

## Utilizing Bodily Knowledge in Patients with Chronic Illness in the Promotion of their Health: A Grounded Theory Study

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### Abstract

**Purpose:** Research findings indicate that people diagnosed with chronic illness possess resources and strategies for health that are not fully recognized and utilized. These resources have been described as patients' embodied knowledge of health and illness. The notion of embodiment as an essential part for health is a relatively new idea in modern Western society and is poorly theorized in models for health promotion. This study explored patterns of patients' experiences/bodily knowledge and actions that contribute to well-being and health in chronic illness. This study is the first to examine Bodyknowledging, which is a process that describes the utilization of bodily knowledge to engage in health-related change. **Methods:** Grounded theory methodology informed data collection and analysis. In-depth interviews were conducted with 56 men and women who were diagnosed with chronic obstructive pulmonary disease, inflammatory bowel disease or stroke. **Results:** Participants' main concerns were the uncertainty, hindrances and limitations of life space introduced by illness. Bodyknowledging, revealed patients' embodied knowledge of coping and health as a powerful resource for successful disease management, prevention of relapses and promotion of health. **Conclusion:** The findings illuminate the importance of attending to personal resources and relational aspects of health, and it adds to the empirical and theoretical basis for utilizing peoples' embodied knowledge in health promotion.

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### Introduction

Chronic illness occurs across the life span. It strikes men and women from different socioeconomic levels and has a serious impact on quality of life. The reasons are varied and often unknown, but better living conditions, improved sanitation and nutrition, and improved disease management have contributed to survival from diseases that previously resulted in premature death. With increased longevity, chronic illness has become the main cause of death and disability worldwide (Carrier, 2009; Department of Health, 2004).

WHO's first report (2010) on non-communicable diseases (NCDs), states that of 57 million global deaths in 2008, 36 million were due to NCDs—mainly cardiovascular diseases, such as stroke, cancer, or diabetes; and lung diseases, mainly chronic obstructive pulmonary

disease (COPD). Data on prevalence are often hard to find and vary among countries. In the United States, 6.3% of adults have been diagnosed with COPD, while in Europe the prevalence varies from 4 - 10% (Kosacz et al., 2012; Halbert et al., 2003). In the United States, the prevalence of stroke in 2010 was 2.6% (Jing et al., 2012). A review of data from Iceland, Norway, Switzerland, and the EU reports that stroke events will increase from 1.1 million per year (in 2000) to 1.5 million per year by 2025 (Truelsen et al., 2006). The prevalence of other chronic illnesses, such as inflammatory bowel disease (IBD), is lower but also projected to increase (Molodecky et al., 2012; WHO, 2010).

### Health Promotion in Chronic Illness

The epidemic proportions of chronic illness necessitate new models of health care that mobilize patients' psychological resources and embodied knowledge along with medical

treatment and expertise. It is important to increase patients' ability to manage their condition, to enhance health and well-being, and to maintain or improve their levels of functioning (Kaplun, 1992; Kralik et al., 2010; Swartz & Dick, 2002; WHO, 1992, 2005). These new models should be easy for the layperson to understand and apply, and be useful for health promoters in practice. Research findings indicate that people who are diagnosed with chronic illness possess resources and strategies for health that are not fully recognized and utilized. These resources have been described in terms of practical knowledge established by the experience of living with the condition over time. The concepts of bodily intelligence, 'the skilful body', and embodied knowledge have been used to describe these resources (Merleau-Ponty, 1994; Benner, 1994; Benner & Wrubel, 1989; Corbin, 2003).

### **Embodied Knowledge as a Resource for Health in Chronic Illness**

The notion of embodiment as an essential part of health is a relatively new idea in modern Western society and is poorly theorized in models for health promotion. Thus, embodied knowledge, that is, people's bodily sense of how to live in their own bodies, may be regarded as an untapped resource with the potential to strengthen people's health. The concept of embodied knowledge is closely connected to the French philosopher Merleau-Ponty's (1994) phenomenological theory that points to the subject role of the body as an intentional entity that is bound up with, and directed toward an experienced world as the person relates to other people, things, and the environment. The body is a subject and an object at the same time, both perceiver and perceived, intentional and material (Leder, 1992; Toombs, 1988, 1993). Phenomenology rejects Descartes' mind-body dualism and therefore suggests new ways of thinking about health and illness.

Watson et al. (1996) argue that any theorizing about the body should be grounded in lay accounts of health and illness and should be incorporated into health promotion theory.

While there is a great deal of research on the embodied experience of chronic illness (Corbin

& Strauss, 1988, 1992; Anderson & Bury, 1988; Toombs, 1988, 1993; Morse & Johnson, 1991; Leder, 1992; Frank, 1995; Thorne et al., 2000, 2003; Corbin, 2003), there have only been a few attempts to describe the significance of embodied knowledge for health and well-being in chronic illness. One example is Benner and Wrubel's research (1989) in which personal practical knowledge of health promotion is embedded in the person's experience of managing their illness. Morse (1997) describes how patients diagnosed with illness experience bodily changes through stages of uncertainty, disruption, and striving to regain self, and how this process helps the person endure suffering. Wilde's research (2003) on embodiment in chronic illness depicts how individuals handle chronic illness by approaching the body as if it were a friend or a silent informant. Paterson et al., (2001) present "the shifting perspectives model", in which people experience shifts between having illness or wellness in the foreground. They argue that it is not clear what contributes to shifts to a wellness-in-the-foreground perspective.

### **Embodiment and Health in Patients Diagnosed with Stroke, COPD and IBD**

Very few studies illuminate embodied knowledge as a resource for health in relation to specific diagnostic categories. One example is Doolittle's study (1992) in which stroke survivors describe their body as a foreign object that they had to command to do certain tasks. Six months after the stroke, patients were only beginning to integrate a new body image. Patients tried out their resources in a brave way, and experienced hope and joy with the attainment of activities they valued before the stroke. Murray and Harrison (2004) describe the experience of stroke in relation to four themes: 1) disrupted embodiment and loss of self, 2) invisibility of emotional difficulties, 3) gender, romance and sexuality, and 4) social interaction. Price (1993) explored health and self-management in patients with asthma and diabetes and found that they used "body listening" to control the illness and to avoid getting into situations where their activities and goals could be restricted. Gullick and Stainton (2008) tell how lung patients experience a

“shrinking life-world” shaped by breathlessness. Patients developed strategies of conscious body management to facilitate breathing, mobility and task completion. Brydolf and Segesten (1996) described how patients diagnosed with ulcerative colitis experienced changes in bodily sensations and how the disease reduced their living space, but also how social support and self-confidence contributed to coping and health.

These research findings above have illuminated the importance of attending to the subjectivity of the body in initiatives for health in chronic illness. However, there is a lack of knowledge about the content of embodied knowledge in chronic illness, how it develops within patient experience, and how it contributes to health and well-being. The purpose of this paper is to describe the outcomes of a study that explored how patients draw on bodily knowledge, experiences, and actions to promote well-being and health within chronic illness. The findings of this study provides empirical evidence for the framework of Bodyknowledging, which was developed in dissertation research and is available in Norwegian (Heggdal, 2003). This study is the first to examine Bodyknowledging. The Bodyknowledging framework can be used to develop health promotion interventions for people at risk for, or diagnosed with, long-term illness.

**Method**

Grounded theory methodology informed data collection and analysis (Glaser, 1992). Qualitative data was collected from patients with three types of diagnoses: stroke, chronic obstructive pulmonary disease (COPD) and chronic inflammatory bowel disease (IBD). The research question was: How do people diagnosed with long-term illness promote their health and what resources for health do they describe?

**Participants**

Participants were chosen from lists of patients who had received medical treatment 6-12 months before in a general hospital located in a

**Table 1**

**Patient material grounding the concept and theory of Bodyknowledging.**

	Men	Women	Total participants	Total interviews
Stroke	8	9	17	17
Chronic Obstructive Pulmonary Disease (COPD)	10	13	23	25
Chronic Inflammatory Bowel Disease (IBD)	7	7	14	19
<b>Total</b>	<b>25</b>	<b>29</b>	<b>54</b>	<b>61</b>

city on the west coast of Norway. Medical doctors who were specialists in COPD, IBD and stroke assisted with the recruitment.

Initially, the sampling was conducted to maximize variation according to functional capacity, gender, age, social background, and duration of illness (1-10 years). Patients received a letter of invitation containing information about the purpose of the research and an assurance that their decision to participate would not have any consequences for their future treatment or relations with the hospital. The researcher’s name, address and telephone number were provided for volunteers to return their answers. About 65 persons were contacted and the final sample consisted of 56 individuals from 18 to 88 years old. All 56 participants satisfied the following inclusion criteria: that their condition had persisted for more than six months, had had an impact on their daily life and functioning, and had required monitoring and implementation of specific management measures (Rolland, 1987). Table 1 presents an overview of the sample. Ethical approval was granted by the Regional Medical Ethics Committee in Bergen, Norway and by the Norwegian National Social Science Service.

**Data Collection**

Data was collected by means of in-depth interviews with individual patients in their homes or at the researcher’s office, according to the participants` choice. Interviews lasted 60-90 minutes. Participants gave their consent for the interviews to be audio taped. The preliminary

interview guide was modified as the conceptual framework emerged. The core interview questions were: How do you experience your life with long-term illness? How do you experience your body? How do you cope and strengthen health and well-being?

Active listening was emphasized to encourage participants to describe their experiences and follow-up questions were posed to gain a deeper understanding. Five participants were interviewed twice in order to achieve saturation. The final data set consists of 61 qualitative interviews representing three diagnostic groups—a rich empirical basis for comparative analysis. All interviews were transcribed to text. Data analysis was performed within each diagnostic group before analyzing the data across groups.

### Analysis

In grounded theory methodology, data collection and analysis is performed concurrently as the conceptual framework is developed inductively from the empirical data through the steps of open, selective, and theoretical coding (Glaser, 1978, 1998, 1992). Open coding implies line-by-line analysis, in which words, phrases, sentences, and the interview as a whole are examined while analytic questions are posed to the material, such as: “What is this data a study of? What are the participants’ main concerns? How do they address their main concerns?” (Glaser, 1978, p.57). Through a process of open coding and constant comparison of incident with incident, different categories emerged from the transcripts such as: “knowing oneself”, “knowing one’s limits”, “health promoting strategies”, and “the impact of social relations”. Memos were written to explore how categories related to one another, to discover specific

concepts, or to identify where more data was needed.

### Results

The participants’ main concerns were “uncertainty”, i.e. about how their condition was going to develop, and “the limitation of life space” (the sphere to act within one’s daily life) introduced by long-term illness. The patients’ embodied knowledge of health and illness stood out as a key concept and a powerful tool for managing their situation. In line with the principles of theoretical sampling, the concept of “embodied knowledge” guided further study of the empirical material and the literature in order to conceptualize a possible process resolving the participants’ main concerns (Glaser, 1992). Embodied knowledge of health was multifaceted and often nonverbal. It became a useful resource through a process of alternating phases of learning and health-related change. A main result of the study was identifying this process and formalizing it in the theory of “Bodyknowledging”. The theory elicits how persons’ embodied knowledge is developed as a resource for health through a dynamic, nonlinear process of interaction with the environment. Bodyknowledging can be defined as “a fundamental process for the development of personal knowledge about one’s own body, coping skills, health and wellbeing” (Heggdal, 2008, p. 34). The following Bodyknowledging phases were derived from the study participants’ descriptions of their health promoting process:

- Uncertainty—denying and escaping the sick body,
- Losing life space—grieving and anger,
- Listening and understanding the body’s signs—strengthening hope, and
- Integrating embodied knowledge—new possibilities for well-being and health.

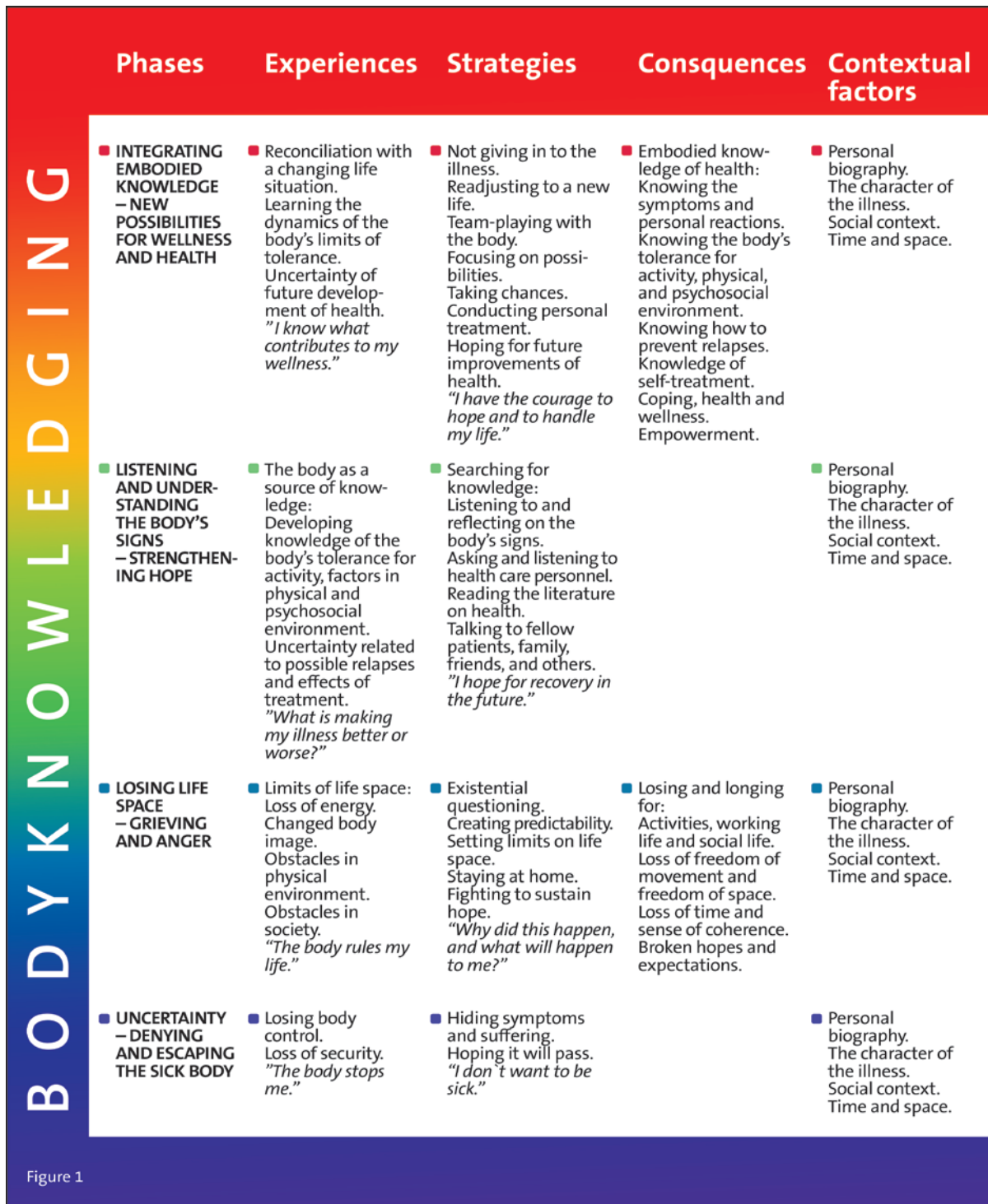


Figure 1

Figure 1 offers an overview of these phases as they relate to participants' experiences and coping strategies, the consequences of those experiences and strategies, and some contextual factors. The next sections examine each phase more closely, with excerpts from participant

interviews (identified by gender and medical diagnosis) for illustrative purposes.

### Uncertainty—Denying and Escaping the Sick Body

This phase occurs when the person notices that his/her body is behaving strangely and that

normal function is no longer possible. The uncertainty of the unpredictable body, and the loss of the safety of being a healthy person, is threatening. The breakdown of taken-for-granted bodily capacities is an important part of this process, making way for the creation of new embodied knowledge by means of experiencing and reflecting on the sick body's reactions. However, the experience of uncertainty is profound, as the person does not know the meaning of the symptoms or the strategies for alleviating them:

I was seventeen when the illness hit me. I got terrible diarrhea and bleeding and had to go to the toilet all the time. I was very tired, felt terrible, and was scared, and I didn't quite understand what it was. I thought I was in bad shape, so I went to a health studio and pushed myself through the exercises and went to work. Then, the illness burst out totally. (Woman: IBD).

Symptoms can be frightening and feelings of anxiety may arise. The person may try to escape the situation by denying or hiding the awareness of bodily changes. However the symptoms strike again and again, creating the experience that 'my body is stopping me', as if the body is a foreign object or an enemy—an obstacle to the unfolding of one's life.

### **Losing Life Space—Grieving and Anger**

This phase is dominated by the experience of loss and of limits on activities the person values as important. Body image may change in response to the nature of the illness. Factors in the physical environment such as the quality of the air, types of food, or seasonal conditions may have new significance if they have a negative impact on the condition. The hallmark of this phase is the experience that 'my body rules my life'. A tension has arisen between the will of the person and the body's way of functioning. Now he/she must face the knowledge that the illness is not going to disappear anytime soon. Instead it demands attention and represents an obstacle to daily life. Suffering can be profound as the person's sick body inhibits functioning and deprives them of

the energy and time for work, leisure activities, and social life. Losses are grieved as many broken hopes and expectations must be faced:

Two years ago, when I got ill, I was very depressed because I had to stop dancing. I was very concerned about everything I couldn't do. This is a process of grieving that chronically ill persons have to live through. You have to let it come into you and let the grieving come out, because you've lost the most fundamental thing in your life. Suddenly you have to change your life totally, and this needs time. You have to work on it, learn to breathe in a new way, relax in the body (Woman: COPD).

Participants held the view that it is important to allow oneself to grieve and to be angry because one must realize that life has changed and one's future health status is uncertain. The ill person engages in existential questioning—'Why has this happened?' The person puts limits on his/her activities and withdraws from social life. Although this may be necessary to prevent relapses and to establish a sense of control and safety, these strategies do not promote health in the long term. Data analysis revealed that some people remain "stuck" in grieving and anger, in which case the process of health promotion turns into a process of hopeless deterioration. Persons diagnosed with chronic illness need confirmation that their grief and anger is valid. They also need support to explore their 'new' body as an important source of knowledge about health. Some may need to be challenged to clarify their goals and needs in order to move on in their process of health promotion.

### **Listening and Understanding the Body's Signs—Strengthening Hope**

Grieving prepares the way for learning. Through time and lived experience, most people become motivated to move on and learn about the illness and how it may be handled. The central theme here is getting to know the body's tolerance levels—for different types and magnitudes of activity, for social interaction, and for factors in the physical environment (i.e. food, air, temperature). Participants' experiences revealed

that learning to observe, listen to and interpret one's bodily reactions—and being in dialogue about these experiences with significant others, health care personnel, and fellow patients—facilitated the health promoting process. Participants also read the literature on their conditions. These sources provided information on common symptoms, possible treatments, and the illness experiences of others. Participants valued all sources as important. However, they regarded their own bodies as the most valuable source of knowledge. It was through experiencing and reflecting on their bodies' reactions that they discovered what worked for them:

It is my body, and only I can know my body if I allow myself to know it, and that's what I've done and it has helped me a lot. You may tell a patient that he or she has to do this and that, but it's not certain that's the right thing to do—you have to find out for yourself. You have to learn to know your body, sit down, take it easy, and take responsibility for your body, because nobody can live for you. I have learned what happens when I get an asthma attack. What happens with my lungs, with my bronchi. It takes some time and requires that you search into yourself and ask: What do I want to do with my future? I'm 38 years old, do I want to feel sorry for myself, to only accept the impressions the doctors give me, or do I want to make my day positive? (Woman: COPD).

This quotation exemplifies how participants consciously chose to acknowledge their bodies, to listen to their bodies' signs and reactions, to reflect on and try to handle their own reactions, and to allow themselves to discover their personal style or strategy for well-being and health. Participants "researched" their potential for health with the following questions in mind: "What is making my illness better or worse? How can I prevent relapses? How can I treat myself? As they engaged in this process, different pieces of knowledge were integrated into a personal knowledge-base that helped the

person handle the uncertainty and life space limitations introduced by the illness.

### **Integrating Embodied Knowledge—New Possibilities for Well-being and Health**

The hallmark of this phase is reconciliation with the illness and a "peace-making" attitude described in the following way: "The illness is there, it walks by my side and I reckon that's how it's going to be." The person does not experience the sick body as an enemy, but as a travelling companion on the journey of life. This does not mean that there are no more symptoms, obstacles, or uncertainties. However, paying attention to embodied knowledge has yielded an understanding of how to manage the condition and how to promote wellness within the situation of chronic illness.

Participants developed and integrated knowledge about the body's tolerance limits and the possibilities for life unfolding in spite of illness. Their health-promoting strategies were varied and individually expressed. However, certain patterns emerged: not giving in to the illness, readjusting to a new life, focusing on possibilities, team-playing with the body according to actual capacity, hoping for future improvement of health and rejoicing in life. At this point the person has made conscious choices about the role of illness in life. The main focus is on possibilities instead of limitations:

It is a question of decision. I've had this illness for many years, and I'm active at work. The illness isn't allowed to play the first violin in my life, and not the second or third either. It's something I have to live with. Sometimes I have pain and I'm pissed off and sorry for myself, but I've decided that the illness isn't going to be the main part of my life (Man: IBD).

Self-care and preventive measures—such as balancing rest and activity, building and strengthening social relationships, engaging in daily activities, work and social life, emphasizing good nutrition, and thinking positively about oneself and one's life situation—had now become a part of the daily



routine. These strategies reduced the likelihood of relapse and prevented deterioration when a setback did occur. As the participants applied their embodied knowledge of health and coping on a daily basis, it was refined, integrated and expanded, constituting an important basis for health within illness.

### Discussion

The purpose of the study described in this paper was to explore how people living with long-term conditions experience and engage in the promotion of wellness and health. Qualitative interviews with patients diagnosed with chronic illness formed the empirical basis for a comparative analysis, resulting in the development of Bodyknowledging as a new framework for understanding health promoting processes on the individual level. Analysis showed that there are different phases of Bodyknowledging but no linear stages in the sense that one gets progressively better. There can be movement up, but also movement down, in and out of phases. It is not possible to say where the process (or particular phases) begins. Patients move among the phases differently, and one phase shades into another. Although patterns were evident, each person's process was unique. There was no predictable trajectory and no final phase. Hence, Bodyknowledging is to be understood as an ongoing process and activity in which new possibilities for wellness are established and renewed in the person's life (Heggdal, 2003, 2008). This is the first study to examine Bodyknowledging.

The need for re-establishing habitual knowledge as part of recovery has been described earlier (Benner, 1989; Merleau-Ponty, 1945/1994; Leder, 1992; Toombs, 1993, 1988; Morse, 1997).

However, the patient's process of re-establishing control, well-being and health through the process of Bodyknowledging is new and useful for understanding and supporting people who are living with long-term illness in their efforts to stay well. The theory was developed through a bottom-up strategy, and is consistent with the principles of empowerment approaches to health

promotion (Naidoo & Wills, 2000; Department of Health, 2001).

According to Davies and Macdowall (2006), theories and models of health promotion in the context of long-term illness should embrace the notion of 'health within illness' and acknowledge our embodiment as an important resource in this regard. Bodyknowledging exemplifies such an approach. The findings are in line with Benner and Wrubel's (1989) phenomenological theory of health in the sense that well-being is fully embodied, and that the possibility for change comes not through some sort of asceticism or denial of the body (mind over matter). Rather, "a coherent and resilient form of health and healing comes from "restoring the sense that the world and the body are trustworthy and capable" (1989, p.161).

This study represents a further development of the concept of embodiment in health as it provides a description of a dynamic, nonlinear process in which a sense of trust in the body is restored through the person's engagement in phases of Bodyknowledging. Thus, health is restored as the person's embodied experience of health and illness is integrated with the knowledge of physiological and psychological measures as part of the health promoting process.

Personal biography, the character of the illness, social context, and time and space were identified as factors that had an impact on the process. The analysis confirms the contextual and relational dimension of health by eliciting the importance of the person's dialogues within social relations and society about their experiences. Knowledge about the condition, understanding and hope were revealed as important properties of the social context, i.e. among family and friends, in the workplace or in health care settings.

Bodyknowledging theory shares some similarities with Morse's (1997) conceptual model (see "Responding to threats to integrity of self") such as the necessity to recognize physical changes and loss of function and to monitor and "read" the body in order to become accustomed



to the imposed limitations. However, the Morse model describes a causal movement through phases as if the person follows a predictable trajectory. This study reveals Bodyknowledging as a continual process of health promotion with no predictable trajectory and no fixed start or end point, but a dynamic movement up and down, in and out of phases as time passes.

The Shifting Perspectives Model introduced by Paterson et al. (2001) illuminates an ongoing process in which people experience shifts between having illness or wellness in the foreground. These shifts of perspective are also found in different phases of Bodyknowledging. The phases of ‘uncertainty—denying and escaping the sick body’ and ‘losing life space—grieving and anger’ correspond with Paterson’s description of ‘illness in the foreground’. A person’s experience of these phases is dominated by the sickness, suffering, loss and burden of chronic illness. Similarly, the phases of ‘listening to and understanding the body’s signals—strengthening hope’ and ‘integrating embodied knowledge—exploring new possibilities for well-being and health’ correspond with Paterson’s ‘wellness in the foreground’. The research presented in this paper adds by describing how shifts towards health are experienced in different phases and how peoples’ engagement in Bodyknowledging contributes to shifts of perspective. However, the findings of this study are contrary to Paterson’s view that ‘wellness in the foreground’ implies that “the self, not the diseased body, becomes the source of identity, as the body is objectified and placed at a distance, altering the relationship between mind and body so that the body is separated out there” (2001, p.23). It was not by distancing themselves from their bodies, but by listening to their bodies’ signs and responses that the study participants achieved a shift of perspective from illness to wellness.

Wilde’s research (2003) on embodiment illuminates how persons diagnosed with chronic illness approach their body as if it were a friend or a silent informant. The findings of this study validate this way of understanding the body as a resource for health and show the benefits of

using Bodyknowledging for the promotion of health.

### **Limitations**

Because the theory of Bodyknowledging was derived from the empirical experiences of participants representing several diagnostic groups, it is probably relevant for many kinds of long-term conditions. However, further investigation is necessary to test the relevance of the theory among, for example, young people under the age of 18 whose health is threatened, people on long-term sick leave due to functional problems, or people who are diagnosed with mental illnesses.

### **Implications for Practice**

The theory of Bodyknowledging has been tested for relevance as part of the research process and shown to be easy to understand for persons living with different kinds of long-term conditions. The research grounding the theory documents a process that promotes health by means of new strategies and actions that strengthen hope among sufferers and that increase their capacity to deal with the consequences of chronic illness. Bodyknowledging adds to the empowerment-oriented models of health promotion as it emphasizes the patient’s personal resources for health within illness. Bodyknowledging theory can be used to help patients, their significant others, and clinicians to learn to act as catalysts for health by encouraging patients to regain a sense of trust in their bodies’ knowledge of and powers for well-being.

### **Conclusion**

The concept and theory of Bodyknowledging was developed and grounded in empirical studies of people’s experience of living with different chronic illnesses. The theory embraces personal knowledge of the body as an important foundation for health promotion.

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