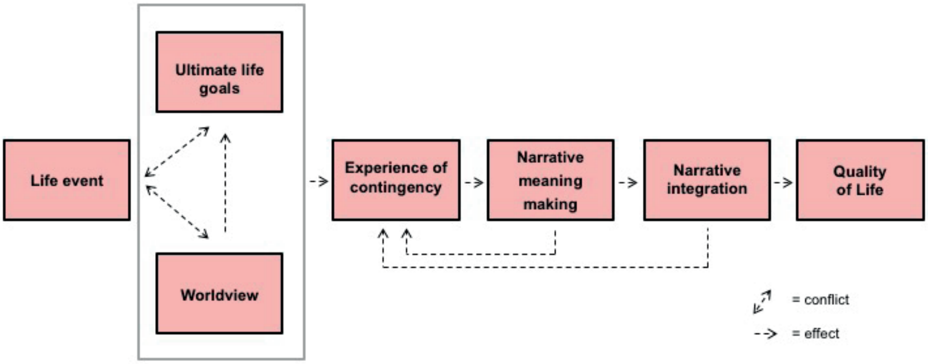

Figure 2. Theoretical model: *narrative meaning making of life events*. The dominant relationships and feedback loops are highlighted.

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 making[6] 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 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

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[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 wat 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 contex 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 explicitely 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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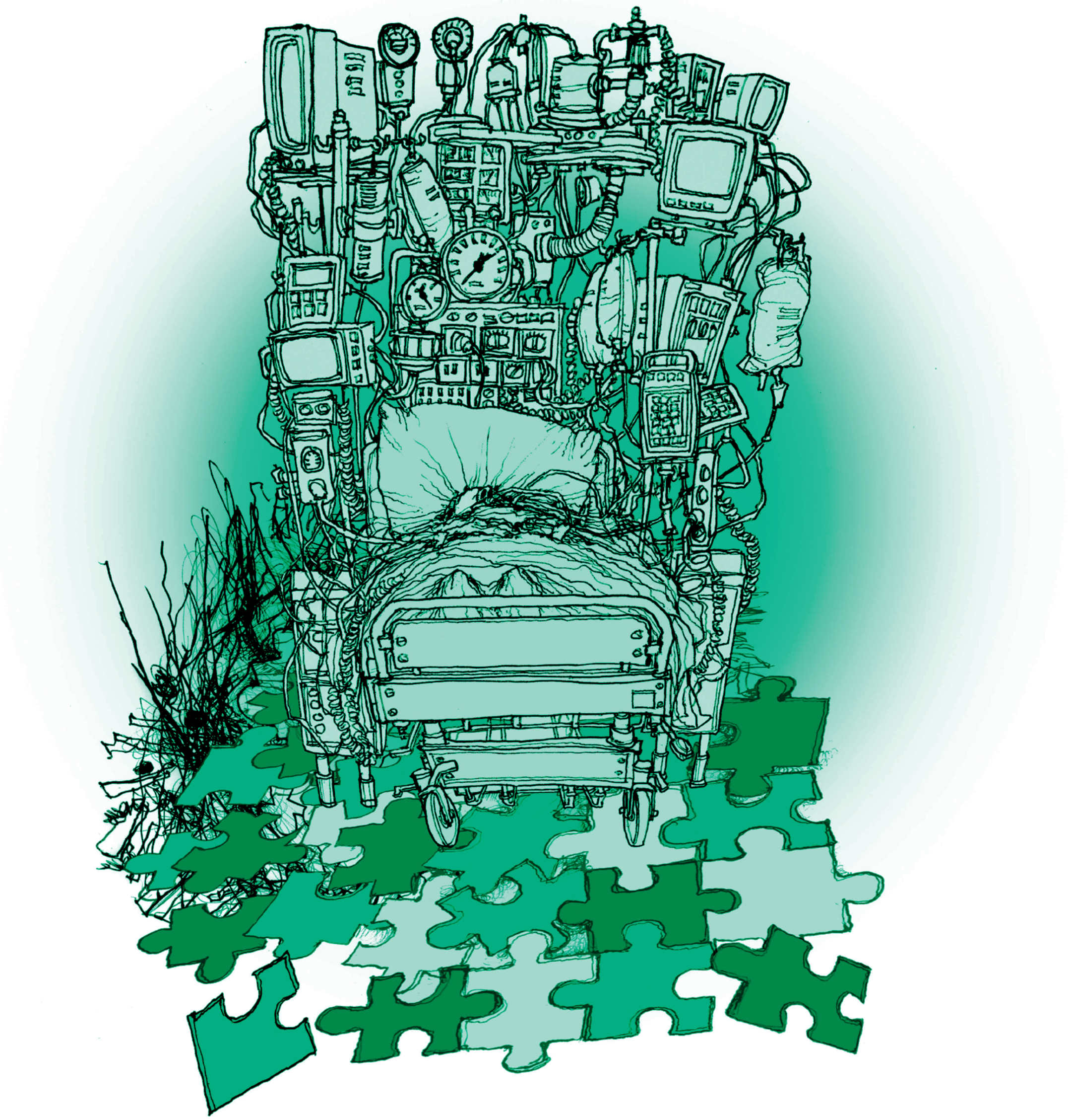

2

MODES OF RELATING TO CONTINGENCY

This chapter is based on:
Kruizinga R*, Hartog ID*, Scherer-Rath M, Schilderman BAM and HWM van Laarhoven. ***Modes of relating to contingency: An exploration of experiences in advanced cancer patients.*** Palliative and Supportive Care, 2017, 15(4): 444-453. * = shared first authorship

Contribution of the author of this dissertation:

The author participated in the conception and design of the study and the analysis of the data. In addition, the author revised several versions of the article (first draft written by RK) and read and approved the final manuscript.

ABSTRACT

Objective

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

Method

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

Results

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

Significance of results

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

INTRODUCTION

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

In traditional communities of the 19th century, actions and choices were constrained because each individual was anchored within the binding structure of social, cultural, and political norms and values, so that the integration of adverse events was taken care of within the community [11]. In our current and more liquid modern times, the identity of people is not so clearly determined by these grounding structures [12, 13]. People define themselves less in social terms and increasingly construct and justify their lives in terms of narratives that support self-control [1, 14]. This allows them to create their own structure of plausibility from which they interpret daily life. The creation of such a structure requires the making of a story [15, 16]. A story creates a context in which events of the past, present, and future are fused into a plausible whole that serves the personal goals that one pursues.

Thus, the activity of linking these events by describing what has happened enables people to understand the meaning of these events [17]. Construction of life narratives is an ongoing process that locates the narrator in the middle of his story, thereby maintaining a continuous process of self-interpretation [18, 19]. The need for these explanatory narratives is even stronger when specific life events force the development of a whole new storyline. Life crises can mark the start of reflection and evaluation of questions about who we are and where we go in life [18, 20].

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

This notion of contingency as described by Wuchterl is not a general psychological notion, although it touches upon different concepts within (health) psychology. Much research has been carried out in the field of coping, describing how people deal with unexpected life events [23-28]. Pargament and others have distinguished a specific form of coping – religious coping – which may positively or negatively contribute to dealing with severe life events [29-32]. In addition, resilience research seeks to answer the question of why some people cope more effectively than others with certain situations [27, 33]. The common denominators in all these approaches are that they are based on stress theory and that they deal with mechanisms of appraisal and adaptive behavior, primarily focusing on how people function. Contingency theory, however, is a specific religious-philosophical approach that deals with the content of how people evaluate situations in relation to their worldview. This evaluation is crucial in the understanding of how people deal with critical situations. Contingency theory can be a valuable addition to the concepts and approaches within (health) psychology since it adds notions of purpose and intent to the functionalist approach of coping-based theories.

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

Wuchterl describes two ways in which people can relate to contingency, that is, narratively integrating these experiences into one's story of life. He describes these ways as “acknowledging” and “encounter with the Other.” People who acknowledge that the world itself is ontologically contingent recognize the fact that unexpected things can happen that cannot always be explained. Questions remain open, and there is space to relate to something beyond our tangible world. An “encounter with the Other” refers to an encounter with something that is beyond human understanding and intelligibility.

This possibility is called a “contingency encounter,” although that which is encountered is the “Total Other.” This encounter creates, as it were, the openness for new possibilities and opportunities. One is open to passively receive things that might happen or insights that might arise from this “new reality.” The different ways of relating to contingency as distinguished by Wuchterl have not yet been examined in clinical practice. Here we aim to examine if we can trace these theoretical distinctions – denying contingency, accepting contingency, encounter with the Other – empirically in the experiences of patients with advanced cancer.

METHODS

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

Development Phase

As a conceptual starting point, we used Wuchterl’s trichotomy (denying, acknowledging[7], encounter), where after 23 interviews with advanced cancer patients had been analyzed. The interviews were conducted by spiritual counselors using a semi structured interview method exploring the patients’ experiences with cancer, as described earlier [34].

The constant comparative method was employed with a directed content analysis approach, while our analyses started with a theory as guidance for the initial codes [35] and making use of the Atlas.ti coding program [36]. We started with the formation of categories, subsequently establishing boundaries, and ended with summarizing the content of each category in a one-page document [37, 38]. Based on these analyses, we came to distinguish four modes of relating to contingency: denying, acknowledging, accepting, and receiving. To improve the quality of the code descriptions, we organized a peer group meeting with eight researchers from Radboud University Nijmegen. These included two professors of pastoral theology and religious studies and six doctoral students working on different projects within practical and empirical religious studies.

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[7] In the published version of this article, we erroneously used the term “accepting” instead of “acknowledging.”

Using their feedback, we improved the code descriptions and defined more strict inclusion and exclusion criteria.

Context of the study

The interviews used for validation of our model were conducted by seven spiritual counselors working in different hospitals. Four of them had Roman Catholic backgrounds, two were Humanists, and one Protestant. All counselors had more than seven years' experience working in a hospital setting. Their experiences with the interview method and the study protocol of a randomized controlled trial (RCT) have been described elsewhere [39, 40] In short, the spiritual counselor asks the patient to draw a lifeline from birth until the present, with highs and lows indicating important life events. The patient chooses three important life events, which are discussed in more detail, and their expectations for the future and life goals are discussed. The spiritual counselors were trained by our research team to examine the experiences of contingency caused by these life events. In the present analysis, we examined one of the three life events identified by all patients, namely, the life event of having incurable cancer.

Validation phase

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

Design of the study

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

RESULTS

Patient demographics are provided in Table 1. Twenty-one males and 24 females were included.

Table 1. Patients' demographics

Sociodemographic characteristics	N 45	% 100
Age		
Mean, SD	60	12
Gender		
Male	21	47
Female	24	53
Education		
< Compulsory	11	24
> Compulsory	34	76
Work		
Working	17	38
Not working	28	62
Living arrangement		
Married	33	37
Living with partner	6	13
Living alone	6	13
Religious affiliation		
Roman Catholic	8	18
Protestant	8	18
Other Christian	5	11
Humanistic	6	13
Atheistic	3	7
Non-religious	15	33

All patients had Dutch nationality, and their mean age was 60. The four codes indicating the four different modes that resulted from our analysis are described below. All quotations are derived from the 45 analyzed interviews that were held as part of an RCT (see Table 2).

Table 2. Quotes

Quote 1 - Denying	Yes, but what is that diagnosis? It is a pure low point when you are told you have cancer, but I don't want to have it. I want to keep going, I'll fight for it, too. I'm still very active in everything. (male, 72, gastric cancer)
Quote 2 - Denying	I didn't want to be written off or anything, I was very ill. And I still have that. I almost never tell people that I'm sick. Because then they think "Oh I don't have to invest in her because she's going to die anyway," or something like that. You know, that kind of feeling. So I just wanted to go on and that's just what I did. (female, 68, neuroendocrine tumor)
Quote 3 - Denying	I: What are important life goals for you? P: Well to keep living for a while. That the cancer doesn't get the better of me. [...] I've arranged everything. […] So it's all on the computer, and if the computer crashes, it's all on a USB stick. Everything is settled. [...] It doesn't dominate my life, though. That wouldn't be good. (male, 64, kidney cancer)
Quote 4 - Acknowledging	Yes, when I heard I was sick. Then everything…, everything changed. [...] Your plans for the future, everything is uncertain. (female,62, gynecological cancer)
Quote 5 - Acknowledging	If they had told me, "You are sick and it is," so to speak, "lung cancer because you have smoked all your life and lived in the wrong way," then I would say okay. But in this case, I just think, "Well… […] a low point, that is something you don't expect. Then you just think it's over. It's done." (Male, 65, gastric cancer)
Quote 6 - Acknowledging	I just didn't understand it. I was really angry about it, yes. Well, don't get me wrong – I don't blame the doctors. But you just think, "Why me again?" "Why does this happen to me for the second time?" Well, nobody can answer that question, neither can I. […] So I let go of it, because it doesn't make sense trying to figure it out. […] I just have to learn to deal with it. (male, 60, bone cancer)
Quote 7 - Accepting	That's a big cliché of course, but yeah, "That's not possible, that can't happen to me. That counts for everyone else, but not for me." I: It shouldn't? P: Well, shouldn't… […] but I accepted it pretty quickly. Really accepted. I thought, "Why should I complain? I'm already 62, such a nice husband, lovely children. […] I have a beautiful life, had a beautiful childhood." I wouldn't know what I could actually give as a reason for why I should be one of the lucky ones not to be affected by the disease. (female, 65, breast cancer)
Quote 8 - Accepting	But that's a whole process of letting go of everything. It doesn't happen automatically. […] I've learned to go deep, really learned how to go deep. Just crying, weeping, shouting it out when I can't manage anymore. God has abandoned me – that kind of feeling. And yet still to pick yourself up again and fight when you have to fight. But you can't keep fighting, and you can't keep going deep. (male, 35, brain cancer)
Quote 9 - Accepting	And I also knew it had helped me get a better understanding of myself. Through the disease, by being confronted with myself when lying on the couch for days in pain, during sleepless nights in agonizing pain, then you start thinking about yourself. Then you start changing things. You notice that some things are not good. And you also see things differently. You start seeing the world differently. […] I really try to go with the flow now. It's difficult, but I have learned from it. […] I've done something with it, and it has brought me something too. Sometimes the lesson is hard. (female, 68, neuroendocrine tumor)
Quote 10 - Receiving	I do believe that I have to go through this. I believe this, and that it happens for a reason. But that you have to learn something valuable from it. Or change your whole life. At least, do something with it. Not just go on like before. (female, 24, gynecological cancer)

Table 2. Quotes (continued)

Quote 11 - Receiving	I'm natural now. I have a much more positive outlook on life and enjoy a lot more things. You know, things used to be just normal. You take everything for granted. […] I think that what this whole thing of being ill has brought me is that I think a lot more about the spiritual side of things. Not that I am suddenly religious or anything. I don't believe in God. I always believed that there is something more but not really by definition a god. But I think about it a lot more now. (female, 24, gynecological cancer)
Quote 12 - Receiving	P: A chance, yes I think so. To develop myself. To change myself. […] I think in your life things happen to you so you can do something with them. So developing yourself in a better way or getting a different perspective on life or whatever. I: Different perspective, that means..? P: Uh yea. To do something with it, what has happened to you. How I see it now. I can talk easily about my breast cancer and when I see how others react to it, I think, "Yes. I am doing something with it, I'm trying to help other people with it." (female, 53, breast cancer)

Development phase

In our analysis, we focused on the three conceptual distinctions proposed by Wuchterl: denying, acknowledging[8], and "encounter with the Other." In our data, we found a lot of statements that indicated acknowledgment and reinterpretation of the contingency of the event, but without full acceptance and integration. These statements did not fit the definition of "acknowledging," nor that of "encounter." Therefore, we defined the additional code of "accepting." Also, for the description of Wuchterl's "encounter," we found that patients talked more about "receiving" something rather than "encountering" something, so we labeled this mode "receiving."

Mode 1: Denying

In the analyzed interviews, patients who talked about their experiences such that they were not engaging in an interpretation process were categorized as "denying" the contingency. Most of the time, denial of contingency is seen in that which is absent, for instance, in a lack of existential questions, rather than clear statements of denial. We did find some statements of patients who did not want "it," or did not want to talk about their cancer, pushed it aside, or emphasized their activeness to live on as they did before (quote 1) (see Table 2). In contingency denial, the patient has not started or has aborted the interpretation process; there is no real confrontation with one's own vulnerability or the limits of one's own abilities (quote 2). Sometimes a definitive explanation of the event is given or the existential meaning of the event is denied, leaving no questions about the event or its cause.

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[8] This paragraph differs slightly from the published version of this article because we had erroneously used "accepting" instead of "acknowledging" there.

This denial is associated with coping, as defined in medical psychology. Coping can be seen as a strategy to restore the balance in life as soon as possible, in order to be functional again and continue with life, thereby avoiding an interpretation crisis (quote 3). The phrases used in the case of contingency denial are often formulated as rationalizations or statements that express the respondent's lack of need to ask questions or need to understand the cause of an event. It most often reveals itself by that which is lacking, when no questions are asked and no process, ultimate meaning, or references to the existential domain are discussed (quote 4). Some patients talk about pure bad luck, but later on also talk about their struggles to incorporate this "bad luck" into their lives. Therefore, statements that mention "chance" or "bad luck" should not automatically be linked to the code of denial. Statements about the existential meaning of this "bad luck" indicate that the interpretation of "bad luck" is the result of a search for a meaningful interpretation and not a definitive answer that immediately halts the interpretation process.

Mode 2: Acknowledging

When contingency is acknowledged, the experience of contingency is "taken seriously," and it is recognized as an event that has an impact on one's life as a whole (quote 5). No definitive explanation is given for the event, but a process of interpretation has been set in motion, searching for the cause and meaning of the life event. The event raises questions that cannot be answered immediately. Important in the acknowledgment of contingency is seeing the non-necessity and non-impossibility of the situation. It is recognized that it goes beyond one's understanding to grasp the cause of the event, but there is a need to relate to something that lies beyond one's capabilities. Asking questions about the cause of the event (e.g., "Why me?" "Why now?" "Why did this happen?") is seen to be a key element in this mode of acknowledging (quote 6). Acknowledgment of contingency is only the first step in the narrative interpretation process, an attempt to place the event within one's life story. The experience of contingency is confronted, and the impact and significance of the event for one's life as a whole are recognized. However, the event is not accepted and not yet integrated into one's life story (quote 7). The phrases that are used to describe this can be formulated as verbs relating to how it should be or what they have to do.

Mode 3: Accepting

In the mode of accepting contingency, not only the contingency of a life event is acknowledged, but also the new reality that comes with it is recognized and accepted as a part of the person's life after the event. This acceptance is one step further toward an integration into the personal life story and in the direction of a new reality (quote 8). In this mode, the statements are more passively formulated compared to the previous mode. The struggle to place the event into the whole life story is also part of acceptance (quote 9). Accepting the contingent life event goes one step beyond acknowledging, because the event is now also an integrated part of one's life. Sometimes this is still a struggle, but in some cases new possibilities are seen and discovered. However, this is only the beginning of the learning process; full integration of this new opportunity is only completed in the mode of "receiving." In accepting, the patients are actively looking for a way in which the event can be integrated into their life. This is often expressed in the form of a process, with the use of verbs, for example, "learning, accepting, seeing." In this mode, the reinterpretation of the event and the significance for one's own life are clearly stated (quote 10).

Mode 4: Receiving

In contrast to "encounter," as defined by Wuchterl, we observed an attitude of receiving: that what is received often concerns patients' ultimate life goals. In this mode of relating to contingency, there is full integration of the event into one's life story. The phrases that are used often denote transformation and deriving new insights, influencing the choices made in life. Patients refer to values that have become more important – for example, being more conscious or aware in life, taking more enjoyment from the here and now, having more meaningful relationships. Such phrases are mostly formulated in the past tense (quote 11). Patients in the mode of receiving often talk about insights they have received from relating to the contingency of an event. They also talk about something that transcends our tangible world – for example, "it happens for a reason" or "someone/some power did this." This transcendence has a broad meaning. It can be something abstract, like "the universe," "the unknown," or the "ultimate good," and some people call it "a higher power/God" (quote 12). In the mode of receiving, "new possibilities" are central, there is space in which to act, and it is preceded by a process of transformation and creation of new insights. There is not only the acknowledging of the world's ontological contingency, but it is a real encounter with "the other side": that which we cannot know and cannot see (quote 13).

Final model

If we look at the four modes, their definitions (see Table 3) and their implications for different dimensions of life, we come to a schematic representation (see Figure 1). The red circle at the bottom of the figure represents a contingent life event. A life event can have a situational meaning for the person in the here and now. It can also have a more existential meaning for a person in terms of his/her life as a whole. Sometimes a life event can have a spiritual meaning for a person, regarding a higher reality. At the left, these three dimensions are specified. The first mode –denying– bends to the right because it represents not acknowledging the impact on one's whole life. When an interpretation process is begun, it is the first step toward integration. This is the second mode – acknowledging. The blue arrow symbolizes a process moving toward full acceptance. In the mode of accepting, there is room for reinterpretation of a life event; hence the black arrow. At the end of the model, the mode of receiving is placed in the dimension of a higher reality, discovering the new possibilities and new insights.

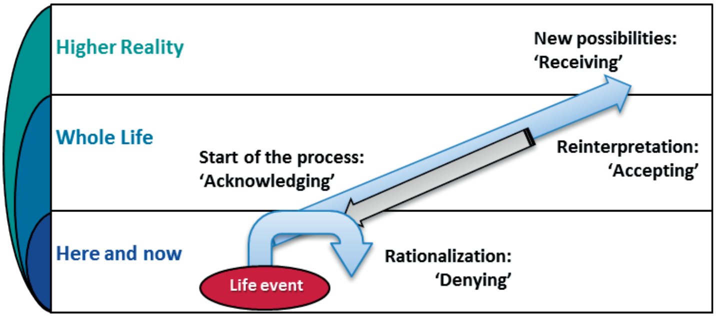

Figure 1. Schematic representation of the four modes.

Table 3. Definitions of the different modes of relating to contingency

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

Validation phase

To test the final code descriptions, an IRR was performed and the calculated value of Cohen's kappa was 0.83, which can be interpreted as "very good agreement" [41]. Of all the interviews (n = 45) that have been encoded, only two were assigned the code of "denying," and two were assigned the code of "receiving." Most (n = 24) were assigned the code of "recognizing," and many were assigned the code of "accepting" (n = 17). We did not observe major differences between the four different modes and the sociodemographic characteristics (see Table 4).

Table 4. Results of the validation phase

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

DISCUSSION

Our study is the first to investigate the theoretical distinctions put forward by Wuchterl regarding the experience of contingency in a clinical setting. The described modes of relating to contingency will make it possible to understand the experiences of cancer patients and allow caregivers to better target and shape individual care. Caring for the existential issues of patients is usually referred to as spiritual care. Spirituality can be an important element of the way patients face chronic illness, suffering, and loss. Spiritual care begins by truly listening to patients' hopes, their fears, and their beliefs and to incorporate these beliefs into the therapeutic plan [42]. This careful listening is a first step toward understanding and subsequently toward an accurate diagnosis of a patient's ability to relate to contingency. A proper diagnosis is a precondition for good counseling in dealing with a possible interpretation crisis. This is especially important when it comes to a severe interpretation crisis [43]. Unmet spiritual needs can lead to depression and a reduced sense of spiritual meaning and peace [44]. It is important to first recognize spiritual needs and to then understand those spiritual needs in all their forms and appearances.

In contrast to Wuchterl, who reserved much space for the description of “denial,” we found indications of this mode of relating to contingency in only two interviews. This discrepancy can have different explanations. First, our study only looked at the life event of having incurable cancer. In other cases, patients might be more inclined to ignore the contingency than in the case of our major event. Second, people who tend to ignore contingency might not be the people who are most likely to participate in studies on talking about their lives [45]. Therefore, the numbers in our study indicating the four different modes should not be used to draw conclusions about more general circumstances. Future studies in different patient populations and examining other life events could enhance our findings.

It should be noted that an interview fragment only represents one particular moment during which the patient reflected on his or her experiences of contingency. Therefore, our findings should not be understood as fixed states, but as modes between which patients can pass back and forth. The different modes may necessitate different approaches to spiritual care. For instance, patients in the mode of denying contingency are more likely to be resistant to the kind of help that focuses on the meaning of a life event in their lives, as they do not recognize this line of thinking. In contrast, patients who are in the mode of receiving are less likely to benefit from help that gently tries to allow the patient to see that the event can have implications for their lives, as the patient has already discovered a new reality and new possibilities resulting from the event.

Our finding of four different ways of relating to contingency gives insight into where a patient can be in terms of relating to existential questions and affords an opportunity to understand the questions that may arise in the different modes. However, this is just the first step in understanding the experience of contingency in advanced cancer patients. We do not yet fully understand the relationship between the different modes, and we do not know whether patients can go through different modes and the direct implications for spiritual care.

Future research is needed to investigate whether these different modes also correlate with the overall wellbeing of patients. Other studies have shown that negative religious coping is associated with poorer quality of life [46, 47], that existential and spiritual domains are related to suffering and quality of life [48], and that spiritual interventions addressing existential themes using a narrative approach can enhance quality of life [34]. Therefore, in addressing spirituality, we believe that an awareness of the contingency of life should gain more attention and be employed as a basic understanding when considering life itself.

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

Strengths and limitations of the study

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

In conclusion, if we want to improve spiritual care in the healthcare setting, we must understand the existential needs and experiences of these patients. Our study provides insight into the essence of the experiences of advanced cancer patients by testing theoretical notions in practice.

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Conflicts of interest

The authors hereby affirm that they have no other conflicts of interests to declare.

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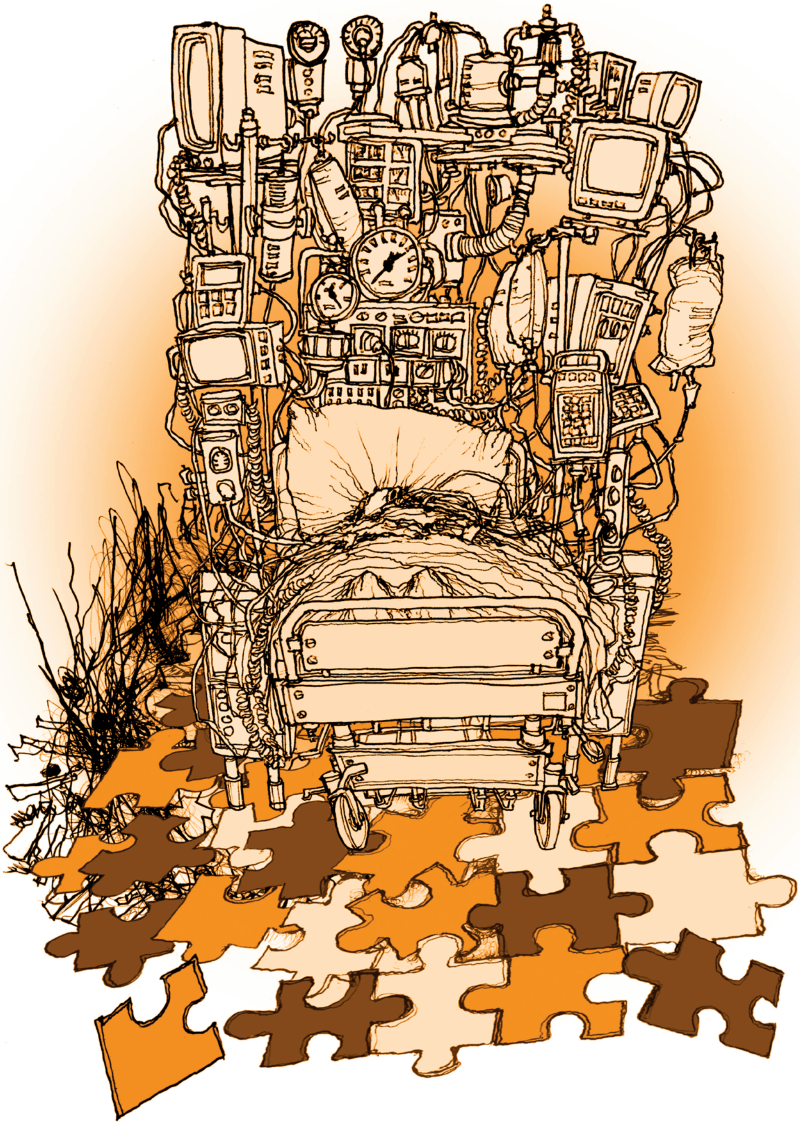

3

PSYCHOMETRIC PROPERTIES OF THE RE-LIFE QUESTIONNAIRE

This chapter is based on:
Hartog ID*, Oreel TH*, Scherer-Rath M, Netjes JE, Vonk ABA, Lemkes JS, Henriques JPS, Sprangers MAG, Van Laarhoven HWM, and PT Nieuwkerk. ***Experience of contingency and narrative integration after a cardiac intervention: psychometric properties of the Reconstruction of Life Events Questionnaire (RE-LIFE).*** *Submitted*. * = shared first authorship

Contribution of the author of this dissertation:

The author participated in the design, planning and organization of the empirical study and in the data collection and interpretation of the data. In addition, the author wrote the first draft of the article and revised several versions based on feedback of all co-authors.

ABSTRACT

To enable research on the process of integrating an experience evoked by a disruptive life event (an experience of contingency) into one's life story, we developed the Reconstruction of Life Events questionnaire (RE-LIFE). The aim was to test its scale structure, the internal consistency reliability of the multi-item scales, and the convergent validity of the two key scales "experience of contingency" and "narrative integration."

Two-hundred-thirty-seven patients with stable coronary artery disease completed the RE-LIFE six months after a cardiac intervention. Convergent measures assessed quality of life (SF-36), post-traumatic growth (PTGI), personality (HEXACO-SPI) and sociodemographic characteristics.

Principal axis factoring identified seven multi-item scales that were theoretically warranted. The internal consistency reliability was acceptable to excellent for the scales with more than two items. The two key scales yielded significant relationships with quality of life and/or post-traumatic growth in the expected direction. Relationships with personality and sociodemographic characteristics were nonsignificant.

The RE-LIFE is a promising tool that may facilitate research and may support spiritual counselors to help patients integrate experiences of contingency into their life narratives.

INTRODUCTION

Falling seriously ill may confront people with the randomness of life and conflict with their life goals and worldview, evoking existential questions [1]. Combining theories on contingency and narrative identity from religious studies, philosophy and narrative psychology, we developed a theoretical model of the way people may integrate such disruptive life events into their personal life story and how this ultimately affects their quality of life (QoL) [2]. This “narrative meaning making and integration of life events” model revolves around the experience of contingency [3] that disruptive life events can evoke. The term “contingency” refers to the “randomness” of life, meaning that the events that befall us could also have been otherwise [4]. An experience of contingency is defined as a crisis of meaning, resulting from high-impact life events that confront people with this randomness of life [5, 6]. This crisis of meaning pertains to two of the three commonly distinguished dimensions of meaning (coherence, purpose and significance [7]), namely purpose and coherence. Such an experience is caused by a conflict between a disruptive life event and one’s ultimate life goals (the “purpose” facet). Such events can initially not be interpreted within the context of one’s life narrative and self-understanding (the “coherence” facet) and thus require narrative reinterpretation, a concept resembling narrative meaning making used in health psychology [7, 8]. During this process of reinterpretation or meaning making, the event may be integrated into the life narrative to a greater or lesser extent, and may be given a meaningful place.

Our theoretical model describes this process of narrative meaning making and integration, entailing seven concepts (see Figure 1). As a *life event*, falling ill may conflict with a person’s *worldview* and/or *ultimate life goals*: the goals that are of ultimate value for the person, which are anchored in their worldview. This conflict may lead to an *experience of contingency*: a confrontation with the randomness of life that disrupts one’s life story, makes one aware of the vulnerability of everything valuable, and evokes existential questions. This experience may start a process of *narrative meaning making* in which the event is reinterpreted within the context of one’s own life narrative. This process, in which the life story has to be reconstructed, may result in *narrative integration* of the life event: the extent to which the life event is given a meaningful place in one’s life story, without disregarding the contingent nature of the event. This narrative integration is expected to lead to a new perspective on the event and one’s life goals, embracement of positive new possibilities, and a changed narrative identity. In terms of meaning in life, it is thought of as restoring one’s sense of comprehensibility and of one’s life making sense (the “coherence” facet) and one’s sense of core goals, aims and direction in life (the “purpose” facet) [7]. Because of the fundamental human need for understanding, coherence and meaning [7, 9], it is hypothesized that experiences of contingency have a negative, and narrative integration a positive impact on the *QoL* experienced by the person. The theoretical model is depicted in Figure 1 and we refer the reader to Hartog et al. 2020 [2] for a more elaborate description of the model.

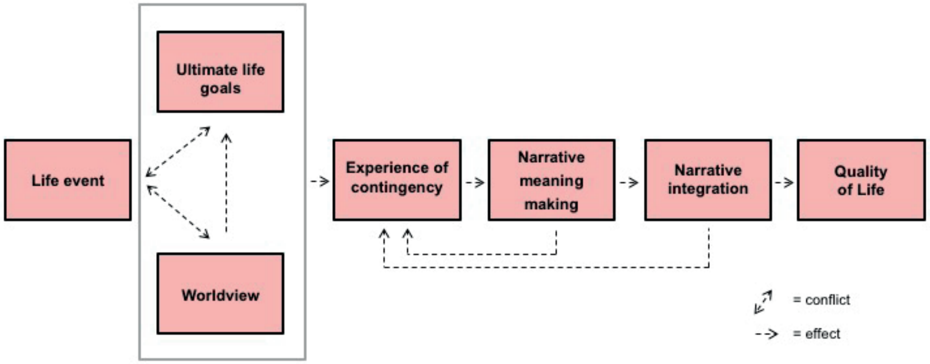

Figure 1. Theoretical model: *Narrative meaning making of life events* [2]

Concepts from religious studies and narrative psychology are increasingly used in interventions aiming to improve patients' QoL through fulfilling existential and spiritual needs. For example, "narrative interventions" aim to support patients in (re)constructing a narrative in which the event of falling ill is included in a meaningful way (See Chapter 5) [10, 11]. However, the effects of the interventions are usually assessed using distal outcome measures such as well-being or health-related QoL (HRQoL), instead of assessing changes in patients' meaning making [10, 12]. We therefore operationalized the concepts of the model "Narrative meaning making and integration of life events" in the Reconstruction of Life Events questionnaire (RE-LIFE). The theoretical background and the development of the concepts and questionnaire have been published before [2]. A previous study confirmed the major hypothesized relationships among the concepts empirically with the aid of mediation analyses [13]. However, the reliability and convergent validity of the scales still need to be investigated.

To test the convergent validity of the RE-LIFE, we examined hypothesized relationships between the key elements, "experience of contingency" and "narrative integration," with other variables. We formulated two main hypotheses. First, in addition to their relationship with overall QoL, we examined their relationship with the more comprehensive construct HRQoL, which pertains to patients' subjective evaluation of the effects of diseases and treatments. We expected people who indicated having "experienced contingency" to have a worse overall QoL and HRQoL than people who did not indicate such an experience. We also expected people who indicated to have achieved "narrative integration” to experience better overall QoL and HRQoL than patients who had not (yet) succeeded to integrate the event in their life narrative.

Second, the concept of narrative integration is thought to concur with the concept of posttraumatic growth, defined as the experience of positive change resulting from the struggle with highly challenging life crises [14]. It is suggested that posttraumatic growth, like narrative integration, mutually interacts with the development and revisions of a person’s life narrative after traumatic life events [14]. Therefore, we expected that patients who experience narrative integration also experience posttraumatic growth.

We further explored whether experience of contingency and narrative integration may be influenced by personal characteristics, such as personality and sociodemographic characteristics. People who score high on *emotionality*, experience more fear, stress and anxiety in response to difficulties in life [15], and may experience more contingency and less narrative integration. Conversely, people who score high on agreeableness are more flexible [16] and more able to adapt, and may therefore experience less contingency and more narrative integration.

As for sociodemographic characteristics, it may be expected that women will reach more narrative integration than men, as women tend to report more benefits after trauma [17]. Whereas the relationship between age and posttraumatic growth has been found to be ambiguous [18], we expected older people to be better able to deal with disruptive life events as a result of experiences with earlier setbacks. Thus, it is expected that older people experience less contingency and more narrative integration than younger people. Lastly, people who consider themselves religious may more frequently relate their actions and life events that befall them to a dimension that transcends our human world than non-religious people [19]. They may have a broader framework of reference that enables them to integrate disruptive life events into their life narrative more easily. Thus, we expect religious people to experience more narrative integration than non-religious people.

In the present study, we administered the RE-LIFE to patients with stable coronary artery disease who had undergone an elective cardiac intervention. We expected the diagnosis of the heart condition, in combination with the cardiac intervention, to be a sufficiently disruptive life event to induce an experience of contingency in many patients. The specific objectives were twofold. First, to identify the underlying scale structure of RE-LIFE items and their corresponding internal reliability consistency. Second, to conduct an initial validation of the RE-LIFE by examining relationships of the key scales experience of contingency and narrative integration with overall QoL, HRQoL, posttraumatic growth, personality and the background characteristics age, gender, and religion.

METHODS

Patients and study design

The RE-LIFE was tested within the context of the IMPACT study (Oreel et al., 2020), in which patients with stable coronary artery disease (CAD) were recruited at the cardiology departments of the Amsterdam University Medical Centers (Amsterdam UMC): Academic Medical Center (AMC) and VU Medical Center (VUmc) locations. Patients of both centers, including those referred by regional hospitals, were discussed in the multidisciplinary "heart teams." Patients were eligible if they were scheduled for an elective percutaneous coronary intervention (PCI; angioplasty) or elective coronary artery bypass graft (CABG; bypass surgery) at the AMC or VUmc and had at least one confirmed diagnosis of an additional chronic, somatic disease. Criteria for exclusion were insufficient command of the Dutch language and having cognitive impairments due to mental retardation, brain hemorrhage, cerebral infarction or dementia. As the central ethics committee decided that the Medical Research Involving Human Subjects Act did not apply, the study was exempted from further ethical assessment. Written informed consent was obtained from all patients.

Consenting patients completed a set of questionnaires, including those on HRQoL, prior to, and two weeks, three months and six months after their cardiac intervention. At three and six months, the RE-LIFE was included in the questionnaire set. For this study, we used the data collected at six months for theoretical and practical reasons. Theoretically, as narrative meaning making and integration is a process that takes time, we expected the process to be more advanced at six months with more patients reporting narrative integration. Practically, because the convergent measure on post-traumatic growth was only administered at the six-month period. Patients had the choice between completing questionnaires on paper or online.

The RE-LIFE questionnaire

Format of the questionnaire

The RE-LIFE starts with a request to draw a "lifeline," with life events as high and low points. Next, respondents are asked to choose the most unexpected negative life event from their lifeline, and answer a series of questions with this event in mind. These questions pertain to the experience of contingency, narrative meaning making, narrative integration and impact of the event on ultimate life goals. After this series of questions, the same questions are repeated with respect to the experience of being diagnosed with a heart condition. Patients are then asked about the importance of each ultimate life goal in general, and their worldview. Finally, patients are asked to rate their overall QoL. For this paper, we analyzed only the responses to items about the experience of being diagnosed with a heart condition, the negative life event of our model that all patients shared, enabling cross-respondent comparisons.

Operationalization of the theoretical concepts

Based on theory [3] and the analysis of in-depth interviews with advanced cancer patients [1], we formulated the self-report items. The hypothesized multi-item scale structure of the RE-LIFE is depicted in Figure 2. The Items and response categories of the multi-item scales are provided in Table 2.

The concept *ultimate life goals* was operationalized by 15 life goals that are thought to give ultimate meaning to people’s lives. Respondents are asked to rate the extent to which the event either hindered or helped them in pursuing each life goal. These items are not expected to form a scale and items are handled individually, as each life goal can be considered a theme in itself and the impact on every life goal may differ.

For the operationalization of the concept *worldview*, we distinguish three types: *absolute immanence* (relating to the human, intelligible world only), *immanent self-transcendence* (contact with or influence/inspiration from the transcendent) and *absolute transcendence* (everything is determined by a higher power). Each type is operationalized by two items.

The concept *experience of contingency* is operationalized by 5 items about crises of meaning, resulting from high-impact life events that confront people with the randomness of life.

The concept of *narrative meaning making* is subdivided into three separate aspects relevant to people’s narrative interpretation of life events: *evaluation* (the attribution of a positive or negative meaning to the life event; 2 items), *agency* (the perceived role of the person as active or passive; 3 items) and *scope* (the scale or span of the meaning the event has for the person: situational, existential or spiritual; 5 items).

The concept of *narrative integration* entails four modes of increasing integration of the event into the life story: *denying* (no acknowledgment of the contingency or the existential meaning of the event), *acknowledging* (the event is interpreted as a disruption of the life story, evoking existential questions), *accepting* (re-interpretation, active search to integrate the event into the life story) and *receiving* (complete integration of the event into the life story, embracing the positive new possibilities that emerge from the life event). Each mode is operationalized with three items. For purpose of convergent validity, we will only use the last scale, *receiving*, indicating complete integration.

Since the final concept *QoL* is measured by well-validated questionnaires, we chose the item on overall QoL from the EORTC Quality of Life Core Questionnaire (EORTC QLQ-C30) [20]. This item assesses respondents' overall quality of life during the past week. The 7-point response scale was transformed into a 0-100 scale, with higher scores indicating better overall QoL.

Convergent measures for experience of contingency and narrative integration

Health-related quality of life

HRQoL was measured with the 36-Item Short Form Health Survey, version 1 (SF-36v1) [21]. This questionnaire assesses eight health concepts of HRQoL that can be combined into two summary scales: the physical (PCS) and mental component score (MCS). PCS and MCS scores range from 0 to 100, with higher scores indicating better HRQoL.

Posttraumatic Growth

Posttraumatic growth was assessed using the Posttraumatic Growth Index (PTGI), developed to determine how successful individuals are in "reconstructing or strengthening their perceptions of self, others, and the meaning of events" after a traumatic event [17]. The questionnaire comprises 21 items and employs a 6-point Likert scale ranging from 0 ("not") to 5 ("to a very great degree"), reflecting how much positive change was experienced as a result of the respondent's crisis. In our study, the word "crisis" was changed into "your heart condition and/or its treatment." A total PTGI score was calculated, with higher scores indicating more posttraumatic growth [14].

Personality

Two personality dimensions, emotionality and agreeableness, were assessed with the HEXACO Personality Inventory – Dutch, simplified version (HEXACO-SPI) [22]. Both dimensions are assessed with 16 items, scored on a five-point Likert scale ranging from 1 (totally disagree) to 5 (totally agree). Mean scores for both dimensions were calculated, with higher scores indicating more emotionality and more agreeableness, respectively. The HEXACO-SPI was administered three months following the cardiac intervention.

Since personality is a more or less stable characteristic and is not likely to change over a three-month period, including it as a convergent measure is warranted.

Background characteristics

At baseline, patients provided sociodemographic information on gender, age and religion. For religion, the response categories Christian, Muslim, Buddhist, and Jewish were aggregated into the category "religious," whereas the categories atheist and "other" were combined into the category "non-religious."

Statistical analyses

Assumption tests

Scores on all items were checked for floor and ceiling effects (percentage of the lowest and highest possible score, respectively), neutral, and missing responses. We assessed the *underlying scale structure* of the multi-item scales belonging to the concepts worldview, experience of contingency, narrative meaning making and narrative integration separately. In order to test the multicollinearity of the data, the determinant r of the correlation matrix was calculated (criterion > 0.00001) [23]. The Kaiser-Meyer-Olkin measure of sampling adequacy (KMO-test) was used to test if our sample was large enough for factor analysis (criterion > 0.5) [23]. To test for redundancy between the variables that can be summarized with a limited number of factors, Bartlett's test of sphericity was used (criterion: significance) [23].

Scale structure

To assess the scale structure, first, principal axis factoring (PAF) with oblimin rotation was performed to identify the number of scales for each concept. Kaiser's criterion (eigenvalues ≥ 1), communality of items ≥ 0.20 and the scree plot were used to determine the number of factor solutions. Next, PAF with a fixed number of components, based on the theoretical model and eigenvalues, was performed. Decisions regarding item removal were based on theory and required factor loadings (≥ 0.40 for all items belonging to their own factor, no loading > 0.30 on another factor, and ≥ 0.20 difference with the second highest component loading).

The *internal consistency reliability* of the identified scales (and the convergent measures) was assessed by Cronbach's α and Spearman-Brown coefficients. Cronbach's α estimates of > 0.60 were considered acceptable, given that the RE-LIFE scales have a limited number of items and response options [23]. For the scales consisting of only two items, Spearman Brown is the most appropriate reliability statistic together with standardized coefficient α [24]. For the convergent scales, internal reliability was assessed using Cronbach's α.

The *convergent validity* of the RE-LIFE was assessed by known-groups comparison. We formed mutually exclusive subgroups of patients who did not report to have experienced contingency (individual mean scores on a 4-point Likert scale from 1 to 2.49) and who did (mean scores 2.50-4); and patients who reported not to have integrated the life event in their life story (receiving scale mean scores on a 5-point Likert scale from 1 to 2.99) and who did (mean score 3-5). Independent t-tests were used to test whether these groups differed on the continuous convergent measures. To examine the magnitude of these differences, effect sizes were calculated using the pooled standard deviations. Following Cohen [25], we interpret effect sizes as small ($d = 0.2$), medium ($d = 0.5$), and large ($d = 0.8$). Chi-square tests were used for testing group differences with respect to categorical convergent measures. We employed a p-value of 0.05. All data were analyzed using "R" Statistical Software, version 3.4.4 [26] (Foundation for Statistical Computing, Vienna, Austria) and SPSS, version 26 (IBM).

RESULTS

Patients

Data collection took place from September 2015 to March 2018. A total of 467 patients were approached for the study, of whom 320 responded (69% response rate). Unfortunately, ethics regulations precluded the investigation for the reasons of non-response. Of the 320 patients who provided demographic information at baseline, 237 (74%) completed the RE-LIFE at the six-month assessment (Table 1). The 83 patients who were lost to follow-up had significantly more often undergone the more invasive bypass surgery (17.7% vs 37.3%; $p < 0.01$). They were not significantly different with respect to age, gender, religion, or number of comorbidities ($p > 0.10$). Of the 237 patients, 169 completed all items of the RE-LIFE, whereas the remaining 68 patients missed one or more items. These latter patients were significantly older (median age 72 versus 67; $p < 0.05$) but were not significantly different with respect to gender, type of cardiac intervention, religion, and number of comorbidities ($p > 0.10$).

Table 1. Sociodemographic and clinical characteristics

	N = 237
Age	
Median (Range)	68 (62-74)
Mean (SD)	67.83 (9.17)
Gender	
Male	172 (72,6%)
Female	65 (27,4%)
Intervention	
Percutaneous coronary intervention	156 (65,8%)
Coronary artery bypass graft	42 (17,7%)
No intervention	39 (16,5%)
Religion	
Non-religious	140 (59,1%)
Religious	97 (40,9%)
Number of comorbidities	
Median (Range)	2 (0-8)
Mean (SD)	2.00 (1.19)

Item characteristics of the RE-LIFE

Floor effects ranged from 0% to 65% and ceiling effects from 0% to 43%. Missing responses ranged from 7% to 12% and neutral responses from 7% to 60%.

Scale construction and internal consistency reliability

For the item scores pertaining to the four concepts, determinant r showed no multicollinearity (*Worldview*: 0.049; *Experience of contingency*: 0.014; *Narrative meaning making*: 0.33; *Narrative integration*: 0.049). The KMO measure of sample adequacy indicated that the sample was large enough to conduct factor analyses for each concept (*Worldview*: 0.78; *Experience of contingency*: 0.85; *Narrative meaning making*: 0.67; *Narrative integration*: 0.84). Bartlett's test of sphericity was significant ($p < 0.001$) for all four concepts.

Worldview

PAF indicated two subscales for worldview, instead of the three hypothesized subscales. The first subscale consisted of the items belonging to the first and second hypothesized subscales: absolute transcendence and immanent self-transcendence. Therefore, we named the first identified subscale "transcendence." The scale on "absolute immanence" was confirmed by the data (see Figure 2). The items of these identified subscales explained 50,9% and 8,4% of the variance, respectively (See Table 2).

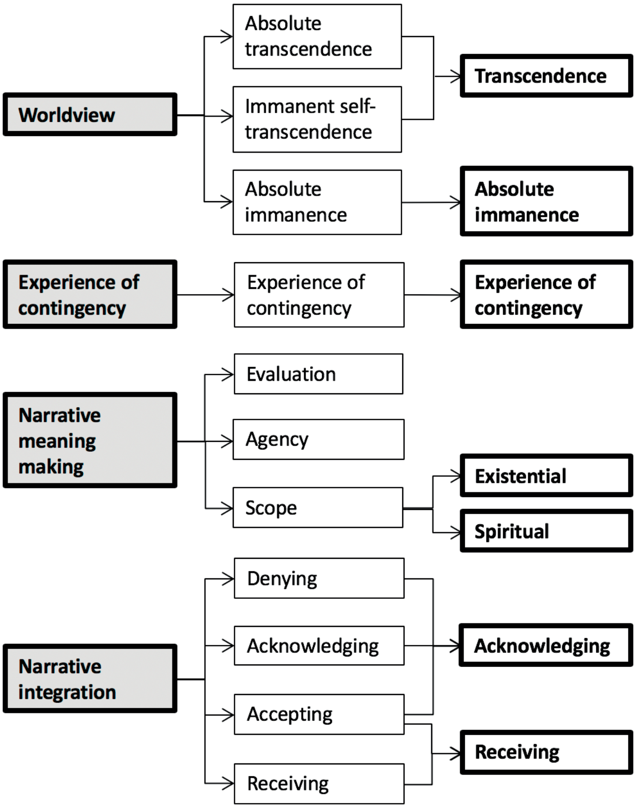

Figure 2. Multi-item scale structure of the RE-LIFE: theoretical concepts (left), hypothesized scales (middle), and identified scales (right).

Experience of contingency

For "experience of contingency," one scale was found, as hypothesized. Its five items accounted for 72% of the explained variance (Table 2).

Narrative meaning making

Five items operationalizing evaluation and agency needed to be removed because they did not meet the criteria as described in Statistical Analyses, or did not comply theoretically with the identified component. For the five remaining items, we identified two subscales, belonging to scope: spiritual and existential (Figure 1). The items of these subscales accounted for 36,1% and 14,7% of the explained variance, respectively (Table 2).

Table 2. Scales, item loadings, Cronbach's α and Spearman-Brown coefficients, commonalities (h^2) and common variances

	Worldview			
Item numbers		**F1**	**F2**	**h^2**
5.1e	What I do in life is ***part of a higher plan*** that I have ***no influence*** over.	0.96	0.16	0.80
5.1c	What I do in life is ***determined by a higher reality***.	0.82	0.01	0.67
5.1a	As a ***free person***, I experience my actions in life as part of ***something that transcends our reality***.	0.71	-0.17	0.66
5.1f	As a ***free person***, I gain ***inspiration/strength*** for the things I do in my life from ***something that transcends our reality***.	0.75	-0.17	0.72
5.1d	What I do in life is ***only determined*** by what exists in ***this world***.	-0.08	0.51	0.30
5.1b	There is ***nothing*** beyond this world that ***influences*** what I do in life.	0.03	0.65	0.40
	Cronbach's α	0.90	0.54	
	Spearman-Brown	0.91	0.54	
	Number of response options	5	5	
	Number of valid cases	213	216	
	F1: Transcendence (% of common variance)	50,9		
	F2: Absolute immanence (% of common variance)		8,4	

	Experience of contingency		
Item numbers		**F1**	**h^2**
3.1c	At the time, getting my heart condition turned my ***world upside down***.	0.93	0.86
3.1b	At the time, getting my heart condition threw me ***off balance***.	0.87	0.76
3.1d	At the time, getting my heart condition made my ***world come crashing down***.	0.89	0.73
3.1e	At the time, getting my heart condition made my ***world come to a standstill***.	0.82	0.66
3.1a	At the time, getting my heart condition came as a ***blow or shock***.	0.73	0.54
	Cronbach's α	0.93	
	Spearman-Brown	0.88	
	Number of response options	4	
	Number of valid cases	220	
	F1: Experience of contingency (% of common variance)	72,0	

	Narrative meaning making			
Item numbers		**F1**	**F2**	**h^2**
3.2i	Looking back, I see that getting the heart condition made me ***feel abandoned***: I missed the presence or support of ***something higher***	0.76	0.41	0.73
3.2j	Looking back, I see ***dealing*** with my heart condition as something ***expected of me by something higher***: a ***calling***	0.72	0.09	0.41

3.2h	Looking back, I see ***dealing*** with my heart condition as ***something I was meant to do in my life***: a ***task or assignment***.	0.66	-0.19	0.48
3.2g	Looking back, I see that getting my heart condition has had ***positive*** consequences for ***my life as a whole***.	-0.51	0.52	0.55
3.2f	Looking back, I see that getting my heart condition has had ***negative*** consequences for ***my life as a whole***. (item is reversely coded)	0.08	0.51	0.26
	Cronbach's α	0.73	0.38	
	Spearman-Brown	0.77	0.38	
	Number of response options	5	5	
	Number of valid cases	224	224	
	F1: Spiritual (% of common variance)	36,1		
	F2: Existential (% of common variance)		14,7	

	Narrative integration			
Item numbers		**F1**	**F2**	**h^2**
3.3b	At the moment, ***I think a lot*** about what my heart condition means for my life. (item is reversely scored)	0.93	-0.42	0.83
3.3c	I find it ***difficult*** to ***come to terms with*** my heart condition. (item is reversely scored)	0.78	-0.11	0.55
3.3a	At the moment, my heart condition makes me ***question*** things about ***my life***.	0.72	0.12	0.61
3.3g	Getting my heart condition currently has a ***great impact*** on my life as a whole.	0.67	0.13	0.46
3.3e	At the moment, I think a lot about the ***cause*** of my heart condition or ***why*** I got it. (item is reversely scored)	0.50	0.31	0.48
3.3d	Meanwhile, I see ***new possibilities*** that have emerged from getting my heart condition.	0.11	0.43	0.24
3.3l	At the moment, I am ***learning*** a lot from getting my heart condition	-0.13	0.84	0.63
3.3j	Getting my heart condition has made me realize what I ***find important*** in life.	0.05	0.58	0.37
	Cronbach's α	0.86	0.64	
	Spearman-Brown	0.82	0.70	
	Number of response options	5	5	
	Number of valid cases	223	224	
	F1: Acknowledging (% of common variance)	40,6		
	F2: Receiving (% of common variance)		11,5	

Responses are scored on a 5-point Likert scale (1 = "strongly disagree", 5 = "strongly agree"), except for the items of "Experience of contingency", which are scored on a 4-point Likert scale (1 = "did not experience", 4 = "experienced very strongly").

Narrative integration

Analyses led to the removal of three items because they did not meet the criteria or did not comply theoretically with the identified components. The analyses of the remaining items indicated two subscales instead of the hypothesized four. The first subscale contained two items pertaining to acknowledging, two items to denying and one item to accepting. These items correspond with the struggle where the life event has not yet been integrated into the life narrative. The items belonging to denying and accepting were reversely scored (see Table 2), their original phrasing pertaining to the meaning of acknowledgement. Therefore, this subscale was named "acknowledging" (Figure 2). The second subscale consisted of two items that belonged to receiving (3.3d and 3.3j), and one item belonging to accepting (3.3l). Because the three items theoretically comply with the meaning of receiving, this subscale was named "receiving." Items of the two subscales explained 40,6% and 11,5% of the variance, respectively (Table 2).

Internal consistency reliability

Internal reliability of most RE-LIFE subscales was acceptable to very high (Cronbach's α ranging between 0.64 and 0.93; Spearman-Brown ranging between 0.70 and 0.91). For two subscales, both consisting of two items, the reliability was insufficient (*Absolute immanence*: Cronbach's α 0.54 and Spearman-Brown 0.54; *Existential meaning*: Cronbach's α 0.38 and Spearman-Brown 0.38). With respect to the convergent scales, internal reliability was good for the personality scales (Cronbach's α 0.70 and 0.78), and excellent for MCS, PCS and PTGI (Cronbach's α 0.90-0.96).

Convergent validity

As expected, patients who indicated to have *experienced contingency* reported significantly lower levels of QoL and MCS than patients who had indicated not to have experienced contingency. The differences for PCS and PTGI were in the expected direction, but only reached marginal levels of statistical significance. Effect sizes were of a small magnitude and ranged from 0.26 to 0.40. Personality and sociodemographic characteristics were not significantly different between the two groups (Table 3).

According to expectation, patients who *received* contingency as an indication of narrative integration, reported higher PTGI scores (large effect size of 0.85). The differences for QOL and PCS were in the expected direction but did not reach statistical significance. Effect sizes were 0.26 and 0.25. The MCS scores, personality, and sociodemographic characteristics were not significantly different between the groups (Table 3).

Table 3. Group differences (t-test or Chi square) based on experience of contingency and narrative integration (receiving scale)

Convergent Variables	**Experience of Contingency**				**Narrative integration: Receiving**			
Quality of life	No	Yes	t	Cohen's d	No	Yes	t	Cohen's d
QoL	N = 94 M = 94.68 SD = 18.97	N = 117 M = 88.18 SD = 20.88	2.37 p<0.05	0.33	N = 131 M = 89.44 SD = 21.70	N = 83 M = 94.58 SD = 17.29	-1.82 p=0.07	0.26
MCS	N = 93 M = 54.21 SD = 8.69	N = 107 M = 49.99 SD = 12.30	2.73 p<0.05	0.40	N = 127 M = 51.85 SD = 11.33	N = 76 M = 52.00 SD = 10.55	-0.92 p=0.93	0.01
PCS	N = 93 M = 41.99 SD = 8.84	N = 107 M = 39.68 SD = 9.27	1.80 p=0.07	0.26	N = 127 M = 40.03 SD = 9.63	N = 76 M = 42.24 SD = 7.89	-1.69 p=0.09	0.25
Post-traumatic growth								
PTGI	N = 95 M = 29.46 SD = 17.31	N = 107 M = 24.30 SD = 19.15	-1.88 p=0.06	0.27	N = 126 M = 16.25 SD = 14.55	N = 80 M = 31.11 SD = 20.09	-5.73 p<0.00	0.85
Personality								
Emotionality	N = 89 M = 3.03 SD = 0.49	N = 110 M = 3.12 SD = 0.48	-1.28 p=0.20	0.19	N = 124 M = 3.04 SD = 3.14	N = 76 M = 3.14 Ad = 0.48	-1.40 p=0.10	0.04
Agreeableness	N = 89 M = 2.80 SD = 0.39	N = 110 M = 2.82 SD = 0.36	-0.51 p=0.61	0.05	N = 124 M = 2.78 SD = 0.36	N = 76 M = 2.87 SD = 0.39	-1.65 p= 0.10	0.24
Sociodemographic characteristics								
Age	N = 100 M = 68.16 SD = 0.05	N = 121 M = 68.33 SD = 8.02	-0.15 p=0.88	0.03	N = 139 M = 67.83 Sd = 8.58	N = 85 M = 68.86 SD = 8.47	-0.88 p=0.38	0.12
Gender								
Male	N = 73 (45,3%)	N = 88 (54,7%)	Chi-Square 0.002 (df = 1) p=0.96		N = 61 (37,9%)	N = 100 (62,1%)	Chi-Square 0.22 (df = 1) p=0.64	
Female	N = 27 (45%)	N = 33 (55%)			N = 26 (41,3%)	N = 37) (58,7%)		
Religion								
Non-religious	N = 59 (46,8%)	N = 67 (53,2%)	Chi-Square 0.40 (df = 1) p=0.53		N = 49 (38,3%)	N = 79 (61,7%)	Chi-Square 0.01 (df = 1) p=0.92	
Religious	N = 40 (42,6%)	N = 54 (57,4%)			N = 37 (38,9%)	N = 58 (61,1%)		

QoL is overall quality of life (EORTC QLQ-C30); MCS is mental component score (SF-36); PCS is physical component score (SF-36), PTGI is posttraumatic growth index (Tedeschi & Calhoun, 1996), Personality (HEXACO-SPI).

DISCUSSION

The major hypothesized theoretical concepts of the RE-LIFE were confirmed in this study. Scales were identified that operationalized “worldview,” “experience of contingency,” “narrative meaning making,” and “narrative integration.” The hypothesized scale “experience of contingency” was confirmed in its entirety as was the subscale “absolute immanence,” belonging to “worldview.” For the other hypothesized subscales, items needed to be removed or combined with other items to form new subscales, including “transcendence” as component of “worldview,” “acknowledging,” indicative of an early phase in narrative integration, and “receiving,” indicative of complete narrative integration. Removal of items resulted in the deletion of two hypothesized scales, “evaluation” and “agency,” belonging to “narrative meaning making.” Finally, one scale had to be split into two, “existential scope” and “spiritual scope,” belonging to “narrative meaning making.” The resulting scales were all theoretically warranted. The scales were also psychometrically sound with acceptable to excellent internal consistency reliability, with the exception of the scales consisting of two items (“absolute immanence” and “existential meaning”). These two subscales were not deleted, as their items provide additional insights.

The convergent validity results confirmed the main hypothesis that patients experiencing contingency have worse overall and mental QoL than those who do not experience contingency. Moreover, the score patterns of overall and physical QoL, when not statistically significant, were in the expected direction. These effect sizes were all of a small magnitude. The expected relationships with personality and sociodemographic characteristics were not found. In an earlier mediation analysis, focusing on the internal relationships of the components of the theoretical model, in the same patient group three months following the cardiac intervention, we found that experience of contingency was also indirectly related with lower levels of QoL (see Chapter 4) [13]. Three months later, the relationship still holds. The results also confirmed that patients who succeeded to integrate the contingent life event in their life story experience more posttraumatic growth than those who are still struggling. This effect was particularly pronounced, given its large magnitude.

Although the concepts of narrative integration and posttraumatic growth are clearly related, we consider the concept of narrative integration a valuable addition. While the items of the PTGI are mainly tapping into behavior resulting from positive change, the acknowledging and receiving scales focus on the interpretation process and the new insights and attitudes resulting from the narrative integration. In addition, the combination of the receiving scale with the acknowledging scale provides information about the process, which is particularly insightful when respondents indicate narrative integration to be absent or incomplete.

The question arises why we did not find relationships with personality, despite the use of a validated personality questionnaire. In hindsight, the dimensions emotionality and agreeableness may have been too distal with respect to their relationship with the experience of contingency and narrative integration. For example, agreeableness was selected for its relationship with adaptive behavior, enabling integration. Moreover, the personality questionnaire was administered three months before the administration of the RE-LIFE. Whereas inclusion of the personality data in this study was warranted given the stable nature of personality, we cannot exclude the possibility that the time lag may have added error variance. Finally, the relationships with personality may not exist in this particular homogenous sample of primarily older men.

The nonsignificant relationships with sociodemographic characteristics also merit attention. Whereas previous results were mixed [18], our homogenous sample with its restricted variance in gender and age may have precluded finding significant results if they would exist. However, the distribution of religious versus non-religious patients was about equal and could therefore not explain the nonsignificant results. Since traditional beliefs have become less dominant [27], the distinction between established versus non-established religions per se may have become less meaningful. We cannot exclude the possibility that respondents who endorsed the non-religious or other category may have adopted a non-traditional religious or spiritual belief relevant for integration.

Limitations and strengths

A number of limitations merit attention. First, the typical cardiac patient sample with predominantly older men, limits the generalizability of the study results. The non-respondent analyses indicated a selective attrition with respect to the more invasive cardiac intervention and older patients missing more items, implying a further restriction of the sample to the more fit respondents. Moreover, having undergone a cardiac intervention may not have been a major, disruptive life event for each patient. The timing of the respondents' diagnosis may have varied, whereas the timing of the cardiac intervention was similar for patients.

Second, the RE-LIFE as administered in the current study, is lengthy, and took most respondents between twenty and sixty minutes to complete because we asked patients to complete most of the items twice, i.e., for two life events. We recommend to focus RE-LIFE on only one negative life event (e.g., self-identified event or a medical condition). Since the resulting RE-LIFE is shorter than the version we had administered, future completion time is expected to be diminished by approximately a half.

Third, by dichotomizing the patient group in those who do or do not experience contingency and have or did not have integrated the life event, we may have lost information in comparison to keeping these variables continuous. Moreover, we kept all respondents in the analyses whereas one may expect to find only substantial differences between patients scoring high or low on these variables. However, our analyses enabled the investigation of all convergent variables in the same way. Finally, our analyses can be criticized for its multiple comparisons in relation to the sample size. However, we formulated specific hypotheses and calculated effect sizes as an indication of the clinical meaningfulness of the findings.

The study also has a number of strengths. Eligible patients were carefully recruited and had medically confirmed diagnoses and comorbidities. All patients had undergone a cardiac intervention that was expected to induce an experience of contingency in most. The longitudinal study design, from baseline to six months, allowed patients time to engage in a process of meaning making and narrative integration. Finally, we used standard and well validated convergent measures.

Future applications

To the best of our knowledge, this is the first time that an attempt has been made to operationalize the process of narrative meaning making with theoretical concepts from religious studies – experience of contingency and narrative integration – into a quantitative questionnaire. The items were not only based on theory [3] but were also informed by in-depth interviews with cancer patients [1]. These and former results [13] suggest that the RE-LIFE is a promising instrument, warranting further refinement and validation. We envision three types of applications.

First and foremost, the RE-LIFE is useful in theoretical research. The questionnaire is semantically related to existential philosophy and psychology and can provide insight into the pragmatic-phenomenological process [28] of the experience of contingency and narrative integration. For example, why do some people reject the changed life circumstances whereas others accept them as inevitable? Why do some people approach the crisis whereas others do anything to avoid it? Why do some people keep trying to achieve unattainable goals whereas others find new ways to make their lives meaningful? Why do some people have no need to find new meaning whereas for others finding new meaning is the *conditio sine qua non* for being able to move further with their life? The RE-LIFE enables the investigation of such questions by focusing on the interpretation process invoked by the confrontation with an existential, disruptive life event, such as a life-threatening disease.

Second, in its final form, the RE-LIFE is intended for use in studies assessing the impact of spiritual interventions aiming to improve respondents' QoL through fulfilling existential and spiritual needs. Third, the RE-LIFE can also be used in clinical practice. For example, it could be administered after falling ill or other disruptive life events as a tool to support the communication between a spiritual counselor and the respondent. Based on the responses to the RE-LIFE, the spiritual counselor may further explore the interpretation process and subsequently help respondents to find meaning and to integrate the disruptive life event into their life narratives. When administered at subsequent times, the process of meaning making and narrative integration can be monitored and support be provided as needed. To exemplify, we are currently conducting a study among advanced cancer patients whom we offer different forms of art to empower them to create their own, new narratives of life. The RE-LIFE is used over time, first to help patients to articulate their current story and then to help them to revise their life story accommodating the contingent life events. It is our hope that the RE-LIFE will provide useful information in such future studies.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author's contributions

MS, HvL, PN, MS-R and JH are responsible for the conception of the study. JN, IH, MS, PN and HvL designed the study. IH and JN planned and organized the study and collected the data, supported by AV and JL. MS and PN supervised the data acquisition. TO and MS-R analyzed the data. IH, MS-R and HvL interpreted the data. IH wrote the first draft of the article. PN and MS revised several versions of the article. All authors commented on the semi-final version of the article. All authors read and approved the final manuscript. IH is the corresponding author.

Ethics approval and consent to participate

As the central ethics committee (Medisch Ethische Toetsings Commissie AMC) decided that the Medical Research Involving Human Subjects Act did not apply, the study was exempted from further ethical assessment. Written informed consent was obtained from all patients.

Competing interests

The authors declare that they have no competing interest.

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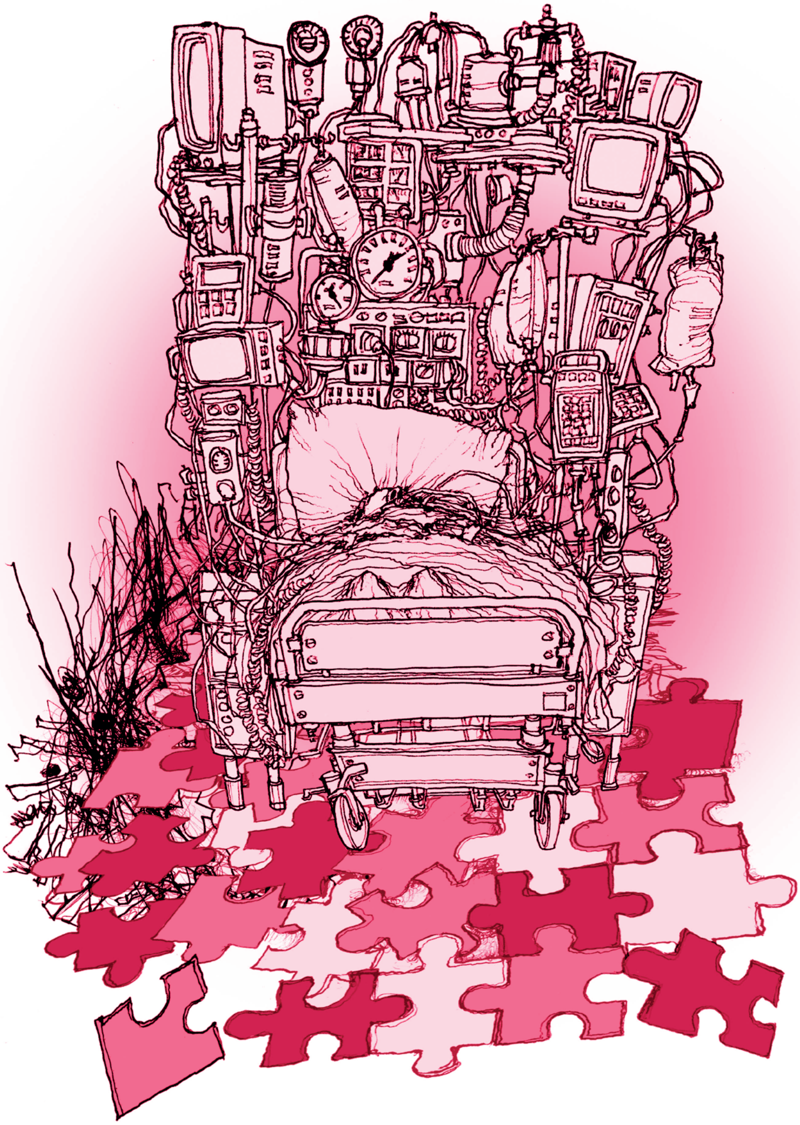

4

RECONSTRUCTING DISRUPTIVE LIFE EVENTS USING THE RE-LIFE QUESTIONNAIRE

This chapter is based on:
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Contribution of the author of this dissertation:

The author participated in the design, planning and organization of the empirical study and in the data collection and interpretation of the data. In addition, the author wrote the first draft of the article and revised several versions based on feedback of all co-authors.

ABSTRACT

The theoretical model: “Narrative meaning making and integration of life events” hypothesizes that life events such as falling ill may result in an “experience of contingency.”

Through narrative meaning making, this experience may be eventually integrated into patients’ life stories, which, in turn, may enhance their quality of life. To contribute to our understanding of this existential dimension of falling ill and to further validate the theoretical model, we examined the relationships among the concepts assessed with the RE-LIFE questionnaire.

Two hypothesized mediation models were assessed using regression-based serial multiple mediation analysis. Model 1, assessing the influence of “experience of contingency” on “acknowledging,” was significant and showed partial mediation by indirect influences through “negative impact on life goals” and “existential meaning.” Model 2, assessing the influence of “experience of contingency” on “quality of life,” was also significant, with a full mediation by the variables “negative impact on life goals,” “existential meaning” and “acknowledging.” In conclusion, several hypothesized relationships within the theoretical model were confirmed. Narrative meaning making and integration significantly influence people’s self-evaluation of their quality of life.

INTRODUCTION

Falling seriously ill is known to have a large impact on a person’s life. Naturally, illness may confront people with physical limitations, burdensome treatment and/or symptoms such as pain or fatigue, reducing their quality of life (QoL). However, illness may also confront people with the “randomness of life,” conflicting with life goals and expectations and invoking existential questions. This, in turn, may also influence the QoL patients perceive [1-3].

To contribute to our understanding of this existential dimension of falling ill, we combined theories of narrative identity and contingency to develop the theoretical model: “Narrative meaning making and integration of life events” [4]. This model hypothesizes that life events that conflict with a person’s “ultimate life goals” or worldview may result in an “experience of contingency” [3, 5]. The word “contingent” means that something is “neither necessary nor impossible” [6], thus referring to the realm of the possible. Applied to humanity, contingency is a fact of life: everything, including our lives and the events that befall us, could have been otherwise [7]. An “experience of contingency” can be seen as a confrontation with this randomness, which confronts us with the limitations of our ability to comprehend the world and life. This confrontation can evoke a “crisis of meaning,” resulting from disruptive life events that initially cannot be interpreted in the context of one’s life narrative and understanding of oneself and the world. Experiences of contingency may therefore lead to a fundamental reorientation of these understandings, through which the discrepancy with the existential meaning of the life event may be reduced [8]. The meaning of the event evolves within this process of “narrative meaning making.”

The idea of contingency implies that human beings are subject to randomness, but it also implies their creativity and ability to find ways of relating to the contingency of life events that befall them [9] and to find meaning [10]. The ever-present possibility of meaning relates to our “narrative intelligence” [11]: our ability to integrate disruptive life events into our life narratives, giving them a meaningful place without dismissing the contingency of these life events.

In combining theories of narrative identity and contingency from narrative psychology, philosophy and religious studies, we propose a humanities approach to illness and other life events. This approach is complementary to psychological and medical approaches: it aims to further our understanding of the existential dimension of the same processes described in psychology and medical sciences. The theoretical basis of our approach converges with that of existential-psychotherapeutic approaches, which focus on finding and experiencing meaning in the face of the contingent nature of the very same meaning, instead of (reducing) psychopathological symptoms [12]. The philosophical foundations of the existential-psychotherapeutic approaches are constituted by existentialism, specifically by the works of Yalom [13] and Frankl [14], theorizing our human "will to meaning" as well as the "existential givens" that are the horizon against which we search for this meaning. According to Yalom, the four most important existential givens are the inevitability of death, our existential social isolation, the lack of pre-given meaning in life ("meaninglessness") and, related to the latter, the inescapable freedom to choose in life [13]. Especially disruptive life events such as falling seriously ill confront us with these existential givens, shattering fundamental assumptions [15] and meaningfulness but also opening up new possibilities and meanings. Our approach emphasizes both aspects of contingency: the boundaries of human action and comprehension as well as the meanings, creativity and action that are made possible by these boundaries.

Our theoretical model describes seven concepts and the relationships among them, see Figure 1. Falling ill and other life events may conflict with one's worldview and/or ultimate life goals: the goals that are of ultimate value to people. This conflict may result in an experience of contingency, followed by narrative meaning making: a process of reinterpretation in which the meaning of the life event may evolve. This process may lead to narrative integration to a greater or lesser extent: the integration of the event into the life narrative, influencing quality of life.

To enable empirical testing, this theoretical model was operationalized in the "Reconstruction of Life Events questionnaire" ("RE-LIFE") [4]. This questionnaire starts with a request to draw a life line with positive and negative life events as high and low points.

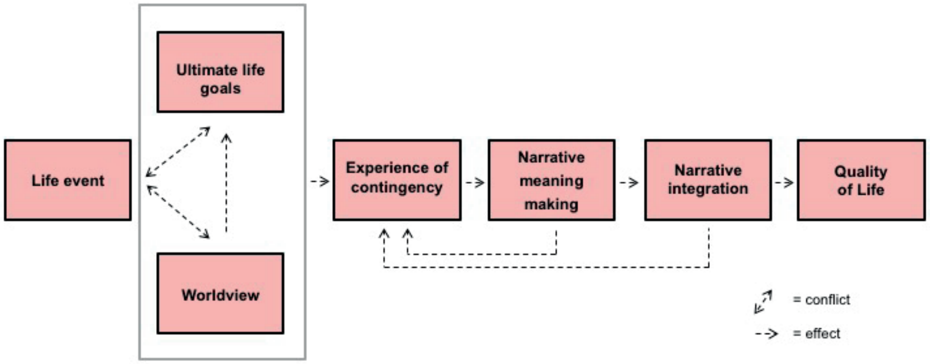

Figure 1. Theoretical model: *Narrative meaning making of life events* [4]

Consequently, respondents are asked to reflect on the meaning of their most unexpected negative life event and the experience of being diagnosed with a heart condition.

The questionnaire was tested in a large-scale longitudinal study on quality of life among heart patients. The psychometric properties and initial validation of the RE-LIFE questionnaire have been assessed previously, see Chapter 3 [16]. The aim of the present article is to examine the relationships among the concepts assessed with the RE-LIFE questionnaire, to further validate the theoretical model.

THEORETICAL MODEL

Below, we describe the theoretical concepts of the model and their operationalization in the RE-LIFE questionnaire. This description will be confined to the conceptual distinctions that were empirically found, as the large-scale study showed that some of the identified scales were different than expected. A more elaborate description of the concepts, and the structure and items of the RE-LIFE questionnaire can be found in Chapters 1 and 3 [4, 16].

Life event

According to narrative theory, life events are occurrences that a person considers meaningful for one's life as a whole [17, 18]. Unless one is convinced that all phenomena in the world can be attributed to religious or natural laws, which denies coincidence [19], all life events can be considered contingent because we can never fully control the course of our lives. However, unexpected negative life events, such as serious illness or other experiences of loss, may especially be experienced as "boundary situations" [20]. They often confront people with the "existential givens of life" such as mortality, vulnerability and the limits of our control and of our ability to understand the world [21, 22]. In this study, only the responses concerning the experience of being diagnosed with a heart condition are presented, because we considered that to be more comparable among respondents than a self-chosen life event.

Worldview

Also referred to as "outlook on life" or "philosophy of life," worldview is broadly defined as the framework of conceptions, beliefs and attitudes by which people interpret reality, explicitly as well as implicitly [23, 24]. In our study, we emphasize the aspect of the "foundational reality" that a person's worldview refers to, which can be immanent or transcendent [25]. Empirically, we found two types of worldview: "absolute immanence" (relating to the human, intelligible world only) and "transcendence" (relating to a transcendent dimension, i.e. “something higher,” which may be religious or non-religious) [26]. The transcendent or “spiritual” dimension provides people with a broader framework to interpret and integrate (disruptive) life events.

Ultimate life goals

Ultimate life goals are the goals or values giving ultimate meaning to people’s lives, in the sense that they cannot be replaced by something else. We adopted the idea of psychologist Robert Emmons that all personal goals are not equally important. They are hierarchically ranked, and can be distinguished as “ultimate” and “instrumental” life goals [27, 28]. In the RE-LIFE questionnaire, we present fifteen potential ultimate life goals: health, happiness, autonomy, enjoyment, self-development, recognition, caring for others, caring for children, connecting with other people, teaching others, being a good person, love, doing what fits oneself, being of significance to others, and freedom. Respondents are asked how important each life goal is for them and how their heart condition positively or negatively influences their striving for each life goal at present.

Experience of contingency

We define an experience of contingency, in line with the field of religious studies, as a “crisis of meaning” [5, 9, 29, 30]. It may be the result of a life event that conflicts with one’s worldview and/or ultimate life goals, which can be seen as a “biographical disruption” or a “breach of trust,” necessitating a reinterpretation of the event [31]. Although people may differ in their inclination or need for narrative meaning making [32], we propose that the initial inability to make sense and meaning of a life event conflicts with our fundamental need for understanding, coherence and meaning [14, 33-35]. The scale consists of items worded as metaphors often used by people when describing disruptive life events.

Narrative meaning making

Narrative meaning making is the process of reinterpretation of the event in the context of one’s personal life narrative. The “scope” of narrative meaning making refers to the scale or span of the meaning of the event. Events can have significance for the situation only (situational), one’s life as a whole (existential) or for a transcendent dimension (spiritual). The latter two concepts were operationalized in two scales. The third concept, “situational scope,” was operationalized as low scores on both “existential scope” and “spiritual scope.”

Narrative integration

Narrative integration refers to the integration of the life event into one’s personal life narrative and thus one’s narrative identity, giving it a meaningful place. Our analysis of the RE-LIFE data indicated three scales: “acknowledging,” “receiving new insights” and “receiving[9].” In the “acknowledging” mode, the event is not yet integrated but interpreted as a disruption of the life story, evoking existential questions and a search for ways to relate to the life event[10]. The modes “receiving new insights” and “receiving” both indicate narrative integration, characterized by openness and receptivity for new insights and possibilities. The first emphasizes learning what’s most important in life and the latter indicates happiness and embracing new possibilities that emerge from the life event[11].

Quality of life

Quality of life (QoL) is a multidimensional construct widely used in research, its meaning depending on the field, context and aims of the research. In the medical sciences, QoL usually refers to the impact of disease or treatment on physical, mental and social functioning. Because our theoretical model revolves around the impact of illness on people’s lives as a whole, we use a broad conception of QoL, i.e. “overall QoL.” We adopted the definition of the World Health Organization (WHO): ‘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’ [36].

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[9] Please note that in Chapter 3, two instead of three scales were found: “acknowledging” and “receiving.” This is based on the data from the six-month assessment, instead of the three-month one.

[10] Based on our analysis of interviews with terminally ill cancer patients [3], our definition of the “acknowledging” mode differs from Wuchterl’s (2019) use of the concept [19]. Wuchterl considers the judgement of an event to be contingent as part of his religious-philosophical definition of contingency, just as “an existential interest” and the need to “deal” with the event. His definition of “acknowledging” focuses on acknowledgement of the limits of reason in our attempts to understand the world and the events that befall us. In Wuchterl’s vocabulary, acknowledging therefore also implies contemplating “the possibility of an Other of Reason.” In our definition, “acknowledging” implies 1) acknowledging the contingency of the event (the fact that it could also not have happened), 2) acknowledging the existential impact of the event, and 3) the need to actively “work” through one’s interpretation of the event, searching for ways to relate to it.

[11] The “receiving” modes that we empirically found in our qualitative [3] and quantitative [16] research are inspired by Wuchterl’s account of “encountering” contingency, but are less religious in their meaning. In Wuchterl’s definition, “encounter” does not leave the “content” of “the Other beyond reason” open, but refers to the revelation of what exists beyond reason, thus entering the realm of religion [19]. Our modes of “receiving” share with this definition the openness for that which transcends our immanent framework, and a receptivity for new possibilities. However, the new insights and new possibilities that are “received” are not necessarily the results of understanding or meeting something beyond our human world.

APPROACH AND MEASUREMENT MODEL

Because the concepts of the theoretical model are configurated as a causal chain, a multiple mediation analysis is the most appropriate analysis to examine if the impact of the heart condition on quality of life is indeed (partly) explained by the variables belonging to the model of narrative meaning making.

To enable assessment of the theoretical model as a serial mediator model using the RE-LIFE data, a few adjustments were made to the model, see Figure 2. First, several background variables as assessed in our study were placed before the concepts of the theoretical model, as independent variables hypothesized to influence these concepts, directly or indirectly. These variables include medical variables (such as the type of cardiac intervention) that are hypothesized to influence how the life event of being diagnosed with a heart condition is experienced. Second, because a conflict between a life event and one's (often abstract and implicit) worldview is difficult to assess and is usually accompanied by a conflict with ultimate life goals, the RE-LIFE assesses the impact of the event on respondents' life goals, and assesses worldview separately. Therefore, the two sub-concepts of "worldview" ("absolute immanence" and "transcendence") were considered as background variables, hypothesized to influence the mediating variables. Third, to assess the impact of the life event, the concepts "life event" and "ultimate life goals" were combined in the operationalization. Respondents were asked about the impact of the life event on their ultimate life goals, as well as the importance of every ultimate life goal. These scores on both variables were combined into the variable "weighted impact on ultimate life goals" and then divided into two variables: "total weighed negative impact on ultimate life goals" and "total weighed positive impact on ultimate life goals" (in short: "negative/positive impact"). Fourth, we reversed the order of the "negative/positive impact" and "experience of contingency" variables in the hypothesized mediation model. The reason for this is that the RE-LIFE questionnaire assesses the "experience of contingency" at the time of the event and the current impact of the event on the ultimate life goals. Because of this order in time, we expected the "experience of contingency" at the time of the diagnosis to have impact on life goals at the time of the assessment.

In addition, "posttraumatic growth" (PTG), a variable that was added as a second outcome to overall QoL (see Chapter 3) [16], was considered as a possible dependent variable for mediation analysis. PTG is defined as the experience of positive change resulting from the struggle with challenging life crises [37] and was therefore hypothesized to concur with our concept of narrative integration [16].

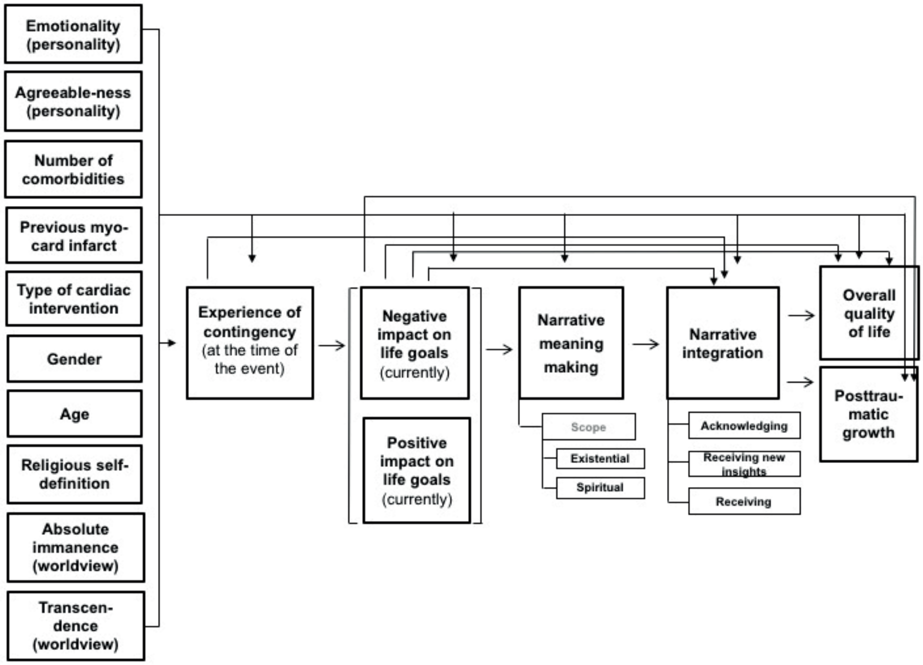

Figure 2. Measurement model for mediation analysis

HYPOTHESES

Hypotheses were formulated considering the relationships between the core concepts of our theoretical model, including QoL. First, we expected “experience of contingency” to influence QoL negatively, with the concepts between them (see Figure 2) functioning as mediators, i.e. accounting fully or partially for the influence of “experience of contingency.”

Second, more “experience of contingency” was hypothesized to be associated with more “negative impact on ultimate life goals” and less “positive impact on ultimate life goals.” The direction of the influence on “positive impact” was not certain: because positive impact on life goals can result from a reinterpretation of a negative life event, “experience of contingency” may also be positively associated with “positive impact.” In addition, “experience of contingency” was expected to have a positive influence on both “existential meaning” and “spiritual meaning,” a positive influence on “acknowledging” and a negative influence on “receiving” and “receiving new insights.” In analogy with “positive impact,” the expected direction of the influence on “receiving” and “receiving new insights” is debatable. Indeed, these two modes of narrative integration could also be positively influenced by the experience of contingency at the time of the diagnosis.

Third, considering narrative integration, “acknowledging” was expected to have a negative influence on QoL, and “receiving” and “receiving new insights” a positive influence. Fourth, “negative impact” was expected to lead to more “acknowledging” and lower QoL, while “positive impact” was expected to result in less “acknowledging” and higher levels of QoL. Fifth, “positive impact” was hypothesized to lead to more, and “negative impact” to less “receiving” and “receiving new insights.”

METHODS

Study design

The RE-LIFE questionnaire was tested within the context of the IMPACT study on quality of life among people with stable coronary artery disease (CAD) scheduled for elective cardiac intervention. After recruitment, respondents completed QoL questionnaires prior to, and two weeks, three months and six months after their intervention. At three and six months, the RE-LIFE was included in the questionnaire set. For the present study, the three-month assessment was used. Sociodemographic information was collected at baseline. Personality and posttraumatic growth and were assessed at the three- and six and month[12] assessments, respectively. Because the central ethics committee confirmed that the Medical Research Involving Human Subjects Act (WMO) did not apply to our study, further ethical assessment of the study was not required. All patients gave written informed consent.

Participants

Participants were recruited at the cardiology departments of the Amsterdam University Medical Centers (Amsterdam UMC): Academic Medical Center (AMC) and VU Medical Center (VUmc). Inclusion criteria were being scheduled for an elective percutaneous coronary intervention (PCI) or elective coronary artery bypass graft (CABG) at the AMC or VUmc and having at least one confirmed diagnosis of an additional chronic, somatic disease. Exclusion criteria were having psychiatric comorbidities or insufficient command of the Dutch language.

RE-LIFE variables

Experience of contingency was measured with 5 items, using a 4-point scale ranging from 1 (“did not experience”) to 4 (“experienced very strongly”). Negative and positive impact on life goals is a variable resulting from combining two other variables. The first variable

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[12] We erroneously mentioned these two assessments in reverse order in the published version of this article.

is the impact of the event on 15 life goals, assessed with a 7-point scale ranging from 1 (“greatly hinders”) to 7 (“greatly helps”). The second variable is the importance of the same 15 life goals, using a 4-point scale ranging from 1 (“not important”) to 4 (“very important”). The two variables were combined into a “weighed total impact,” ranging from -12 for greatly hindered very important life goals, to +12 for greatly helped very important life goals. Consequently, this variable was separated into the two variables “total negative impact” and “total positive impact” (only the first one met the criteria for mediation analysis). “Total negative impact” scores range from 1 to 12, with higher scores indicating more negative impact of the life event on ultimate life goals.

Existential and spiritual meaning were measured with 2 and 3 items respectively, employing a 5-point Likert scale ranging from 1 (“totally disagree”) to 5 (“totally agree”).

Acknowledging, Receiving new insights and *Receiving*[13] were measured with 5, 2 and 2 items respectively, using a 5-point Likert scale ranging from 1 (“totally disagree”) to 5 (“totally agree”).

Outcome measures[14]

Overall QoL was assessed with an item from the EORTC Quality of Life Core Questionnaire (EORTC QLQ-C30) [38]. The item assesses respondents’ overall QoL during the past week, employing a 7-point response scale ranging from 1 (“very poor”) to 7 (“excellent”). This item is also included in the RE-LIFE questionnaire.

Posttraumatic growth was assessed using the Posttraumatic Growth Index (PTGI) [39]. The questionnaire comprises 21 items and employs a 6-point Likert scale ranging from 0 (“not”) to 5 (“to a very great degree”), reflecting how much positive change was experienced as a result of the respondent’s “crisis.” In our study, the word “crisis” was changed into “your heart condition and/or its treatment.” A total PTGI score was calculated, with higher scores indicating more posttraumatic growth [37].

Background variables[3]

Personality: Two personality dimensions, “emotionality” and “agreeableness,” were assessed with the HEXACO Personality Inventory – Dutch, simplified version (HEXACO-SPI) [40]. Both dimensions are assessed with 16 items, using a 5-point Likert scale ranging from 1 (“totally disagree”) to 5 (“totally agree”). Mean scores for both dimensions were

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[13] Please note that in Chapter 3, one “receiving” subscale was found, consisting of 3 items, based on the data from the six-month instead of the three-month assessment.

[14] Previously described in Chapter 3 [16].

calculated, with higher scores indicating more emotionality and more agreeableness, respectively.

Worldview: Absolute immanent and Transcendent worldview, in this study considered as background variables, were assessed with 2 and 4 items respectively. A 5-point Likert scale was used, ranging from 1 (“totally disagree”) to 5 (“totally agree”). These items are also part of the RE-LIFE questionnaire.

Socio-demographic variables: Participants provided sociodemographic information at baseline, including gender, age and religion. For religion, the response categories of subjective religion (Christian, atheist, Muslim, Buddhist, Jewish and “other”) were aggregated into the categories “religious,” “nonreligious” and “other.”

Medical variables: The following medical information was obtained from patients' medical files: the type of intervention received (in descending order of impact: bypass surgery, percutaneous intervention or only cardiac catheterization); occurrence of myocardial infarcts in the past; and the number of comorbidities.

Selection of variables for mediation analysis

We conducted a regression-based serial multiple mediation analysis, using the PROCESS-macro in SPSS developed by Hayes [41, 42]. Because of the hypothesized serial mediation in our model, we used “model 6,” which allows for analyzing two to four mediators (see Figure 3). As shown in the figure, every mediator consists of one variable, in contrast to our measurement model in which concepts are sometimes divided into more variables, such as negative/positive impact on life goals and existential/spiritual meaning. This meant that for every “step” in our measurement model, only one variable could be selected to assess its possible mediating role (e.g. in the case of narrative meaning making, either “existential” or “spiritual”).

To assess which variables met the criteria for possible mediation, a table with all bivariate correlations including the background variables was inspected (see Additional table 1. at the end of this chapter). For the independent variables in the mediation models, only the background variables and “experience of contingency” were considered, and only if they correlated ≥ 0.20 with at least one of the possible mediators and one of the outcome measures. For the mediators, RE-LIFE variables were considered if they correlated ≥ 0.20 with one of the background variables as well as with one of the outcome measures. For the dependent variables, the outcome measures were considered as well as the “narrative integration” variables.

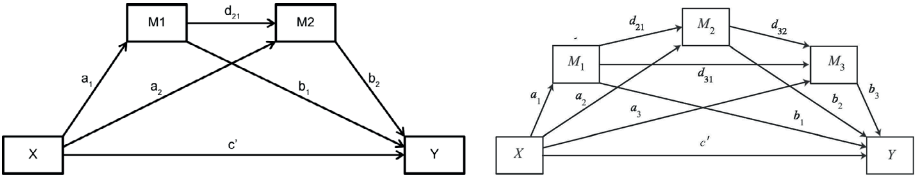

Figure 3. Conceptual diagrams of “Model 6” with two and three mediators in the PROCESS macro
X = dependent variable; Y = dependent variable; M = mediator

Statistical analyses

For this study, only complete cases were analyzed. All data were assessed to check whether they met the assumptions for regression analysis: homoscedasticity, normality of estimation error, independence of observations, and linearity for all the direct and indirect effects. After the selection of variables for mediation analysis, regression-based serial mediation analyses were conducted for two different models. The 3.2 version of the PROCESS macro (Hayes 2013) for SPSS (IBM 2014) was used for these analyses. To assess the significance of the indirect effects, bootstrap samples (N = 5,000) were taken to calculate 95% bias-corrected confidence intervals. Because the variables in the two mediation models were assessed using different response scales, standardized Beta coefficients and adjusted R^2 values were calculated to facilitate comparison of the magnitudes of the effects. Results (unstandardized) are in terms of the independent variable: for every “unit” increase in X, there is an a_1 or a*b change in M or Y. Standardized Beta coefficients are given in terms of standard deviations and thus range between 0 and 1.

To further examine the influence of the independent variable (“experience of contingency”), a Student’s t-test was performed to differentiate between respondents with and without an experience of contingency. For this purpose, two categorial variables were created: “No EoC” (mean scores for “experience of contingency” 1-2.99 on a 4-point Likert scale) and “EoC” (mean scores 3-4)[15]. Means for the dependent variables “negative impact,” “existential scope,” “acknowledging” and “QoL” were calculated for both groups. Based on our theoretical model, we hypothesized that compared to the group without an experience of contingency, respondents with an experience of contingency would show higher mean scores on “negative impact,” “existential scope” and “acknowledging” and lower mean scores on QoL.

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[15] In the published version of this article, we erroneously wrote “5-point Likert scale” and “mean scores 3-5.”

RESULTS

Participants

246 participants (71% male) completed the questionnaire, with a mean age of 68 (SD 8.6). The number of complete cases varied per scale (between 218 and 224 cases).See Table 1 for the characteristics of the participants.

Table 1. Participant characteristics

	Sample (N = 246)
Age	
Median (range)	69 (46-87)
Mean (SD)	68 (8.7)
Gender	
Female	71 (29%)
Male	175 (71%)
Religion	
Religious	105 (43%)
Non-religious	89 (36%)
Other (not specified)	35 (14%)
Missing	17 (7%)

Selection of variables for mediation analysis

Based on the correlation table, the bivariate regression coefficients and the theory underlying our model, three possible models of serial mediation were selected, see Figures 4a and 4b. Of the background variables, only the personality dimension “Emotionality” met the criteria for functioning as an independent variable in a mediation model, with QoL as the outcome. Because of our focus on our theoretical model in this article, here we will confine ourselves to the two mediation models in which “experience of contingency” is the independent variable.

The first hypothesized mediation model (Figure 4a) consists of the core concepts of the theoretical model: “Experience of contingency” (X) influencing “Acknowledging” (indicating no narrative integration) (Y) through the mediators “Negative impact” (M1) and “Existential meaning” (M2). The underlying idea is that the influence of “experience of contingency” on “acknowledging” may be partly or fully explained by one or both mediators. Based on the theory underlying our model, we hypothesized all direct and indirect effects to be positive. As for the mediation, we expected the relationship between “experience of contingency” and “acknowledging” to be fully mediated by “negative impact” and “existential meaning.” Indeed, the “experience of contingency” at the time of the event could only be expected to lead to more acknowledging (existential struggle) at the present moment if there was currently a negative impact on life goals and an existential meaning of the event. Thus, the direct effect (c') was hypothesized to become nonsignificant as a result of adding the two mediators.

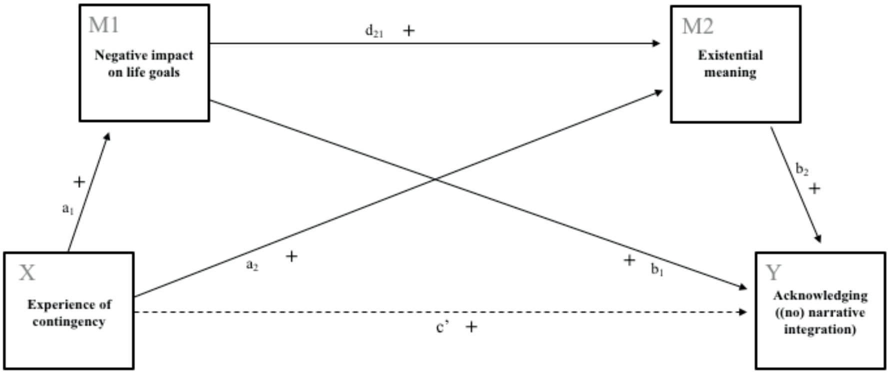

figure 4a. Hypothesized mediation model 1
+ = positive effect; − = negative effect; -----> = nonsignificant effect

The second hypothesized model (Figure 4b) encompasses this "core model," adding one variable relevant for the medical context of our study: Quality of life (QoL) as the dependent variable (Y) of the model. Thus, it was hypothesized that "experience of contingency" would influence QoL, through the mediators "negative impact," "existential meaning" and "acknowledging." Considering the mediation, in this model we also expected the direct effect (c') to become nonsignificant after adding the three mediators. It was hypothesized that an "experience of contingency" at the time of the diagnosis would only be detrimental to QoL in the case of current "negative impact in life goals" and "acknowledging."

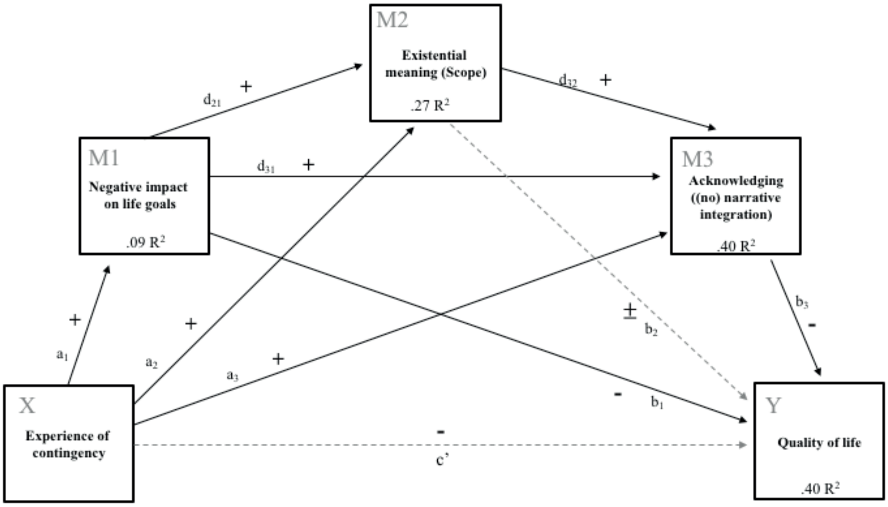

Figure 4b. Hypothesized mediation model 2
+ = positive effect; − = negative effect; -----> = nonsignificant effect

Statistical analyses

Inspection of the data showed that all variables met de assumptions for regression-based mediation analysis. See Table 2 for means and standard deviations of the variables in mediation models 1 and 2.

Table 2. Means and standard deviations

Variable	Mean	SD
Experience of contingency		
Experience of contingency[1]	2.00	0.88
Impact on life goals		
Negative impact[2]	1.67	1.34
Narrative meaning making		
Existential (scope)	3.30[16]	0.88
Spiritual (scope)	2.24	0.76
Narrative integration		
Acknowledging	2.72	0.86
Receiving new insights	3.16	0.74
Receiving	1.97	0.67
Quality of life		
Overall QoL	5.35	1.23

Responses are scored on a 5-point Likert scale (1 = “strongly disagree,” 5 = “strongly agree”), unless stated otherwise with superscript: [1] = 4-point scale (1 = “did not experience,” 4 = “experienced very strongly”).
[2] = 12-point combined scale (1 = very low weighed negative impact on life goals, 12 = very high weighed negative impact on life goals)

Mediation model 1

Results from the serial mediation analysis with two mediators indicated that the total effect of “Experience of contingency” on “Acknowledging” ($c = .54$, $p < .001$) could indeed be explained by significant indirect effects through “Negative impact on life goals” and “Existential meaning” as well as through both mediators, see Figure 5. Contrary to expectation however, only a partial mediation was found, as the direct effect of “experience of contingency” on “acknowledging” remained significant ($c' = .41$, $p < .001$). This means that part of the influence of “experience of contingency” at the time of the diagnosis on current “acknowledging” is not explained by the negative impact on life goals and the existential meaning of the event. See Table 3 for all results of the first mediation analysis.

A 95% bias-corrected confidence interval based on 5,000 bootstrap samples showed that the long-way indirect effect ($a1*d21*b2 = .02$) as well as both shortcut-effects ($a1*b1 = .07$, $a2*b2 = .03$) were entirely above zero. This indicates with 95% certainty that the indirect effects are indeed positive.

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[16] In the published version of this article, we erroneously included 2.68 instead of 3.30.

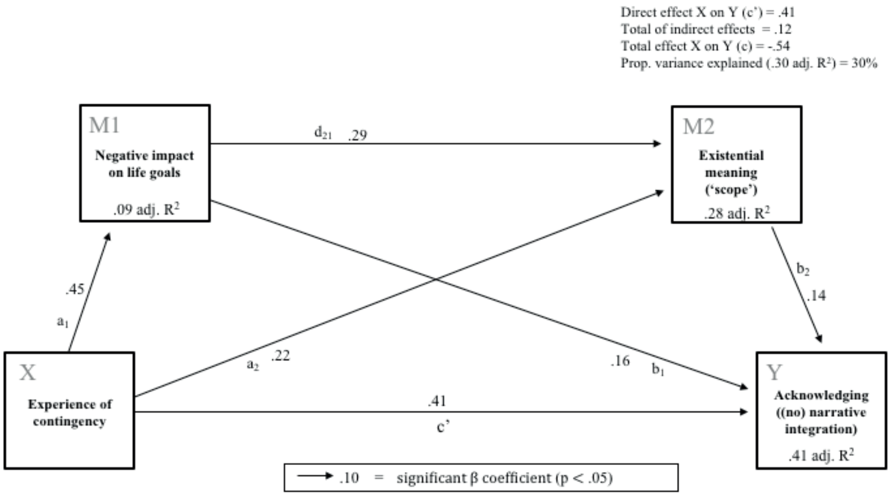

Figure 5. Results from mediation analysis—two mediators (Model 1)

Table 3. Results from mediation analysis — two mediators (Model 1)

Path	Direct effects	B	β	95%CI	se	t	R	Adj. R^2
a_1	Experience of Contingency on **Negative impact**	.45***	.30***	.26 – .65	.10	4.53	.30***	.09***
a_2	Experience of Contingency on Existential meaning	.22***	.22***	.10 – .35	.06	3.50		
d_{21}	Negative impact on **Existential meaning**	.29***	.43***	.21 – .37	.04	6.95	.53***	.28***
b_1	Negative impact on Acknowledging	.16***	.26***	.09 – .24	.04	4.14		
b_2	Existential meaning on Acknowledging	.14*	.15*	.01 – .27	.06	2.36		
c'	Experience of Contingency on **Acknowledging (direct)**	.41***	.42***	.30 – .52	.06	7.31	.64***	.41***
Path	**Total effect**	**B**	**β**	**95%CI**	**se**	**t**	**R**	**Adj. R^2**
c	Experience of Contingency -> **Acknowledging (total)**	.54***	.55***	.42 – .65	.06	9.47	.55***	.30***

Path	Indirect effects	B	β	95%CI	se
a_1*b_1	Experience of Contingency -> Negative Impact -> Acknowledging	.07	.08	.06 – .20	.02
a_2*b_2	Experience of Contingency -> Existential meaning -> Acknowledging	.03	.03	.00 – .07	.02
a_1*d_{21}*b_2	Experience of Contingency -> Negative impact -> Existential meaning -> Acknowledging	.02	.02	.00 – .04	.01
-	Total of indirect effects	.12	.13	.06 – .20	.03

*** =** p<.05
**** =** p<.01
***** =** p<.001
B = regression coefficients
ß = standardized regression coefficients
se = standard error
Adj. R^2 = adjusted R-square (standardized)

The direct and indirect effects of “experience of contingency” together explain 30% of the proportional variance (R^2) in “acknowledging.” Combined with the direct effects of the two mediators this explains 41% of the proportional variance in “acknowledging.”

Mediation model 2

Serial mediation analysis with three mediators indicates that the total effect of “experience of contingency” on QoL (c = -.51, p < .001) is fully mediated by the variables “negative impact,” “existential meaning” and “acknowledging,” see Figure 6. Indeed, the direct effect of “experience of contingency” on QoL becomes nonsignificant (c’ = -.14, p. = .25) when the mediators are added.

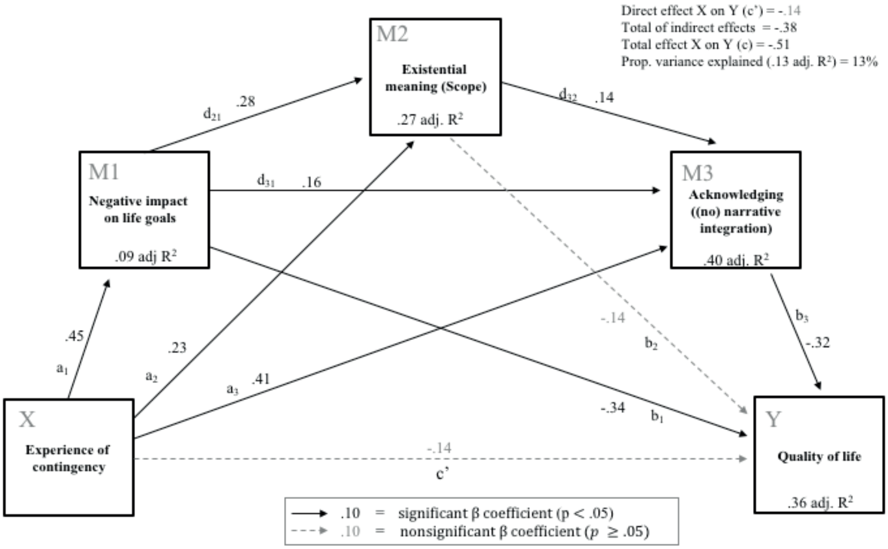

Figure 6. Results from mediation analysis – three mediators (model 2)

The 95% bias-corrected confidence interval based on 5,000 bootstrap samples showed that the total of indirect effects (-.38) as well as five of the seven shortcut-effects through one, two and three mediators, were entirely above zero when holding the other mediators constant. This indicates with 95% certainty that these indirect effects are indeed negative. As hypothesized, the direct effect of “existential scope” was shown to be nonsignificant, which means that the mediator “acknowledging” indeed accounts for the influence of “existential meaning” on QoL. See Table 4 for all results of the second mediation analysis.

Table 4. Results from mediation analysis – three mediators (model 2)

Path	Direct effects	B	β	95% CI	se	t	R	Adj. R^2
a_1	Experience of Contingency -> **Negative impact**	.46***	.30***	.26 – .66	.10	4.50	.30***	.09***
a_2	Experience of Contingency -> Existential meaning	.23***	.22***	.10 – .35	.06	3.50		
d_{21}	Negative impact -> **Existential meaning**	.28***	.42***	.18 – .38	.05	5.74	.52***	.27***
a_3	Experience of Contingency -> Acknowledging	.41***	.42***	.29 – .52	.06	7.10		
d_{31}	Negative impact -> Acknowledging	.16***	.25***	.08 – .24	.04	4.40		
d_{32}	Existential meaning -> **Acknowledging**	.14*	.15*	.02 – .26	.06	2.10	.63***	.40***
b_1	Negative impact -> QoL	-.34**	-.37**	-.54 – -.13	.10	-3.29		
b_2	Existential meaning -> QoL	*-.14*	*-.10*	*-.32– .05*	*.09*	*-1.46*		
b_3	Acknowledging -> QoL	-.32**	-.23**	-.53 – -.12	.10	-3.11		
c’	Experience of Contingency -> **QoL (direct)**	*-.14*	*-.10*	*-.32 – .05*	*.09*	*-1.46*	.62***	.38***
Path	**Total effect**	**B**	**β**	**95% CI**	**se**	**t**	**R**	**Adj. R^2**
c	Experience of Contingency on **QoL (total)**	-.51***	-.37***	-.70 – -.33	.09	-5.59	.36***	.13***

Path	Indirect effects	B	β	95% CI	se
$a_1 * b_1$	Experience of Contingency -> Negative impact -> QoL	-.15	-.11	-.28 – -.05	.06
$a_2 * b_2$	Experience of Contingency -> Existential meaning -> QoL	*-.03*	-.02	*-.08 – .02*	*.03*
$a_3 * b_3$	Experience of Contingency -> Acknowledging -> QoL	-.13	-.09	-.23 – -.04	.05
$a_1 * d_{21} * b_2$	Experience of Contingency -> Negative impact -> Existential meaning -> QoL	*-.02*	*-.01*	*-.05 – .01*	*.02*
$a_1 * d_{31} * b_3$	Experience of Contingency -> Negative impact -> Acknowledging -> QoL	-.02	-.02	-.05 – -.01	.01
$a_2 * d_{32} * b_3$	Experience of Contingency -> Existential meaning -> Acknowledging -> QoL	-.01	-.007	-.03 – -.0001	.007
$a_1 * d_{21} * d_{32} * b_3$	Experience of Contingency -> Negative impact -> Existential meaning -> Acknowledging -> QoL	-.01	-.004	-.02 – -.0002	.004
-	Total of indirect effects	-.38	-.27	-.54 – -.22	.08

*** =** p<.05
**** =** p<.01
***** =** p<.001
Italics **=** 95% CI including zero, i.e. non-significant effect
B = regression coefficients
ß = standardized regression coefficients
se = standard error
Adj. R^2 = adjusted R-square (standardized)

The direct and indirect effects of "experience of contingency" together explain 13% ($R^2 = .13$, $p < .001$) of the proportional variance in QoL. Combined with the direct effects of three mediators, this explains 36% of the proportional variance in QoL ($R^2 = .36$, $p < .001$).

T-test "Experience of Contingency"

Table 5 shows the results of the t-test, examining the differences between people with and without an experience of contingency. Although the group reporting an experience of contingency was relatively small (N=39, 18%), all differences in means between the two groups were significant. As hypothesized, respondents with an experience of contingency showed higher mean scores on "negative impact," "existential scope" and "acknowledging" and lower mean scores on QoL. Notably, the largest difference was seen in "acknowledging" between "No EoC" (M = 2.51, SD = 0.73) and "EoC" (M = 3.70, SD = 0.73): -1.19 on a 5-point scale (t(215) = -9.09, p < .000).

Table 5. Group differences based on "experience of contingency"

		N	Mean	SD	Mean difference	t	df
Negative impact[1]	No EoC	178	1.48	1.06	-1.03	-3.00**	42.56
	EoC	39	2.51	2.05			
Existential scope[2]	No EoC	182	3.20	0.86	-.63	-4.18***	219
	EoC	39	3.83	0.86			
Acknowledging[2]	No EoC	180	2.51	0.73	-1.19	-9.09***	215
	EoC	37	3.70	0.73			
Quality of life[3]	No EoC	172	5.53	1.06	1.04	-3.98***	46.27
	EoC	39	4.49	1.55			

** p < .001 *** p < .000

[1] **=** 12-point combined scale (1 = no weighted negative impact, 12 = very high weighted negative impact).

[2] **=** 5-point scale (1 = "strongly disagree", 5 = "strongly agree")

[3] **=** 7-point scale (1 = "very poor", 7 = "excellent")

DISCUSSION

The aim of this study was to examine the relationships between the concepts of the "Narrative meaning making of life events" model, using data collected with the RE-LIFE questionnaire. After assessing the data to identify possible mediators, two models were assessed with two and three mediators respectively.

Model 1

The first model indicated that respondents who reported a stronger experience of contingency at the time of the diagnosis also reported more "acknowledging," indicating that the event was not yet integrated into their life stories. While a part of this influence was a direct effect, another part of the effect was the result of influences of “experience of contingency” on the two mediators, and their influences on the outcome “acknowledging.” These results support our theoretical assumption that an experience of contingency evokes a process of narrative meaning making. However, our hypothesis that this would lead to a certain degree of narrative integration could not be confirmed. Indeed, in our sample, the variables “receiving new insights” and “receiving,” indicating narrative integration, did not meet the criteria to function as mediators or dependent variables. This could be due to the fact that only a small part (18%) of the respondents reported an “experience of contingency.” Apparently, the life event of being diagnosed with a heart condition did not lead to a crisis of meaning in the majority of respondents, and therefore did not necessitate reinterpretation and narrative integration.

Looking at the standardized coefficients, which allow for comparison, the total of indirect effects accounted for by the mediators is relatively small. Thus, in this model, the effect of “experience of contingency” on “acknowledging” is mainly a direct effect. As we hypothesized a full mediation, this is contrary to expectation. Apparently, a stronger experience of contingency at the time of the diagnoses may lead to current struggles and existential questions, regardless of the current negative impact on life goals and the scope of the meaning. This indicates that the current negative impact of the event on life goals plays a smaller role in people’s struggle to integrate the event than we hypothesized. In future use of the RE-LIFE questionnaire, the impact on life goals at the time of the event could be assessed to examine its influence on the experience of contingency and consequently on acknowledging.

However, the fact that all effects are significant and positive can still be seen as an indication for the validity of the theoretical model. “Experience of contingency” shows a relatively large direct effect on “acknowledging.” In addition, 30% of the proportional variance of “acknowledging” is explained by “experience of contingency” (including the indirect effects) and 41% including the direct effects of the mediators. These are interesting results in themselves, as these two concepts are of central importance in the model. They indicate that the experience of contingency, associated with the confrontation with “existential givens” that falling ill often implies, plays an important role in the process of meaning making that follows.

Model 2

The second model showed that more experience of contingency at the time of the diagnosis leads to a lower quality of life at the time of the assessment. In addition, as hypothesized, the effect turned out to be fully explained by indirect effects through the mediators. This means that it is not the experience of contingency at the time of the diagnosis as such that influences the quality of life experienced at the time of the assessment. This influence is only significant for respondents whose experience of contingency led to more negative impact on life goals, more existential meaning of the event, and more acknowledging (the struggle indicating no narrative integration), which is detrimental to the experienced quality of life. These results support our theoretical assumption that as a "crisis of meaning," an experience of contingency evokes a process in which people struggle to come to terms with the event in the context of their life narratives. However, to confirm this assumption, more research is needed among respondents who predominantly report an experience of contingency.

The fact that 13% of the proportional variance in QoL is explained by "experience of contingency" (including indirect effects) and 40% by the whole model, indicates that indeed, QoL is also influenced by other variables than the concepts of our model. However, considering that people's QoL is influenced by a myriad of variables in many domains of their lives, the explanatory power of our model can be considered quite satisfactory. It can be concluded that narrative meaning making and integration play a significant role in people's self-evaluations of their quality of life. These results indicate that indeed, complementary to psychological variables such as coping styles, narrative meaning making and integration are important in our understanding of the QoL people experience. The results of the t-test support this conclusion, as they showed that people with an experience of contingency reported significantly lower levels of QoL than people without an experience of contingency.

Clinical Relevance

Our results show that experiences of contingency lead to a struggle to integrate the event into one's life story in a meaningful way, reducing quality of life. Therefore, our suggestion for psychological or spiritual counselling and psychotherapy would be to discuss the existential issues that clients raise, including the incomprehensibility of the event. In some psychotherapeutic approaches, meaning-centered topics are not explicated because discussing these is seen as an intellectual defense mechanism that shifts away from the "real problems" [43]. However, people who seek help after being confronted with a serious illness or other disruptive life events often want to discuss the existential questions evoked by this confrontation. Nowadays, meaning is increasingly considered clinically relevant, and studies show that clients define recovery in the context of mental health problems as building a meaningful life [44]. Research shows that existential therapies, especially the types using a meaning-centered approach, seem beneficial for clients in reducing psychopathology and increasing meaning, purpose in life [45], quality of life [46] and posttraumatic growth [43]. The relationship between the latter and narrative integration may be worthwhile to investigate further. Previous analysis of data collected with the RE-LIFE questionnaire indicated that all three ‘narrative integration’ variables (“acknowledging,” “receiving new insights” and “receiving”) positively correlated with posttraumatic growth, while “acknowledging” negatively correlated with overall QoL (see Chapter 3)[16].

As stated in the introduction, our approach converges with the theoretical foundations of existential-psychotherapeutic approaches. While most existential therapies share a pragmatic-phenomenological approach to meaning [43], several “schools” can be distinguished. They predominantly focus on either “meaning in life” (e.g. meaning-centered / logotherapy, based on the works of Frankl), or on facing the existential givens of life, such as mortality and meaninglessness (e.g. existential-humanistic approaches, rooted in the works of Yalom). Our approach is in line with recent attempts to integrate these two approaches, while simultaneously integrating psychology, philosophy, psychiatry and theology [22]. In our emphasis on the experience of contingency, the confrontation with existential givens and the boundaries of our comprehension are explicated together with shattered meanings and conflicts with life goals that are of ultimate concern. The concept of narrative integration implies the duality of searching for meaning in the face of these existential givens. Therapies addressing contingency may help people in constructing narratives while being aware of the contingency of the world, also described as “creative contingency” [47]. Integrating disruptive life events into one’s life narrative implies giving them a meaningful place and realizing what is of ultimate meaning in life, while remaining open to other possible meanings and the contingency of life in general.

Limitations

Several limitations in this study should be acknowledged. First, the original theoretical model was adjusted to enable mediation analysis in PROCESS, using the RE-LIFE data. As a result, the model could not be validated in its entirety, nor could the original sequence of the concepts be followed (e.g. “impact on life goals” at the time of the event influencing “experience of contingency”). An important consequence is that we cannot draw conclusions on narrative integration in the sense of “receiving” and “receiving new insights,” but only on the absence of narrative integration (“acknowledging”). Depending on the aims, future empirical studies may use adapted versions of the RE-LIFE questionnaire. For example, the impact of the life event on life goals at the time of the diagnosis (instead of at the time of the assessment) may be assessed. The RE-LIFE may also be administered shortly after a diagnosis or other life event, rather than in anticipation of a medical intervention. In addition, as described previously (see Chapter 3)[16], some of the RE-LIFE item categories, such as the “worldview” categories, may benefit from revisions. As a result, they may also qualify to function as independent variables, mediators or moderators in the mediation models.

Second, our specific study population (heart patients, predominantly males aged between 60 and 70) limits the generalizability of the results to other patient or general populations. In addition, as mentioned above, being diagnosed with stable coronary artery disease may not have been a major disruptive event for all respondents. Therefore, the life event may not have led to an experience of contingency in all cases. This assumption is supported by the t-test as well as by the mean of the scores on this scale: 2.00 (SD 0.88), reflecting the "experienced somewhat" response option in the questionnaire. In addition, mean scores for "negative impact on life goals" are also low (1.67 on a scale ranging from 1 to 12). It is conceivable that the results of our mediation analyses would have been different if a more disruptive life event had been assessed, such as bereavement or being diagnosed with a terminal disease. Indeed, especially events that confront people with the "existential givens" in life leave people empty-handed when it comes to making meaning of the event. Without such a crisis of meaning, people's framework of interpretation may not be opened up to allow new insights and possibilities.

Third, the observational design of our study, with data collection at one time point, does not allow conclusions about causality. For example, instead of "acknowledging" influencing QoL, the association between the two could also be interpreted the other way around. It could be argued that a lower QoL, impacted by the disease, the intervention or other circumstances, leads to more struggle and existential questions. Therefore, although the hypothesized nature and directions of the relationships between the concepts are derived from the theories underlying our model, their sequence cannot be confirmed. It thus remains possible that alternate models may offer the same degree of explanation of the data.

Fourth, a relatively large number of variables was assessed and selected for our mediation models, given the size of our sample. This reduces the statistical power of the mediation analyses. Therefore, the results need to be interpreted with caution and confirmed in future, well-powered studies.

Conclusion

In conclusion, serial mediation analyses using the data collected with the RE-LIFE questionnaire indicate that "experience of contingency," "negative impact on life goals," "existential meaning" and "acknowledging" significantly influence people's self-evaluation of their quality of life. However, it is not the experience of contingency at the time of the diagnosis as such that influences the quality of life experienced at the time of the assessment, but its influence through “negative impact on life goals,” “existential meaning” and “acknowledging.”

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Additional table 1. Correlations between all variables

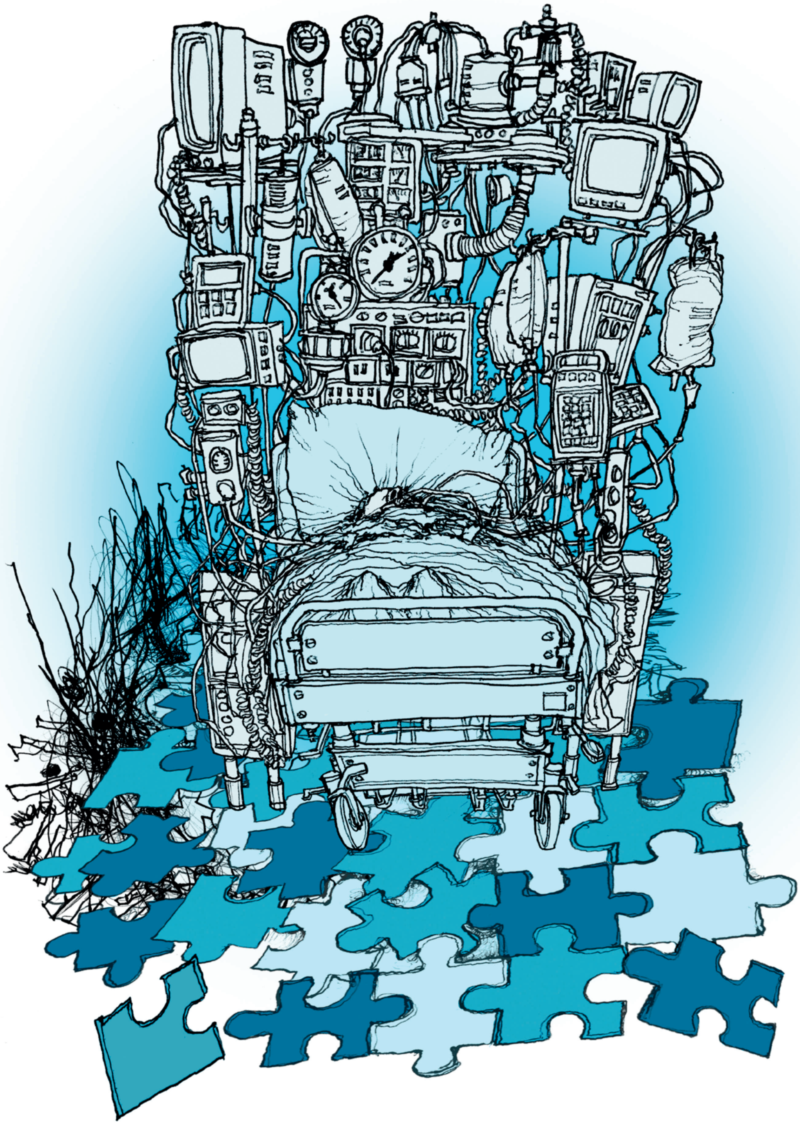
	P-Emo	P-Agree	W-Imm	W-Trans	QoL	PTG	EoC	Spir	Exist	NI-Ack	NI-RecNI	NI-Rec	Neg-Imp	Pos-Imp
Gender^3	,187**	,168*	**,215****	,082	,107	,108	,032	,109	,112	,009	,128	,042	,062	,062
Age^1	,049	,050	-,040	,166*	,027	-,068	**-,226****	-,096	-,124	**-,261****	-,094	,035	-,155*	,085
Edu^2	-,110	,027	-,174*	,026	,196*	-,081	-,053	-,060	,003	-,180*	-,024	,064	-,128**	-,101
Rel^3	,154	,121	**,352****	**,484****	,056	,112	,142*	,148	,182*	,095	,052	,151	,181*	,127
Comorb^1	,062	,085	,047	,010	-,003	-,049	,140*	-,020	,000	,122	-,031	-,137*	,084	-,034
PrevMI^3	,049	,029	,042	,019	,096	,082	,004	,026	,081	,016	,127	,096	,036	,025
PrevInt^3	,026	,093	,027	,096	,177**	,055	,121	,090	,096	,001	,010	,028	,095	,092
Int.type^2	,138*	,030	-,018	-,010	,028	,012	,081	,081	-,035	-,042	-,177**	-,041	-,018	,040
P-Emo^1		-,019	-,115	,143*	**-,350****	**,215****	**,376****	**,310****	,197**	**,358****	,055	-,065	**,261****	-,051
P-Agree^1			-,179**	,181**	,064	-,106	-,094	-,005	-,064	-,054	-,008	,024	**-,207****	,099
W-Imm^1				**-,408****	-,008	,071	,069	-,199**	,049	,164*	,017	-,110	,023	,006
W-Trans^1					,137*	**,210****	,026	**,387****	**-,257****	-,014	,149*	,165*	**-,209****	**,317****
QoL^1						,037	**-,340****	-,181**	**-,405****	**-,460****	,014	,095	**-,532****	**,241****
PTG^1							**,223****	,138	-,121	**,244****	,195**	**,237****	-,104	**,378****
EoC^1								**,270****	**,320****	**,545****	,192**	-,075	**,312****	,063
Spir^1									,023	**,350****	,190**	**,319****	,098	,020
Exist^1										**,410****	-,114	**-,296****	**,481****	**-,263****
NI-Ack^1											**,264****	,066	**,444****	-,109
NI-RecNI^1												**,240****	-,105	**,345****
NI-Rec^1													**-,227****	,111
NegImp^1														**-,283****

^{1} = Pearson's correlation coefficients 'r' (variables at interval, ratio or scale level)

^{2} = Spearman's correlation coefficients 'rho' (variables at the ordinal x interval, ratio or scale level)

^{3} = Eta (η) (dichotomous or nominal variables x variables at the interval, ratio or scale level)

* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed).
P-Emo = Emotionality (personality)
P-Agree = Agreeableness (personality)
W-Imm = Absolute immanence (worldview)
W-Trans = Transcendence (worldview)
QoL = Overall quality of life
PTG = Posttraumatic growth
EoC = Experience of contingency
Spir = Spiritual
Exist = Existential
NI-Ack = Acknowledging (narrative integration)
NI-RecNI = Receiving new insights (narrative integration)
NI-Rec = Receiving (narrative integration)
Neg-Imp = Negative impact on life goals
Pos-Imp = Positive impact on life goals



5

THE EFFECT OF NARRATIVE INTERVENTIONS ON QUALITY OF LIFE

This chapter is based on:

Kruizinga R, Hartog ID, Jacobs M, Daams JG, Scherer-Rath M, Oreel TH, Schilderman JBAM, Sprangers MAG, and HWM van Laarhoven. ***The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis.*** Psycho-Oncology, 2015, *25*(3), 253-265.

Contribution of the author of this dissertation:

The author participated in the screening of titles and abstracts for inclusion, read the full text of all selected articles, assessed the risk of bias of and participated in the interpretation of the data. In addition, the author gave feedback on several versions of the article (first draft written by RK) and read and approved the final manuscript.

ABSTRACT

Objective

The aim of this study was to examine the effect of spiritual interventions on quality of life of cancer patients.

Methods

We conducted our search on June 6, 2014 in Medline, PsycINFO, Embase, and PubMed. All clinical trials were included that compared standard care with a spiritual intervention that addressed existential themes using a narrative approach. Study quality was evaluated by the Cochrane Risk of Bias Tool.

Results

A total of 4972 studies were identified, of which 14 clinical trials (2050 patients) met the inclusion criteria, and 12 trials (1878 patients) were included in the meta-analysis. The overall risk of bias was high. When combined, all studies showed a moderate effect (d) 0.50 (95% CI = 0.20–0.79) 0–2 weeks after the intervention on overall quality of life in favor of the spiritual interventions. Meta-analysis at 3–6 months after the intervention showed a small insignificant effect (0.14, 95% CI = -0.08 to 0.35). Subgroup analysis including only the western studies showed a small effect of 0.17 (95% CI = 0.05–0.29). Including only studies that met the allocation concealment criteria showed an insignificant effect of 0.14 (95% CI = -0.05 to 0.33).

Conclusions

Directly after the intervention, spiritual interventions had a moderate beneficial effect in terms of improving quality of life of cancer patients compared with that of a control group. No evidence was found that the interventions maintained this effect up to 3–6 months after the intervention. Further research is needed to understand how spiritual interventions could contribute to a long-term effect of increasing or maintaining quality of life.

BACKGROUND

Spirituality within the context of a healthcare environment is defined as that aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred [1]. Spirituality expresses the reflective human quest for identity and meaning beyond a purely pragmatic approach to life [2]. In defining spirituality as a broad notion of finding meaning, purpose and making sense of one's own existence, religion might be a part of this, but that is not necessarily the case [3].

Provision of spiritual care is regarded as part of palliative care [4] and aims at addressing the existential needs of patients, including questions about meaning of life and death, as well as the search for peace, spiritual resources, hope and help in overcoming fears [5]. Indeed, spiritual needs can become of particular importance when one is facing the finitude of life [6,7]. The possibility to discuss existential questions is one of the unmet needs of advanced cancer patients who are confronted with the end of life [5,8–10].

One way of alleviating existential needs may be found in the telling of stories. Such stories, or narratives, are more than just an enumeration of events in serial order: they organize these events into an intelligible whole [11,12]. A narrative can be defined as "the creation of a world by picturing particular events and making that world coherent and intelligible by evoking a network of relations – causal links, psychological motivations, goals, plans – among the events" [13]. In this way, meaning and purpose as well as experiences of connectedness to the moment, to self, to others, to nature, and to the significant or sacred may be expressed. Narrative interventions in public health are aimed at letting the patient talk and letting them construct their own meaningful framework by the power of storytelling [14].

Telling one's life story in such a way is thus believed to have a positive impact on patients' quality of life (QoL) near death [1,15,16]. However, the evidence to support this statement is scarce. Little is known about the effect of spiritual interventions using narrative approaches on quality of life of patients. Some studies show that existential therapies are beneficial [17], but others have pointed out the gaps in this research field, including lack of knowledge and discrepancies between spiritual care as theoretical value and as it is practiced in a healthcare setting [18,19]. Therefore, we conducted a systematic review and meta-analysis to address the question whether spiritual interventions that address existential needs using a narrative approach improve QoL of cancer patients.

METHODS

This review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement [20].

Eligibility criteria

Interventions were limited to those addressing existential issues using a narrative approach. Study population of the intervention should include >50% cancer patients, with all types of cancer, and aged 18 years and older. Studies had to include a control group of either no intervention or a placebo intervention. The outcome should include QoL or subjective well-being measured with a validated questionnaire. No publication date or publication status restrictions were imposed. Language restrictions were imposed: all languages other than English, German and Dutch were excluded. Relevant studies were identified by comprehensive searches in PubMed, PsycINFO, Embase, and by selecting relevant trials from the Cochrane Library.

Search

The final search was run on July 6, 2014. All citations were downloaded into Endnote version x7 (Thomson Reuters, New York City, NY, USA). Together with an experienced librarian (J. D.), the first author (R. K.) developed the search strategies using sensitive terms for identifying clinical studies. We pilot-tested search strategies and modified them to ensure that they identified known eligible articles. The final strategies used the following terms: spirituality, cancer, quality of life, (non)- cancer specific questionnaires, supportive care, specific therapies, and trial numbers from trial registers. Specific therapies were also included in the search: reflective journaling, dignity therapy, psycho-spiritual integrative therapy, life completion, meaning-making, meaning reconstruction, narrative therapy, reminiscence, and life review. A customized search strategy was conducted for each database.

Data collection process

Two researchers (I. H. and R. K.) independently screened titles and abstracts for inclusion and then read the full text of the selected articles. A senior researcher (H. v. L.) was consulted in case of disagreement or doubt. Data collection was carried out by the first author (R. K.). Authors were sent an e-mail to obtain more information about the study or study data such as standard deviations (SD) or specific QoL data at different time points. If the authors did not respond the first time, a reminder was sent, with a maximum of three. From each included trial, we extracted the following information: (1) author; (2) year of publication; (3) study design; (4) type of intervention; (5) profession of the person who performed the intervention; (6) type of patients; (7) number of patients; (8) primary study outcome; and (9) instrument used to measure quality of life.

Risk of bias in individual studies

The Cochrane Collaboration's tool for assessing risk of bias was used to assess the risk of bias on adequacy of sequence generation, allocation concealment, blinding of patients and outcome assessors, blinding of outcome assessment, reporting on incomplete outcome data, selective outcome reporting, and other sources of bias [21]. The researchers (R.K., I.H., and M.J.) assessed the risk of bias independently, and a senior researcher (H. v. L.) was consulted in case of disagreement. It is known that in narrative interventions, blinding of patients and personnel cannot be carried out because of the face-to-face intervention. Also, in most studies, outcome assessors could not be blinded for the intervention, as patients were the assessors and they knew to which group they were assigned. The allocation concealment criteria, however, are considered an important determinant for study quality [22]. Therefore, we conducted a subgroup analysis with all the studies that included the allocation concealment, as described in the Cochrane Collaboration's tool. To explore heterogeneity, we a priori hypothesized that the difference in effect size might be a result of the difference in the methodological quality of the studies, the duration of the intervention, the type of intervention (multidisciplinary or mono-disciplinarily), and whether a study assessed a western or non-western population.

Summary measures

The primary outcome was the mean difference in quality of life between the control group and intervention group 0–2 weeks after the intervention. The secondary outcome was the mean difference in QoL 3–6 months after the intervention. We first extracted data of all studies at the two different time points. From each study, we extracted the data on (1) mean QoL; (2) SD; and (3) sample size. Only one study included in the meta-analysis reported data on a placebo group in addition to a control group [23]; therefore, we selected only the data from the control group as we did for the other studies. Because the studies used different questionnaires to measure overall quality of life, meta-analyses were performed by computing standardized mean difference using the random-effects model. All scores were converted to a 0–100 scale in order to facilitate the comparison (e.g., score 2 on scale from 0–10 became 2/11*100=18). Cohen's d was chosen to report the effect size and p-value to assess significance; p-values less than 0.05 are reported as statistically significant [24]. We tested for heterogeneity with the I^2 statistic, which can be interpreted as the proportion of total variability explained by heterogeneity [25]. An I^2 of 25% can be considered as low heterogeneity, 50% as moderate, and 75% as high heterogeneity [26].

Synthesis of results

First, we differentiated between the western and nonwestern studies. Second, we conducted a meta-analysis on the studies that scored high on study quality. The last meta-analysis was conducted on subgroups for the different types of intervention. We divided all the studies into three groups as follows: (1) life-reviewing interventions (reconstructing valuable aspects of one's life); (2) multidisciplinary interventions (with a session on spirituality); and (3) meaning-making interventions (facilitating the search for meaning).

Publication bias

Publication bias was assessed by eyeballing a funnel plot of the trial standardized mean differences for asymmetry. In the absence of publication bias, the studies are expected to be distributed symmetrically around the mean effect size because the sampling error is random [24]. A strong case for publication bias is present when the funnel plot is asymmetrical and there are more studies missing at the bottom of the plot, which can result from the nonpublication of small trials with negative results.

RESULTS

Study selection

The search identified 6376 records. After removal of duplications, 4972 records remained. Four thousand nine hundred fifteen records were excluded because they did not meet the inclusion criteria. For the final selection, all 57 records were screened by reading the full text articles. After selection, 14 studies met the inclusion criteria and were included in the systematic review. Authors were sent an e-mail to obtain more information about the study: two authors responded and sent more information; three authors responded to the e-mail but did not give more information as they no longer had access to their databases or other reasons; one author did not respond at all. As a result, two of these were excluded from the meta-analysis [27,28] because of insufficient data, and for one other study [29], we calculated the average SD from two studies [30,31] that used the same questionnaire in assessing QoL (Figure 1).

Study characteristics

Intervention

All 14 studies were published between 2005 and 2013. The types of interventions ranged from only spiritual interventions to multidisciplinary interventions with spiritual components. The interventions were performed by various trained people, mostly psy-

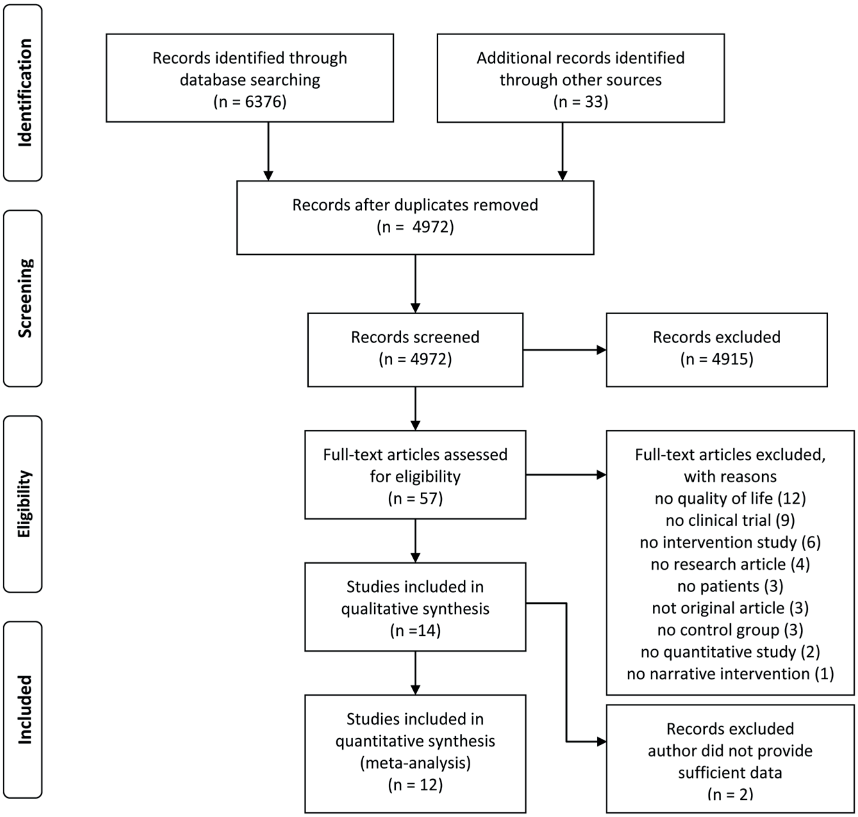


Figure 1. Flow diagram of study selection

chologists/psychiatrists (n = 6) and oncology professionals (n = 3) or general healthcare professionals (n = 2). One intervention was conducted by spiritual healers. Two studies did not provide background information on the profession of the person who conducted the intervention. In two cases, a chaplain contributed to the intervention.

Patients

The patients included in the studies were mostly advanced cancer patients without a specific cancer diagnosis mentioned (n = 10); breast cancer patients (n = 1); cancer patients at least 1 month diagnosed (n =1); cancer patients with depressive disorder (n = 1); and advanced ovarian cancer patients (n = 1). The total number of patients included was 2050.

Outcome

In the selected studies, quality of life or subjective wellbeing was assessed by the Functional Assessment of Cancer Therapy-General (n = 3), the McGill Quality of Life Questionnaire (n =

3), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (n = 2), two-item Quality of Life Scale (n = 2), the Edmonton Symptom Assessment System (n = 1), Linear analogue self-assessment (n = 1), the Quality of Life at the end of life questionnaire (n = 1), and the Quality-of life Concerns in the End-of-life (n = 1). Characteristics of included studies are shown in Table 1.

Table 1. Study characteristics

Nr	Author	Year	Study Design	Intervention	Intervention performed by	Patients	Sample size	Primary outcome	Measuring instrument
1	Breitbart W,	2012	pilot RCT	Individual meaning centered psychotherapy	Trained clinical psychologist or psychology doct. students	Advanced cancer patients	120	Spiritual WB, Qol	MQOL
2	Chochinov HM,	2011	RCT	Dignity therapy	Trained psychologist / psychiatrist or palliative care nurse	Advanced cancer patients	441	Distress, end-of-life experience	QOL-S
3	Daly, BJ	2013	clinical trial	Multidisciplinary intervention	Experienced oncology professionals	Advanced cancer patients	610	QoL	FACT-G
4	Hall S,	2011	phase II trial	Dignity therapy	Trained professionals working in palliative care	Advanced cancer patients	45	Distress	QOL-S
5	Henry, M	2010	pilot RCT	Meaning-making intervention	One psychologist	Advanced ovarian cancer patients	28	Existential wellbeing	MQOL
6	Jafari N,	2013	RCT	Spiritual therapy	Three experienced spiritual healers	Breast cancer patients	68	QoL	EORTC C30
7	Kristeller JL,	2005	clinical trial	Oncologist-assisted spiritual intervention	Four trained oncologists-hematologists	Cancer patients (> 1 m diagnosed)	118	Patients satisfaction	FACT-G
8	Loyd-Williams, M	2013	pilot RCT	Focused narrative interview	One researcher, no background information	Advanced cancer patients	100	Anxiety, depression	ESAS
9	Mok, E	2012	RCT	Meaning of Life intervention	Trained healthcare professionals	Advanced cancer patients	84	QoL	QOLC-E
10	Piderman, KM	2013	RCT	Multidisciplinary intervention	Psychologist / psychiatrist (chaplain co-facilitated)	Advanced cancer patients	131	Spiritual QoL	FACT-G

Table 1. Study characteristics (continued)

Nr	Author	Year	Study Design	Intervention	Intervention performed by	Patients	Sample size	Primary outcome	Measuring instrument
11	Rummans, TA	2006	RCT	Multidisciplinary intervention	Trained psychologist / psychiatrist (chaplain co-facilitated)	Advanced cancer patients	103	QoL	LASA
12	Steinhauser, KE	2008	pilot RCT	Preparation, life compl. intervention (outlook)	One research-assistant	Seriously ill patients; 84% cancer patients	82	Functioning	QUAL-E
13	Vega, BR	2010	RCT	Narrative therapy	Trained psychologist / psychiatrist	Cancer patients with depressive disorder	72	QoL, depression	EORTC C30
14	Xiao, H	2013	RCT	Life review intervention	One trained oncologists nurse	Advanced cancer patients	80	QoL	MQOL

RCT = randomized controlled trial; QoL = quality of life; MQOL = McGill QoL questionnaire; QoL-S = QoL Scale; FACT-G = Functional Assessment of Cancer Therapy-General; EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; ESAS = Edmonton Symptom Assessment System; QUAL-E = QoL at the end of life questionnaire; LASA = Linear analogue self-assessment.

Risk of bias within studies

The Cochrane Risk of Bias tool was used to assess the risk of bias [21]. Five studies scored high on study quality [23,32–35]. Risk of bias within studies is shown in Table 2.

Table 2. Risk of bias within studies assessed by Cochrane Risk of Bias tool

Nr	Author	Year	Study Design	Adequate sequence generation	Allocation concealment	Blinding of patients / personnel	Blinding of outcome assessors	Incomplete outcome data addressed	Free of selective reporting	Free of other bias
1	Chochinov HM,	2011	RCT	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
2	Hall S,	2011	phase II trial	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear
3	Jafari N,	2013	RCT	Yes	Unclear	Unclear	Unclear	Yes	Yes	Unclear
4	Kristeller J,	2005	clinical trial	No	Unclear	Unclear	Unclear	Yes	Yes	Unclear
5	Daly, BJ	2013	clincal trial	No	No	Unclear	Unclear	Unclear	No	Unclear
6	Piderman KM,	2013	RCT	Unclear	Unclear	Unclear	Unclear	Yes	No	Unclear
7	Rummans TA,	2006	RCT	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Unclear

Table 2. Risk of bias within studies assessed by Cochrane Risk of Bias tool (continued)

Nr	Author	Year	Study Design	Adequate sequence generation	Allocation concealment	Blinding of patients / personnel	Blinding of outcome assessors	Incomplete outcome data addressed	Free of selective reporting	Free of other bias
8	Steinhauser KE,	2008	pilot RCT	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Unclear
9	Vega BR,	2010	RCT	Yes	Unclear	Unclear	Unclear	Yes	Yes	Yes
10	Loyd-Williams, M	2013	pilot RCT	Unclear	Yes	Unclear	Unclear	Unclear	No	Unclear
11	Xiao H,	2013	RCT	Yes	Unclear	Unclear	Unclear	Yes	Yes	Unclear
12	Breitbart	2012	pilot RCT	Yes	Yes	Unclear	Unclear	Unclear	Yes	Unclear
13	Henry, M	2010	Pilot RCT	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear
14	Mok, E	2012	RCT	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear

Results from the meta-analysis

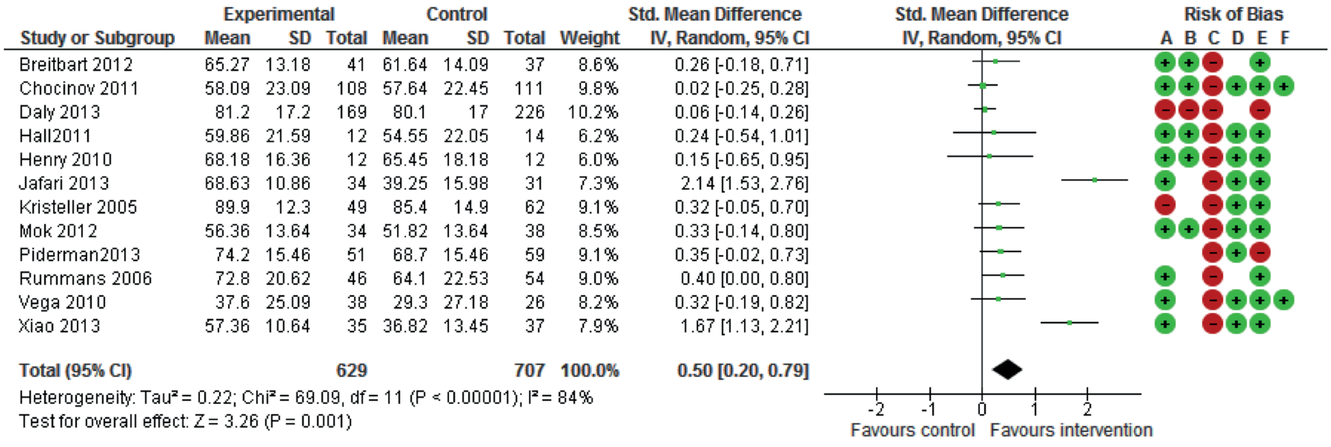
All studies included

The overall mean effect size for 12 studies on quality of life 0–2 weeks after intervention was $d = 0.50$ (95% CI: 0.20–0.79). This effect was statistically significant ($p = 0.001$) and can be considered a moderate effect size [36]. Heterogeneity was very high ($I^2 = 84\%$.) (Figure 2). The overall effect size of the five studies that assessed quality of life 3–6 months after intervention was $d = 0.11$ (95% CI: -0.08–0.35), a small and insignificant effect ($p = 0.21$). Heterogeneity was low ($I^2 = 0\%$) (Figure 3).

Western versus non-western studies

At 0–2 weeks after intervention, a small, non-significant effect ($d = 0.17$; 95% CI: -0.05–0.29) was observed within the subgroup of western studies (Canada, USA, Australia, UK, and Spain); the heterogeneity was low ($I^2 = 0\%$). The non-western studies (Iran, China, and Hong Kong) showed a large effect ($d = 1.37$), but within a large range (0.26–2.47) and with high heterogeneity ($I^2 = 92\%$) (Figure 4).

Figure 2. Standardized mean difference (SMD) and 95% CI: patients' QoL 0–2 weeks after intervention



	Experimental			Control				Std. Mean Difference	Risk of Bias					
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**	**A**	**B**	**C**	**D**	**E**	**F**
Breitbart 2012	65.27	13.18	41	61.64	14.09	37	8.6%	0.26 [-0.18, 0.71]	+	+	−		+	
Chocinov 2011	58.09	23.09	108	57.64	22.45	111	9.8%	0.02 [-0.25, 0.28]	+	+	−	+	+	+
Daly 2013	81.2	17.2	169	80.1	17	226	10.2%	0.06 [-0.14, 0.26]	−	−	−		−	
Hall2011	59.86	21.59	12	54.55	22.05	14	6.2%	0.24 [-0.54, 1.01]	+	+	−	+	+	
Henry 2010	68.18	16.36	12	65.45	18.18	12	6.0%	0.15 [-0.65, 0.95]	+	+	−	+	+	
Jafari 2013	68.63	10.86	34	39.25	15.98	31	7.3%	2.14 [1.53, 2.76]	+		−	+	+	
Kristeller 2005	89.9	12.3	49	85.4	14.9	62	9.1%	0.32 [-0.05, 0.70]	−		−	+	+	
Mok 2012	56.36	13.64	34	51.82	13.64	38	8.5%	0.33 [-0.14, 0.80]	+	+	−	+	+	
Piderman2013	74.2	15.46	51	68.7	15.46	59	9.1%	0.35 [-0.02, 0.73]			−	+	−	
Rummans 2006	72.8	20.62	46	64.1	22.53	54	9.0%	0.40 [0.00, 0.80]	+		−		+	
Vega 2010	37.6	25.09	38	29.3	27.18	26	8.2%	0.32 [-0.19, 0.82]	+		−	+	+	+
Xiao 2013	57.36	10.64	35	36.82	13.45	37	7.9%	1.67 [1.13, 2.21]	+		−	+	+	
Total (95% CI)			**629**			**707**	**100.0%**	**0.50 [0.20, 0.79]**						

Heterogeneity: Tau² = 0.22; Chi² = 69.09, df = 11 (P < 0.00001); I² = 84%
Test for overall effect: Z = 3.26 (P = 0.001)

Risk of bias legend
(A) Sequence generation
(B) Allocation concealment?
(C) Blinding of participants, personnel and outcome assessors
(D) Incomplete outcome data
(E) Selective outcome reporting
(F) Other sources of bias

Figure 3. SMD and 95% CI: patients' QoL 3–6 months after intervention

	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Breitbart 2012	62.55	12.91	33	62.36	15.82	34	16.9%	0.01 [-0.47, 0.49]
Daly 2013	85.8	15.7	100	86	15	146	43.0%	-0.01 [-0.27, 0.24]
Henry 2010	72.73	15.45	12	62.73	20	12	6.5%	0.54 [-0.28, 1.36]
Rummans 2006	71.9	19.41	47	68.4	23.48	49	22.7%	0.16 [-0.24, 0.56]
Vega 2010	49.14	25.09	32	32.84	27.18	16	11.0%	0.62 [0.01, 1.24]
Total (95% CI)			**224**			**257**	**100.0%**	**0.14 [-0.08, 0.35]**

Heterogeneity: Tau² = 0.01; Chi² = 4.85, df = 4 (P = 0.30); I² = 18%

Test for overall effect: Z = 1.24 (P = 0.21)

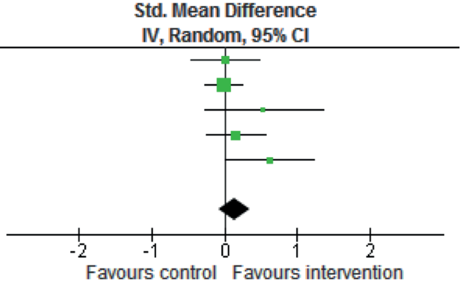
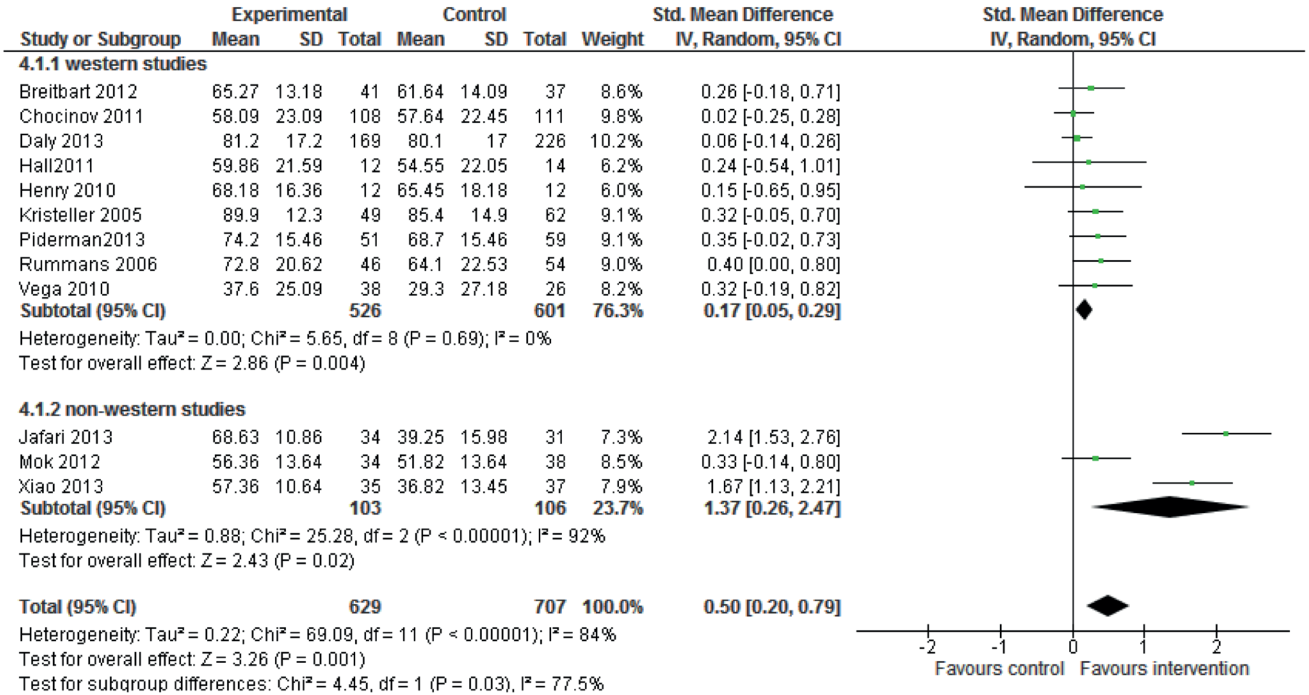


Figure 4. SMD and 95% CI: patients' QoL 2–4 weeks after intervention; western and non-western studies



Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
4.1.1 western studies								
Breitbart 2012	65.27	13.18	41	61.64	14.09	37	8.6%	0.26 [-0.18, 0.71]
Chocinov 2011	58.09	23.09	108	57.64	22.45	111	9.8%	0.02 [-0.25, 0.28]
Daly 2013	81.2	17.2	169	80.1	17	226	10.2%	0.06 [-0.14, 0.26]
Hall2011	59.86	21.59	12	54.55	22.05	14	6.2%	0.24 [-0.54, 1.01]
Henry 2010	68.18	16.36	12	65.45	18.18	12	6.0%	0.15 [-0.65, 0.95]
Kristeller 2005	89.9	12.3	49	85.4	14.9	62	9.1%	0.32 [-0.05, 0.70]
Piderman2013	74.2	15.46	51	68.7	15.46	59	9.1%	0.35 [-0.02, 0.73]
Rummans 2006	72.8	20.62	46	64.1	22.53	54	9.0%	0.40 [0.00, 0.80]
Vega 2010	37.6	25.09	38	29.3	27.18	26	8.2%	0.32 [-0.19, 0.82]
Subtotal (95% CI)			**526**			**601**	**76.3%**	**0.17 [0.05, 0.29]**
Heterogeneity: Tau² = 0.00; Chi² = 5.65, df = 8 (P = 0.69); I² = 0%								
Test for overall effect: Z = 2.86 (P = 0.004)								
4.1.2 non-western studies								
Jafari 2013	68.63	10.86	34	39.25	15.98	31	7.3%	2.14 [1.53, 2.76]
Mok 2012	56.36	13.64	34	51.82	13.64	38	8.5%	0.33 [-0.14, 0.80]
Xiao 2013	57.36	10.64	35	36.82	13.45	37	7.9%	1.67 [1.13, 2.21]
Subtotal (95% CI)			**103**			**106**	**23.7%**	**1.37 [0.26, 2.47]**
Heterogeneity: Tau² = 0.88; Chi² = 25.28, df = 2 (P < 0.00001); I² = 92%								
Test for overall effect: Z = 2.43 (P = 0.02)								
Total (95% CI)			**629**			**707**	**100.0%**	**0.50 [0.20, 0.79]**
Heterogeneity: Tau² = 0.22; Chi² = 69.09, df = 11 (P < 0.00001); I² = 84%								
Test for overall effect: Z = 3.26 (P = 0.001)								
Test for subgroup differences: Chi² = 4.45, df = 1 (P = 0.03), I² = 77.5%								

High-quality studies

Five studies met the allocation concealment criteria. In these studies, a small, non-significant effect of the intervention was visible (d =0.14; 95% CI: -0.05 to 0.33) with low heterogeneity (I^2 =0%) (Figure 5).

Interventions

Furthermore, we conducted a meta-analysis with the interventions grouped into three subgroups as follows: (1) life reviewing interventions; (2) multidisciplinary interventions; and (3) meaning-making interventions. All studies showed a trend towards a positive outcome on QoL of cancer patients in favor of the intervention. The strongest effect was seen in subgroup 3: meaning-making interventions (d = 0.63; 95% CI: 0.01–1.26, p = 0.05) (Figure 6).

Risk of bias across studies

The graphical funnel plot of the 12 controlled trials appears symmetrical, except for the two outliers; therefore, we assume no publication bias (Figure 7).

Figure 5. SMD and 95% CI: patients' QoL 2–4 weeks after intervention; high quality studies

	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Mok 2012	56.36	13.64	34	51.82	13.64	38	17.0%	0.33 [-0.14, 0.80]
Henry 2010	68.18	16.36	12	65.45	18.18	12	5.7%	0.15 [-0.65, 0.95]
Hall2011	59.86	21.59	12	54.55	22.05	14	6.2%	0.24 [-0.54, 1.01]
Chocinov 2011	58.09	23.09	108	57.64	22.45	111	52.6%	0.02 [-0.25, 0.28]
Breitbart 2012	65.27	13.18	41	61.64	14.09	37	18.5%	0.26 [-0.18, 0.71]
Total (95% CI)			**207**			**212**	**100.0%**	**0.14 [-0.05, 0.33]**

Heterogeneity: Tau² = 0.00; Chi² = 1.78, df = 4 (P = 0.78); I² = 0%

Test for overall effect: Z = 1.41 (P = 0.16)

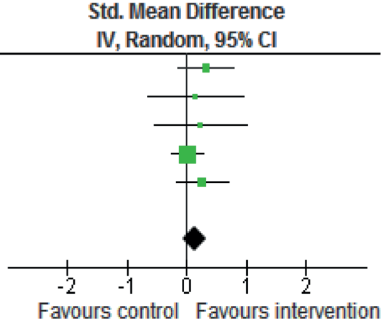
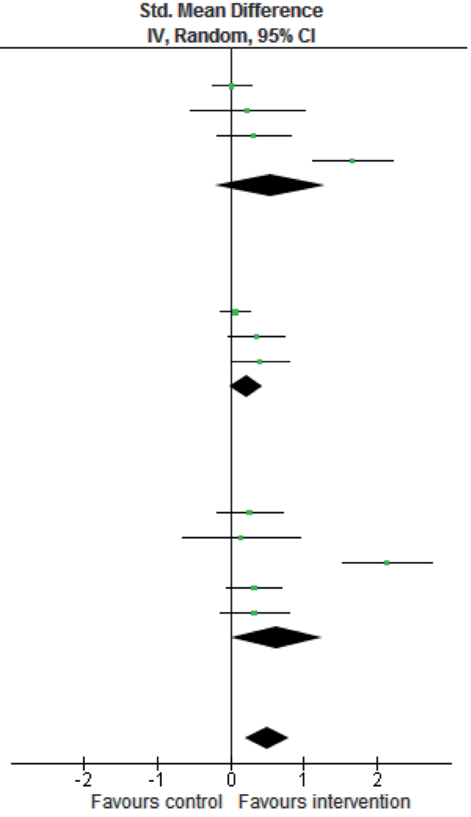


Figure 6. SMD and 95% CI: patients' QoL 2–4 weeks after intervention; different types of intervention

	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
3.1.1 life review interventions								
Chocinov 2011	58.09	23.09	108	57.64	22.45	111	9.8%	0.02 [-0.25, 0.28]
Hall2011	59.86	21.59	12	54.55	22.05	14	6.2%	0.24 [-0.54, 1.01]
Vega 2010	37.6	25.09	38	29.3	27.18	26	8.2%	0.32 [-0.19, 0.82]
Xiao 2013	57.36	10.64	35	36.82	13.45	37	7.9%	1.67 [1.13, 2.21]
Subtotal (95% CI)			**193**			**188**	**32.2%**	**0.55 [-0.19, 1.30]**
Heterogeneity: Tau² = 0.51; Chi² = 28.93, df = 3 (P < 0.00001); I² = 90%								
Test for overall effect: Z = 1.45 (P = 0.15)								
3.1.2 multidisciplinary interventions								
Daly 2013	81.2	17.2	169	80.1	17	226	10.2%	0.06 [-0.14, 0.26]
Piderman2013	74.2	15.46	51	68.7	15.46	59	9.1%	0.35 [-0.02, 0.73]
Rummans 2006	72.8	20.62	46	64.1	22.53	54	9.0%	0.40 [0.00, 0.80]
Subtotal (95% CI)			**266**			**339**	**28.3%**	**0.22 [-0.01, 0.45]**
Heterogeneity: Tau² = 0.02; Chi² = 3.25, df = 2 (P = 0.20); I² = 39%								
Test for overall effect: Z = 1.86 (P = 0.06)								
3.1.3 Meaning making interventions								
Breitbart 2012	65.27	13.18	41	61.64	14.09	37	8.6%	0.26 [-0.18, 0.71]
Henry 2010	68.18	16.36	12	65.45	18.18	12	6.0%	0.15 [-0.65, 0.95]
Jafari 2013	68.63	10.86	34	39.25	15.98	31	7.3%	2.14 [1.53, 2.76]
Kristeller 2005	89.9	12.3	49	85.4	14.9	62	9.1%	0.32 [-0.05, 0.70]
Mok 2012	56.36	13.64	34	51.82	13.64	38	8.5%	0.33 [-0.14, 0.80]
Subtotal (95% CI)			**170**			**180**	**39.6%**	**0.63 [0.01, 1.26]**
Heterogeneity: Tau² = 0.43; Chi² = 30.30, df = 4 (P < 0.00001); I² = 87%								
Test for overall effect: Z = 1.98 (P = 0.05)								
Total (95% CI)			**629**			**707**	**100.0%**	**0.50 [0.20, 0.79]**
Heterogeneity: Tau² = 0.22; Chi² = 69.09, df = 11 (P < 0.00001); I² = 84%								
Test for overall effect: Z = 3.26 (P = 0.001)								
Test for subgroup differences: Chi² = 2.01, df = 2 (P = 0.37), I² = 0.7%								



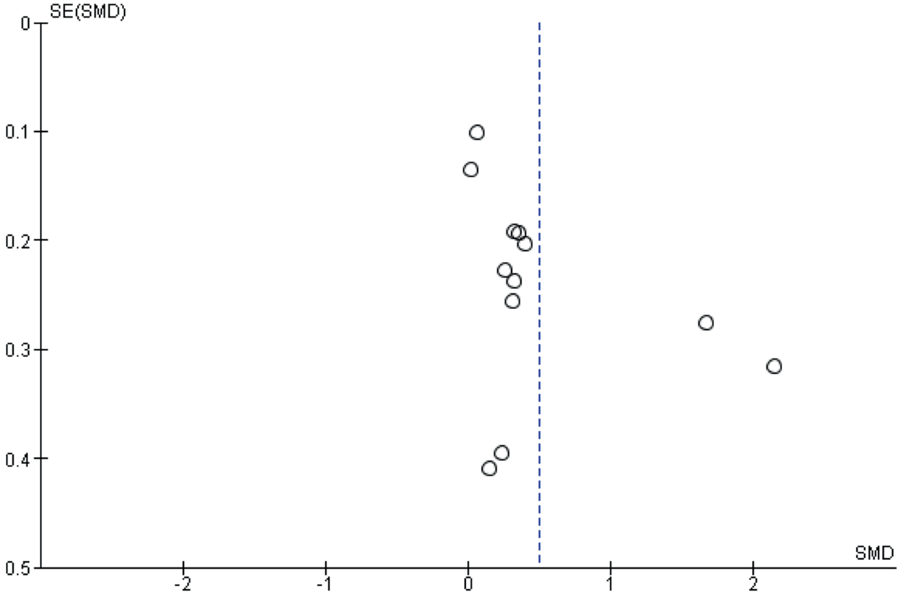


Figure 7. Funnel of plot all included studies 0–2 weeks after intervention.
Assessed on December 16, 2014.

DISCUSSION

Summary of evidence

To the best of our knowledge, this is the first systematic review and meta-analysis that examines the effect of spiritual interventions that address existential needs on QoL of cancer patients. We included a total of 12 controlled clinical trials. Our results show that spiritual interventions increase patients' QoL directly after the intervention. However, our results do not support a long-term effect. A possible explanation is that the effect of the spiritual intervention is negated by the deteriorating physical and mental condition due to disease progression. Based on our findings, we cannot conclude which kind of interventions is most contributing to QoL of cancer patients. It should be noted that only five studies scored high on study quality. This indicates that the field of spiritual interventions could be improved by adopting a more stringent methodology.

Other research

A meta-analysis of the effects of existential therapies also reported on the low quality of the included studies [17]. As a result, researchers are not able to identify which intervention works best for which patient groups. The variety of the studies included in our meta-analysis supports the findings of Henoch and Danielson that underscored the need for more knowledge on how to target existential interventions to specific patient groups [18]. Yet, our finding of a positive effect on overall QoL in favor of the interventions is consistent with the literature review on evidence-based spiritual care that Kalish conducted from June 2010 to December 2011 [19]. She found 10 original research studies with oncology patients, of which four studies pointed out the importance of meeting patients' spiritual needs. One study found a short-term life review effective for alleviating distress [37]. The other five studies showed positive correlations between the provision of spiritual care or meeting the spiritual needs and QoL of cancer patients and therefore conclude that addressing spiritual needs in clinical settings is critical in enhancing QoL [38–42].

Limitations

Our finding that the overall quality of all included studies was quite poor can be related to the specific field of spiritual care, in which performing evidence-based research is relatively new. In spite of a rapidly growing interest in research on religion, spirituality, and health since 2000 [43], there is still much heterogeneity among the different spiritual intervention studies, for instance, the variety of instruments used to measure patients' quality of life and the timing of the assessments. Also, the duration of the interventions greatly varied (1 day to 12 weeks) as well as the training of people who performed the intervention. These limitations were also touched upon by Kalish, as she concludes in the literature review that clarity and consensus are still lacking regarding what the best methods are for providing spiritual care [19]. Furthermore, the included studies did not distinguish between type and stage of cancer, while these factors may impact perceived QoL.

Future research

As this meta-analysis shows, spiritual interventions with a narrative approach can have a positive impact on QoL in cancer patients. However, from this meta-analysis, we cannot conclude which specific approach is most beneficial for which type of patient because of the large heterogeneity across studies in terms of the outcome measures, the times of outcome measurements and randomization. To obtain more knowledge on this topic, we should strive for more uniformity. This could be achieved by following guidelines on the design of this kind of intervention studies [44], such as standardization of the outcome measurement "quality of life" by using the EORTC QLQ-C30 or C15-PAL questionnaire. In oncology, these questionnaires are regarded as the gold standard to measure QoL in cancer patients [45]. Other guidelines for setting up a clinical study should be followed more adequately, such as including a control-arm and applying proper randomization and allocation methods.

Our finding that the effect of spiritual interventions did not last up to 3–6 months could be explained by the dynamic nature of personal life stories. It may be hypothesized

that a spiritual intervention with a narrative approach is likely to be more effective when it takes into account the ongoing process of defining and reconstructing one's life story. Using narratives, people continuously refine their stories about certain events and change it in order to fit these events into their lives [46]. This process is unlikely to be sufficiently stimulated by a one-time intervention.

The report of the Consensus Conference on Spiritual Care also concludes that appropriate follow-up of patients' spirituality should be included into the treatment plan [1]. Evidence suggests that psychosocial interventions, in general, do not exert long-lasting effects [46], with the exception of cognitive behavioral therapy, which has been shown to improve quality of life in cancer survivors at both short-term and long-term follow-ups [47,48].

Westerhof and Bohlmeijer showed that a narrative approach, aimed at unraveling a sense of meaning, substantially contributed to one's wellbeing [49–52]. The group of nonreligious people is growing rapidly, and more people may consider themselves "spiritual but not religious" [53–55]. Therefore, spiritual interventions within healthcare settings should be inclusive when it comes to spirituality in the broad sense, and it may be hypothesized that interventions with a focus on meaning making aspects, rather than faith contents, will be more effective in enhancing peoples' QoL. Because we live in a late modern society where social or religious constructs no longer determine how we understand ourselves and the world around us, people create their own biographical story, which they have to (re)construct and justify for themselves [46,56–59].

Furthermore, interventions should be theoretically well substantiated and developed in a way that it is potentially reproducible. In addition, it would be of interest to look into specific approaches to remind, trigger, and stimulate patients in developing the insights they have gained by the intervention. More structured research is needed to determine whether spiritual interventions, with the focus on the ongoing process of meaning-making, could contribute to a long-term effect on QoL.

Conclusions

In conclusion, narrative spiritual interventions can improve QoL of cancer patients in the short term. However, more structured and guided research on this topic is needed to identify the type of interventions from which cancer patients benefit most and to assess which interventions may provide longer-term benefit.

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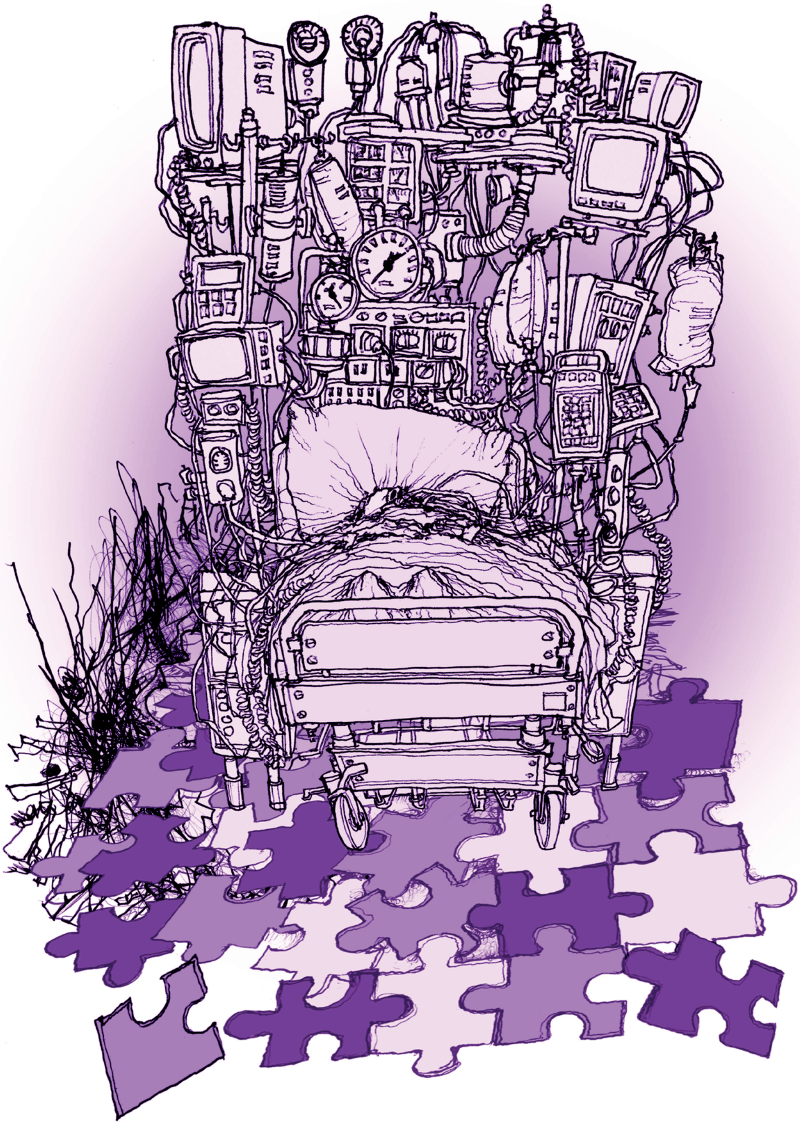

6

INFLUENCE OF RESPONSE SHIFT AND DISPOSITION ON MEDICAL DECISIONS

This chapter is based on:

Hartog ID, Willems DL, Van den Hout WB, Scherer-Rath M, Oreel TH, Henriques JPS, Nieuwkerk PT, Van Laarhoven HWM and MAG Sprangers. ***Influence of response shift and disposition on patient-reported outcomes may lead to suboptimal medical decisions: a medical ethics perspective.*** BMC Medical Ethics, 2019, *20*(1), 61.

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The author participated in the design of the study and performed the ethical analysis. In addition, the author wrote the first draft of the article and revised several versions based on feedback of all co-authors.

ABSTRACT

Background

Patient-reported outcomes (PROs) are frequently used for medical decision making, at the levels of both individual patient care and healthcare policy. Evidence increasingly shows that PROs may be influenced by patients' response shifts (changes in interpretation) and dispositions (stable characteristics).

Main text

We identify how response shifts and dispositions may influence medical decisions on both the levels of individual patient care and health policy. We provide examples of these influences and analyze the consequences from the perspectives of ethical principles and theories of just distribution.

Conclusion

If influences of response shift and disposition on PROs and consequently medical decision making are not considered, patients may not receive optimal treatment and health insurance packages may include treatments that are not the most effective or cost-effective. We call on healthcare practitioners, researchers, policy makers, health insurers, and other stakeholders to critically reflect on why and how such patient reports are used.

BACKGROUND

Medical decisions at the individual patient (micro) level as well as at the healthcare policy (macro) level increasingly involve patients' self-reports. These patient-reported outcomes (PROs), such as health-related quality of life (HRQoL), can only be provided by patients. For example, pain, fatigue, difficulty performing tasks, satisfaction, and overall quality of life reflect patients' highly personal experiences. The emergence of PROs is the result of a more patient-centered approach in healthcare and research. Moreover, treatments increasingly yield comparable clinical outcomes such as survival, while PROs may vary widely.

All data reported by patients themselves may be subject to unmeasured influences. We focus here on two types of such influences that have not been given due attention. The first is response shift, which is defined as a change in the meaning of one's self-evaluation, as a result of changes in internal standards, values, and/or conceptualization of the PRO [1]. These shifts are often induced by health-changing events, such as falling seriously ill or undergoing treatment. For example, a patient undergoing chemotherapy that causes severe fatigue may change her internal standard for fatigue severity as a result of adaptation. Consequently, her scores may indicate lower levels of fatigue than would be expected, given the impact of the chemotherapy [2]. Thus, whereas these response shifts are often a sign of adaptation, they may distort the interpretation of changes in PRO scores over time.

The second type of unmeasured influences is disposition, referring to stable characteristics that people exhibit across circumstances and time, e.g. personality. There is ample evidence that people have a disposition for certain attributes that influence PROs, e.g. optimism/pessimism, denial/catastrophizing, and feeling happy/unhappy [3]. Patients' dispositions affect individual self- evaluations and may lead to differences in PRO results among patients with the same health state [4].

In this paper we define "health state" as the level of "statistically normal biological functioning" [5], using the biomedical definition of health as the absence of pathology [6]. The biomedical perspective aims to distinguish people's health from their own standards and preferences, which may be adaptive and culturally informed [7]. This thus enables us to theoretically distinguish the contribution of people's health states to the reported HRQoL from the contribution of response shifts and dispositions.

Currently, the potential influence of response shifts and dispositions on medical decision making is only taken into account to a limited extent – and usually only implicitly

– in consultation rooms, and not at the level of healthcare policy. Consequently, medical decisions may be taken on insufficient grounds and hence may be suboptimal. At the micro level, patients may not receive optimal treatment, as argued below. At the macro level, basic health insurance packages may include treatments that are not the most clinically effective or cost-effective. At present, it is unknown which decisions may be influenced and in what ways. Therefore, here we aim to identify the possible influences of response shifts and dispositions on PROs that have unintended consequences for medical decision making. To illustrate these influences, we provide hypothetical scenarios at the individual patient and policy level. We analyze these examples from three ethical perspectives for the micro level and two ethical theories of distribution for the macro level, to clarify which consequences are problematic – either because they are detrimental to individual patients or to society as a whole.

PATIENT-REPORTED OUTCOMES IN CLINICAL STUDIES

Clinical studies – including PROs – form the basis of medical decision making, both in the consultation room and on the policy level. Response shift may systematically influence PROs in several types of clinical studies [8]. In cross-sectional studies, response shifts induced by events in the past may result in higher or lower PROs than would be expected based on patients' health states. During prospective cohort studies, patients may undergo new response shifts that lead to an underestimation or overestimation of health changes over time. Similarly, in randomized controlled trials (RCT) and, consequently, in cost-effectiveness studies, the compared treatments may induce different degrees or directions of response shift in the same or even in different PROs. As a consequence, treatment effects may be underestimated or overestimated. For example, health deterioration due to illness progression or treatment may require adaptation by patients. As a result, a greater response shift may be induced by such a treatment than by treatments resulting in less health deterioration. This is illustrated in Scenario 1.

Scenario 1: Influence of response shift in clinical studies

An RCT in patients with metastatic gastric cancer is conducted to compare treatment with a doublet of cytotoxic agents followed by a third cytotoxic agent upon progression (regimen A; standard care) with a combination treatment with a triplet of cytotoxic agents (regimen B). The survival outcomes of both treatments turn out to be similar, but at follow-up, health states for group A are slightly better. Moreover, patients in group B experience more acute side effects during treatment, including neutropenic fever. This results in a greater response shift for group B than for group A. At follow-up, these acute side effects have disappeared. The stronger response shift in group B results in higher reported HRQoL scores than in group A, even though their health state is slightly worse, as is shown in Figure 1.

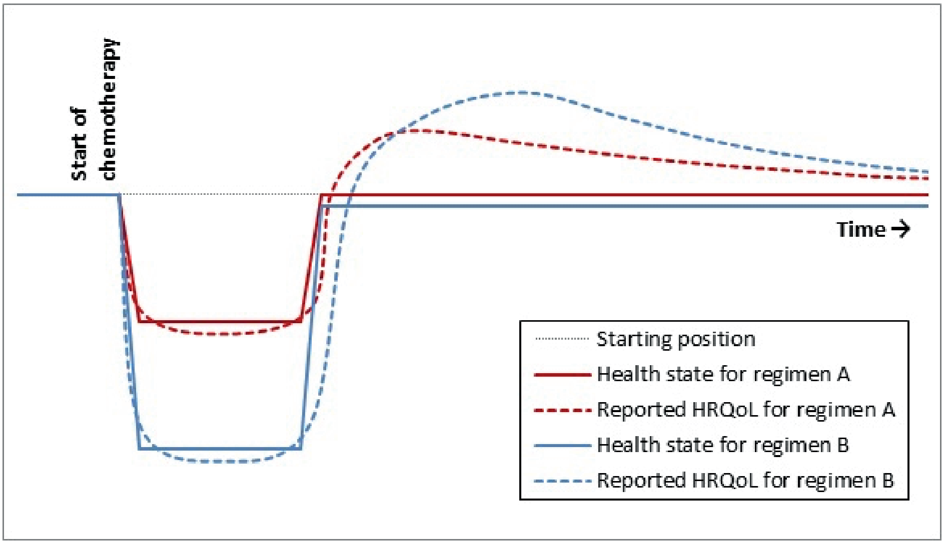

Figure 1. Health states and reported HRQoL after treatment with regimen A versus regimen B (Scenario 1)

Disposition may also influence PROs in clinical studies. For example, optimism may lead to higher HRQoL scores than would be expected based on health state, and rigidity may lower the changeability of HRQoL and thus influence conclusions about the effects of treatments. Furthermore, patients with a certain disposition may agree to participate in studies more often than other patients. Dispositions are not likely to influence the results of RCTs and consequently of cost-effectiveness studies, as group differences at baseline are due to chance. However, in cross-sectional or prospective studies, disposition may systematically influence PROs if groups of patients have different dispositions that are related to the outcome, i.e. if a disease is associated with a certain disposition. This is illustrated in Scenario 2.

Scenario 2: Influence of disposition in clinical studies

A cross-sectional study is conducted to compare HRQoL of two groups of patients with congenital heart disease: pulmonary valve stenosis and Marfan's syndrome with mitral valve stenosis. Research suggests that psychological dispositions that negatively impact HRQoL may be part of the phenotype of Marfan's syndrome [9]. This could result in Marfan patients reporting lower levels of HRQoL than patients with pulmonary stenosis, given the same health state. As a result, the health state of Marfan patients may be systematically underestimated.

MEDICAL DECISION-MAKING IN THE CONSULTATION ROOM: ETHICAL PRINCIPLES

As shared decision-making (SDM) is becoming more important, patients' self-evaluations and preferences are increasingly taken into account [10]. In this context, healthcare practitioners may inform patients about published PRO data to support their decision-making. Thus, response shifts and dispositions may influence SDM to the extent that it is informed by self-reports. Below, we will discuss different types of influences and provide examples with consequences from an ethical perspective.

Three ethical principles

We use three principles for moral reasoning in biomedical ethics that are relevant for the level of individual patient care: nonmaleficence, beneficence and respect for autonomy [11]. The first principle, nonmaleficence, supports avoidance of harm to the patient and is based on the ancient maxim, "First, do no harm." In many cases, this principle is considered together with the principle of beneficence, for example, in weighing the benefits and risks of a certain treatment for a patient. The second principle is beneficence, and refers to acting in the best interest of the patient and promoting goods such as health and wellbeing. This includes relieving, lessening, or preventing harm, such as pain and suffering, disease, disability, and death. The third is respect for autonomy. This principle implies respect for the patient's capacity for self-determination, i.e. respecting and supporting autonomous decisions of the patient. In medical practice, this means that healthcare practitioners usually present treatment options and make recommendations. Patients, in collaboration with their healthcare practitioners, make (informed) decisions about accepting or refusing treatments, partly based on personal values and beliefs [12].

The fourth principle, i.e. justice, may also be at stake at the level of individual patient care, in the sense of equal treatment among the patient populations of individual healthcare practitioners. However, we did not include this principle as we consider it less relevant for individual patient care. For healthcare practitioners, over- or undertreatment of a patient is problematic as such, and not only in relation to the care provided to other patients. Neither is distributive justice considered relevant. In most Western countries at least, in the consultation room, healthcare practitioners are not concerned with the just allocation of resources in healthcare, but rather with providing good healthcare for each individual patient.

Influences of response shift and disposition on SDM

We can distinguish three types of influence of response shift or disposition on SDM. First, they may have influenced published PRO results that are used in the decision-making process (for an example and its ethical analysis, see Scenario 3). Second, response shifts and dispositions may influence patients' own self-reports. These self-reports may be provided by questionnaires or symptom diaries, or informally, in response to a physician's enquiries. Third, response shifts and dispositions may also influence patients' preferences for or against certain treatments. Scenario 4 provides an example combining the second and third type of influence and its ethical analysis.

Scenario 3: Influence of response shift on medical decision-making (micro level)	**Ethical analysis: nonmaleficence, beneficence, autonomy**
An oncologist discusses published PRO data from an RCT (see Scenario 1) with a patient with metastatic gastric cancer. Based on the PRO data, the patient prefers regimen B (the triplet of cytotoxic agents) over regimen A, because QoL scores of this group are higher at follow-up. Whether or not the patient would undergo the same response shift as the study respondents is not certain. Not knowing about the response shift causing the higher HRQoL scores means that the patient's decision is not fully informed. Consequently, the patient may be overtreated, resulting in unnecessary side-effects and lower health state at follow-up than regimen A would have yielded.	The example is problematic from the perspective of nonmaleficence. At the moment of the decision, no harm is done yet. However, the overtreatment that may be the consequence, leading to a worse health state, equals 'doing harm'. In addition, the principle of autonomy is at stake as well, since the decision is not fully informed. Whereas possible differences between study groups and the individual patient – such as gender, age, and possibly lifestyle – are ideally taken into consideration, influences of response shifts and dispositions are less well-known and rarely discussed in SDM. However, the patient is still included in the decision-making and informed about options, expected benefits and risks. Therefore, this may be considered only a minor violation of the autonomy principle, especially as it is not possible to tease out all health changes from response shift and disposition in PRO data.

Scenario 4: Influence of disposition on medical decision-making (micro level)	**Ethical analysis: nonmaleficence, beneficence, autonomy**
A cardiologist sees a patient with stable coronary artery disease and low ischemic burden, and consequently no indication for coronary angioplasty. The patient reports four occurrences of chest pain per day. Due to high trait anxiety, he is not only vulnerable to over-perceiving heart symptoms, but also inclined to catastrophize the occurrences of chest pain [13]. Furthermore, his anxiety about the chest pain results in a strong preference for angioplasty over continuing conservative treatment (medication). Finally, the cardiologist decides to refer the patient for angioplasty, leading to medically unnecessary treatment [14] and consequently unnecessary medical risks.	The disposition of the cardiac patient influences his self-evaluation as well as his treatment preference (requesting angioplasty). The consequent unnecessary treatment is in conflict with both the beneficence and nonmaleficence principles. As there are no health benefits that outweigh the health risks of the intervention, the treatment is not in the best interest of the patient and the health risks imply possible harm. Whereas the treatment may comfort this anxious patient, leading to a (presumably temporary) improvement in self-reported health or wellbeing, it would have been better to refer the patient for treatment of his anxiety. Concerning the principle of autonomy, the situation does not seem problematic as it is the patient's own self-evaluation and preference that informs the decision leading to sub-optimal care. However, the patient is probably unaware of the influence of disposition on his self-evaluation. Not being able to take this into account raises the question of whether the decision is optimally informed and, consequently, autonomous.

DECISIONS IN HEALTHCARE POLICY: ETHICAL THEORIES OF DISTRIBUTION

On the macro level, PRO data from clinical studies are used for decisions in healthcare policy. Below we discuss different types of decisions that may be influenced by response shift and disposition, and analyze examples from an ethical perspective.

Two ethical theories of distribution

We use two of the ethical theories of distribution that are relevant for the macro level and frequently guide health policy decisions in Western European countries: classical utilitarianism and fair equality of opportunity.

Classical utilitarianism is a consequentialist theory usually associated with the work of the philosophers Jeremy Bentham and John Stuart Mill. It states that actions are just when they maximize “utility,” usually defined as wellbeing, welfare, or happiness. According to Mill’s account of “hedonistic” utilitarianism, decisions should lead to the greatest happiness for the greatest number of people, i.e. maximizing pleasure and minimizing pain.

When applied to healthcare, utilitarianism implies maximizing total (expected) utility within the boundaries of limited healthcare resources, regardless of how resources and utility are distributed [15]. People may differ in how much utility they can “derive” from the same amount of resources (“capacity to benefit”). For example, one patient might benefit more from a certain treatment than another patient, in terms of health or wellbeing [16]. Following health economics, we take peoples’ valuations of their health-related quality of life as the “good” that should be maximized, indicating the relative desirability of these health states. The utility of a medical treatment is thus the valuation of the incremental quality of life, combined with the duration of the quality of life levels.

“Fair equality of opportunity” is the egalitarian account of Norman Daniels, applying Rawls’ “Theory of justice” to healthcare. It considers the protection of the ability of individuals to participate in the political, social, and economic life of their society [17]. According to Daniels, by keeping people close to “normal functioning,” healthcare can provide people their fair share of the “societal normal range of opportunities” that reasonable people would choose in that society. Applied to decisions in healthcare policy, it is this functioning that is taken into account and not the impact of disease and treatment on patients’ wellbeing, happiness, or other types of utility [18]. Thus, fair equality of opportunity implies that every patient should have access to a certain minimum level of healthcare, to promote normal functioning and thus protect fair equality of opportunity [19]. This also implies that people with severe illness or disabilities who nevertheless report high levels of life satisfaction or quality of life can still appeal to support in obtaining a fair share of an opportunity range, because they have an objective loss in their range of capabilities and opportunities [20].

HEALTHCARE POLICY DECISIONS

We distinguish between two types of healthcare policy decisions that may be affected by response shifts and dispositions. The first type is devising treatment guidelines for specific conditions, to designate which treatment is preferred. For some conditions, these decisions are based on data from RCTs (see Scenario 5).

Scenario 5: Influence of response shift on guidelines (macro level)	**Ethical analysis: Utilitarianism**	**Ethical analysis: Fair equality of opportunity**
An RCT is conducted to compare the effects of bypass surgery (open heart surgery) and angioplasty (catheter intervention) on frail patients. In the longer term, both treatments produced the same health status. However, as bypass surgery requires several months of recovery and thus adaptation, it may induce a greater response shift than angioplasty. As a result, after six months the bypass group reports higher levels of HRQoL than the angioplasty group, even though their health states are similar. This shows that the guidelines may be suboptimal, with an unwarranted preference for bypass surgery, leading to suboptimal care: unneeded treatment with unnecessary medical risks.	Since utility should be maximized, influences of response shifts or dispositions on self-evaluations are not an issue as such. The situation is problematic because bypass surgery is more expensive than angioplasty and has more medical risks, in this case without greater health benefits. However, the higher HRQoL scores due to response shift may justify the preference for bypass surgery, despite the medical risks. Nonetheless, especially when the costs and risks of bypass surgery are substantially higher, one might question whether these “extra” resources would not be better spent on other healthcare or even services other than healthcare. Indeed, this may yield a larger increase of total utility in the broad sense, i.e. the wellbeing of the population.	The situation is problematic. The guideline may lead to medical risks of unneeded bypass surgery, which could cause a loss in the range of capabilities and opportunities of this patient group.

In the second type, PRO data are used in cost-effectiveness analyses to decide which treatments should be included or excluded in the basic healthcare package. Response shift and disposition may influence these decisions at two points. First, as explained above, response shifts may influence PROs, e.g. EuroQol (EQ-5D) health questionnaire data. Second, such PRO data are combined with “utility tariffs,” to calculate the utility of a treatment in terms of quality-adjusted life years (QALYs). Utility tariffs are valuations of health states, indicating the relative desirability of these health states. Utility is anchored at 0 (as bad as death) and 1 (as good as perfect health). For reasons of democratic legitimacy, most national guidelines require that utility tariffs are estimated from the public's perspective. These tariffs thus reflect how the general public values health states as described by patients. Generally, valuations by the general public are lower than patient valuations, which may be affected by response shifts induced by disease experience – one of the known causes of this discrepancy [21]. However, the size of the discrepancy between valuations from the public and patients may vary, depending on health states and patient groups. For example, there are indications that larger discrepancies may be expected for patients with worse health states [22]. As a result, the cost-effectiveness analyses may lead to different conclusions than if the utility scores of patients had been used (see Scenario 6).

Scenario 6: Influence of response shift on inclusion in healthcare package (macro level)	**Ethical analysis: Utilitarianism**	**Ethical analysis: Fair equality of opportunity**
A cost-effectiveness (costs per QALY) study carried out is among patients with Crohn's disease. Treatment A (standard care) is a colostomy, after which patients need to use stoma bags. Treatment B delays the need for a colostomy for six years, has no side-effects, and costs EUR 53,000. The total costs of stoma care for six years (group A) are estimated at EUR 7,000. Treatment B thus costs EUR 46,000 more than standard care. Utility is determined from the perspective of the general public. Based on a scenario describing aspects of life with a stoma, the general public estimates life with a stoma at a value of 0.8 [23]. Treatment B would increase this utility from 0.8 to 1.0 for six years. Treatment B would thus yield 0.2 x 6 = 1.2 QALY, at incremental costs of EUR 46,000. Thus, treatment B has a cost-effectiveness of EUR 38,000 per QALY, which is acceptable in most Western countries. However, the health valuations by patients with colostomies are significantly higher, at 0.92 [23], probably partly due to response shift. If the patients' own utility scores had been used, the incremental utility would only be 0.08 for six years, leading to a smaller incremental value of 0.08 x 6 = 0.48 QALYs. Combined with the incremental costs of EUR 46,000, the cost-effectiveness would be EUR 96,000 per QALY, which might not be acceptable in many Western countries [24]. Thus, using the valuations of the general public, treatment B would be reimbursed, while it would not if patients were asked to value their own health states.	The situation is not problematic. Using utility tariffs derived from the general public instead of the patient group for cost-effectiveness analyses does not conflict with a utilitarian point of view. Utilitarianism does include the option to let society determine the desirability or undesirability of health states. In other words, it may be left to the general public to determine how 'bad' it considers certain health states to be, and the amount of money it is willing to spend to improve these health states.	The situation is problematic in the sense that only health benefits that improve *functioning* should be taken into account in decisions for reimbursement, instead of self-reported HRQoL (including influences of response shift and disposition) or valuations of health states (utility). Thus, using utility tariffs is always in conflict with the theory of fair equality of opportunity. The more utility tariffs (derived from the general public) differ from the actual health states of patients, the more problematic it becomes. In this case, the patients' valuations would be higher than the valuations derived from the general public, partly due to response shift. Therefore, using the valuations of the general public is less problematic than using patient valuations. In this particular example, using valuations of the general public leads to reimbursement of treatment B, with six extra years of functioning without having to use stoma bags. Thus, the patients' range of capabilities and opportunities is optimally protected.

CONCLUSIONS

Response shifts tend to mitigate or amplify changes in PROs, and differences in disposition may lead to different PRO scores among people with the same health state. This may influence medical decisions at both the levels of individual patients and health policy, leading to suboptimal care.

The question arises of how serious the consequences are if these influences are not considered. The answer is not only dependent on empirical data and the ethical theory applied but also on the health concept used. As Haverkamp et al. have shown, different practices may require different concepts of health [25]. In this paper, we have used the biomedical concept of health. Other, broader conceptions of health have been proposed and debated, including positively phrased definitions of health such as “overall physical, mental and social wellbeing” [26] and “the ability to adapt and self-manage” [27]. From these perspectives, healthcare should aim to improve biological functioning as well as to improve overall wellbeing and adaptation. Thus, in these latter approaches, the influences of response shifts and dispositions on PROs may be viewed as beneficial. However, as with the biomedical perspective, these influences still need to be teased apart from actual health states. We believe that patients may be entitled to know about the influences of response shifts and dispositions on PROs that inform their treatment decisions. Healthcare practitioners may need to learn about their patients’ dispositions and how patients adapt to their disease in order to provide good care. Moreover, patients who have adapted to symptoms and functional problems or who are not inclined to report them may still benefit from treating these burdens of disease.

Also on the level of healthcare policy, medical decision-making could benefit from taking into account the influence of response shift and disposition. The ethical analysis of the scenarios presented above also show that decisions about guidelines and reimbursement of treatments may not be fully informed. Not only reflecting on the possible influences of response shift could enhance the decision-making; the different ethical perspectives and conceptions of health and their differential implications for healthcare policy also need to be considered.

Pertinent questions arise from a biomedical perspective towards health. For example, how many decisions are influenced by response shift and disposition, and result in suboptimal care, health inequities, or inefficient use of healthcare resources? Does it make a difference ethically if under- or over-treatment is caused by the influences of response shifts or dispositions? What is more problematic: unnecessary treatments for demanding patients, or under-treating patients who downplay their symptoms?

Given the importance of the patient’s perspective in healthcare and research, and the fact that PROs cannot be replaced by clinical measures, it is our intention to improve rather than criticize the use of PROs. Our aim is to raise awareness of the potential influences of disposition and response shifts on medical decisions via PROs. We call on healthcare practitioners, researchers, policy makers, health insurers, and other stakeholders to critically reflect on how and why such patient reports are used. For example, is the aim to assess the impact of a treatment on patients' wellbeing, or on their health state? We would particularly encourage healthcare practitioners to ask patients more probing questions about symptoms and functional problems, or how they respond to a certain treatment. Existing SDM training programs for healthcare practitioners could incorporate the subjects of response shift and dispositions to provide them with the knowledge and skills needed to explain such influences to their patients. It is also our hope that this reflection will stimulate empirical research into the effects of response shift and dispositions on medical decision-making. In cross-sectional and prospective studies, dispositions could be assessed to investigate their influence on PROs and possibly enable the correction of these influences in future research. Considering response shift, as a first step, we need to investigate which types of treatments are likely to induce response shifts. Knowledge about the PROs that are most susceptible to response shifts [28] and statistical techniques distinguishing response shifts from actual health changes are available [29]. We thus have the tools to start the investigation, with the aim of improving the use of PROs in medical decision-making.

DISCLOSURES AND ACKNOWLEDGEMENTS

Abbreviations

HRQoL: health-related quality of life;
PRO: patient-reported outcome;
QALY: quality-adjusted life year;
RCT: randomized controlled trial;
SDM: shared decision-making.

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Authors' contributions

MS, HvL, DW, PN, MS-R and JH made substantial contributions to the conception of the study. IH, MS, WvdH and DW designed the study, HvL and JH contributed to the scenarios for the article. IH and MS drafted the article and wrote the final manuscript. TO, MS, DW, WvdH, JH, HvL, PN and MS-R revised the article. IH is the corresponding author. All authors read and approved the final manuscript.

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Availability of data and materials

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Competing interests

The authors declare that they have no competing interests.

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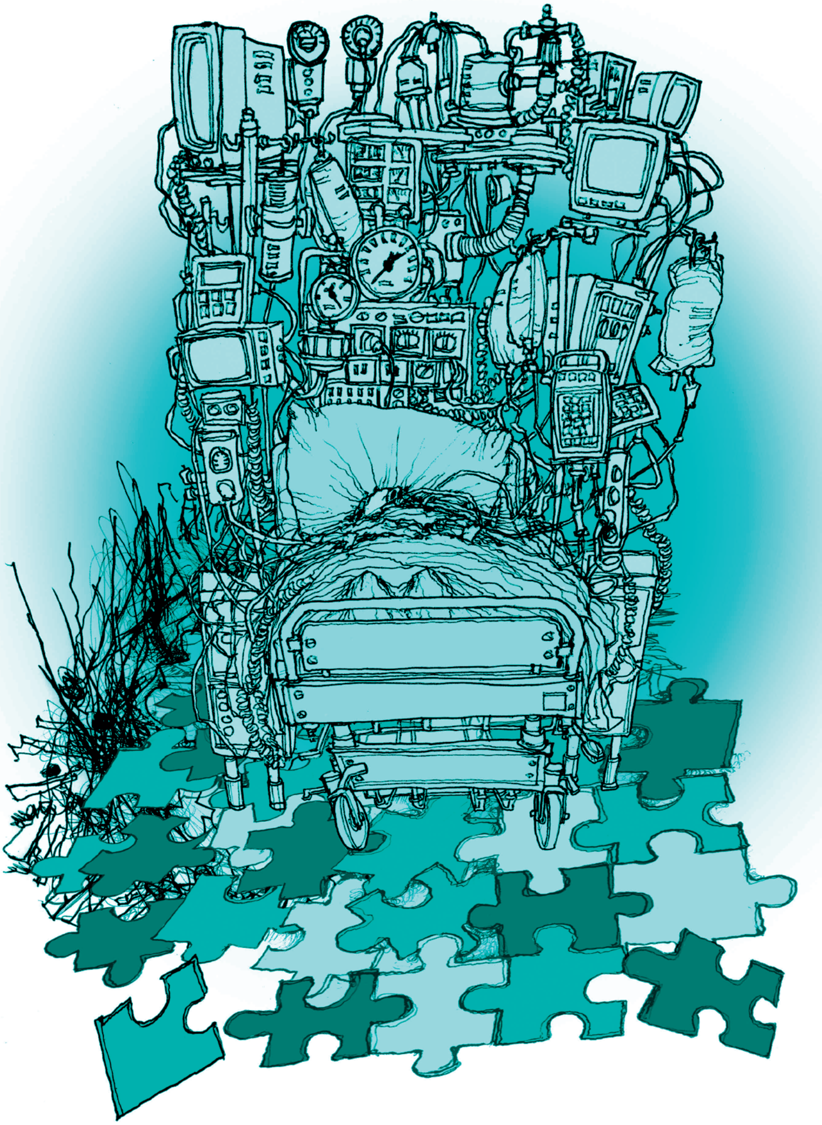
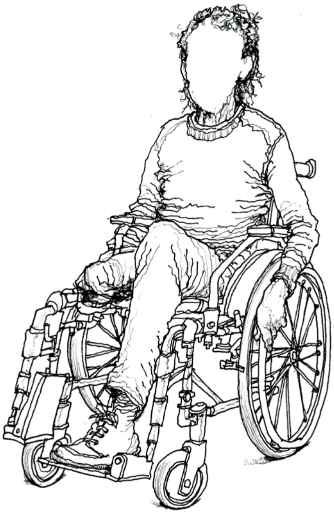


7

SUMMARY AND GENERAL DISCUSSION

Contribution of the author of this dissertation:
The author designed and wrote the first draft of this chapter and revised several versions of the chapter based on feedback of MS-R, MS, HvL and PN.



INTRODUCTION

In this chapter, the previous chapters will first be summarized followed by a table providing an overview of the research questions, answers and directions for future research as presented in the previous chapters (see Table 7.1). In the subsequent general discussion, the added value of this study is evaluated and a few overarching topics are discussed.

SUMMARY

This dissertation is about disruptive life events causing an “experience of contingency,” and the ways people make meaning of such events and integrate them into their life narratives. Certain life events, for example falling seriously ill, 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” and evoke existential questions. In religious studies, these crises of meaning are often called “experiences of contingency,” which make us aware of our vulnerability and finitude and confront us with the randomness of life. “Contingency” refers to the randomness of the world and everything that happens. Our study departs from the concept of experience of contingency as developed by religious-philosopher Kurt Wuchterl, characterised by the inability to “grasp” and make meaning of disruptive life events and their randomness. According to Wuchterl, people can relate to contingency in several ways, depending on their worldview. The concept of narrative integration that we developed building on his distinctions and our empirical study, brings together the two meanings of contingency that are central in this dissertation: 1) the randomness of life events that befall us; and 2) the new possibilities that may be found in the process of narrative meaning making and integration.

Although several findings suggest that adverse life events such as falling seriously ill negatively impact QoL, some people find remarkably positive ways to relate to such events, and experience higher levels of QoL than would be expected. These high levels of QoL 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) the new life circumstances. A related finding is that in research into health-related QoL, which pertains to patients’ subjective evaluation of the effects of diseases and treatments, patients sometimes report surprisingly stable levels of QoL despite apparent changes in health status. In this dissertation, two possible causes are addressed: 1) people’s relatively stable characteristics (“dispositions,” or “traits”); and 2) shifts of meaning, called “response shifts.” These shifts of meaning, for example in the importance of certain values or goals (“reprioritization”), are often induced by a change in health due to disease or treatment, leading to obfuscation of these health changes.

In this thesis, **we propose an interdisciplinary approach to meaning making relating to QoL, integrating perspectives and methods from both humanities and medical sciences.**

Our **first aim** was 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. **To this end, 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 aimed to qualitatively investigate whether the theoretical concepts of dealing with contingency (resulting in narrative integration) can be distinguished in the empirical reality and/or have to be refined based on empirical findings. Our **second aim** was 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. The **third aim** of this study was to investigate the effects of meaning making interventions (often referred to as “spiritual” interventions) that use a narrative approach. Lastly, our **fourth aim** was 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 data. The consequences of these influences were analyzed from a medical-ethics perspective.

In **Chapter 1**, the theoretical model “Narrative meaning making and integration of life events” was presented: 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. This 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.* Based on this model, the Reconstruction of Life Events questionnaire (RE-LIFE) was developed (see Appendix 1 at the end of this dissertation).

Chapter 2 addressed the research question how patients make meaning of their “experiences of contingency” after the life event of being diagnosed with incurable cancer.

It presented the results of our qualitative study into experiences of contingency of advanced cancer patients. In a development and validation phase, we respectively analyzed 23 and 45 in-depth interviews, resulting in four modes of relating to contingency: “denying,” “acknowledging,” “accepting,” and “receiving”.

In the mode of **denying**, the interpretation process is aborted rather than engaged in. The contingency and/or the existential relevance of the event is denied, leaving no questions about (the cause of) the event or the consequences for one’s life. In the mode of **acknowleding**, the contingency of the event is taken seriously and interpreted as a disruption of the person’s life story. 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 the mode of **accepting**, the person actively searches for ways to integrate the event in the personal life narrative, re-interpreting the event. Nevertheless, in this mode, the narrative reconstruction is still a struggle. In the final mode, **receiving**, the integration of the event in the life story is completed. “New possibilities” that emerge from the life event are embraced as part of the reinterpretation, such as new insights that the life event has brought.

Our study was the first to investigate Wuchterl’s theoretical concepts of relating to contingency empirically, in a clinical context. The modes of relating to contingency found in our study improve our understanding of narrative meaning making and integration of experiences of contingency evoked by disruptive life events such as falling terminally ill. Our findings may help caregivers to better target and shape care for patients experiencing contingency, and allow operationalization into a quantitative instrument to enable further research into narrative meaning making and integration of disruptive life events.

In **chapter 3**, we address the second research question: How can we quantitatively assess (dealing with) experiences of contingency, narrative meaning making and narrative integration? It presents the psychometric properties of the RE-LIFE Questionnaire, among which its scale structure, the internal consistency and reliability of the scales, and the convergent validity of the two key scales “experience of contingency” and “narrative integration.” Convergent measures assessed health-related QoL (SF-36), posttraumatic growth (PTGI) and personality (HEXACO-SPI).

The RE-LIFE was completed by 237 patients with stable coronary artery disease, six months after revascularization. Principal axis factoring identified seven multi-item scales that were theoretically warranted. For worldview, two instead of three scales were identified: “transcendence” and “absolute immanence.” One scale for “experience of contingency” was found, as hypothesized. For “narrative meaning making,” two of the six hypothesized scales were identified, belonging to the scope of the meaning of the life event: “spiritual” and “existential.” Finally, two of the four expected “narrative integration” scales were found: “acknowledging” and “receiving.” The internal consistency reliability was acceptable to excellent for the scales with more than two items. As expected, patients who indicated having experienced contingency, experienced lower levels of QoL. Patients indicating to have “received” contingency, indicating narrative integration, reported more posttraumatic growth.

This study was the first attempt to operationalize the process of narrative meaning making with theoretical concepts from religious studies – experience of contingency and narrative integration – into a quantitative questionnaire. The RE-LIFE is a promising tool that may facilitate research and may support spiritual counselors to help patients integrate experiences of contingency into their life narratives.

In **Chapter 4**, the third research question is addressed: What are the relationships between disruptive life events, the experience of contingency, ultimate life goals, worldview, narrative meaning making, narrative integration and QoL? It presents the results of a multiple mediation analysis that assessed the relationships between the concepts of our theoretical model underlying the RE-LIFE Questionnaire. Using the data collected at three months after the revascularization procedure, correlations and bivariate regression coefficients including the background variables were inspected to assess which variables met the criteria for possible mediation. This led to two models for possible mediation with “experience of contingency” as the independent variable, which were assessed using regression-based serial multiple mediation analysis.

“Experience of contingency” partially influenced “acknowledging” (indicating no narrative integration) via “negative impact on life goals” and via “existential meaning,” thereby confirming the hypothesized relationships in Model 1. The influence of “experience of contingency” on “QoL” was completely explained by its influence on “negative impact on life goals,” “existential meaning” and “acknowledging,” thereby confirming the hypothesized relationships in Model 2.

In conclusion, several hypothesized relationships within the theoretical model were confirmed. Our results suggest that experiences of contingency lead to a struggle to integrate the event into one’s life story in a meaningful way, influencing people’s self-evaluation of their QoL negatively. In addition, narrative meaning making and integration significantly influence QoL. Our suggestion for psychological or spiritual counselling and psychotherapy would be to discuss the existential issues that clients raise, explicitly addressing contingency, for example discussing the disruptive nature and the incomprehensibility of the event.

In **chapter 5**, the fourth research question is addressed: What are the effects of meaning making interventions (often referred to as “spiritual” interventions) using a narrative approach, on the QoL of cancer patients? To answer this question, we conducted a systematic search for randomized controlled trials comparing spiritual interventions that addressed existential themes using a narrative approach with standard care for its effect on QoL or subjective wellbeing.

A total of 4972 studies were identified, of which 12 trials (1878 patients) could be included in the meta-analysis. The outcome measures used in the studies varied, and the overall risk of bias was high. Meta-analysis of the twelve studies combined showed a moderate positive effect on overall QoL at 0–2 weeks after the intervention, in favor of the spiritual interventions. However, at 3–6 months after the intervention, this effect was only small and nonsignificant. Subgroup analysis including only the western studies showed a small but significant effect of the spiritual interventions compared to standard care. Including only studies that met the allocation concealment criteria showed a nonsignificant effect. Finally, dividing the studies into life reviewing interventions, multidisciplinary interventions and meaning making interventions, the largest effect on QoL was seen in the latter group.

In conclusion, spiritual interventions addressing existential themes using a narrative approach had a moderate beneficial effect directly after the intervention, in terms of improving QoL of cancer patients compared with that of a control group. No evidence was found that the interventions maintained this effect up to 3–6 months after the intervention. It may be hypothesized that spiritual interventions with a narrative approach are likely to be more effective when providing not one, but a series of sessions. Further research is needed to understand how spiritual interventions could contribute to a long-term effect of increasing or maintaining QoL.

In **Chapter 6**, the fifth and last research question is answered: How may dispositions and response shifts influence patient-reported outcomes (PROs) and consequently medical decisions, and what are the ethical implications of these consequences? PROs are frequently used for medical decision-making, at the levels of both individual patient care and healthcare policy. Evidence increasingly shows that PRO data may be influenced by patients’ response shifts (changes in interpretation) and dispositions (stable characteristics). We mapped the possible unintended consequences of these influences for medical decision-making in individual patient care and policy making. In addition, we provided examples of these consequences and analyzed these from a medical ethics perspective.

At the micro level, we distinguished three *types of influence* of response shift or disposition on shared decision-making. First, they may have influenced published PRO results (of clinical trials) that are used in the decision-making process. Second, response shifts and dispositions may influence patients' own formal or informal self-reports. Third, response shifts and dispositions may also influence patients' preferences for or against certain treatments. These influences may result in treatments (or withholding needed treatments) for individual patients that are not the most beneficial, in terms of health benefits and risks.

At the macro level, we distinguished between two *types of healthcare policy decisions* that may be affected by response shifts and dispositions. The first type is devising treatment guidelines for specific conditions to designate which treatment is preferred, based on data from RCTs. Influences of response shift or disposition on these data may result in suboptimal guidelines, for example prescribing a treatment that is more invasive than the alternative, but results in higher levels of QoL due to response shift. The second type is the cost-effectiveness analyses based on RCT data to decide which treatments should be included or excluded in the basic healthcare package. In these cases, PRO data are combined with "utility tariffs" to calculate the utility of a treatment in terms of quality-adjusted life years (QALYs). These tariffs reflect how the general public values health states as described by patients. As a result, these cost-effectiveness analyses may lead to different conclusions than if the utility scores of patients had been used, which may be affected by response shifts induced by disease experience.

If influences of response shift and disposition on PRO data and consequently medical decision-making are not considered, patients may not receive optimal treatment and health insurance packages may include treatments that are not the most effective or cost-effective. We call on healthcare practitioners, researchers, policy makers, health insurers, and other stakeholders to critically reflect on why and how such patient reports are used.

Table 1. Overview of research questions, answers and directions for future research

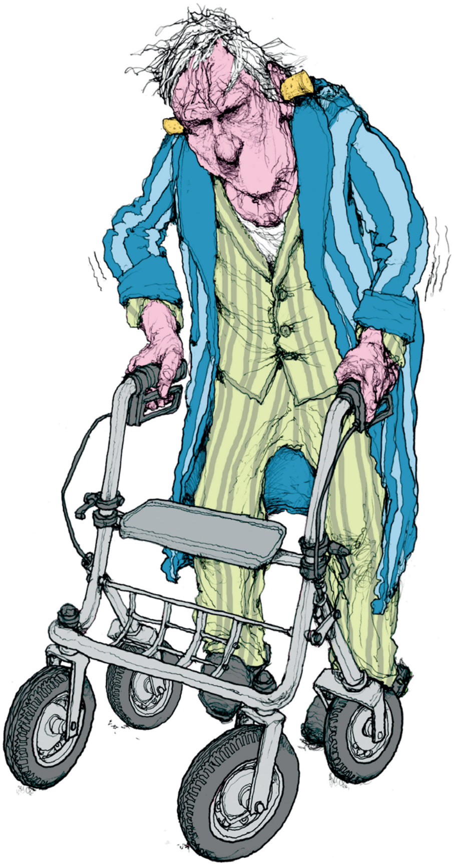
	Research question	Answers to the research question	Directions for future research
Chapter 2 (qualitative)	How do patients make meaning of their 'experiences of contingency' after the life event of being diagnosed with incurable cancer?	In the meaning making of the event of getting incurable cancer, four modes of relating to contingency can be distinguished: "denying", "acknowledging", "accepting" and "receiving". These modes indicate increasing narrative integration, leading to embracing the new possibilities that emerge from the life event.	• Investigate whether these different modes also correlate with the overall well-being of patients. *See chapters 3 and 4* • Examine at what moment in the course of cancer patients' disease trajectory spiritual care can best be offered.
Chapter 3 (quantitative)	How can we quantitatively assess (dealing with) experiences of contingency, narrative meaning making and narrative integration?	The RE-LIFE is a quantitative questionnaire, operationalizing the concepts of the theoretical model "Narrative meaning making and integration of life events". Factor analysis identified seven scales that were theoretically warranted: "transcendence" and "absolute immanence" (worldview), "experience of contingency", "spiritual" and "existential" (narrative meaning making – scope), and "acknowledging" and "receiving" (narrative integration). The internal consistency reliability was acceptable to excellent for the scales with more than two items. Patients who indicated having experienced contingency, experienced lower levels of QoL. Patients indicating to have "received" contingency, indicating narrative integration, reported more posttraumatic growth.	• Further refinement and validation of the RE-LIFE in future research. For example, the items of the hypothesized subscales belonging to "worldview" and "narrative integration" (especially "denying") may benefit from revisions. • Use of the (refined) RE-LIFE in studies assessing the impact of spiritual interventions aiming to fulfilling existential and spiritual needs, because narrative integration may be more proxy to these aims than measures such as QoL. We recommend to focus RE-LIFE on only one negative life event (e.g., self-identified event or a medical condition). • Use of the (refined) RE-LIFE in research to expand theoretical knowledge of the differences between people in how they react to disruptive life events and changed life circumstances (rejecting, accepting, trying to achieve unattainable goals or finding new ways to make their lives meaningful). • Assessing the usefulness of the (refined) RE-LIFE in clinical practice. For example, administering it after falling ill or other disruptive life events as a tool to support the communication between the respondent and a spiritual counselor. When administered at subsequent times, the process of meaning making and narrative integration can be monitored and support be provided as needed.

Table 1. Overview of research questions, answers and directions for future research (continued)

	Research question	Answers to the research question	Directions for future research
Chapter 4 (quantitative)	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?	Multiple mediation analysis indicated that "experience of contingency" significantly influences "acknowledging", partially mediated by indirect influences through "negative impact on life goals" and "existential meaning". "Experience of contingency" also significantly influenced "QoL" with a full mediation by the variables "negative impact on life goals", "existential meaning" and "acknowledging". Experiences of contingency may lead to a struggle to integrate the event into one's life story in a meaningful way, influencing people's self-evaluation of their quality of life negatively. Narrative meaning making and integration significantly influence quality of life.	• Research among respondents who predominantly report an experience of contingency, such as people with incurable cancer, to further test the hypothesis that an experience of contingency evokes a process in which people struggle to come to terms with the event in the context of their life narratives. • Use of the RE-LIFE adapted to enable validation of the original sequence of the theoretical model. For example, retrospectively assessing the impact of the life event on life goals at the time of the diagnosis instead of at the time of the assessment, which requires adaptation of the "impact on ultimate life goals" items. And/or administering the RE-LIFE shortly after a diagnosis or other life event rather than in anticipation of a medical intervention, with follow-ups every few months. This would enable momentary assessment of the experience of contingency instead of retrospectively, as well as changes over time. • Further research into the relationship between posttraumatic growth and narrative integration.
Chapter 5 (systematic review)	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?	Meta-analysis of the twelve studies combined showed a moderate beneficial effect directly (0-2 weeks) after the spiritual intervention, in terms of improving quality of life of cancer patients compared with that of a control group. No evidence was found that the interventions maintained this effect up to 3–6 months after the intervention. The outcome measures and time points used in the studies varied, and the overall risk of bias was high.	• Further research to understand how spiritual interventions could contribute to a long-term effect of increasing or maintaining QoL. • To assess which specific type of spiritual intervention is most beneficial for which type of patient, we should strive for more uniformity of future studies in terms of the outcome measures, the time points of assessment and of randomization. This could be achieved by following guidelines on the design of this kind of intervention studies, such as standardization of the outcome measurement 'quality of life' by using the EORTC QLQ-C30 or C15-PAL questionnaire. Other guidelines for setting up a clinical study should be followed more adequately, such as including a control-arm and applying proper randomization and allocation methods.

Table 1. Overview of research questions, answers and directions for future research (continued)

	Research question	**Answers to the research question**	**Directions for future research**
Chapter 6 (ethical analysis)	How may dispositions and response shifts influence patient-reported outcomes and consequently medical decisions, and what are the ethical implications of these consequences?	Response shifts tend to mitigate or amplify changes in PROs, and differences in disposition may lead to different PRO scores among people with the same health state. This may influence medical decisions at both the levels of individual patients and health policy, leading to suboptimal care. If these influences are not considered, patients may not receive optimal treatment and health insurance packages may include treatments that are not the most effective or cost-effective.	• Empirical research into the effects of response shift and disposition on medical decision-making. In cross-sectional and prospective studies, dispositions could be assessed to investigate their influence on PROs and possibly enable the correction of these influences in future research. • Investigating which types of treatments are likely to induce response shifts, using the existing knowledge about the PROs that are most susceptible to response shifts, and statistical techniques distinguishing response shifts from actual health changes. • Critical reflection on why and how patient reports are used in future research (e.g. the impact of a treatment on patients' wellbeing, or on their health state).



GENERAL DISCUSSION AND FURTHER DIRECTIONS FOR FUTURE RESEARCH

Although the summary above reads as if in the course of our project every step and every result was necessary in the sense that it could not have been otherwise, every study including the present one is of course contingent. For example, the study design was guided by policy and funding decisions and influenced by the background, expertise and interests of the researchers involved, and over the course of the project several unexpected situations necessitated a change of plans. Moreover, contingency awareness encourages us to view the results of scientific studies as “contingent certainties.” It refers to provisional truths, leaving open the possibility that they do not reflect reality, that other interpretations or demarcations may do more justice to reality, or even that our (social) world is not intelligible at all.

Apart from the contingent certainties that our study provides, many questions and other “uncertainties” remain. In each of the previous chapters, the specific limitations, implications for practice and directions for future research of that particular study were already discussed. Therefore, in this discussion, more general topics will be discussed regarding dealing with contingency, narrative identity, response shift, QoL, and possible directions for future research.

Contingency competence

Several characteristics of late modernity – especially in Western countries – that are mentioned in the introductory chapter, indicate that “dealing with contingency,” or “contingency competence” [1, 2], may be an important challenge for individuals nowadays. Processes of individualization and detraditionalization, including the decreasing role of religious traditions and “grand narratives,” have increased contingency awareness in both meanings of contingency as discussed in this dissertation: non-necessity and possibility. First, although scientific progress may provide explanations for phenomena that used to be more mysterious, our world has become highly complex. Many people cannot explain events that befall them, as they cannot refer to a higher power that gives them necessity. Individuals increasingly have to create their own frame of reference, and construct and revise their own interpretations, including meaning making of life events that befall them. Second, the processes of individualization and detraditionalization have led to endless possibilities for people to shape their lives, make their own choices, and strive for their own life goals. These possibilities not only imply freedom but also the *imperative* to choose.

Sociologists such as Beck [3] add to this the notion of the “risk society”. Naturally, human beings have always been susceptible to risks, usually external, such as natural disasters. Nowadays however, people are also subjected to risks created by modernity itself, through industrialization, globalization, information and communication technology, and other technical innovations such as in medicine. Although these risks are produced by people themselves, these are often too complex for individuals to oversee and consider or mitigate. Modernity thus creates new risks that are beyond the scope of its own influence, escaping its control [3]. These developments add uncertainty to the imperative to choose, as people are often unable to oversee the consequences of their choices. In the case of complex systems, the unintelligibility of our worlds and events is also increased. Thus, “contingency competence” is needed, both in the sense of meaning making and integrating life events and in the sense of bearing uncertainty and unintelligibility.

While dealing with contingency is thus part of the daily lives of people nowadays, being confronted with severe illness may still be one of the extraordinary life events that most often leads to an experience of contingency, as it is a direct threat to their existence. As seen in Chapter 3, becoming diagnosed with stable coronary artery disease is not always experienced as such a threat: almost half of the respondents indicated not to have experienced contingency. With other diseases, such as cancer and progressive lethal diseases, it may be expected that a larger proportion will experience contingency. The existential questions that such an event may evoke could lead to distress in times in which people are often already overwhelmed by complex medical aspects and decisions regarding treatment, and the practical changes in their daily lives. Again, the “contingency competence” that is needed concerns making meaning of the life event of falling ill as well as bearing uncertainty. In many cases of severe illness, such as a cancer diagnosis, people have to make decisions regarding treatments, possibly informed by empirical evidence about their risks, but still with little certainty about what it might mean for *their* future.

Our finding that for cardiac patients the experience of contingency impacts QoL through the negative impact on life goals, the attribution of an existential meaning to the event, and acknowledging contingency (Chapter 4) indicates possibilities for interventions. People struggling with existential questions, uncertainties, and the impact of life events on their life goals may be helped to reflect on their experience of contingency and their situation of uncertainty, integrate these events in their life narrative, re-evaluate their life goals and explore potential new possibilities. Because we consider dealing with contingency a central challenge in late modern life and “contingency competence” [1] may be an ongoing learning process, narrative integration of disruptive life events may also help to deal with contingency in the future (see also the sub-section *The theoretical model,* page 215).

While discussing such experiences may be seen as the exclusive task of spiritual / humanist counselors, psychologists and psychotherapists, patients may also benefit if physicians, nurses and other (health) care professionals place more attention on experiences of contingency. For patients there is no separation between the world of their diagnosis and treatment and the world of their experiences and their struggles to integrate their new situation into their daily lives. Talking about the randomness and impact of the event of falling ill and about the uncertainties regarding the treatment options may help people to better endure these experiences of contingency.

In addition to the meanings of narrative integration and bearing uncertainty, contingency competence is sometimes defined in a third way: as the ability to envision possibilities [2]. This requires realizing that someone's situation and the way he/she relates to it is only one of many possibilities that have yet to be discovered. Contingency competence in this sense is the ability to *think* these possibilities, although they may seem "unthinkable" in one's current situation. This competence seems important for anyone in difficult situations such as severe illness, but also for specific professions. For example, for therapists, spiritual counselors, social workers and consultants, helping their clients to see new possibilities may be seen as central in their work. As argued above, we may add healthcare providers to this list. In addition, researchers, other scientists and inventors need this competence to see the possibilities beyond the status quo and create new knowledge and ways of thinking and acting.

The merits and spectrum of narrative identity

In this study we combined contingency theory with Ricoeur's idea of narrative identity in our theoretical model. Below, Ricoeur's conceptualization will be placed in a broader perspective. Its merits for understanding and investigating the experiences and (changing) interpretations of people after disruptive life events will be evaluated, and criticism of narrative identity theories will be discussed.

Conceptualizations of narrative identity

The idea of narrative identity goes beyond identity as conceptualized in psychology in the sense of personal persistence over time, i.e. to consider (and be considered) oneself as oneself at different times in one's life ("numerical" identity). It implies that a person's self-understanding through time has a narrative structure [4]. That being said, several theories of narrative identity exist in psychology and philosophy, some of these also empirically supported by mainly psychological research. Particularly influential accounts of narrative identity include the theories of psychologist McAdams [5, 6] and philosophers Schechtman [7] and Ricoeur [8, 9], whose conceptualizations differ and emphasize different aspects of identity.

McAdams, known for his statement that “we are the stories we tell” [5], describes narrative identity as an inner story of the self, integrating the reconstructed past, perceived present, and anticipated future. This constructed story not only provides a person’s life with unity, coherence, purpose, and meaning, but also with an explanation of how one has become the person (s)he is becoming [10]. Schechtman goes a step further in considering the centrality of narrativity, for example by stating that our narrative self-conceptions implicitly shape the ways we interpret our experiences and perceive the world. In addition, she emphasizes the unifying nature of integrating actions, values, and experiences in one’s self-narrative, and poses that having a self-narrative is constitutive for being a person [4, 7].

Like McAdam’s theory, Schechtman’s account does not elucidate the role of disruptive life events and experiences of contingency in a person’s narrative identity. Ricoeur’s account of narrative identity seems to bring us further in this regard, helping us to understand how people make meaning over the course of time. Like Schechtman, he emphasizes that our self-understanding is selective and interpretative in the selection and connection of events, just like the stories we read. However, he goes further than Schechtman, by attributing mediating and unifying roles to emplotment, while at the same time leaving room for contingency. An example is the mediation between “sameness” and “selfhood”. While sameness (“idem”) refers to the “what” of a person, i.e. to stable characteristics and behavior over time, “selfhood” (“ipse”) refers to the “who,” the answer to which cannot be reduced to impersonal descriptions but has the form of a narrative of a reflexive agent, who may or may *not* act in concordance with one’s actions in the past [4, 9, 11]. This form of narrative mediation is related to a second form: between “concordance” and “discordance.” Although emplotment configures and unifies separate events into a whole in which events are understood in the light of the whole, this synthesis is still one of heterogeneity and may include discontinuities [11]. In terms of the research question of our study, narrativity thus mediates between our identities and the contingency and disruptive character of certain life events. Contingent life events are interpreted in the light of our whole life narrative, and configured into this life narrative, while maintaining the tension of their discordant relation to the storyline. In this process, the life narrative and thus one’s narrative identity, is changed.

Criticism of narrative identity theory

The common ground of these theories of narrative identity, i.e. the idea of our self-understanding having a narrative structure, has not been gone undisputed.[17] Some scholars mainly question if narratives are true to the incoherencies and contingencies of real life [12] or criticize the idea of "unification" in the sense that people's lives revolve around overarching practices or goals, or have explicit "ultimate life goals" as described in our theoretical model [12, 13]. Some point out the possible deceptiveness of life narratives because the (re)construction of life stories, being a largely unconscious process, involves fiction, confabulation, and revision. The philosopher Strawson, for example, emphasizes that our memory may edit, delete, and reorder, and that revisions of life stories may be motivated by moral emotions such as pride, regret, self-love, and guilt [13]. He quotes Sartre, who puts it poetically: "One must choose: live or tell stories." In his view, narrativity seems to lead to inauthenticity [13]. This quote brings to mind images of tourists, experiencing their holidays through the lens of their camera, anticipating the story they would like to tell when they return home. The question is whether this is indeed comparable: might the narrative pre-structuring of our experiences indeed hinder our experiences and self-understanding, or does it rather enable them? Should we compare the narrative pre-structuring to the camera and the anticipated photo presentation, or rather to our brain that makes sense of the images it receives from our eyes?

The philosopher Vice adds that narrativity, involving aesthetic criteria, leads to artificiality because one's life is led over-consciously [12]. Therefore, it is said that the search for narrative coherence may hinder more than enhance our self-understanding. However, according to Ricoeur, narrativity indeed does not exclude inauthenticity, and inauthentic self-representations can very well be part of narratives. I would add that this criticism seems to ignore the idea that no historical account, be it of a person's life or a country's past for example, can be "neutral." Moreover, every attempt to characterize a person, with or without considering his/her past and future plans, involves selection, deletion, emphasis and structuring, which is what Ricoeur means by "fiction."

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[17] The accounts of Schechtman and in particular Ricoeur also include explicit and strong normative ideals, of credible life stories and constant self-examination (Cf. Socrates' statement that "the unexamined life is not a full human life"), which allow persons to take responsibility and be able to live with others. This normative aspect will not be further discussed here because it does not play a role in our theoretical model, although it has been criticized even more than the descriptive idea of narrative identity, by Strawson and many others.

Strawson takes a step further with his claim that the whole idea of people understanding themselves in terms of a story is false [13-15]. He argues that the psychological and self-constitution narrativity theses may be true for some people, but do not reflect a universal human condition. His main argument is that some persons, like himself, do not strongly identify with their past and future selves. He calls this form of self-understanding "episodic," in contrast to *diachronic* self-experience: figuring oneself, considered as a self, as something that was there in the (further) past and will be there in the (further) future. The episodic type of self-experience can still entail a sense of temporality and even continuity of oneself as a human being taken as a whole, as one *knows* that the person in the past is the same human being as one is now. However, according to Strawson, this is not the same as continuity of one's self-experience: the experience of the self as an inner mental entity. Although he does not equate episodic self-experience with non-narrativity, he does say that people with episodic self-experience ("episodics") are likely to have no particular tendency to see their life in narrative terms." As anecdotal proof, he refers to statements from novelists and poets, and to the fact that he considers himself an "episodic" and a non-narrative person [14].

Reconciling conflicting views on narrative identity

Although some aspects of Ricoeur's ideas may not concur with episodic self-conception, such as the concept of "life plans," the basic idea of the narrative structure of our identity does not seem to conflict with episodic forms of self-understanding. Ricoeur's idea of narrative identity explicitly incorporates the possibility of discordance and change, although always *as part of* a unity. It may even be argued that the experience of not being the same person as one used to be, is usually part of a person's life narrative. While Strawson views discordance and change as reasons to discard the idea of unity, one may question if his "former selves" are indeed in no way part of his self-understanding. If he looked at a picture of himself as a child, commenting that he does not identify with it although he acknowledges that it is him, wouldn't that still be part of his narrative? And how would he answer the "who"-question, if not with a story? Unfortunately, apart from the statement that it is not narrative, Strawson does not provide a clear conceptualization of identity.

In conclusion, Strawson's non-narrativity account does not seem to offer a perspective that may help us understand the way people experience disruptive life events such as falling seriously ill and how these experiences may change them. Agreeing with the philosopher Aboulafia [16], we propose that if Strawson's accounts gives cause to any conclusions, it is that people's identities may vary in terms of diachronic/episodic and narrative self-understanding. Rather than debating whether narrative or non-narrative people exist, we may think of narrative identity as universal not in the sense of applying to every human, everywhere and always, in the same way, but as universal in the sense of typical for human beings. Narrativity may be seen as a continuum or spectrum: some are at one end of the spectrum, with a highly narrative self-understanding, while others employ very “thin” narration. In the same way, one’s life narrative including life goals and plans may be very conscious and explicit, while for others these processes are mainly unconscious and implicit. In addition, people may also differ in terms of reflexivity, memory, and verbal inclination, influencing the stories they tell about themselves.

Implications for our theoretical model and possible narrative interventions

These ideas raise interesting questions about our theoretical model, such as if people who are less narrative will still experience contingency after adverse life events. After all, we have characterized an experience of contingency as a “crisis of meaning” that necessitates reinterpretation of a life event in the context of one’s life narrative. However, from Wuchterl’s religious-philosophical definition of contingency, it does not follow that non- or less narrative persons would not experience or acknowledge contingency. In our model, experiences of contingency may result from a conflict between a life event and one’s ultimate life goals or worldview, which is probably not confined to highly or explicitly narrative persons. Ultimate life goals refer to what a person deems valuable for his/her life, which may often be implicit rather than an explicit and overarching life plan. In addition, disruptive life events may be unintelligible and thus raise existential questions for non- or less narrative persons as well. However, it may still be the case that non- or less narrative persons experience less contingency, or experience contingency in a different way – for example by asking existential questions that do not pertain to the cause of the event or the implications for their future. It may also be that people with an explicit and (self-)examined life story and explicit ultimate life goals would integrate experiences of contingency into their life narratives more easily.

In research into experiences of contingency, we should thus consider that people may not only differ in narrativity, but also in how reflective and verbally inclined they are, how explicit their interpretations and life goals, and the resources they use for their (re)interpretations. During the pilot testing of the RE-LIFE questionnaire, none of the participants were reluctant or hesitant to draw their life line, or unable to answer the RE-LIFE questions. However, some of the current wordings of the RE-LIFE items may not resonate with every respondent. Currently, a research project is being carried out building on the theoretical model of narrative meaning making as described in this dissertation, aiming to offer patients with advanced cancer resources from literature and art to enrich their reinterpretation of the event of getting cancer [17]. In this study, patients are not (only) asked to complete the RE-LIFE and talk about the meaning of having cancer and treatments, but also to draw a “rich picture” of their experiences and work together with artists to reinterpret their experiences in a process of cocreation. It may be interesting to explore for which respondents the RE-LIFE items align with their own interpretations and language, and which respondents prefer other forms of reflecting on their experiences.

Response shifts as "shifts of meaning"

Although response shift is not the central topic of this dissertation and was not assessed empirically, it was thought that developing a theory on the way people make meaning of disruptive life events and how this process influences their QoL could also improve our understanding of response shift. At the same time, the concept of response shift could complement our knowledge about making meaning of disruptive life events.

One of the hypotheses in this dissertation was that an experience of contingency is the result of the conflict between a life event and ultimate life goals, negatively impacting one's evaluation of QoL. This was confirmed in the empirical study presented in Chapter 4. It may be hypothesized that the self-transformation implied by narrative integration would lead to response shifts in QoL assessments. Finding and embracing new possibilities may result in more positive evaluations of overall QoL and possibly also health-related QoL, because the meaning of QoL may shift ("reconceptualization" response shift). In addition, new insights, for example about what one really values in life, may lead to "reprioritization" response shift. Some life goals may become more important while others become less significant. In addition, finding new possibilities may result in new instrumental life goals replacing instrumental life goals that were hindered by the event. As a result, the conflict between the underlying ultimate life goal and the life event may be diminished or even removed. In QoL data, these changes may also result in "reprioritization" response shift, e.g., when impaired physical functioning may become less important for one's overall QoL, and one's relationships with loved ones may take on a more prominent role.

More interdisciplinary research into this existential dimension of response shift is needed to improve our understanding of response shifts, the circumstances in which they may occur, their meaning for patients, and the implications for our interpretations of QoL data. A first step is currently being taken in a PhD study by Tom Oreel, which is also being conducted in the context of the Impact study. In his study, response shift was detected using statistical methods, and related to the same RE-LIFE data that were used in this dissertation. Structural Equation Modelling (SEM) has shown that higher scores on the "receiving" scale (see Chapter 3) were associated with more "reprioritization response shift" (see Chapter 1, page 42) in the "role physical" subscale of the generic health-related quality of life questionnaire SF-36. This indicates that for patients who have integrated the life event of developing their heart condition, their ability to fulfill their usual roles had become more important for their (evaluation of) their physical health [18].

In addition, it would be of interest to assess response shift and narrative integration among patient groups in which response shift and narrative integration are most expected. Patients recently diagnosed with a progressive, lethal disease could be considered. Such diseases have a high probability of drastically changing one's life and ideas about the future. In terms of our theoretical model, they conflict with one's life goals and threaten one's narrative identity, thus necessitating reinterpretation. Lastly, it would be worthwhile to assess whether interventions aiming to facilitate narrative integration after experiences of contingency would also induce shifts of meaning that could be detected as response shifts in QoL research.

Towards a narrative conceptualization of quality of life?

This study was performed within the context of the interdisciplinary Impact study, of which one important aim was to improve the conceptualization of QoL. Hence, the question arises of what the implications of the findings in this study are for the conceptualization of QoL. Do they provide a reason to propose a narrative conceptualization of QoL?

Current definitions of QoL

In the introduction chapter, we defined QoL, based on the WHO definition, as "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" (see Chapter 1, pages 21 and 55). This conceptualization also encompasses health-related QoL and can be operationalized, measured, and influenced by traits and shifts of meaning. Although considerably broader than the more functional and symptom-oriented definition of health-related QoL, this definition still places the concept of QoL outside the theoretical model of narrative meaning making of contingent life events. One's life narrative and meaning making may *influence* QoL, but does not equal QoL. Below, two alternative conceptualizations will be discussed in which narrativity is central enough to speak of *narrative conceptualizations* of QoL: QoL defined as narrative integration, and QoL as one's life narrative. Which of these three conceptualizations is the most helpful to understand and investigate people's QoL, may depend on the context and goals of research, as has previously also been argued for different concepts of health [19].

QoL as one's life narrative

An alternative way of conceptualizing QoL could follow from the narrative approach we have proposed: the quality of one's life *is* the life narrative one tells. This conceptualization departs from an entirely different understanding of "quality": not how "good or bad" something is, but what is "typical of one thing and makes it different from other things" [20]. In other words, "quality" may refer to the distinctive form, nature or attributes of something (in Dutch: "aard" or "hoedanigheid") [21]. One could say that in this conceptualization, QoL is not an outcome of our theoretical model or a convergent measure for narrative integration assessed with the RE-LIFE questionnaire, as it was used in this study. It rather encompasses the whole model, as it refers to someone's entire life story including worldview, life goals, life events, experiences of contingency, and (re)interpretations of life events.

Following the conceptualization of QoL as one's life narrative, a person's QoL cannot be measured, as there is no better and worse, and no improvement or deterioration. The QoL in this sense refers to the content, structure, and "coloring" of one's life story. For example, one's QoL can be more or less congruent and harmonious, shared with others, and encompass more implicit or explicit life goals, worldview, interpretations, and disruptive life events. The content and structure are different for every life story and may change not only because of life events but also through reinterpretation. Although unmeasurable, one's QoL may be investigated, described, and visualized in various ways, as the respondents of the RE-LIFE were asked to do by drawing their life line and answering the questions of the RE-LIFE, and as was done in the interview study. Further research may be conducted, for example, into the "properties" of one's life narrative, as Praas distinguished in his study into the narrative identity of organizations: "aimed at a fulfilled life," "rich," "shared," and "adequate" in the sense of congruent with one's actions. [22]

Departing from this alternative conceptualization, our study sheds new light on the diversity of people's QoL. The concepts of worldview, life goals, experience of contingency, and narrative meaning and integration improve our understanding of people's QoL and offer directions for further research. However, in my opinion, using the term "quality of life" for the "nature" and coloration of one's life story would not be of additional value and only lead to conceptual confusion.

Quality of life as narrative integration

Another conceptualization of QoL in which narrative identity is more central than in the WHO definition is the idea that narrative integration does not merely *influence* but *equal* one's quality of life. This perspective ties in with recent developments in the conceptualization of health, which lately has been defined broadly, encompassing life domains usually associated with overall wellbeing and QoL. Huber, for example, advocates the “positive” and dynamic conceptualization of health as “the ability to adapt and self-manage” [23], as discussed in Chapter 6. In this conceptualization, adaptation and self-management are not viewed as possible influences on health but as *constituting* health. Similarly, QoL as narrative integration implies that it is not life’s adversities such as illness, but the way people *relate* to them that constitutes one’s evaluation of their QoL. In this view, QoL equals the narrative integration of disruptive life events in one’s life story, i.e. whether they have been given a meaningful place in one’s life story, in congruence with one’s ultimate life goals that (still) can be pursued. “Contingency competence” would then be vital for a good QoL.

This perspective resonates with Cassell’s theory of suffering, influential in the practice of euthanasia and assisted suicide (EAS) in the Netherlands. According to Cassell, suffering is the experience of distress that is threatening to a person’s intactness [24, 25]. With “intactness” he refers to being able to be the person one wants to be [24]. In the vocabulary of our theoretical model, people suffer when they cannot pursue their ultimate life goals, which are vital to their identity. QoL as narrative integration may be seen as the opposite: a good QoL means that a person has integrated life events that caused an experience of contingency, and that one’s (perhaps recently changed and newly accepted) ultimate life goals can (still) be pursued, to be who one wants to be, i.e. to maintain one’s identity.

The conceptualization of QoL as narrative integration may be a fruitful perspective to integrate into health research and medical practice, which is enabled by the development of the RE-LIFE, making narrative integration measurable. Equaling narrative identity to QoL may be a valuable perspective in medical decision-making, because it revolves around the possibilities to be who one wants to be and to strive for one’s life goals. This perspective stresses the need for physicians to try to get to know their patients in order to find out what is important for them and which treatment may contribute to that, especially in cases of chronic illness or palliative care. In addition, it calls for attention to patients’ experiences of contingency, existential questions and uncertainty. However, in striving for “good care,” the WHO definition including health-related quality of life will always remain important to evaluating treatments and other interventions. It also enables us to investigate the influence of experiences of contingency and narrative integration on overall- and health-related QoL. It thus enables us to bring the humanities perspective including the perspectives of contingency and narrative integration into the medical world, which usually focuses on measurements rather than developing and understanding concepts and phenomena in their entirety and complexity. The conceptualization of QoL as narrative integration *adds* that “good care” should always take into account people’s (narrative) identities, as what is perceived as “good” depends on what a person finds important in one’s life.

Directions for future research

In addition to the questions and suggestions for future research described in Chapters 2 to 6 (see also Table 1), the following questions and hypotheses may direct future research.

The RE-LIFE Questionnaire

In the further refinement and validation of the RE-LIFE that was recommended, the operationalization of the worldview types and the modes of narrative integration especially require attention. Operationalizing these religious-philosophical concepts for quantitative assessment was challenging. Some of the concepts were already difficult to distinguish in interview transcripts, for example the modes of narrative integration, which are held to be dynamic and fluid. In Chapter 1 (page 55), statements possibly pointing to the concept of “denying” were discussed that illustrate this difficulty. However, in the qualitative study, the entire interview with the respondents provided the context for the researchers to enable the interpretion of the statements regarding narrative integration. Operationalizing narrative integration into a quantitative assessment was even more challenging. The different modes needed to be operationalized in a mutually exclusive way. This means that the statements corresponding to one mode, for example “accepting,” needed to be formulated in such a way that they would not be endorsed by people who were in a different mode of narrative integration, for example “receiving.” This was complicated because “receiving” also implied acceptance, and because the difference between them was quite subtle. These subtleties may have been the cause of not finding all the hypothesized scales in the factor analyses, as described in Chapter 3.

The operationalization of the mode “denying” appeared to be particularly challenging. This mode is characterized in negative terms, as *not* acknowledging the contingency of the event and *not* asking existential questions. To avoid double negatives when respondents do not endorse the statements in the questionnaire, most of these statements were positively phrased (and reversely scored). However, because of the relationship between the meanings of “acknowledging” and “denying” as “non-acknowledging,” the statements corresponding to both concepts clustered in the factor analysis. As a result, “denying” could not be assessed as a separate component. It could only be derived from low scores on the “acknowledging” scale, which was not desirable because of their ambiguity; these low scores could also be due to the absence of an experience of contingency. These findings urge a search in the future for statements that are unambiguously interpretable as denying the contingency or the existential impact of the event, as well as positively phrased, expressing what *is* experienced and interpreted by the respondent instead of what is *not*.

The theoretical model

A few hypotheses considering our theoretical model were not empirically tested in this study, and may be addressed in future research. The first hypothesis is that an experience of contingency is more likely to occur or be more profound when a life event not only conflicts with people's ultimate life goals, but also directly with their worldview, challenging their beliefs and outlook on life. More research is needed to investigate what such a conflict would entail, which types of events may cause it, whether it indeed results in a more profound experience of contingency, and what the implications are for narrative integration and possibilities to facilitate this process.

The concept of narrative integration also holds questions. For example, we do not know whether the four modes of increasing narrative integration are phases that people go through – each mode presupposing the former mode – or whether modes can be "skipped." Whereas we expect linear processes to be rare, we do not know under what conditions people may jump back and forth to achieve narrative integration. Further research is needed to investigate these processes.

It is likely that many other relationships between the concepts of our theoretical model exist than the ones depicted and discussed in this dissertation. For example, it might be interesting to investigate the direct influence of worldview on narrative meaning making, and the influence of worldview and ultimate life goals on QoL. In addition, the process of narrative meaning making and narrative integration could change a person's worldview and (the importance of) ultimate life goals [26]. These changes, in turn, may reduce or remove the conflict between the life event and the person's worldview and/or ultimate life goals, but may also lead to altered ideas about what QoL is.

Narrative integration could also influence the way a person makes meaning of life events in the future, because the ability to integrate life events in one's life story could be a learning process. Some people who have experienced negative life events that confronted them with the contingency of life may have successfully integrated these events into their life story and realize and accept that contingency is a part of life. With new life events emerging, the experience of contingency may be less severe and a meaningful interpretation of the event may be found more easily.

Hypotheses can also be derived with respect to the different aspects of meaning making and integration. For example, a more tentative hypothesis refers to the relationship between *scope* and *receiving*. When the scope of the meaning attributed to an event is spiritual, the person refers to a transcendent dimension. This indicates an openness to relate to that which transcends our perceivable, intelligible world. As such, individuals attributing a spiritual meaning to a life event may arrive at the “receiving” mode of narrative integration more often than people attributing a situational or existential meaning to the event [27, 28].

End-of-life care and research

The subject of narrative integration of experiences of contingency may also be an interesting angle for research in the adjacent field of end-of-life care and research. Whereas the life event of developing a heart condition did not lead to an experience of contingency for all patients in our study, it may be expected that this would be the case for many people diagnosed with a terminal disease. The relationship between narrative integration and QoL also raises interesting questions regarding a self-chosen death in situations of terminal illness. If narrative integration plays a positive role in people’s evaluations of their QoL, it may make suffering bearable and in part explain why some people with a severe disease request euthanasia or assisted suicide (EAS), while others in comparable situations do not.

It seems obvious that this diversity has something to do with one’s worldview and attitude towards death and dying [29, 30], values, need of control, attitude towards dependency, decline and uncertainty, and previous experiences with the dying of others close to them [31-34]. “Contingency competence” may have a direct or mediating influence as well, in all three senses discussed above: narrative integration of disruptive life events, bearing uncertainty, and envisioning possibilities. Thus, narrative integration of the life event of becoming terminally ill could help people re-evaluate their life goals and bear their situation, including dependency and suffering. On the other hand, one may hypothesize that narrative integration of the life event of becoming terminally ill could also *result* in a euthanasia request. Narrative integration could lead to an evaluation of one’s life as a whole, accepting one’s impeding death and feeling ready to say farewell to one’s loved ones and life.

Contingency competence may also play a role in the situations and interpretations of older people without severe illness who consider their lives “completed” and develop a wish to die. The dominant image of “completed life” in the Dutch political and societal debate is that of people who are not suffering but nevertheless decide that they want to end their lives. This image ties in with the concept of “narrative foreclosure,” defined by Bohlmeijer et al. as “the conviction that no new interpretations of one’s past nor new commitments and experiences in one’s future are possible that can substantially change one’s life-story” [35]. Although “completed life” sounds rather positive and peaceful, recent large-scale empirical research among people with a death wish without severe illness suggests the opposite. Their stories are of physical decline, loneliness, the loss of significant others, the loss of an active (working) life, and other disruptive life events [36, 37]. For this group of people, narrative foreclosure resulting in a death wish does not seem to reflect a well-rounded story in which disruptive life events and other adversities are narratively integrated. According to Fortuin, crises of meaning resulting from disruptive life events may indeed lead to narrative foreclosure. In these cases, people do not see possibilities to repair what has gone wrong in the past, and the present life story does not seem to allow actions that may change the story for the better in the future [38]. This may be inability, but also more active forms such as reluctance and resistance. For some people, the loss of abilities, of significant others, or of an active (working) life means a threat of losing their identity, which can only be avoided by choosing death.

Interestingly, a recent longitudinal study showed that even people who firmly rejected the possibility of new turns and perceptions in life experienced remarkable changes in their lives and shifts of meaning that regenerated their will to live [37, 39]. It may therefore be interesting to conduct research into experiences of contingency, narrative foreclosure, and (unsuccessful) narrative integration among people with a death wish without severe illness.

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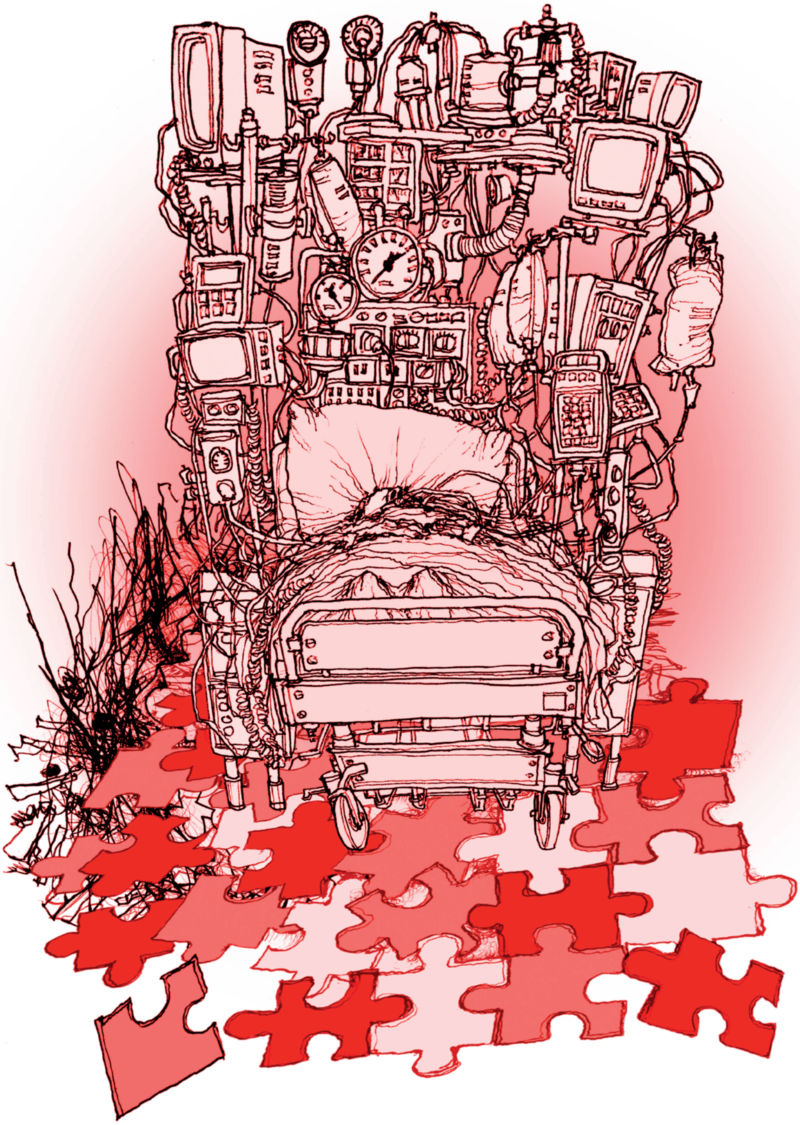
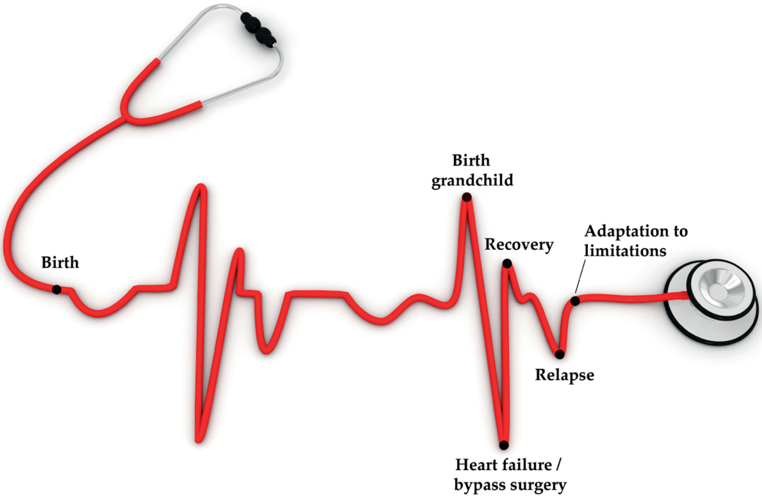


APPENDIX 1

RE-LIFE QUESTIONNAIRE

(RECONSTRUCTION OF LIFE-EVENTS)



INTRODUCTION

This questionnaire is about ***important events in your life***, which include getting your ***heart condition***. With this questionnaire we want to gain insight into the way people deal with unexpected life events. Your answers will help us to understand how these kinds of events can influence people's quality of life.

The questions are about your own life history and are therefore personal. You may need some time to think about the questions. For this reason, it is best to complete the questionnaire when you have a quiet moment to yourself.

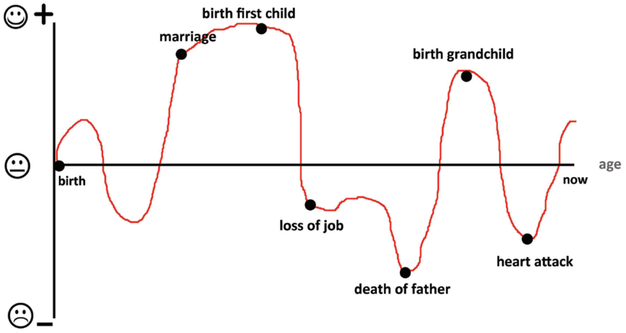
We are interested in *your* experiences and thoughts. There are ***no wrong answers***.
The questionnaire consists of five parts (1 to 5). In the interests of this study, we ask you to complete the parts ***in the given order*** and to ***not skip any single part***. It is important that you always circle only ***one number for each question***.

If you wish to ***change an answer***, you can do this by ***crossing out*** the answer (the circled number) and circling the right number.

Your answers will be dealt with in strict ***confidentiality*** and processed anonymously.

PART 1 – LIFE EVENTS

Below you see an ***example*** of a 'lifeline' connecting dots that represent several 'life events'.



The ***high points*** are events that had a ***positive*** meaning ***at the time***.

The ***low points*** are events that had a ***negative*** meaning ***at the time***.

1.1 LIFELINE

Without thinking about it too long, please ***draw your own lifeline on the separate sheet*** (the appendix). Please include ***a minimum of 4 and a maximum of 8*** life events that have been important in your life.

Please draw ***at least one negative event*** in the lifeline (possibly in addition to the heart condition). This is necessary to be able to answer the follow-up questions.

You can construct the lifeline by first thinking about which ***life events*** you will put on the line.

You can draw these as ***dots*** between ‘birth’ and ‘now’. You can place the dot up high if it was a high point and down low if it was a low point. Please ***name each event*** by writing one or more key words next to the dot. Finally, you can draw a line that connects all the dots, as in the example above.

The lifeline does not have to be completely accurate. Its main purpose is to help you answer the following questions.

PART 2 – UNEXPECTED NEGATIVE LIFE EVENTS

2.1 MOST UNEXPECTED NEGATIVE LIFE EVENT

Most unexpected life event (‘low point’)	Keyword: ....

Now, we would like to learn more about ***the most unexpected negative life event*** you have drawn in your lifeline.

The heart condition will be dealt with in part 3. Was getting the heart condition, or its medical treatment, the most unexpected negative event for you? Then you should ***now*** choose the second most unexpected negative event.

Please, note down below ***the 'low point' from your lifeline*** that was the ***most unexpected*** for you.

First, we would like to ask you to ***think back to this event***. You can think about things such as:
- The moment the event happened;
- What made the event unexpected for you;
- What you think caused the event (e.g. chance, caused by yourself, no cause, an unknown cause, fate/predestination);
- How the event has influenced your life since;
- The extent to which you have learned to deal with the consequences of the event.

Now we will ask a few ***questions about the unexpected event*** you just chose.

Was this event not a specific moment but **a period**? Then please consider this period as an event when answering the questions. You can also consider an important event from this period.

2.2 EXPERIENCE OF THE NEGATIVE EVENT

People can experience unexpected events in different ways. Below are some statements about such experiences.

How did you experience ***the unexpected negative event*** at the time?

For each question, please circle only one number that corresponds to your chosen answer.

	Did not experience	**Experienced somewhat**	**Experienced strongly**	**Experienced very strongly**
a. ***At the time**,* the event came as a ***blow or shock*** to me.	1	2	3	4
b. ***At the time**,* the event threw me ***off balance***.	1	2	3	4
c. ***At the time***, the event turned my ***world upside down***.	1	2	3	4
d. ***At the time***, the event made my ***world come crashing down***.	1	2	3	4
e. ***At the time***, the event made my ***world come to a standstill***.	1	2	3	4

2.3 LOOKING BACK ON THE NEGATIVE EVENT

People ***look back*** on events that have taken place in their lives in different ways.

To what extent do the descriptions below correspond with ***how you NOW look back*** on the unexpected negative event?

Below you will come across the phrase '***something higher***'. When answering these questions, you can interpret 'something higher' in your own way. It can be ***anything that transcends us as human beings***; anything greater, higher or deeper than ourselves.

	Looking back...	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
a.	.... I see the event as ***negative***.	1	2	3	4	5
b	.... I see the event as ***positive***.	1	2	3	4	5
c.	.... I see the event as something that ***happened*** to me.	1	2	3	4	5
d.	.... I see the event as something I ***caused myself***.	1	2	3	4	5
e.	.... I see the event as something caused by ***something or someone else***.	1	2	3	4	5
f.	.... I see that the event has had ***negative*** consequences for ***my life as a whole***.	1	2	3	4	5
g.	.... I see that the event has had ***positive*** consequences for ***my life as a whole***.	1	2	3	4	5
h.	.... I see the event, or ***dealing with*** the event, as ***something I was meant to do in my life:*** a ***task or assignment***.	1	2	3	4	5
i.	.... I see that the event made me ***feel abandoned***: I missed the presence or support of ***something higher***.	1	2	3	4	5
j.	.... I see the event, or dealing with the event, as something ***expected of me by something higher:*** a ***calling***.	1	2	3	4	5

2.4 CURRENT MEANING OF THE NEGATIVE EVENT

People ultimately interpret the meaning of an unexpected negative event in different ways. The following statements are about ***the meaning your chosen event has in your life NOW***.

To what extent do you agree with the following statements about the event?

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a.	At the moment, the event makes me ***question*** things about ***my life***.	1	2	3	4	5
b.	At the moment, I ***think a lot about*** what the event means for my life.	1	2	3	4	5
c.	I find it ***difficult*** to ***come to terms with*** this event***.***	1	2	3	4	5
d.	Meanwhile, I see ***new possibilities*** that have emerged from the event.	1	2	3	4	5
e.	At the moment, I think a lot about the ***cause*** of the event or ***why*** it happened to me.	1	2	3	4	5
f.	I can now ***deal well*** with the event and its consequences.	1	2	3	4	5
g.	At the moment, the event has a ***great impact*** on my life as a whole.	1	2	3	4	5
h.	***In the end, I am happy*** that this event happened to me.	1	2	3	4	5
i.	My life has not been ***influenced*** by this event ***at any time***.	1	2	3	4	5
j.	The event has shown me what I ***find important*** in life.	1	2	3	4	5
k.	This event or earlier events, made me ***realize*** that unexpected negative events ***can always happen*** to us (it’s ***part of life***).	1	2	3	4	5
l.	At the moment, I am ***learning*** a lot from this event.	1	2	3	4	5

2.5 CURRENT INFLUENCE OF THE NEGATIVE EVENT ON YOUR GOALS IN LIFE

The following questions are about ***what you find important in your life***. We also call this '***goals in life***' or 'values': the things you pursue or find important and valuable in life, and which make life worthwhile.

The pursuit of important goals in life can be ***hindered by negative events*** or even be ***made impossible***. On the other hand, such events can also make the pursuit of these goals ***easier***.

A number of goals/values that many people find important in life are mentioned below.

To what extent does the ***unexpected negative event currently*** hinder or help your pursuit of the life goals mentioned below?

			greatly hinders		neither hinders nor helps			greatly helps
a.	Health	-3	-2	-1	0	1	2	3
b.	Being / becoming happy	-3	-2	-1	0	1	2	3
c.	Independence / autonomy	-3	-2	-1	0	1	2	3
d.	Enjoyment	-3	-2	-1	0	1	2	3
e.	Develop myself / grow	-3	-2	-1	0	1	2	3
f.	Being valued / recognition	-3	-2	-1	0	1	2	3
g.	Caring for others	-3	-2	-1	0	1	2	3
h.	Raising / caring for children	-3	-2	-1	0	1	2	3
i.	Connection with other people	-3	-2	-1	0	1	2	3
j.	Teaching others something / 'passing something on'	-3	-2	-1	0	1	2	3
k.	Doing good / being a good person	-3	-2	-1	0	1	2	3
l.	Love (partner, family, friends)	-3	-2	-1	0	1	2	3
m.	Doing what fits with who I am	-3	-2	-1	0	1	2	3
n.	Doing something for / meaning something to others (individuals, groups, society)	-3	-2	-1	0	1	2	3
o.	Freedom	-3	-2	-1	0	1	2	3

PART 3 – HEART CONDITION

We would now like to find out more about ***what your heart conditions means to you***. Even if you did not include the heart condition in your drawing of the lifeline, you can still answer these questions.

First, we would like to ask you to think back to ***the moment you were first confronted with your heart condition*** and then to how the condition has ***played a role in your life***. You can consider things such as:

- The moment you first started having complaints;
- The diagnosis;
- Whether getting the heart condition was expected or unexpected;
- What you see as the cause of your heart condition (e.g. chance, genetic predisposition, no cause at all, an unknown cause, fate/predestination, lifestyle);
- How the condition has influenced your life since;
- The extent to which you have learned to deal with the consequences of the heart condition;
- The medical treatment of your heart condition (including the bypass or angioplasty) and its consequences.

Now we will ask a few questions about what your heart condition means to you (or has meant to you).

3.1 EXPERIENCE OF GETTING THE HEART CONDITION

The way people experience getting a condition or illness can differ. Below are some statements about such experiences.

What did you ***experience when you were first confronted with your heart condition***?

For each question, please circle only one number that corresponds to your chosen answer.

		Did not experience	**Experienced somewhat**	**Experienced strongly**	**Experienced very strongly**
a.	At the time, getting my heart condition came as a ***blow or shock***.	1	2	3	4
b.	At the time, getting my heart condition threw me ***off balance***.	1	2	3	4
c.	At the time, getting my heart condition turned my ***world upside down***.	1	2	3	4
d	At the time, getting my heart condition made my ***world come crashing down***.	1	2	3	4
e.	At the time, getting my heart condition made my ***world come to a standstill***.	1	2	3	4

3.2 LOOKING BACK ON GETTING THE HEART CONDITION

The way people ***look back*** on their experience of getting a condition or illness can differ.

To what extent do the descriptions below correspond with ***how you NOW look back*** on getting your heart condition?

Below you will come across the phrase '***something higher***'. When answering these questions, you can interpret 'something higher' in your own way. It can be ***anything that transcends us as human beings***; anything greater, higher or deeper than ourselves.

Looking back...	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
a. .... I see getting my heart condition as something ***negative***.	1	2	3	4	5
b. .... I see getting my heart condition as something ***positive***.	1	2	3	4	5
c. .... I see getting my heart condition as something that ***happened*** to me.	1	2	3	4	5
d. .... I see getting my heart condition as something I ***caused myself***.	1	2	3	4	5
e. .... I see getting my heart condition as something caused by ***something or someone else***.	1	2	3	4	5
f. .... I see that getting my heart condition has had ***negative*** consequences for ***my life as a whole***.	1	2	3	4	5
g .... I see that getting my heart condition has had ***positive*** consequences for ***my life as a whole***.	1	2	3	4	5
h. .... I see ***dealing*** with my heart condition as ***something I was meant to do in my life***: a ***task or assignment***.	1	2	3	4	5
i .... I see that getting the heart condition made me ***feel abandoned***: I missed the presence or support of ***something higher***.	1	2	3	4	5
j .... I see ***dealing*** with my heart condition as something ***expected of me by something higher***: a ***calling***.	1	2	3	4	5

3.3 CURRENT MEANING OF THE HEART CONDITION

Having a (chronic) condition can ultimately mean different things to different people. The following statements are about ***the meaning your heart condition NOW has for you in your life***.

To what extent do the descriptions below correspond with ***how you NOW look back*** on getting your heart condition?

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a.	At the moment, my heart condition makes me ***question*** things about ***my life***.	1	2	3	4	5
b.	At the moment, ***I think a lot*** about what my heart condition means for my life.	1	2	3	4	5
c.	I find it ***difficult*** to ***come to terms with*** my heart condition.	1	2	3	4	5
d.	Meanwhile, I see ***new possibilities*** that have emerged from getting my heart condition.	1	2	3	4	5
e.	At the moment, I think a lot about the ***cause*** of my heart condition or ***why*** I got it.	1	2	3	4	5
f.	I can now ***deal well*** with my heart condition and its consequences.	1	2	3	4	5
g.	Getting my heart condition currently has a ***great impact*** on my life as a whole.	1	2	3	4	5
h.	***In the end***, I am ***happy*** that I got a heart condition.	1	2	3	4	5
i.	My life has ***in no way*** been ***influenced*** by getting my heart condition.	1	2	3	4	5
j	Getting my heart condition has made me realize what I ***find important*** in life.	1	2	3	4	5
k	Getting the heart condition, or earlier events, made me ***realize*** that unexpected negative events ***can always happen*** to us (it’s ***part of life***).	1	2	3	4	5
l.	At the moment, I am ***learning*** a lot from getting my heart condition.	1	2	3	4	5

3.4 CURRENT INFLUENCE OF THE HEART CONDITION ON YOUR GOALS IN LIFE

The pursuit of important goals in life can be ***hindered by illness*** or even be ***made impossible***. On the other hand, such events can also make the pursuit of these goals ***easier***.

A number of goals/values that many people find important in life are mentioned below.

To what extent does ***your heart condition currently*** hinder or help your pursuit of the life goals mentioned below?

			greatly hinders			**neither hinders nor helps**		**greatly helps**
a.	Health	-3	-2	-1	0	1	2	3
b.	Being / becoming happy	-3	-2	-1	0	1	2	3
c.	Independence / autonomy	-3	-2	-1	0	1	2	3
d.	Enjoyment	-3	-2	-1	0	1	2	3
e.	Develop myself / growth	-3	-2	-1	0	1	2	3
f.	Being valued / recognition	-3	-2	-1	0	1	2	3
g.	Caring for others	-3	-2	-1	0	1	2	3
h.	Raising / caring for children	-3	-2	-1	0	1	2	3
i.	Connection with other people	-3	-2	-1	0	1	2	3
j.	Teaching others something / ‘passing something on’	-3	-2	-1	0	1	2	3
k.	Doing good / being a good person	-3	-2	-1	0	1	2	3
l.	Love (partner, family, friends)	-3	-2	-1	0	1	2	3
m.	Doing what’s right for me / what fits with who I am	-3	-2	-1	0	1	2	3
n.	Doing something for / meaning something to others (individuals, groups, society)	-3	-2	-1	0	1	2	3
o.	Freedom	-3	-2	-1	0	1	2	3

PART 4 – GOALS IN LIFE

4.1 THE IMPORTANCE OF GOALS IN LIFE

The same goals/values that you answered questions about in parts 2 and 3 are mentioned below.

Here we would like to know ***how important*** each life goal is for you ***at the moment***. More specifically, to what extent does ***pursuing*** each of these life goals play ***a role*** in your ***daily life***?

How important is ***pursuing the following life goals*** in your daily life ***at the moment***?

Circle one number for each life goal.

		Not important	Somewhat important	Important	Very important
a.	Health	1	2	3	4
b.	Being / becoming happy	1	2	3	4
c.	Independence / autonomy	1	2	3	4
d.	Enjoyment	1	2	3	4
e.	Develop myself / growth	1	2	3	4
f.	Being valued / recognition	1	2	3	4
g.	Caring for others	1	2	3	4
h.	Raising / caring for children	1	2	3	4
i.	Connection with other people	1	2	3	4
j.	Teaching others something / ‘passing something on’	1	2	3	4
k.	Doing good / being a good person	1	2	3	4
l.	Love (partner, family, friends)	1	2	3	4
m	Doing what’s right for me / what fits with who I am	1	2	3	4
n	Doing something for / meaning something to others (individuals, groups, society)	1	2	3	4
o	Freedom	1	2	3	4

PART 5 – OUTLOOK ON LIFE AND QUALITY OF LIFE

A person’s outlook on life affects the way he or she experiences important life events. The following questions are about your outlook on life (i.e., the way you view people and the world).

5.1 OUTLOOK ON LIFE

To what extent do you agree with the following statements?

Below you will come across the phrases ‘***higher reality***’ and ‘***something that transcends our reality***’. When answering these questions, you can interpret ‘higher reality’ in your own way. It can be ***anything that transcends us as human beings***; anything greater, higher or deeper than ourselves.

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a.	As a free person, I experience my actions in life as part of something that transcends our reality.	1	2	3	4	5
b.	There is nothing beyond this world that influences what I do in life.	1	2	3	4	5
c.	What I do in life is determined by a higher reality.	1	2	3	4	5
d.	What I do in life is only determined by what exists in this world.	1	2	3	4	5
e.	What I do in life is part of a higher plan that I have no influence over.	1	2	3	4	5
f.	As a free person, I gain inspiration/strength for the things I do in my life from something that transcends our reality.	1	2	3	4	5

5.2 QUALITY OF LIFE

Finally, we would like to ask you about your ‘***quality of life***’.

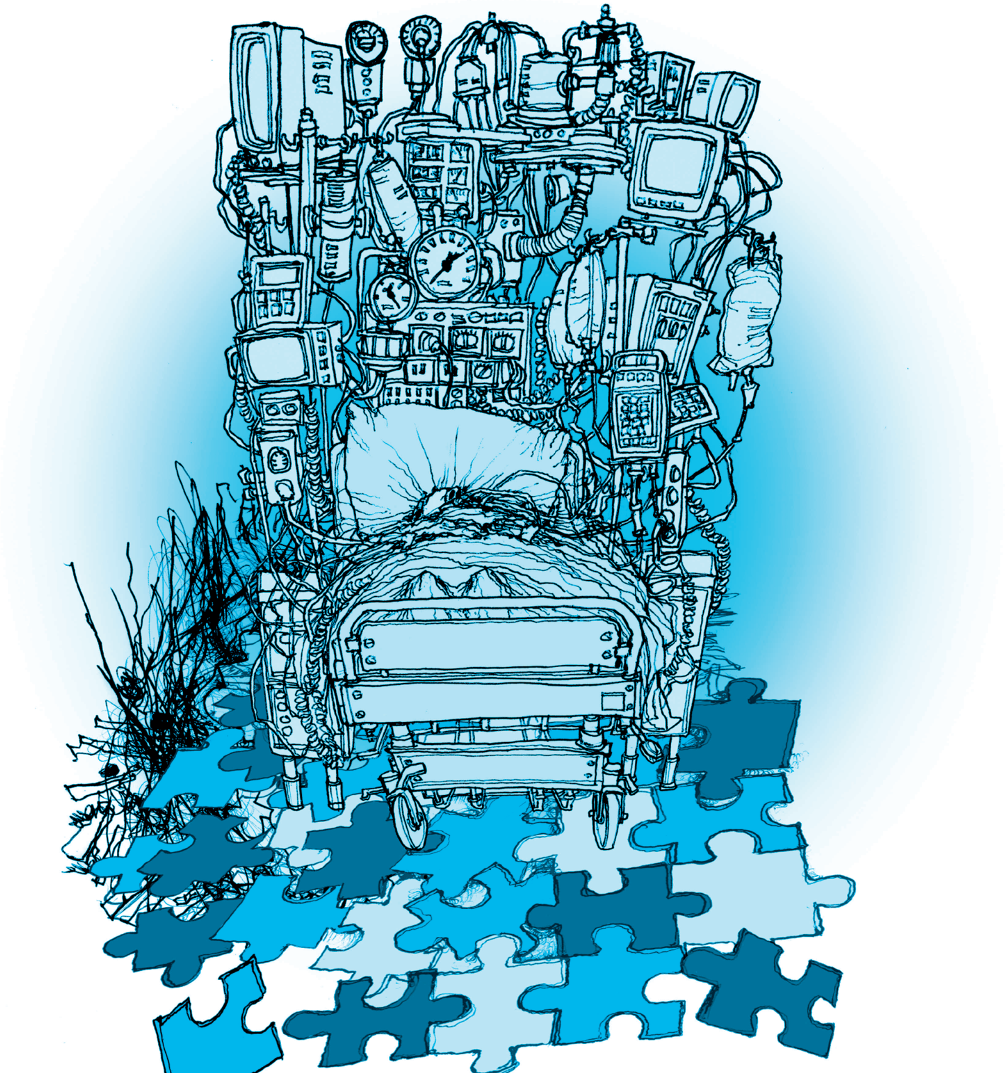
a. How would you rate your overall quality of life during the past week?

Very poor						Excellent
1	2	3	4	5	6	7

End of the questionnaire

You can keep the separate sheet with your lifeline.
We welcome any comments you may have. Please write these down in the space below.

Thank you very much for your cooperation.



APPENDIX 2

Dankwoord *(Acknowledgements)*

Over de auteur *(About the author)*

PhD portfolio

DANKWOORD *(ACKNOWLEDGEMENTS)*

Een promotie is te karakteriseren als een levensgebeurtenis waarvan de betekenis vooral wordt bepaald door de reis ernaartoe. Een flinke reis, deels van tevoren uitgestippeld, maar natuurlijk ook contingent, met zijwegen en onvermoede etappes. Een leerzame tocht, met de nodige hindernissen om te overwinnen. Dit promotietraject was ook een reis door verschillende werelden waarin verschillende talen worden gesproken: de medische wereld, meer specifiek de wondere wereld van het AMC, de medische psychologie, de religiewetenschap en de (medische) filosofie.

Bovenal is een reis als deze een gezamenlijke onderneming, want een proefschrift komt tot stand in samenwerking met vele anderen. Ik wil dan ook iedereen heel hartelijk bedanken die heeft bijgedragen aan de reis en de totstandkoming van dit proefschrift, waarvan een aantal met naam en toenaam.

Allereerst gaat mijn dank uit naar alle patiënten die hebben deelgenomen aan ons onderzoek, gedurende een toch al intensieve en spannende periode rondom een behandeling aan het hart. Zonder jullie deelname was ons onderzoek niet mogelijk geweest.

Natuurlijk ook mijn grote dank aan mijn zeer diverse “promotieteam”.

Hanneke: met beide voeten in de medische wereld en tevens geworteld in de religiewetenschap, wist je altijd beide werelden met elkaar te verbinden. Als ik het overzicht kwijt was, wist jij me altijd terug te leiden naar de hoofdzaken, en bliksemsnel knopen door te hakken. Dank daarvoor!

Mirjam: dank voor je begeleiding gedurende deze reis, je hulp bij mijn ‘inburgering’ in de Medische Psychologie, en je precieze en uitgebreide feedback op al mijn teksten, waar ik heel veel van heb geleerd.

Michael: dank voor jouw vertrouwen, de talloze leerzame gesprekken over betekenisgeving in de religiewetenschap en de relaties tussen de verschillende disciplines, en je geduldige uitleg over alle statistische analyses.

Pythia: dank voor je begeleiding bij dit project, waarvan de inhoud toch iets anders was dan gebruikelijk bij de medische psychologie. Dank voor je nuchtere blik en alles wat je me hebt geleerd met betrekking tot “kwaliteit van leven”, vragenlijsten en statistiek.

José, geen copromotor maar natuurlijk essentieel in ons IMPACT-team: dank dat je Justine en mij wegwijs maakte in de wereld van de interventiecardiologie en cardiochirurgie. Jouw gesprekken met patiënten, de dotterbehandelingen en de bypassoperatie hebben een blijvende indruk achtergelaten (en niet alleen doordat ik bijna van mijn stokje ging). En bovenal: dank voor je interesse in (en openheid voor) al die “ingewikkelde materie” uit de geesteswetenschappen.

Ook mijn promotiecommissie wil ik natuurlijk hartelijk bedanken. Paul, Irma, Yvonne, Ignaas, Els en Yvette: veel dank dat jullie bereid waren mijn proefschrift te lezen, beoordelen en/of een vraag voor te bereiden voor de verdediging.

Justine: met jou als mijn PhD-maatje heb ik een erg leuke tijd gehad bij de afdeling Medische Psychologie. Dank voor het samen optrekken, het sparren, de gezellige lunchwandelingen en etentjes. Heel leuk en passend dat je, ook al scheidden onze wegen, als paranimf toch nog deel uitmaakt van mijn promotie.

Tom: dank voor de fijne samenwerking sinds jij ons project in stapte. Ook voor de leuke methodologische én filosofische discussies en mijmeringen in Amsterdam. Ik hoop voor je dat jouw proefschrift spoedig ook voltooid zal zijn.

Hasi, Pomme, Julia en Mariska: dank dat jullie als assistenten ons onderzoek hielpen draaiende te houden, ook toen Justine ons project verliet. Zonder jullie inspanningen bij het werven van patiënten en verwerken van vragenlijsten was dat niet mogelijk geweest.

Alle (ook voormalige) collega’s van de Medische Psychologie: hartelijk dank voor jullie gezelligheid en samenwerking.

Mijn collega’s van de afdeling Empirische en praktische religiewetenschap aan de Radboud universiteit te Nijmegen: dank voor alle interessante uitwisselingen van gedachten, bijvoorbeeld tijdens de “research ateliers”.

Dick en Jeannette, dank dat ik mocht deelnemen aan de groep “Filosofie van de Zorg”, waarin ik me in meerdere opzichten erg thuis voelde. Dank aan alle deelnemers voor de interessante bijeenkomsten en gezelligheid. In het bijzonder veel dank aan mijn intervisiegroepje: Renske, Marianne en Annemarie. Ons bondgenootschap heb ik erg waardevol gevonden.

De coauteurs van de artikelen in dit proefschrift, nog niet hierboven genoemd: Hans, Wilbert, Alexander en Jorrit, veel dank voor jullie waardevolle bijdragen.

Iris Maher, dank voor het corrigeren van een aantal artikelen die zijn opgenomen in dit proefschrift. De samenwerking was altijd erg plezierig en ik heb veel van je correcties geleerd.

Paul, heel veel dank dat ik je prachtige tekeningen mocht gebruiken voor mijn proefschrift, dat daarmee de kroon is geworden op mijn “Steen”-verzameling.

Hoewel niet direct gerelateerd aan dit proefschrift, wil ik ook “De Onvoltooiden” bedanken. Els, Vera, Margot, Carlo, Ghislaine, Alfred en Cuno, bedankt voor het avontuur dat ons onderzoek naar “voltooid leven” in 2019 was, waar ik ontzettend veel van heb geleerd wat betreft onderzoek en samenwerking. En waarnaast ik verder kon werken aan mijn proefschrift.

Dank aan mijn collega’s van mijn huidige drie werkplekken: de Regionale Toetsingscommissie Euthanasie, de afdeling Medische Filosofie, Ethiek en Geschiedenis van het ErasmusMC en het Expertisecentrum Palliatieve Zorg van het LUMC. Dank voor het vertrouwen en de mogelijkheid om verder te gaan in onderzoek, onderwijs en toetsing op het gebied van ziekte, gezondheid, zingeving en ethiek.

Mijn vrienden, vriendinnen, ouders (en hun partners) en verdere familie: dank voor het verhogen van mijn “kwaliteit van leven” met alle borrels, films, etentjes, goede gesprekken, concerten en andere voorstellingen, kamermuziek-avondjes, (strand)wandelingen, spelletjesavonden, schaatsrondjes, vakanties en moestuin-uurtjes. Ook in de periode dat dit boekje me flink wat weekend-uren kostte. En excuses voor het feit dat het op feestjes tegenwoordig vaak over de dood gaat, na de vraag “..en wat doe jij, in het dagelijks leven?”

Thijs: jou wil ik natuurlijk specifiek noemen – dank voor onze schrijfdagen en -retraites, die het afronden van dit proefschrift niet alleen mogelijk, maar ook minder eenzaam hebben gemaakt. En natuurlijk dank voor je aanmoediging tijdens een van die retraites in oktober 2018 om op een vliegtuig naar Sardinië te stappen – obviously.

Mariken: dankjewel dat je al sinds het eerste jaar van onze studie met me optrekt in het leven. Fijn dat we delen in elkaars hoogte- en dieptepunten in het leven, en het ook met z’n vieren zo goed kunnen vinden. Dank dat je samen met Justine mijn paranimf wil zijn (zo ben je toch nog een soort “getuige”).

Sander: pas achteraf krijgt een relatief onbeduidende gebeurtenis als op een vliegtuig stappen de betekenis van een belangrijke levensgebeurtenis. Dank dat je het avontuur met mij aan gaat, ik kan en wil me nu al geen leven meer voorstellen zonder jou (en zonder Marre). Ik kijk uit naar ons nieuwe woon-avontuur, dat voor onze neuzen verrijst. En naar onze reis naar Madagaskar. Ik heb er alle vertrouwen in dat we elkaar zullen blijven boeien, en in zowel de hoogte- als dieptepunten onze levensverhalen met elkaar zullen blijven delen.

OVER DE AUTEUR *(ABOUT THE AUTHOR)*

Iris Hartog (Amsterdam, 1983) groeide op in Haarlem, waar zij aan de Vrije School haar VWO-diploma behaalde. Na een jaar gewerkt te hebben in de zorg, begon zij in 2003 aan de bachelorstudie Humanistiek aan de Universiteit voor Humanistiek te Utrecht. Gedurende haar studie volgde zij ook de opleiding tot “trainer morele oordeelsvorming” bij Governance & Integrity Nederland en Business Universiteit Nyenrode, en was zij binnen de Universiteit voor Humanistiek actief in de medezeggenschap en als onderwijsassistent, -coördinator en beleidsmedewerker. In 2012 voltooide zij de driejarige masteropleiding (*cum laude*) met een masterscriptie waarvoor zij de Rabobank NBN Scriptieprijs voor Bedrijfsethiek ontving.

Gedurende en na haar studie werkte Iris o.a. als trainer morele oordeelsvorming in publieke organisaties, als junior docent Zorgethiek aan de Universiteit voor Humanistiek en als freelance docent bio-ethiek bij de Universiteit van Amsterdam en Universiteit Leiden.

In 2014 zette zij definitief de stap naar de medische wereld, door te starten met haar promotieonderzoek bij de afdeling Medische psychologie van het Academisch Medisch Centrum te Amsterdam en de afdeling Praktische en Empirische Religiewetenschap van de Radboud Universiteit Nijmegen.

Gedurende haar promotietraject gaf Iris binnen de Geneeskunde-opleiding les in de medische ethiek en arts-patiëntcommunicatie. Ook begeleidde zij als mentor een groep eerstejaars studenten en gaf zij les in Academische Vaardigheden.

Na haar aanstelling als promovendus werkte zij gedurende 2019 aan het “voltooid leven-onderzoek” aan de Universiteit voor Humanistiek: een grootschalig onderzoek naar mensen met een doodswens zonder ernstige ziekte, in opdracht van het Ministerie van VWS. In dat jaar werd zij tevens benoemd als ethicus-lid (“deskundige op het gebied van ethische- en zingevingsvraagstukken”) bij de Regionale Toetsingscommissies Euthanasie (RTE).

Sinds januari 2020 is Iris ook werkzaam als docent Medische Ethiek bij de afdeling Medische Ethiek, Filosofie en Geschiedenis van het ErasmusMC te Rotterdam, waarnaast zij in oktober 2020 haar proefschrift voltooide. In november 2020 werd zij tevens aangesteld als postdoc onderzoeker “Palliatieve geneeskunde” bij het Expertisecentrum Palliatieve Zorg van het LUMC.

PHD PORTFOLIO

1. PhD Training

Course	Year(s)
The AMC World of Science, Graduate School for Medical Sciences, AMC, Amsterdam	2014
Qualitative Health Research, Graduate School for Medical Sciences, AMC, Amsterdam	2015
Qualitative Analysis with Atlas.ti, Graduate School for the Humanities, Radboud University Nijmegen	2015
Project Management, Graduate School for Medical Sciences, AMC, Amsterdam	2015
Designing a PhD Project, Graduate School for the Humanities, Radboud University Nijmegen	2015
The art of presenting science, Graduate School for the Humanities, Radboud University Nijmegen	2016
Justice & Priority setting in Health Care, Catholic University Leuven, Belgium	2016
Introduction day including Scientific Integrity course, Graduate School for the Humanities, Radboud University Nijmegen	2017
Statistics for PhD students using SPSS, Graduate School for the Humanities, Radboud University Nijmegen	2017
University Teaching Qualification (Basiskwalificatie Onderwijs, BKO) "Leergang Activerend Onderwijs", Center for Evidence-Based Education, AMC, Amsterdam	2018/19

2. Presentations

International conferences	Title	Year
"Religion and the Crisis of Meaning" Conference, Nederlands Genootschap voor Godsdienstwetenschap. Radboud University Nijmegen, The Netherlands.	The relationship between the interpretation of contingent life events and quality of life (*oral presentation*)	2015
European Conference on Religion, Spirituality and Health, Institute for Spirituality and Health. University of Gdánsk, Poland.	Towards a narrative understanding of quality of life: Making meaning of contingent life events (*oral presentation*)	2016
Annual Conference of the International Society for Quality of Life Research (ISOQoL). Kopenhagen, Denemarken.	Towards a narrative understanding of quality of life: Making meaning of contingent life Events (*poster presentation*)	2016
32nd European Conference on Philosophy of Medicine and Health care, European Society for Philosophy of Medicine and Health Care (ESPMH). Lisbon, Portugal.	Narrative meaning making and integration of falling ill: Reconstruction of Life Events (RE-LIFE) (*oral presentation*)	2018
Annual Conference: "Ethics in Action", European Association of Centres of Medical Ethics (EACME). Amsterdam, The Netherlands.	Patient-reported outcomes and medical decision making: ethical implications of response shifts and dispositions (*oral presentation*)	2018
Dutch research group meetings		**Year(s)**
NWO (Netherlands Organization for Scientific Research) "Quality of Life and Health" meetings, Amsterdam.	IMPACT: Improving the conceptualization and measurement of quality of life (*oral presentations*)	2015, 2016, 2017

"Research Ateliers" Empirical and practical Theology and Religious studies, Radboud University Nijmegen.	Improving the conceptualization and measurement of quality of life (*oral presentation*); RE-LIFE: The Reconstruction of Life Events Questionnaire (*oral presentation*); Towards a narrative understanding of quality of life: Making meaning of contingent life events (*oral presentation*)	2015, 2016, 2017
Research meetings Department of Medical Psychology, Academic Medical Center, Amsterdam.	Towards a better understanding of quality of life (*oral presentation*); The influence of narrative meaning making of contingent life events (*oral presentation*); Improving the conceptualization and measurement of quality of life (*oral presentation*)	2015, 2016, 2017
Research meetings Philosophy of Care group, Academic Medical Center, Amsterdam.	Towards a better understanding of quality of life (*oral presentation*)	2015
Research day "Over de Amstel, Departments of Medical Psychology, Academic Medical Center and VU Medical Center, Amsterdam.	The reconstruction of life events questionnaire (*oral presentation: "pitch"*)	2015
Kick-off meeting Mental Health research program, The Amsterdam Public Health Research Institute, Amsterdam.	Towards a narrative understanding of how falling ill influences quality of life: Narrative meaning making of contingent life events (*oral presentation*)	2016
Seminar "Empirical and practical Theology and Religious studies", Radboud University Nijmegen.	Towards a narrative understanding of quality of life: Making meaning of life events (*oral presentation*)	2018

3. Teaching

Practical classes Ethics (third-year medical students), AMC, Amsterdam.	2015-2017
Practical classes doctor-patient communication (first- and second-year medical students), AMC, Amsterdam.	2016-2018
Mentorship: practical classes on academic skills and individual meetings (twelve first-year medical students), AMC, Amsterdam.	2017-2018

4. Publications

In this thesis

Hartog, I.D.*, Oreel, T.H.*, Scherer-Rath M, Netjes, J.E., Vonk, A.B.A., Lemkes, J.S., Henriques, J.P.S., Sprangers, M.A.G., Van Laarhoven, H.W.M., and P.T. Nieuwkerk. **Experience of contingency and narrative integration after a cardiac intervention: psychometric properties of the Reconstruction of Life Events Questionnaire (RE-LIFE).** *Under review, 2021*. * = shared first authorship

Hartog, I.D., Scherer-Rath M., Oreel, T.H., Netjes, J.E., Henriques, J.P.S., Lemkes, J.S., Vonk, A.B.A., Sprangers, M.A.G., Nieuwkerk, P.T., and H.W.M. van Laarhoven. **Reconstructing disruptive life events using the RE-LIFE Questionnaire: Further validation of the "Narrative meaning making of life events" model using multiple mediation analysis.** *Journal of Empirical Theology*, 2019, *32*(2), 251-280. doi: 10.1163/15709256-12341394

Hartog, I.D., Willems, D.L., Van den Hout, W.B., Scherer-Rath, M., Oreel, T.H., Henriques, J.P.S., Nieuwkerk, P.T., Van Laarhoven, H.W.M., and M.A.G. Sprangers. **Influence of response shift and disposition on patient-reported outcomes may lead to suboptimal medical decisions: a medical ethics perspective.** BMC Medical Ethics, 2019, *20*(1), 61. doi: 10.1186/s12910-019-0397-3

Hartog, I.D., Scherer-Rath, M., Kruizinga, R., Netjes, J., Henriques, J.P.S., Nieuwkerk, P.T., Sprangers, M.A.G., and H.W.M. van Laarhoven. **Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life.** Journal of health psychology, 2020, 25(6): 738-754. First Published September 26, 2017. doi: 10.1177/1359105317731823

Kruizinga, R.*, **Hartog, I. D.*,** Scherer-Rath, M., Schilderman, J.B.A.M., and H.W.M. van Laarhoven. **Modes of relating to contingency: an exploration of experiences in advanced cancer patients.** *Palliative & Supportive Care,* 2016, 15(4): 444–453. doi: 10.1017/S1478951516000018 * = shared first authorship

Kruizinga, R., **Hartog, I.D.**, Jacobs, M., Daams, J.G., Scherer-Rath, M., Schilderman, J.B.A.M., Sprangers, M.A.G., and H.W.M. van Laarhoven. **The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis**. *Psycho-Oncology*, 2015, *25*(3), 253-265. doi: 10.1002/pon.3910

Other international peer-reviewed publications

Van Wijngaarden, E., Merzel, M., Van den Berg, V., **Hartog, I.**, and C. Leget. **Understanding multifaceted trajectories of wishes to die among older people: a longitudinal phenomenological study.** *Under review, 2021*

Oreel, T.H., Nieuwkerk, P.T., **Hartog, I.D.**, Netjes, J.E., Vonk, A.B.A., Lemkes, J.S., Van Laarhoven, H.W.M., Scherer-Rath, M., Henriques, J.P.S., Oort, F.J., Sprangers, M.A.G., and M.G.E. Verdam. **Response shift after coronary revascularization**. *Submitted,* 2020

Van den Berg, V., Van Thiel G., Zomers, M., **Hartog, I.**, Leget, C., Sachs, A., Uiterwaal, C., and E. van Wijngaarden. **Euthanasia and physician assisted suicide in patients with multiple geriatric syndromes.** *JAMA Internal Medicine, 2020.* doi:10.1001/jamainternmed.2020.6895

Hartog, I.D.,* Zomers, M.L.,* Van Thiel, G.J.M.W., Leget, C., Sachs, A.P.E., Uiterwaal, C.S.P.M., Van den Berg, V., and E. van Wijngaarden. **Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey.** *BMC Geriatrics,* 2020, 20.1: 1-14. doi: 10.1186/s12877-020-01735-0
* = shared first authorship

Oreel, T.H., Nieuwkerk, P.T., **Hartog, I.D.**, Netjes, J.E., Vonk, A.B., Lemkes, J., Van Laarhoven, H.W.M., Scherer-Rath, M. Sprangers, M.A.G., and J.P.S. Henriques. **Gender differences in quality of life in coronary artery disease patients with comorbidities undergoing coronary revascularization.** *PloS one*, 2020, *15*(6), e0234543. doi: 10.1371/journal.pone.0234543

Oreel, T.H., Delespaul, P., **Hartog, I.D.**, Henriques, J.P.S., Netjes, J.E., Vonk, A.B., Lemkes, J., Scherer-Rath, M., Van Laarhoven, H.W.M., Sprangers, M.A.G., and P.T. Nieuwkerk. **Ecological momentary assessment versus retrospective assessment for measuring change in health-related quality of life following cardiac intervention.** *Journal of patient-reported outcomes*, 2020, 4.1: 1-10. doi: 10.1186/s41687-020-00261-2

Oreel, T.H., Borsboom, D., Epskamp, S., **Hartog, I.D.,** Netjes, J.E., Nieuwkerk, P.T., Henriques, J.P.S., Scherer-Rath, M., Van Laarhoven, H.W.M., and M.A.G. Sprangers. **The dynamics in Health-Related Quality of Life of patients with Stable Coronary Artery Disease were revealed: a network analysis.** *Journal of Clinical Epidemiology*, 2019, 107: 116-123. doi: 10.1016/j.jclinepi.2018.11.022

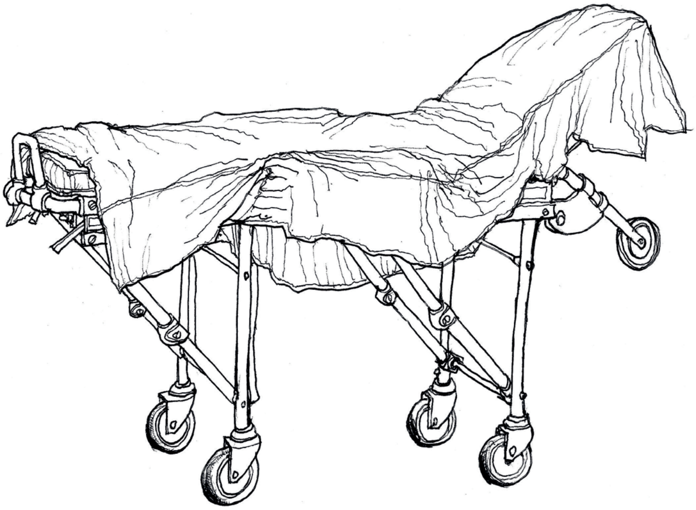
Kruizinga, R., Scherer - Rath, M., Schilderman, J.B.A.M., **Hartog, I.D.,** Van der Loos, J.P.M., Kotzé, H.P., Westermann, A.M., Klümpen, H., Kortekaas, F., Grootscholten, C., Bossink, F., Schrama, J., Van de Vrande, W., Schrama, N.A.W.P., Vos, F.Y.F.L. de, Kuin, A., Meijer, W.G., Van Oijen, M.G.H., Sprangers, M.A.G., and H.W.M. van Laarhoven. **An assisted structured reflection on life events and life goals in advanced cancer patients: Outcomes of a randomized controlled trial (Life InSight Application (LISA) study)**. *Palliative Medicine,* 2018, *33*(2), 221-231.

Publications in Dutch

Joep Dohmen & **Iris Hartog** (2014) **Bildung en burgerschap. Martha Nussbaums pleidooi voor een brede humanistische vorming.** In: Ronald Tinnevelt & Yvonne Denier (red.) *Martha Nussbaum: Filosofie als activisme*. Monografie in de serie ‘Denkers’. Zoetermeer: Klement & Pelckmans.

Joep Dohmen & **Iris Hartog** (2013) **Het gevaarlijke woord ‘wij’. Op zoek naar nieuwe vormen van gemeenschap.** In: *Filosofie Magazine*. Themanummer: Het nieuwe wij. Participatiesamenleving: dwang of kans? Nr. 12/2013, december 2013.

Iris Hartog (2013) **De helpende hand. Menselijke natuur en moraal bij Frans de Waal.** In: *Waardenwerk* [voorheen: *Tijdschrift voor Humanistiek*] Nr. 54/55, december 2013.



Certain life events, such as falling seriously ill, have so much impact that these disrupt our life story. Because of the connection between our life story and identity, such events can lead to a “crisis of meaning” and evoke existential questions. In religious studies, these crises of meaning are called “experiences of contingency”: experiences that make us aware of our vulnerability and finitude and confront us with the randomness of life.

Although several findings suggest that adverse life events negatively impact people’s “quality of life”, some people find remarkably positive ways to relate to such events, leading to a better quality of life than would be expected.

This dissertation is about experiences of contingency caused by disruptive life events, and the ways people make meaning of such events and integrate them into their life narratives, influencing their quality of life. It describes the results of theoretical, qualitative and quantitative research, combining perspectives from both humanities and medical sciences.

Iris Hartog (1983) works as a researcher at the Center of Expertise Palliative Care, Leiden University Medical Center, as a teacher in medical ethics at the Department of Medical Ethics, Philosophy and History, Erasmus Medical Center Rotterdam, and as an ethicist for the Regional Euthanasia Review Committees. She conducted her doctoral research at the chair of Empirical and Practical Religious Studies, Radboud University, in collaboration with the Department of Medical Psychology, Amsterdam UMC.