ORIGINAL ARTICLE

Developing the concept of self-reformulation

MARIA J. MAYAN, JANICE M. MORSE & LYNN P. ELDERSHAW

International Institute for Qualitative Methodology, University of Alberta

Abstract

In this article, we argue that the processes that transform the self differ in people who are dying (i.e. self-transcendence), and people who are “facing death” and subsequently recover (i.e. self-reformulation). In this study, we explicate the latter concept. Eighteen participants who were long term survivors, chronically ill or caregivers who had lost a significant other at least six months previously, were interviewed about the course of the illness and in particular about their emergence from suffering. The attributes of self-reformulation identified were an ability to reorder priorities (including maximizing the present, a disregard for material things, an appreciation for one’s own abilities and exit from unsatisfying relationships); a need for reciprocity; and a valuing of the experience of suffering. Self-reformulation is considered the goal of rehabilitation and the ultimate state of health. Suggestions for further research are discussed.

Key words: Self-transcendent, self-reformulated, concept development, qualitative inquiry

Introduction

Facing death compels individuals to reconsider how they live their lives. After suffering and surviving a serious accident, emerging from a near-death experience, recovering from chronic disease in remission, or caring for a relative during diagnosis, treatment and ultimately, death, individuals become profoundly changed. Suffering involves a period of enduring to “get through” the critical event followed by a period of emotional suffering to release emotions (Morse, 2005; Morse & Carter, 1996). Through enduring and emotional suffering, many individuals emerge with a newfound wisdom and attitude towards life. These individuals undergo a process of re-ordering their life priorities, making deliberate decisions to reformulate (Carter, 1994) their lives.

Health practitioners, who care for these individuals while they battle illness and injury, have observed them experiencing enduring and emotional suffering, and have then witnessed patterns of behavior akin to reformulation. This article delineates the responses of individuals who have confronted mortality and experience a reformulated approach to living. Part of the imperative to stipulate this phenomenon is to distinguish it from the transformation of self that occurs when individuals are dying, and, because many competing terms exist in the literature, to clarify the terminology attributes to these concepts.

Literature review

Many researchers (Block, 2001, Davis & McKearney, 2003; Frankl, 1964; Hall, 2001; Lukkarinen, 1999; Orne, 1995) have observed and used various term for what we have now labeled as the concept of self-reformulation. Self-reformulation is an approach to living, and is manifest as significant, permanent changes in the values of those who have been close to death. Accounts of this “new way of living” surfaced in the literature in the early 1990s, and such descriptions of self-used terms such as “self-transcendence” (Coward & Reed, 1996; Kinney, 1996). King and Jensen (1994) used the term “moving on” when female cardiac patients attained a different outlook in life and talked about “taking time to smell the roses” (p. 103).

A comparable term, transformative, has been used to describe cancer survivors (Vachon, 2001) and
AIDS patients who have come to interpret the illness as positively transformative in their lives (Coward, 1995; Hall, 2001; Mellers, Elen, Coons & Lucke, 2001). Similarly, the experience of finding positive meaning in suffering is depicted in the literature in relation to individuals with spinal cord injury (Al-Samidi, Soudi, Obiedat & Shnnaigat, 1996), multiple sclerosis (Pollock & Sands, 1997), coronary artery disease (Lukkarinen, 1999) and chronic disabilities (King et al., 2003). As transformative, finding meaning in suffering overlaps with the literature that addresses the transcendence and reformulation experience of individuals. Thus, it is evident that there are many concept labels for the same experience.

In a meta-analysis of qualitative research on people living with chronic illness, the terms used are similar. Thorne and Patterson (1998) found that the literature in the 1990s introduced being courageous, maintaining hope, regaining control, finding meaning, transformation, reframing, restructure self, and self-transcendence to characterize the experiences of individuals who lived with chronic illness. They noted this more optimistic perspective of the 1990s to be a dramatic shift from the loss and burden perspective of the 1980s, when living with chronic illness was predominantly oriented as inherently suffering, involving dramatic biographical disruption and depicting individuals in the sick role (Thorne & Patterson, 1998, p. 175).

Regardless of the term chosen, there is a lack of consensus regarding the definition of both concepts, self-transcendence and self-reformulation, and an ad hoc application of the concepts throughout the literature. Very few attempts have been made to examine critically how these concepts are defined, operationalized and actually manifest.

Thus, the problem with separating self-transcendence from self-reformulation is that there is a bricolage of overlapping and poorly conceived attributes (or characteristics) associated with these two states. While some attributes overlap initially in both concepts we have found that later the process is different, with those who have transcended, internalizing or cocooning (Olson, Morse, Smith, Mayan & Hammond, 2001), finding peace in dying and those who have reformulated, reevaluating their priorities and developing a strong desire to give back to others who are suffering. Thus, while self-transcendence and self-reformulation are experientially allied, they are conceptually distinct concepts involving some shared and some divergent attributes, each serving different purposes and describing different processes.

**Self-transcendence**

From the perspective above, the concept of self-transcendence has been inaccurately associated in the past with mental health among older, and oldest-old adults (Reed, 1991a), among healthy populations (Coward, 1996), and as a predictor of well-being among individuals with chronic illnesses and life-threatening illnesses such as cancer survivors (Carter, 1994; Coward, 1998; Coward & Khan, 2004; Kinney, 1996), and AIDS patients (Coward, 1995; Mellers et al., 2001). Self-transcendence was found to be inversely correlated with depression (Ellermann & Reed, 2001) and has been linked to finding meaning in the caregiver experience (Acton & Wright, 2000; Enyert & Burman, 1999), and as a vehicle through which generalized personal suffering, such as divorce, may be alleviated (Barnes, 1994). Emblem and Pesut (2001) propose a model to facilitate transcendent meaning in the suffering experience. Many defer to the definition provided by Reed (1996), Transcendence refers to an awareness of one's true nature that is unbounded by the experiences of the usual self, such as the here and now, space, physical illness, and separation between the person and the environment (p. 2). It is the capacity to expand self-boundaries intrapersonally (toward greater awareness of one's philosophy, values, and dreams), interpersonally (to relate to others and one's environment), temporally (to integrate one's past and one's future in a way that has meaning for the present), and transpersonally (to connect with dimensions beyond the typically discernable world) (Reed, 2003, p. 147).

**Self-reformulation**

However, the concept of self-reformulation, or the reformulated self, has received scant attention in the literature and it is a relatively new concept. Carter (1994) was first to identify and name it as reformulated in her examination of women recovering from breast cancer, characterizing the process as one that constitutes a reinterpretation of self. Self-reformulation results from the experience of a self that is mortal, accompanied by a loss of one's previous identity associated with health, career, and relationships. An attendant awareness of a self that is vulnerable to a relapse if cancer is present, as is a shift in focus toward self and close relationships. An acquired sense of self as a survivor is definitive of reformulation in this context. Others have used the concept, but have again inadequately delineated the attributes (e.g. Sjoling, Agren, Olofsson, Hellzén & Asplund, 2005, equated finding meaning in suffering experiences, but did not illuminate the elements that
characterize this newfound meaning, nor how this new perspective is achieved).

From Carter's (1994) study of long-term survivors of breast cancer, the term reformulated self was used by Morse and Carter (1996) and by Morse (2001, 2005) as a label for the state that persons entered as they emerged from emotional suffering. Once participants had emotionally suffered enough, hope seeped in (Morse & Penrod, 1999) and enabled the person to exit suffering and to self-reformulate. However, these data focused on suffering per se, and contained only brief descriptions of self-reformulation.

In summary, because self-transcendence and self-reformulation have been casually applied in the literature to a vast array of illness scenarios, there is a need to conceptually hone and clarify these concepts in the clinical and research literature. In this article, we begin this task by identifying and describing the conceptual attributes of self-reformulation.

**Method**

Qualitative inquiry is used to investigate undeveloped or immature concepts (Morse, Mitcham, Hupcey & Tasón, 1996), and to clarify or develop scientific concepts. The confusion in both concept labels and definitions between the more established concept of self-transcendence and the newer concept of self-formulation could be clarified by developing the concept of self-reformulation to identify its attributes using qualitative inquiry. If the concept of self-reformulation can be developed using qualitative research, then it is reasonable to support the development of two separate concepts; if not, then we will recommend that self-reformulation be dropped in future research, and the concept of self-transcendence be solely used to explicate this change in persons who are emerging from suffering.

Unstructured interactive videotapes were conducted with 18 persons who were caregivers for terminally ill relatives, or who themselves, had a serious illness or injury at least 6 months previously. These participants were simply asked to tell their story, and these tapes were transcribed verbatim and content analyzed using MSWord.

The categories were then examined for clusters, or sets of categories, that appear to address a single topic. Once we were satisfied that the main categories were reasonably independent of each other, each category was labeled as an attribute, and described as comprehensibly as possible.

**Findings**

The primary context and precondition of self-reformulation is suffering. All participants endured “facing death” and emotionally suffering a loss. Once they eventually accepted their altered future lives, questioning ceased; a state of quietude emerged, accompanied with an assertive need to reorder their lives. They recognized that the experience could not be erased; that it matured them; it had made them wise. The experience had taught them about themselves, others, and life. Participants recognized how much they did not know, nor could they comprehend, before the event that caused the suffering. This process is self-reformulation.

So great was this changed perspective, as they emerged from emotional suffering, that they appeared to others as a fully changed person. Others found it difficult to adjust to this new person, and our participants felt pressured by family and friends to “return to normal” or to “be the people they were before” the event occurred, and experienced these pressures as distressing.

My husband expected me to be this person I was before I ever got sick, and I can’t ever be that person again. Like my whole world is new . . . . And I just found it so hard that he couldn’t hear me, he just couldn’t hear me. And it hurt so much to think that somebody that you’ve spent all these years with, just didn’t get it . . . . I am a different person now and I need you to hold me.

Then my family figured I should be the person I was before I was diagnosed. Like just, ‘I don’t want to hear any more about it. Just get on with your life.’ Well, I mean, the world looks different, will always look different. Once you’ve faced your mortality, it’s just a whole new ball game—for me, anyway.

The three attributes or characteristics that constitute the concept of self-reformulation are: (1) an ability to re-order priorities, which gave participants the capacity to maximize the present, disregard material things, appreciate one’s own abilities, and reject unsatisfying relationships; (2) a need for reciprocity: or a desire to alleviate the suffering of others by giving back to others; and (3) a valuing (even treasuring) of the experience of suffering.

1. An ability to re-order priorities

Facing mortality was the impetuous for this altered perspective on living. Participants’ told us that they no longer feared death, and that they “weren’t afraid
to die.” They approached life with a new wisdom and spiritual sensitivity.

Hey, I’ve had to face cancer. I know I’m going to die. I can do anything. God will decide when I’m going to die, so I’m going (on a vacation), and if I die over there, well, then, I guess that’s what God wanted me to do.

I’m seeing so much clearer now as far as what the important things are and, uh, I’m learning so much more about myself… So, this advice … um, be kinder with yourself…

This change brought an appreciative affect toward life itself. While they were tolerant of any major catastrophe that may be brought onto themselves or others in the future, they had an overwhelming desire to make the most of every moment. They maximized the present, developed a disregard for material things, gained a new appreciation for their own abilities, and left unsatisfying relationships.

Maximize. With this new attitude, came the zest to live for today, and to fully enjoy each moment. They sought the company of people and activities now deemed important. This was exemplified when individuals changed their plans at a moment’s notice to live every opportunity.

If somebody says, ‘Let’s go somewhere,’ I’m gone, because life is precious and—and I don’t lay in bed at night worrying about tomorrow; I just live today and make it the best.

They had reprioritized their lives, and said: “It is important to enjoy life.”

Disregard material things. A very common occurrence among participants who were self reformulating was the lack of desire for accumulating material possessions. They plainly stated that this was truly something they do not struggle with, as without possessions, they were able to play, to concentrate on relationships, or on those things that they perceived to be priorities.

I thought now… he’ll understand how I’ve changed, how these things that you’re so worried about, the big house and the car, I don’t care. I don’t care about material things. I just care about time together and time to play while I’m still here.

Ambitions and goals targeted towards material ends, once considered worthwhile life objectives, and culturally supported ideals of a “good life”, were casually dismissed.

Appreciate one’s own abilities. An ongoing part of being a different person was participants’ needs to focus on their strengths, on the positives in their lives; to focus on what they can do, not what they can no longer do. Again, this is very distinct from emotional suffering when one wants to be consoled, to be taken care of, and to be pitied. Focusing on the positive provided them with the strength to “get on with their life”.

The other the thing that’s I guess that’s key is that there are only consequences. I looked for the advantages … If you focus on what you’ve lost, you’ve got a problem. If you focus on what you’ve got, then it’s like climbing a mountain to the top. I think that that’s pretty important.

Exit from unsatisfying relationships. Participants made the effort to reject and remove themselves from unsatisfying or stifling relationships that they perceived as unrewarding, or even harmful to their new lives, and felt such changes were immediately imperative and essential for their future happiness. They made strong statements rejecting previously tolerated relationships and conditions: “I won’t live like this”.

The act of disentangling themselves often took enormous confidence, a confidence that they did not have prior to suffering. However, self-reformulation gave them a new assertiveness that astonished even themselves. Their determination to “not live like this” in some cases meant divorce or leaving their home and financial security, or changing or leaving a job. These decisions were made with little hesitation:

I just decided, I remember the day, I took my rings off, I went to see a lawyer, I thought ‘I can do this’ and you know, the funny thing is, I thought as long as I have my books, my music and my candles, I will be fine… I thought ‘No thanks, I am not going to live with this anger, I have worked too hard for my dignity, to ever, ever, ever compromise it again.’ And I stood up and—my God, it’s our twenty-fifth anniversary this February, and I wish I had done it 25 years ago… And I tell you, (now) I put up with nothing. It’s zero tolerance time. And all those years of thinking that, being so scared that he was going to leave.
2. A need for reciprocity

The second attribute was the strong desire among participants to “give back,” to assist those who were enduring and emotionally suffering. Having freshly emerged from the intensity of emotional suffering, they felt compelled, pulled and even driven to volunteer, especially with others currently immersed in emotional suffering. This is something they had to do. Participants described how these actions gave meaning; it was their calling.

When I said, ‘I’ve discovered what I want to do. I’m going to volunteer in palliative care, he said, ‘What? You don’t even have time to do the stuff around here that you need to do for me!’ I said, ‘Well, you know what buddy, I don’t need your permission. I am doing this because I was meant to do this and I feel every ounce of my being is being directed to this. If you don’t like it, I’m sorry, but I’m doing it. Bye.’

Participants primarily volunteered within the hospital and in support groups, by doing such things as driving those who were undergoing therapies to their appointments, and singing to patients in palliative care. This gave additional satisfaction and significance to their lives, reinforcing their new way of being.

3. A valuing of the experience of suffering

Participants found meaning in and contrary to what would be expected, appreciated their suffering, and were grateful for having gone through the experience. Participants stated clearly that they “would not wish the experience on anyone” but, on the other hand, “treasured” the experience. They felt free as a result of going through what they did, and realized that they are a better person for it, were better able to help others as a result of their experience, and were grateful for the changes in the way they now lived their lives.

I think that what was very interesting about it was, from my experience... I knew that what people got out of helping [the dying person] would help them. Like, they would always treasure that time that they’d spent [with the dying person]... And, at the end of the day, that’s what you have. Like you; you’re free... if you get involved, you have... you have those times, like those things that they’ve said to you.

For a man of so very few words he definitely, he definitely got a lot of things across to a lot of people. And if I could take that journey again with my Dad, I’d do it again. I would definitely do it again.

Discussion

Our findings suggest that self-reformulation is a concept with three distinct attributes that describe experiences of surviving a serious accident, emerging from a near-death experience, recovering from chronic disease in remission, or caring for a relative during the diagnosis, treatment, and death. The act of facing mortality profoundly changes or self-reformulates these individuals so that their lives are forever altered. This experience, previously enmeshed with concepts of self-transcendence and other overlapping terms, is sufficiently distinct to warrant separate development as a concept in its own right. While the concept was first described as reformulated self (Carter, 1994) we have relabeled it as self-reformulated to make the name parallel to self-transcendence and to emphasize participants’ active engagement with the external world.

The attributes delineating the concept are newly identified, but the behaviors classified in this study have been previously recognized by others. For example, the shift of putting relationships first and identifying what is important has been identified in the literature by Coward (1996) and Lukkerinen, (1999). The notion of focusing on one’s abilities has been observed by Sjoling et al. (2005), who found that some individuals faced with physical limitations and pain as result of their disability were able to compensate by emphasizing what they could do rather than lamenting what they could no longer do. Reciprocity, as a constant urge among individuals to “give back” to those that are now suffering, was noted by Hall (2001) who described volunteering that shifts the focus from self to other. This of course, is another sign within our research that the individual has exited suffering and is now able to respond to the needs of others.

Yet by delineating the concept of self-reformulation, we are left with many questions.

What is the capacity of family members to live with this new self-reformulated person?

Our study suggests that for family members, living with the newly self-reformulated person is an uneasy transition. The self-reformulated person commonly, and unexpectedly, experienced a lack of support and understanding from close relatives who had difficulty making the experiential leap to empathize. Significant others wanted life “to go back to normal” while “normal” as the condition prior to the experience of
suffering was no longer welcome by participants. This precipitated the necessity to make life changes. Indeed, Sjoling et al. (2005) and Lukkarinen (1999) found that having supportive relations within the health care professionals, family, and friends facilitated positively enhanced reformulation in participants with circumstances of chronic illness.

What are the consequences of making these life-altering decisions so closely following a life-altering event?

Since some participants experienced a lack of support and understanding from close relations, our finding of exiting relationships and conditions previously tolerated, was vital for maximizing the present. This is contrary to the advice offered by many health professionals who counsel individuals not to make major life changes following a serious illness or bereavement. We found that participants made life-altering changes with little hesitation. The issue of whether or not it is advisable to make these significant and immediate changes should be further explored. A longitudinal study needs to be conducted to examine the permanence and possibility of regrets of decisions made so soon after a major life altering event, and if such changes are not made, the quality of life of those who remained in such unfulfilling relationships.

What about those who do not self-reformulate?

At the time of the study, only two of our participants had not shown the signs of self-reformulation. One of these individuals exhibited enduring, while the other individual was caught in emotional suffering. Indeed, there is ample research that suggests that people do not always self-reformulate. Tomich and Helgeson (2002) found that after five years into recovery, breast cancer survivors did not experience more personal growth or increased meaning in life than women facing other stressors that were not life threatening. Similarly, elevated levels of depressive symptoms have been found among individuals with chronic secondary health problems related to spinal cord injury (Coyle, Shank, Kinney & Hutchins, 1993). However, Lukkarinen (1999) found that individuals with coronary artery disease were divided in their respective acceptance of their condition. Why had they not all self-reformulated? We can only speculate that the nature of the illness, the timing of its onset (age of individual), their past experiences with life challenges, and so forth, all collude to complicate the trajectory toward self-reformulation.

What are the implications for clinical care?

Certainly, self-reformulation is the ideal outcome from suffering, and health practitioners understandably want to facilitate this ideal in patients who are suffering. Practitioners question, when does suffering become unhealthy? How do we know when to help move someone through this process of suffering to self-reformulation? How can we facilitate and ease suffering so that the outcome is one of self-reformulation, and ultimate health?

However, can we, and must we, allocate this assessment and therapeutic responsibility to therapeutic health practitioners? The enduring, emotional suffering, and self-reformulation trajectory complicates the impulse to know when and how to facilitate movement through each stage. Is the progression through suffering a normal and natural process that individuals will proceed through at their own pace, or is it one that can be therapeutically manipulated?

A corollary of this is if individuals are identified as having self-reformulated, is the assumption that they have “made it” and that they do not need further care? Recall that the model of suffering is not linear, and individuals may return to emotional suffering as they choose or feel the need (Morse, 2001). As Thorne and Patterson (1998) warn, overemphasizing the autonomy of individuals living with chronically illness potentially misrepresents the intricacies of the experience and minimizes the continuing assistance and support that those living with chronic illnesses often require.

In conclusion, in this article, we have delineated the attributes for the concept of self-reformulation and stipulated its application to individuals who have faced death. In so doing, we have assisted to clarify the conceptually muddled literature combining self-reformulation and self-transcendence. As participants emerge from suffering into self-reformulation, they are inspired to re-order priorities, to give back to others, and even to cherish the experience of suffering. While some participants knew that their illness might still limit their lives, death was no longer a threat, and they determinedly lived life to the fullest. Surely, we wish this therapeutic goal for all of our patients. More importantly, it expands our notion of health to a notion of ultimate health that is realized by living life to the fullest and making the most of every moment, regardless of physical status intrinsic to the experience evidenced in our participants. The lives of these individuals were uniquely enhanced by the intimate knowledge of mortality that propelled this shift in consciousness.
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