

## EMPIRICAL STUDIES

**Hope in action—facing cardiac death: A qualitative study of patients with life-threatening disease**MARGRETHE AASE SCHAUFEL, PhD<sup>1,2</sup>, JAN ERIK NORDREHAUG, PhD<sup>2,3</sup>, & KIRSTI MALTERUD, PhD<sup>1,4</sup><sup>1</sup>Department of Public Health and Primary Health Care, University of Bergen, Bergen, Norway, <sup>2</sup>Department of Heart Disease, Haukeland University Hospital, Bergen, Norway, <sup>3</sup>Institute of Medicine, University of Bergen, Bergen, Norway, and <sup>4</sup>Research Unit for General Practice, Uni Health, Bergen, Norway**Abstract**

Coping with existential challenges is important when struck by serious disease, but apart from cancer and palliative care little is known about how patients deal with such issues and maintain hope. To explore how patients with life-threatening heart disease experience hope when coping with mortality and other existential challenges, we conducted a qualitative study with semi-structured interviews. We made a purposive sample of 11 participants (26–88 years) who had experienced life-threatening disease: eight participants with serious heart disease, two with cancer, and one with severe chronic obstructive pulmonary disease. Analysis was by systematic text condensation. The findings showed that hope could enhance coping and diminish existential distress when patients were confronted with mortality and other existential challenges. Hope was observed as three types of dynamic work: to shift perception of mortality from overwhelming horror toward suppression or peaceful acceptance, to foster reconciliation instead of uncertainty when adapting to the new phase of life, and to establish go-ahead spirit instead of resignation as their identity. Meaning of life could, hence, be sustained in spite of serious threats to the persons' future, everyday life, and self-conception. The work of hoping could be supported or disturbed by relationships with family, friends, and health care professionals. Hope can be regarded as an active, dynamic state of existential coping among patients with life-threatening disease. Physicians may support this coping and thereby provide personal growth and alleviation of existential distress by skillfully identifying, acknowledging, and participating in the work of hoping performed by the patient.

**Key words:** Heart disease, existentialism, mortality, hope, qualitative research, trust*(Accepted: 13 February 2011; Published: 18 March 2011)***Introduction**

Coping with existential challenges among patients with life-threatening disease has been increasingly explored concerning cancer and palliative care (Hench & Danielson, 2009; LeMay & Wilson, 2008). Though existential issues need not result in distress (Blinderman & Cherny, 2005), it is important for health care providers to be able to identify and address these aspects of patients' experiences due to potential negative consequences like anxiety, depression, and loss of will to live (Chochinov et al., 2005; McCoubrie & Davies, 2006) as well as predicting positive outcomes (Vollman, LaMontagne, & Wallston, 2009) and understanding

complex decision-making processes (Schaufel, Nordrehaug, & Malterud, 2009). *Existential distress* is “the distressed state of an individual confronting their own mortality, and arising from the consequent feelings of powerlessness, futility, meaninglessness, disappointment, remorse, death anxiety and the disruption of personal identity; the experience of life without meaning” (Kissane, 2000). Physicians who intend to support patients in these states need knowledge and skills that focus on the individual person and narrative understanding (Charon, 2006; Greenhalgh & Hurwitz, 1999; Sundin, Bruce, & Barremo, 2010), enhancing the patient's strong sides (Hollnagel & Malterud, 1995).

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Little is known about how cardiac patients are confronted with existential challenges (Selman, Beynon, Higginson, & Harding, 2007) and how they experience hope when exposed to life-threatening heart disease (Davidson, Dracup, Phillips, Daly, & Padilla, 2007a). In a study among terminally ill persons, *hope* was described as “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985). Hope is viewed as a central yet complex phenomenon when facing life-threatening disease (Johnson, 2007; McClement & Chochinov, 2008), and the conceptualization and meaning of hope among cardiac patients need further investigation (Davidson et al., 2007a; Kristofferzon, Lofmark, & Carlsson, 2008; Rustoen, Howie, Eidsmo, & Moum, 2005). Based on this knowledge gap and our clinical experience with patients with serious heart disease in hospital (MAS and JEN) and general practice (KM), we chose cardiac patients as our main sources when we wanted to develop knowledge about how people experience hope when confronted with serious disease and mortality.

## Objective

We set up a study to explore how hope can be experienced by patients with life-threatening heart disease when coping with mortality and other existential challenges.

## Methods

We conducted a qualitative study based on semi-structured, individual interviews (Kvale, 1996). Such interviews are suitable to develop knowledge about experiences, compared to, for instance, observational studies where there is no access to what is behind actions and expressions. We chose individual and not group interviews as the topic may be regarded as deeply personal and thereby easier to discuss in a one-to-one setting.

## Ethics statement

This study was conducted according to the principles of the Declaration of Helsinki. Ethical approval was obtained from The Regional Committee for Medical Research Ethics (nr 06/1943) and The Norwegian Social Science Data Services (nr 14818). Informed consent was obtained from all participants.

## Participants

The first author (MAS) interviewed individuals constituting a purposive sample of 11 participants (six women) aged 26–88 years, where diversity regarding age, sex, cardiac diagnosis, religion, and education was aimed for. Participants were recruited among patients at a cardiac department handling more than 6000 emergency admissions a year. They had all been struck by life-threatening disease including ventricular arrhythmias, STE-ACS (ST-elevation acute coronary syndrome), nSTE-ACS (non-ST-elevation acute coronary syndrome), severe mitral valve regurgitation, severe aortic stenosis, severe heart failure (New York Heart Association class IV), dilated cardiomyopathy (ejection fraction 20%), and pulmonary edema. In addition, one participant with metastatic breast cancer, one with lung cancer, and one with severe COPD (chronic obstructive pulmonary disease GOLD stage IV) from the same hospital were chosen to supplement and challenge the cardiac sample. The time between their first experience of the actual disease and the interview varied from 3 days to 11 years.

## Data collection

We used semi-structured interviews (16–71 min) to collect data April 2007 until May 2009 (Kvale, 1996). The interviews took place in the hospital. The questions covered experiences of existential character related to their illness, taking Vetlesen’s unalterable fundamental conditions of existence as a starting point (mortality, vulnerability, dependence, existential loneliness, and the fragility of relations) (Vetlesen & Irons, 2009). The participants were asked questions like “Could you tell me about a situation in your illness trajectory where you faced mortality in a particular way?” After the first five interviews and preliminary analysis, the interview guide was revised closer to everyday language with questions like “How has the illness affected you as a human being?” Interviews were audio-taped, transcribed, and encrypted. Data collection was closed when saturation was achieved and new main issues did not appear in subsequent interviews.

## Analysis

The analysis was performed in collaboration by the authors MAS and KM following systematic text condensation (Malterud, 1993). Analysis proceeded through the following stages: (1) reading all the material to obtain an overall impression, bracketing previous preconceptions; (2) identifying units of meaning, representing different aspects of the

participants' existential experiences of hope, and coding for these; (3) condensing and abstracting the meaning within each of the coded groups; and (4) summarizing the contents of each code group to generalized descriptions and concepts reflecting the most important aspects of existential experiences of hope reported by the participants. When the main themes were identified after thorough discussion between MAS and KM, the units of meaning were systematically obtained by scrutinizing the text line by line, looking for material that could shed light on the study's objectives. At the last analytical stage (4) we assessed our findings' relevance by comparing them to existing empirical studies and theory on the matter, thereby deciding the need for additional analytical discussion and review. Analysis was done stepwise with new interviews supplementing the sample, and a decision trail (Whitehead, 2004) documented the choices during the analytical process. We used an inductive editing analysis style as described by Crabtree and Miller (1999). Their theories add further perspectives to how the analytical process is conducted, particularly to which extent it is theory-driven, data-driven, or obtains an in-between, editing position like the one we have chosen. This analytical position allows the categories to be developed from the empirical data while at the same time acknowledging that the theoretical framework will influence the patterns identified. Inspired by Vetlesen, our findings reflected different aspects of his unalterable fundamental conditions (Vetlesen & Irons, 2009), but were not organized in a theory-driven template analysis style. Comparison between different patient categories was done after all the interviews had been incorporated into the analysis by extracting the non-cardiac participants' material from the rest. After the differences and similarities had been studied and evaluated, the non-cardiac participants were reintegrated to illustrate these findings.

## **Findings**

Hope could enhance coping and diminish existential distress when patients were confronted with mortality and other existential challenges. Hope was observed as three types of dynamic work: to shift perception of mortality from overwhelming horror toward suppression or peaceful acceptance, to foster reconciliation instead of uncertainty when adapting to the new phase of life, and to establish go-ahead spirit instead of resignation as their identity. Meaning of life could, hence, be sustained in spite of serious threats to the persons' future, everyday life, and self-conception. The work of hoping could be

supported or disturbed by relationships with family, friends, and health care professionals.

The cardiac patients normalized their condition to a greater extent than the non-cardiac sources, who seemed to be more intensely confronted with death. However, they all focused on positive aspects of their lives, their abilities, and meaningful relationships when performing the work of hoping. Below we elaborate especially on the findings from the cardiac sample.

### *Perceiving the realities of death—between overwhelming horror and peaceful acceptance*

The experience of hope was described in a variety of ways among participants when confronted with death and mortality. Some of them said that they did not want to admit that their symptoms could be that serious and became overwhelmed when given the diagnosis. One described it like being startled, as if someone had slapped his face. Thoughts and concerns about their children, spouse, and job flashed through their mind. A dawning horror could be experienced as an atmosphere of seriousness filling the room and procedures like urinary tract catheterization being carried out with little information. A woman in her 40s with severe heart failure described it like this:

It was one shock after the other, and they talked about heart transplant, and I had an ICD [implantable cardioverter defibrillator] implanted. And I haven't managed to digest it all yet, because it's been such a short time and I am still working on it. (Megan)

As a contrast, quite a few participants stated that they were not anxious nor feeling especially vulnerable or confronted with death even though they had experienced serious and life-threatening heart disease. They chose to think they would have a good prognosis, and viewed death as something natural that would happen to everyone some day. Dying from a heart attack was even perceived to be a good death, described as just turning off the light. Several were spiritual or religious, but did not specifically seek consolation or strength in their faith when coping with illness and mortality. The older participants had a particularly relaxed view on death. They lived from one week to another, not looking far ahead, expressed by a vital woman in her 80s suffering from severe mitral valve leakage:

If I don't undergo surgery, the physician said I would have from 4 months to 1 year more to live with the [valve] leakage I have today. He asked if I

was afraid I might not wake up again, but I've got nothing to lose, so I don't care. Either I will see my [deceased] husband again, or I will meet the angels working on this ward. (Clare)

A striking similarity in peaceful acceptance was declared by one of the youngest participants, describing hope in a peculiar way. Being in her 30s and knowing that her cancer disease was terminal, she did not connect her hope to being cured but to a meaningful present:

I don't have a hope for a future because I've realized that I don't have a future. And it doesn't hurt to think about it, because what I'm doing is having a good time right now. My hope is not connected to the length of a future, but to the contents of the present. (Angela)

*Adapting to the new phase of life—between reconciliation and uncertainty*

All of our participants with cardiac disease focused on the positive sides of life and everything they could be grateful for. They tried to reconcile themselves with the situation, valuing the level of functioning that they had. Some of them regarded themselves as being fortunate compared to those worse off. Many of them were content with their life as it was, although marked by illness. Similarly, the participants with non-cardiac disease tried to forget about the symptoms and clung to a positive attitude. Maintaining a good spirit and humor was important to them. It was acknowledged as part of life to cope with the different ups and downs and they just had to make the best of it, expressed by this man in his 70s admitted with acute coronary syndrome:

I'll just have to live with it. You cannot keep pondering on it. It's useless. You have to take what comes in this world. There's not much more you can do about it. You could take your precautions, you know, but apart from that there's not much you can do. (Jordan)

As a contrast, some struggled with a profound sense of uncertainty. They were afraid how the disease might progress, what the future would be like, and were troubled by death anxiety. Uncertainty was increased by discontinuity and insecurity of not knowing who your physician would be from day to day, and difficulties understanding the messages delivered to them by the physicians. They stated that the most important thing for them to feel secure would have been more information and the experience of being listened to. Struggling with anxiety

some lay awake at night, like a man in his 20s with recurrent ventricular tachycardia, afraid of another episode of arrhythmia:

I'm very cautious. I don't dare to exercise or push myself, because I'm thinking maybe... (...) I've been awake many nights, not being able to sleep. I just seem to be lying there and feel my heart. It's disturbing. (Charles)

*Identity as seriously ill—between go-ahead spirit and resignation*

Both the participants with heart disease and the ones suffering from non-cardiac illness revealed eagerness and motivation to fight the restrictions of the disease and make life style changes. They wanted to go back to work and handle as much as possible on their own. They identified themselves strongly with being persons that did not give up and forced themselves forward. Some engaged in meaningful hobbies, giving them a sense of achievement. Reaching some of their goals, like being able to perform some tasks at work or be useful to others, was experienced as rewarding and inspiring and made them proud. They valued and revealed their own strengths, like the oldest participant approaching her 90s:

He [the physician] said: "We've done some investigations. It looks like you're a very strong lady." And I heard it when they were performing the thing down here [gastroscopy]. I didn't move a finger. (...) No, I didn't make a single move. And then he told the one next to him: "This is an exceptionally stable lady." (Clare)

On the other hand, some of them faced hopelessness, helplessness, and inadequacy. At some point they doubted that they would recover, and were so ill that they were not able to manage basic tasks like eating, washing themselves, or getting dressed. This was experienced as one of the worst parts of being severely ill both by the cardiac and non-cardiac participants. Some of them literally felt as if their heart was worn out and hope was gone. Asking for help was difficult, as they naturally preferred to be independent. They felt sorry they could no longer do all the things they wanted or had been used to, like this woman with dilated cardiomyopathy:

I try to go for a little walk and keep feeling this inadequacy. (...) It's hard when you sense that you cannot do what you want. I spent an evening being totally depressed because I'll maybe never

learn how to snorkel. (...) I'm only 40 years old.  
(Megan)

*The impact of relationships—between support and concern*

Almost everyone in this study pointed to the great importance of spending time with family and friends by whom they felt supported and cared for. Several of them obtained hope and inspiration from knowing and talking to friends or relatives who had survived the same disease and who now lived good lives. Some of the cardiac participants were leaning on the fact that coronary heart disease is common. If others had survived it, so would they. A common hope for the present and for the future was expressed by the spouse of one of the participants suffering from acute coronary syndrome, ventricular tachycardia, and heart failure:

It's actually been almost 8 years now that he's been well. And now he's getting this heart starter. Then we hope everything will be ok this time, too.  
(Anne)

The work of hoping described above could also be challenged and disturbed by relationships. Some of the non-cardiac as well as some cardiac participants said that their disease was just as horrible or even worse for their significant others to cope with. Discussions and interactions could be difficult. Children were a source of inspiration and meaning but could also cause tremendous worries, expressed by a man in his 50s suffering from lung cancer:

She [daughter] had read on the Internet, and of course she was worried about her father. It would have been horrible if she wasn't. And she finds it hard to talk about. But what constitutes the difficulty is this: are you gonna die from it?  
(Geoffrey)

The feeling of being taken care of by skilled personnel provided the participants with hope. The majority of them displayed a profound trust in the health care professionals, and they got relieved when the physicians said that everything would turn out fine or that together they should do something about it. The opposite was experienced when they felt that the physicians did not know exactly what to do and what illness trajectory to expect. They scrutinized the meaning of the physicians' words in order to find out if they were going to die or if they could be cured. Most of them felt secure and content at the hospital, expressed like this:

I'm under total control and assume that they [the physicians] are doing their best. That's how it appears to me. Someone out on the streets might be more exposed than I am as a patient. (Paul)

## **Discussion**

This study has demonstrated how patients with life-threatening disease may apply hope when coping with mortality, their new life situation, and identity. Below, we discuss the strengths and limitations of the study design and the impact of our findings.

### *Validity and transferability*

The interviews took place in the hospital in which the participants presently received treatment and were performed by an affiliated physician. However, their balanced accounts of both positive and negative aspects of the care received and their personal life make it likely that they disclosed their stories in honest terms. The asymmetrical power relation was somehow reduced by the fact that the interviewer was a woman of young age. Timing of the interviews also had an impact on the data. Several of the participants with acute coronary syndromes, where rapid and effective treatment is available, were interviewed a couple of days after the intervention and gratefully focused on being alive and well treated. Their answers probably illustrated how coronary intervention may instill a placebo effect against existential challenges because of its strong symbolic meaning of technical protection from death.

The theoretically based concepts in the initial interview guide were too complicated for some of the participants. Developing new questions based on their own language made our data collection more tuned to their authentic stories. We did not ask specifically how they experienced hope, but converged around this concept from the various descriptions of participants' challenges as patients. Applying an inductive bottom-up method, we approached at the meaning, content, and function of the concept "hope in action," which gives our material additional relevance and pragmatic validity compared to other studies. Our goal was not to estimate hope related to a certain point in an illness trajectory, but to develop knowledge about how this can be experienced and enacted when struck by serious disease.

Our participants were mostly suffering from heart disease and recruited from one hospital. However, the fact that their diagnosis, age, and time lived with the disease varied considerably and adds

transferability to the material. The accounts of the participants with non-cardiac illness also demonstrated a similar work of hoping to maintain their identity, everyday life, and meaning, although they seemed to normalize their condition to a lesser extent. Thus our findings may be applied in other clinical contexts where an illness is potentially life-threatening. Our study was, however, carried out in a modern western hospital with only White participants and the majority described themselves as either Christians or non-religious. The results may, therefore, not be transferable to a different cultural and religious setting.

### *Hope as existential coping*

The findings of this study are consistent with previous research demonstrating how cardiac patients may face existential uncertainty (Bremer, Dahlberg, & Sandman, 2009; Jensen & Petersson, 2003), death (Stromberg & Jaarsma, 2008), challenges regarding relations and self-conceptions (Leegaard & Fagermoen, 2008), and yet create a sense of coherence (Antonovsky, 1987; Norekval et al., 2009). We also confirm the importance of different attributes of hope when experiencing life-threatening disease (Johnson, 2007; Roberts, Johnson, & Keely, 1999) and the association between hope and coping (Felder, 2004; Herth, 1990). Our study adds to previous knowledge by presenting empirically based descriptions of how patients perform a dynamic work of hoping when facing mortality within the curative paradigm of cardiology. It demonstrates how these patients cope with existential challenges by applying hope to fight existential distress, and shows how physicians are in a special position of supporting or disrupting the work of hope among their patients. This can serve as a basis for developing supporting strategies among physicians and other health care professionals. Our study also provides more knowledge about how patients with life-threatening disease perceive their situation and offers guidance to how existential distress can be approached. It deepens our understanding of similarities and differences of experiencing severe heart disease compared to other serious illnesses.

Patients' wish and need to live a normal life and "false optimism" about recovery has previously been presented in cancer research (Bertero, Vanhanen, & Appelin, 2008; The, Hak, Koeter, & van Der Wal, 2000). These patients may be viewed by some health care professionals to be in a state of denial, even though they are actually coping with their life-threatening illness (Wilkinson, 1996). Coping strategies among cardiac patients have been described as

avoidance, disavowal, denial, and acceptance (Buetow, Goodyear-Smith, & Coster, 2001). Disavowal in this context can rather be considered a "healthy denial," through which "patients, who basically understand the threat to their life situations, seek hope through positively reconstructing this threat" (Buetow et al., 2001). This coping strategy resembles the way our participants reached a state of reconciliation. Learning from the patients about the different elements of hope that are helpful to them and can be nurtured is essential to facilitate coping (Herrestad & Biong, 2010). By understanding the multidimensionality of hope, physicians may contribute to a salutogenic effect helping the patients to create meaning in their new life situation and address important issues of concern:

[A]cknowledging of the changing of life circumstances; restructuring of daily life and expectations; help in dealing with vulnerabilities; information, support and incorporation in care planning; and support to achieve normalization and resolution of uncertainty. (Davidson, Dracup, Phillips, Padilla, & Daly, 2007b)

From an existential point of view, the unalterable fundamental conditions of existence offer conceptual tools relevant to health care for perceiving what constitute our lives and our interactions (Aase, Nordrehaug, & Malterud, 2008; Schaufel et al., 2009; Vetlesen & Irons, 2009). These conditions are universal characteristics of human life, comprising certain given phenomena we cannot avoid or escape as human beings. Mortality as an unalterable condition for being human must be acknowledged in health care despite technological advances in order to impart honest information and provide adequate care. Thus, the entire field of cardiology—not only the domain of heart failure—may profit by integrating knowledge from palliative care (Goodlin, 2009) where the different dimensions of human life are dealt with in order to promote the patient's quality and authenticity of life *and* death.

### **Conclusions**

Hope can be regarded as an active, dynamic state of existential coping among patients with life-threatening disease. Physicians may support this coping and thereby provide personal growth and alleviation of existential distress by skillfully identifying, acknowledging, and participating in the work of hoping performed by the patient. This implies attentive listening and adequate information, as well as helping the patient focus on personal resources, supporting relationships, and meaningful activities.

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