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Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life

Journal of Health Psychology
1–17

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DOI: 10.1177/1359105317731823

journals.sagepub.com/home/hpq



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Abstract

Falling seriously ill is often experienced as a life event that causes conflict with people's personal goals and expectations in life and evokes existential questions. This article presents a new humanities approach to the way people make meaning of such events and how this influences their quality of life. Incorporating theories on contingency, narrative identity, and quality of life, we developed a theoretical model entailing the concepts life event, worldview, ultimate life goals, experience of contingency, narrative meaning making, narrative integration, and quality of life. We formulate testable hypotheses and describe the self-report questionnaire that was developed based on the model.

Keywords

biographical disruption, contingency, interpretation, life events, life goals, meaning making, narrative integration, quality of life, worldview

Introduction

Falling ill may have a profound impact on people's quality of life (QoL) (Glaser and Strauss, 1975). 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" (World Health Organization (WHO), 1997). In the medical sciences, research into health-related QoL is commonly restricted to patients' subjective evaluation of the adverse effects of diseases and treatments. For example, the widely used measures EuroQoL five dimensions questionnaire

(EQ-5D) (The EuroQoL Group, 2006) and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993) almost exclusively assess symptoms, side effects,

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and limitations in functioning. While these measures are useful and important, they assess only part of the QoL people experience. Moreover, they do not capture the processes leading to people's evaluation of their QoL.

When people fall seriously ill, for example, when they are diagnosed with cancer or a heart disease, they are often confronted with existential questions (Bolmsjö, 2001; Fife, 2002; Kruizinga et al., 2017; Van der Spek and Verdonck-de Leeuw, 2016). Previous theoretical and empirical research suggests that the way people make meaning of their disease and other life events, in brief "meaning making," influences people's well-being and QoL (Affleck et al., 1987; Albrecht and Devlieger, 1999; Cohen et al., 1996; Park, 2010; Sprangers, 2015; Van der Spek and Verdonck-de Leeuw, 2016). For example, the way cancer survivors interpret their illness was found to correlate with coping strategies and QoL (Büssing and Fischer, 2009), and meaning-focused coping was found to be associated with positive affect in people with chronic stress (Folkman and Moskowitz, 2000) and with positive affect and well-being in earthquake victims (Folkman, 2010; Folkman and Moskowitz, 2000, 2007; Guo et al., 2013).

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 falling ill (Antonovsky, 1987; Büssing and Fischer, 2009; Folkman and Moskowitz, 2007; Lazarus and Folkman, 1984; Park, 2010, 2013; Park and Folkman, 1997; Park and George, 2013; Ryan and Deci, 2000; Sales et al., 2013; Tedeschi and Calhoun, 1996; WHOQoL SRPB Group, 2006). Also, important determinants in these processes have been considered, including religion, worldview, and life goals (Emmons, 1986; Emmons et al., 1998; Friedman et al., 2010; Hullmann et al., 2015; Janse et al., 2015; Jenkins and Pargament, 1995; King et al., 1998; Koenig et al., 2001; Levin, 1996; Riley et al., 1998; Roberts et al., 2007; Sprangers et al., 2010; Sprangers and Schwartz, 2008).

As shown in an extensive review by Park (2010), myriad theoretical perspectives on meaning making exist. "Meaning" as defined by Baumeister (1991) is a "mental representation of possible relationships among things, events and relationships. Thus, meaning *connects* things" (p. 15). The meaning making model proposed by Park and Folkman (1997) and Park (2010, 2013), 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" or "shattering." They 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 (Park, 2010). For the "products" of these processes of meaning making, Park uses the term "meanings made". 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 post-traumatic growth. Since 2010, several empirical studies have been carried out that can be placed within the framework of Park's model (e.g. Davis and Novoa, 2013; Dezutter et al., 2015, 2017; Park and George, 2013; Rajandram et al., 2011).

In this article, we propose a *humanities* approach to meaning making¹ relating to QoL. Our model combines theories on contingency and narrative identity, emphasizing the crisis of meaning people may experience when confronted with the "randomness" of life, which requires narrative reconstruction. Falling ill is an example of a *contingent* life event:

something that befalls people but could also have been otherwise. In other words, a contingent event is “something that is neither necessary nor impossible” (Luhmann, 1995; Wuchterl, 2011). The word contingent refers to the idea that everything, including one’s own life, could have been different (Makropoulos, 1997; Zirfas, 2014). In late modern societies, people have become increasingly aware of the contingency of the world and their own lives (Joas, 2016; Makropoulos, 1997; Scherer-Rath et al., 2012). As a result of globalization, secularization, and individualization, traditional structures lost influence, leaving individuals responsible for their own beliefs and choices in life (Bauman, 2013). Because events no longer have a self-evident place in people’s personal perspective on life, they have to find their own interpretations and reactions in accordance with their personal needs, desires and expectations (Scherer-Rath et al., 2012). Meaning making, especially of negative events that impact people’s lives profoundly, is thus a challenge for individuals, requiring constant appraisal and accommodation (Keupp, 2010; Scherer-Rath, 2014).

Making meaning of life events is often done in a *narrative* way, by telling stories that configure separate events into a meaningful whole. By constructing stories, people try to make sense of their experiences, providing a sense of overall meaning and purpose to their lives (Baumeister, 1991; Emmons, 1999; McAdams, 1993; McAdams and Manczak, 2015; Straub, 2005). According to the philosopher Ricoeur (1984), 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 that already contain 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 (Ricoeur, 1984). This means that people “read” their own life story, integrating their life events and experiences in the way they understand themselves. Thus, a person’s life narrative can be seen as a form of identity that both reflects and shapes who the person is (McAdams, 1993; Ricoeur, 1995). 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 change the identity of the person (Singer, 2004). Our theoretical model thus entails the concepts “narrative meaning making” and “narrative integration” of life events.

Although our approach shows kinship with several psychological concepts included in Park’s framework, a new perspective is introduced in our comprehensive approach that integrates contingency theory and theories of narrative identity. As stated by Park (2010), little research has been carried out on the integration of stressful life events and the identity change related to it. In our model, meaning making is seen as *narrative* reconstruction, leading to a certain extent of narrative integration. While psychological approaches mainly focus on psychological processes and mechanisms and how they influence functioning, we emphasize the existential dimension of the same process of relating to the life events that befall us (Gendlin, 1962; Singer, 2004). For example, in our model, re-interpretation of life events is always explicitly connected with one’s

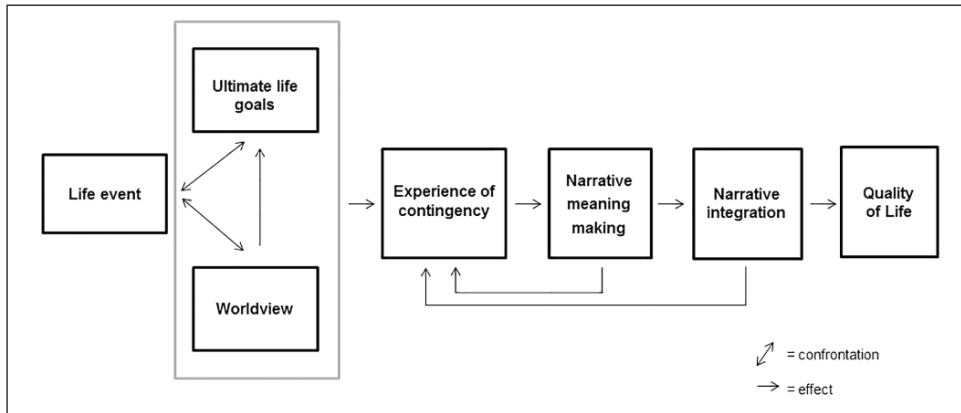


Figure 1. Theoretical model: *narrative meaning making of life events*. The dominant relationships and feedback loops are highlighted.

worldview and ultimate life goals, and with the meaning of the event in the context of one's personal life narrative. The substantial approach we use, allows for investigating and understanding the *contents* of people's interpretations, going beyond explaining how existential concepts function in the process of reducing discrepancies and maintaining or restoring well-being. While a process such as cognitive reappraisal may very well play a role in the process of narrative meaning making, the latter cannot be reduced to just another coping process. Rather, narrative meaning making can be seen as the existential dimension underlying coping and adjustment. In addition, the narrative perspective implies that it is not distress per se that evokes existential questions and initiates a process of meaning making, but the narrative disruption by the life event itself, causing an experience of contingency, as we will explain below.

With our model, we aim to combine approaches from humanities and medical sciences, to develop a substantive theory on how meaning making influences QoL. By developing a theoretical framework on narrative meaning making of life events, combining narrative theory and contingency theory, we aim to improve our understanding of the way life events such as illness influence patients' QoL.

Methodological approach

As a starting point, we used the conceptual model for reconstructing the interpretation of life stories that was described and empirically tested previously (Kruizinga et al., 2013; Scherer-Rath, 2013; Scherer-Rath et al., 2012; Van Dalen et al., 2012; Van den Brand et al., 2014, 2016). This model combines contingency theory (Wuchterl, 2011) and narrative theory (Ricoeur, 1995; Straub, 2005), focusing on the role of narrative interpretation of life events in the construction of personal identity (Van den Brand et al., 2014). 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, worldview, well-being and QoL, and refined and adapted the model.

Theoretical model

The resulting theoretical model describes the dominant relationships between the following elements, as illustrated in Figure 1. 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 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 "biographical 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 (Ricoeur, 1995). If a person considers an event as significant for his or her life as a whole, we speak of a *life event* (Frijda, 2007). 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 (Wuchterl, 2012). 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 (Park, 2013; Vos, 2015). 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 (Janoff-Bulman, 2010).

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 (Kraft, 2008; Schnell and Keenan, 2011). 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 (2013) framework).

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 (Tillich, 1963; Van den Brand et al., 2014). 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 (Walach, 2011). This transcendent reality can be personal (such as "God") or impersonal (such as "a higher power" and "something higher") (Bucher, 2014) and can be experienced as something external but also as something within the self, often referred to as the "more," as in "what we see, is not all there is" (Elkins et al., 1988). 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 (De Pater et al., 2008; Scherer-Rath et al., 2012).

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” (Van Straten et al., 2013). 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 (Van der Ven, 1998; Van Straten et al., 2013).

Ultimate life goals

People’s worldview beliefs, encompassing—often implicit—visions on “the good,” give rise to their personal goals (Emmons, 1999). Their worldview thus anchors and justifies their personal goals that determine the meaning attributed to a life event (Baumeister, 1991; Frijda, 2007). As detailed by Emmons, people usually have many personal goals, which are not all equally important: they are hierarchically ranked (Baumeister and Vohs, 2003; Emmons, 1999). 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 (Emmons, 1992, 1999; Frijda, 2007; Kruizinga et al., 2013; Van den Brand, 2016; Van den Brand et al., 2014). An example of an ultimate life goal is “taking care of my child,” anchoring the instrumental life goal “helping my daughter with her homework.”

Experience 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 (Bury, 1982; Holzinger, 2015; Kruizinga et al., 2013; Scherer-Rath, 2013; Scherer-Rath et al., 2012; Van Dalen et al., 2012; Wuchterl, 2012). 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 (Giddens, 1990; Scherer-Rath, 2014). In religious studies, experience of contingency is also called “interpretation crisis” or “crisis of meaning” (Dalferth and Stoellger, 2000; Geertz and Banton, 1966; Scherer-Rath, 2013, 2014), emphasizing the inability to understand and grasp the life event (Wuchterl, 2012). This inability to make sense and meaning of the life event, conflicts with the fundamental human need for understanding, coherence, and meaning (Baumeister, 1991; Baumeister et al., 2013; Frankl and Lasch, 1962; Heine et al., 2006; Schnell, 2009; Williams, 1984).

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. 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 (Vos, 2015). Such an event can also conflict with people's worldview, thereby shattering people's most fundamental assumptions about themselves, the world and the relationship between the two (Janoff-Bulman, 2010). 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, expressing 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" (Kruizinga et al., 2017; Van Dalen et al., 2012). 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 (Boylstein et al., 2007; Petrie and Oshlag, 1993). 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?

Narrative meaning making

Narrative meaning making 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. 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 (Emmons, 1992, 1999; Kruizinga et al., 2013). 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, people were found to find a positive meaning (Affleck et al., 1987; Emmons, 1999; Helgeson et al., 2006; Tedeschi and Calhoun, 1996).

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 (Kruizinga et al., 2013; Scherer-Rath et al., 2012). 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 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 (Scherer-Rath et al., 2012).

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 (Scherer-Rath, 2014; Williams, 1984). 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 (Ricoeur, 1986). Such life events are thus narratively "worked" to make them plausible but without disregarding their contingency (Straub, 2005, 2016). The event is still interpreted as a disruption of the life story, but is given a meaningful place (Scherer-Rath, 2014).

Some people may be more able than others to integrate life events causing an experience of contingency in their life story, also depending on the type of event and the specific situation and life phase. Based on a previous study among cancer patients (Kruizinga et al., 2017), we distinguish 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 natural laws or from "absolute chance" (Wuchterl, 2011). 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 (Wuchterl, 2011).

In both types of denying, there is no need to search for a meaningful place for the event in one's life story, and the event is described as in no way part of the person's life. In this mode, people may talk about the life event in terms of "necessity" or "moving on," such as "This was meant to be, all part of His plan for me" and "I just want to go on, so that's what I'm doing."

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 the Ricoeurs (1984) stages of mimesis, 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 positive “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 (Straub, 2016). 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.”

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 re-interpretation 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.

Hypotheses

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 1; all represent hypotheses that are yet to be tested.

The first hypothesis is that an experience of contingency implies a conflict between a life event and ultimate life goals or worldview. A related hypothesis is that an experience of contingency is more likely to occur or more profound when a life event does not only conflict with people’s ultimate life goals, but also directly with their worldview, challenging their beliefs and outlook on life.

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.

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 (upper feedback loop) 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.

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. Hypotheses can also be derived with respect to the different aspects of meaning making and integration. For example, a more disputable 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 (Kruizinga et al., 2017; Scherer-Rath et al., 2012).

Fifth, 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 well-being is associated with the ability to integrate positive as well as negative experiences into one's life story and perception of the self (Bauer et al., 2008; Bohlmeijer et al., 2008; McAdams, 1993; Pot et al., 2010; Scherer-Rath, 2013; Van den Brand et al., 2014; Van Straten et al., 2013; Weiss et al., 2016; Westerhof et al., 2010a, 2010b). Because this association suggests that a more complete integration of negative experiences results in higher levels of well-being, we expect that more narrative integration results in higher levels of QoL (Keupp et al., 1999).

Thus, our expectation is that the combination of meaning making and integration will lead to a larger reduction of the experience of contingency and consequent enhancement of QoL than meaning making alone. The extent to which both narrative meaning making and integration are needed for experiencing good levels of QoL remains to be investigated. Because previous studies suggest that autobiographical reasoning might not always increase well-being (McLean and Mansfield, 2011), and that denial may be beneficial to social and emotional outcomes in cancer patients (Vos et al., 2011), it may be the case that after specific traumatic life events, denying would—at least in the short term—lead to higher levels of QoL than actively engaging in the process of narrative meaning making and integration.

The concept of narrative integration also holds other 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 that 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 exist that are not shown in the (simplified) figure. For example, it might be interesting to investigate the direct influence of worldview on narrative meaning and the influence of worldview and ultimate

life goals on QoL. Moreover, we expect more feedback loops to exist than are shown in the model. For example, the process of narrative meaning making and narrative integration could change a person's worldview and (the importance of) ultimate life goals (Gutierrez and Park, 2015). 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. Furthermore, we expect time to be of importance: people often have a different perspective on life events shortly after the event, than months or even years later.

Finally, 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 in 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.

Toward an operationalization of the theoretical model: the RE-LIFE Questionnaire

To allow for empirical testing of our theoretical model, we developed a self-report questionnaire: The "Reconstruction of Life Events" Questionnaire (RE-LIFE), see Appendix 1 and Online Appendix. 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, will be published separately.

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 (Kruizinga et al., 2013; Scherer-Rath, 2013, 2014, 2016; Scherer-Rath et al., 2012; Van Dalen et al., 2012; Van den Brand et al., 2014). This instrument consists of a topic list for semi-structured interviews about experiences of contingency caused by life events. The items then were further developed using transcriptions of in-depth interviews with advanced cancer patients that were held using the qualitative instrument mentioned above (Van Dalen et al., 2012). The "narrative integration" scale was developed in a qualitative study described previously (Kruizinga et al., 2017). The questionnaire was then refined and adapted in 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.

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 (Kruizinga et al., 2013; Van den Brand et al., 2014). 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. The questionnaire is currently being tested in a large-scale, longitudinal study among cardiac patients undergoing coronary angioplasty or bypass surgery.

Conclusion

Our theoretical model elucidates how people make meaning of illness in a narrative way. Falling seriously ill may be experienced as a life event that conflicts with the person's ultimate life goals and/or worldview, resulting in experience of contingency and lower levels of QoL. The way people make meaning of such

life events may lead to some degree of “narrative integration,” which in turn is expected to reduce the experience of contingency (the “crisis of meaning”), increasing the experienced QoL.

As stated before, our theoretical model can be placed within the meaning-making framework as proposed by Park, and the concepts show parallels with well-known psychological concepts such as adaptation, acceptance, and coping. 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 (Park, 2010).

However, the integration of contingency theory and theories of narrative identity in our model allow for a substantive account of meaning making. The model facilitates the investigation of the meaning that life events have for people in the context of their personal life narrative, and the content of ultimate life goals and worldviews that play a role in the construction of meaning. Characteristic of our model is the concept of narrative integration after an experience of contingency caused by a life event, in which life events are given a meaningful place without disregarding their contingent and disruptive nature, and may lead to changes in people’s narrative identity.

Many aspects of the theoretical model need to be further explored. The resulting hypotheses need to be tested in large-scale, longitudinal research incorporating narrative meaning making and a broad conceptualization of QoL. The proposed theoretical model and the RE-LIFE Questionnaire may be used for further research on the relationship between meaning making, narrative integration, and QoL, to enhance our understanding of patients’ QoL.

Acknowledgements

The authors gratefully acknowledge Dr Adri van der Wurff for his helpful comments on an earlier draft of this article.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by the Netherlands Organisation for Scientific Research (NWO) (grant number NWO319-20-003) and Merck Sharp & Dohme (MSD).

Note

1. 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.

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Appendix I

Table I. Concepts and items in the RE-LIFE Questionnaire.

| Concepts | Items |
|---------------------------|--------------------|
| Life event | 2.1 |
| Ultimate life goals | 2.5; 3.4; 4.1 |
| Worldview | 5.1 |
| Experience of contingency | 2.2; 3.1 |
| Meaning making | |
| Evaluation | 2.3a–b; 3.2a–b |
| Agency | 2.3c–e; 3.2c–e |
| Scope | 2.3f–j; 3.2f–j |
| Narrative integration | |
| Denying | 2.4b,e,i; 3.3b,e,i |
| Acknowledging | 2.4a,g,k; 3.3a,g,k |
| Accepting | 2.4c,f,l; 3.3c,f,l |
| Receiving | 2.4d,h,j; 3.3d,h,j |
| Quality of life | 5.2 |