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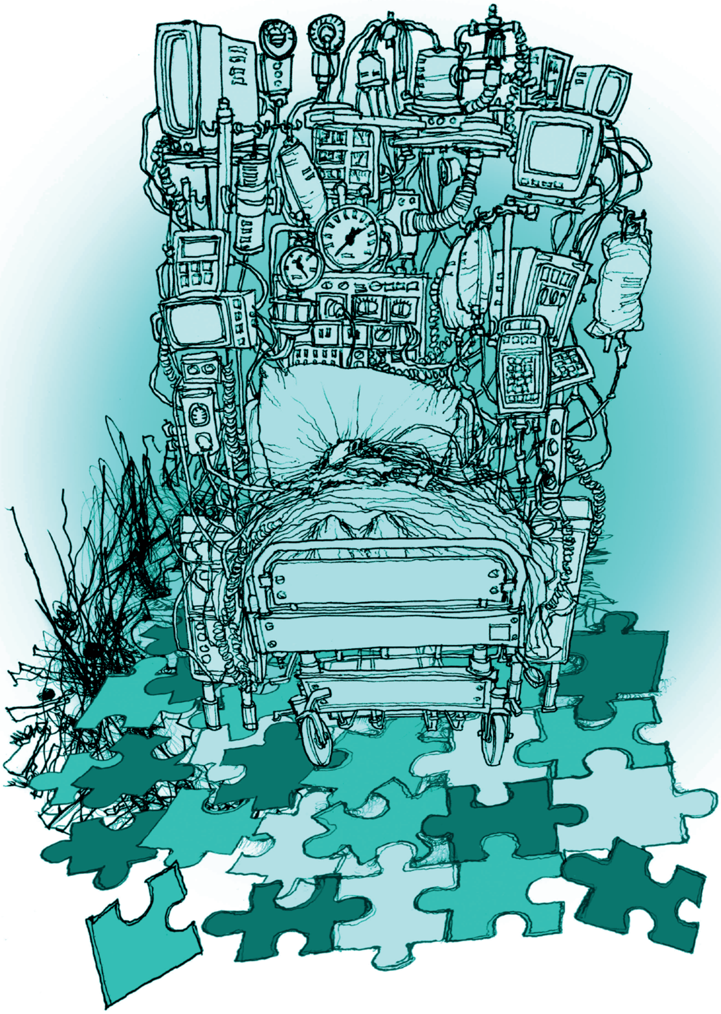
SUMMARY AND GENERAL DISCUSSION



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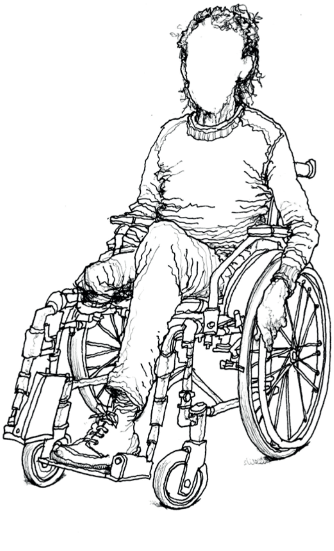
SUMMARY AND GENERAL DISCUSSION

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

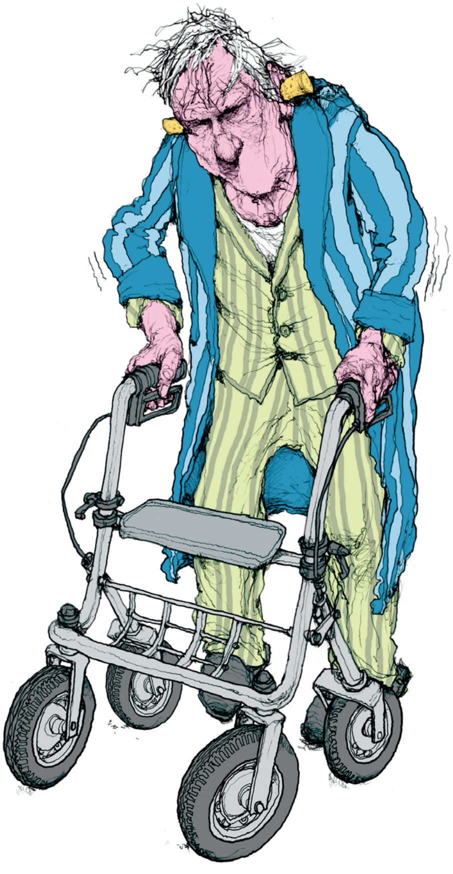
	Research question	Answers to the research question	Directions for future research
Chapter 2 (qualitative)	How do patients make meaning of their 'experiences of contingency' after the life event of being diagnosed with incurable cancer?	In the meaning making of the event of getting incurable cancer, four 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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