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**Miriam Hjeldsbakken Engevold**  
Universitetet i Oslo

**Kristin Heggdal**  
Universitetet i Stavanger

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# Patients' experiences with changes in perceived control in chronic illness: A pilot study of the outcomes of a new health promotion program in community health care

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**People diagnosed with chronic illness have the possibility to achieve positive changes in perceived control through engagement in the Bodyknowledging Program, write Miriam Hjeldsbakken Engevold and Kristin Heggdal.**

BY: Miriam Hjeldsbakken Engevold and Kristin Heggdal

An increasing number of people worldwide are facing chronic illnesses. About 52 million people in Europe aged 55–74 report that they have a long-standing illness or health problem, while in the U.S. approximately 133 million people are affected ([Harbers & Achterberg, 2012](#); [National Health Council, 2014](#)). Chronic illness has been defined as «the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability» ([Lubkin & Larsen, 2013](#), p. 6). Chronic illness disrupts many aspects of the individual's life, including physical, emotional, social, and vocational functioning ([Taylor, 2009](#); [World Health Organization, 2009](#)). Some of the main challenges are the *uncertainty* and the *loss of control* arising from changes in health and functioning ([Mishel, 1988, 1990](#); [Toombs, 1993](#)). A main consequence is that many individuals who are diagnosed with a chronic illness are at risk of developing emotional problems such as depression, anxiety, and distress in addition to their physical discomfort ([De Graaf & Bijl, 2002](#); [Mittermaier, Dejaco, Waldhoer, Oefflerbauer-Ernst, Miehsler, Beier, Tillinger, Gangl, & Moser, 2004](#))

The symptoms may appear as an unpleasant surprise to the person, they can be painful and frightening, fade away, and then appear again later, and the time before medical advice is sought may vary substantially. The person experiences the sensation that the previously ithooth functioning of the healthy body is being lost ([Corbin, 2003](#); [Frank, 2013](#); [Leder, 1992](#)). Uncertainty prevails, because there are numerous alternative interpretations of the meaning of the symptoms and reasons for their appearance. Questions patients have are: What type of illness it is? How it is going to develop? What are the possibilities for medical treatment? Uncertainty also concerns how the progression of the condition will affect the person's ability to participate in daily living activities, one's working capacity, and one's social functioning. Mishel (1981, p. 1) defined uncertainty as a «cognitive state created when an event cannot be adequately defined or categorized due to lack of information.» This definition implies

that the patient, the doctor, or other helpers do not know which factors cause the illness and therefore do not know how the problem can be diminished or «solved.» As a result, the affected person has to live with symptoms that seem to be inexplicable, and he or she often lacks the means to handle the situation. Depressed mood and anxiety are natural reactions to this state of affairs. Emotional distress in connection with uncertainty in chronic illness has been confirmed in research on stroke survivors, on patients with fibromyalgia, chronic pain, and cancer, and on a range of other patient groups (Ch'Ng, French, & Mclean, 2008; Lubkin & Larsen, 2013).

The experience of uncertainty in illness seems to be accompanied by the experience of a lack of perceived control (i.e., the lack of belief that one can influence one's own behavior, the environment, and the desired outcome) (Taylor, 2009). Anderson and Bury (1988) described the loss of control in chronic illness as biographical disruption in which the person is cast out of his or her life plans, social roles, and daily activities into a life situation dominated by uncertainty and identity crisis. Toombs (1988, pp. 206-207) argues that corporal identity is the basis of self and that long-term illness not only implies the loss of this corporal identity but also deprives the person of his or her existential, epistemic basis. Hence, «Illness is experienced by the patient not so much as a breakdown in the mechanical functioning of the biological body, but more fundamentally as a disintegration of his/her world.»

Corbin (2003, pp. 259-260) summarizes her findings as follows: «Illness intrudes into life, disrupting biographical time, and mortality enters into body and health through the degree of control that one has over one's body.» Locus of control (Rotter, 1966) concerns whether people attribute events in their lives to themselves (internal control) or something outside of their power (external control). This source of control is conceptualized as a continuum. Wallston and Wallston (1978) developed the concept of health locus of control by applying Rotter's construct of locus of control to the domain of health. Studies indicate that people who have a strong internal locus of control are less likely to suffer from severe psychiatric disorders such as chronic depression (Abramson, Seligman, & Teasdale, 1978; Lefcourt, 2014). On the other hand, studies have shown that people who experienced perceived absence of control over a situation's outcome (i.e., learned helplessness) had increased pain and disability as well as increased levels of anxiety and depression (Maier & Seligman, 1976). This tendency was also confirmed in a study of people diagnosed with a chronic illness such as musculoskeletal disease (Nicassio, Wallston, Callahan, Herbert, & Pincus, 1985). Several studies offer documentation of the link between internal locus of control and coping (Brown & Nicassio, 1987; Härkäpää, Järvikoski, & Vakkari, 1996; Thompson & Spacapan, 1991). Taylor (2009) argued that the person's beliefs about the illness's controllability are an important part of the coping process. This research illustrates that uncertainty and loss of control in chronic illness represent additional burdens for the affected person that are hard to handle. It also demonstrates that there is a need to attend to these issues in health care encounters in order to prevent exacerbation and psychological comorbidity. Kralik, Paterson, and Coates (2010)

argue that it is not enough to offer information about the illness and ensure that the best treatment is given. It is also necessary to mobilize the individual's strengths to enhance coping, health, and empowerment. Lazarus and Folkman (1984) distinguish between problem-focused and emotion-focused coping, wherein the first component involves doing something actively with the source of the stressor and the second implies regulating emotional reactions.

In this article, we present a study of patients' experiences with the outcomes of engaging in a new health promotion program in which their bodily knowledge was utilized as a resource for promoting coping and health in chronic illness. The study was part of a larger one in which the program was tested in specialist care (Heggdal, 2015a).

### **The Bodyknowledging Program (BKP)**

The theoretical framework of Bodyknowledging served as the conceptual framework for the new intervention. It refers to «a fundamental process for the development of personal knowledge about one's own body, coping skills, health, and wellbeing» (Heggdal, 2013, p. 65). The theory asserts that people have bodily knowledge that constitutes an important resource for handling the uncertainty and lack of bodily control in chronic illness. This unique yet undervalued knowledge is recognized and strengthened through the person's engagement in the model and by means of dialogue with health professionals and peers. The intervention was organized into seven sessions. The first three sessions were held weekly and the next three sessions were held every second week. The final, seventh session was scheduled three and a half to four months after the program started. Sessions were held in groups of six to eight people and lasted for three hours with a 30-minute break to eat and socialize. The group leaders were interdisciplinary health professionals who had undergone 80 hours of training before the onset of the program. Sessions began with 15 minutes of physical exercises that focused on breathing, balance, and movement. Then group leaders used a poster to introduce the Bodyknowledging health process and the phases: 1) Uncertainty – denying and escaping the ill body; 2) Losing life space – grieving and anger; 3) Listening and understanding the body's signs – strengthening hope; and 4) Integrating embodied knowledge – new possibilities for wellness and health. These phases were introduced one by one in the sessions that followed. By using the model as a backdrop, participants were invited to reflect on uncertainty and loss of control in chronic illness as well as how health and wellbeing could be enhanced in their life situations. The components and methods in BKP are outlined in other publications (Heggdal, 2015a, 2015b).

Because the results in specialist care demonstrated that the program was a flexible tool for health promotion across diagnosis and settings, we were interested in how it might function in community care. The following research questions guided the study: How do patients in the community experience being part of the program? Do they experience any changes in perceived control, health, and coping, and if so, what are

these changes?

## Methods

Interpretative Phenomenological Analysis (IPA) was chosen as the methodological approach because it is suitable for in-depth studies of program participants' experiences with outcomes (Smith & Osborne, 2008).

The study followed the ethical principles of the «World medical association declaration of Helsinki» (2013). Participants were given a letter containing information about the project, stating that their participation was voluntarily, allowing for the possibility to withdraw from the study, and stipulating how the researchers could be contacted for interview appointments. Participants' integrity was protected throughout the entire research process (i.e., by showing them respect, listening to their stories, and making their expressions anonymous in the presentation of results).

### Study context and participants

In order to establish rich empirical data material for IPA, a variety of ages, diagnoses, and both genders were emphasized in the inclusion of participants. The main selection criteria were that they had been living with long-term illness for at least six months and had accomplished the new community-based health promotion program. In order to recruit patients to the pilot implementation, we collaborated with health care personnel in a community health care and hospital-based center for patient education, known as a «learning and mastery center» (LMC). Health care personnel recruited 18 patients for the pilot implementation by handing over the letter of invitation at the last session so as not to «disturb the group processes» before the program was completed. A sample of three men and eight women ( $n = 11$ ) between the ages of 30 and 60 volunteered to participate, signed informed consent forms, and approved audio recording of the interviews. This meant that four communities in the eastern part of Norway were involved in the study. The diagnoses represented were chronic fatigue syndrome, stroke, and musculoskeletal pain. Seven participants were living with a spouse, three were living alone, and one lived with her children. The majority of participants were on early disability pension due to their condition. Three were working part time but were on long-term sick leave while they participated in the program.

### Data collection and analysis

Data were collected in semi-structured interviews from two different group completions of the program. Examples of questions are: How was your experience with participating in the program? Have you noticed any changes in your health and your way of handling illness-related challenges? What do you do to promote your health and wellbeing? The first author conducted in-depth, individual interviews with one man and two women from one group completion, and the second author conducted a group interview with eight participants who belonged to another group completion. Each

interview lasted between 60 and 90 minutes, and all audio-recorded data were transcribed to text.

Each of the interviews was analyzed in six steps according to the IPA procedure as described by (Smith, Larkin, & Flowers, 2009). The first step involved immersing ourselves in the original data material. Then we commented on similarities, differences, and contradictions in experiences, and we summarized thoughts, connections, and preliminary interpretations. Step three involved reaching the interpretative level by studying the transcripts once more, outlining emerging themes, and «breaking up» the natural flow of the text in order to put the parts together again in a new holistic way. Then connections between themes were studied and the core findings were labeled. The fifth step entailed performing the same procedure in the other interviews one by one. Finally, we were looking for patterns of themes across cases and identified superordinate themes. To check the trustworthiness of the findings and to ensure inter-subjectivity, we invited a researcher in health psychology who had not taken part in the analysis of the interview material to engage in critical discussion of our findings.

## **Findings**

Participants described their engagement in the Bodyknowledging Program as an enlightening experience that contributed to positive change, personal growth, and better health. The outcomes were identified as changes in self-awareness, accepting one's capacity, and regaining control.

### **Changes in self-awareness**

Participants reported that the program had helped them come to know themselves better as people living with a long-term health problem. Many of the participants had been living with their illness for years. However, they described their awareness of personal needs, opportunities, and what was important in their lives as having been raised, and leading up to this change, they attained greater self-knowledge and understanding of their surroundings. Learning to know oneself involved a challenging self-exposure. Within this realization, participants gained knowledge of their own weaknesses, strengths, and resources. Such self-understanding involved letting in avoided and suppressed feelings and thoughts. The changes in self-awareness demanded hard work and effort on patients' own behalf, and the Bodyknowledging Program facilitated a genuine opportunity to work with these issues. One woman explained how she experienced honesty in the group as an important revelation and how the program led her to a broader understanding of her current situation, which in turn enabled her to make changes in her family life, activities of daily living, and work situation.

### **Changes in attitude**

In accordance with raised self-awareness, participants reported extending their horizons, leading to enhanced perspectives and understanding of their own existences. They argued that this insight was a result of changes in their ways of thinking. By studying their own patterns of thinking, the program allowed for and helped participants focus on their own situations. It also enabled them to understand and see solutions for themselves. One participant put it this way:

*The most important realization for me was to change my way of thinking, getting on the right track, and to dare to think new thoughts. I understood that the solutions already were there; I just needed to look in a different direction. Before, I was so afraid of ruining what I had, and I was so stubborn and stuck in the same place.*

This woman's engagement in the program led to a change in her work situation that involved an adjustment in the fulfillment of her needs, whereby she arranged better working hours customized to her family situation and less exhausting and more flexible work tasks. This was a new possibility she had not seen before her attendance in the program.

### **Awareness of one's body**

In the past, many of the participants experienced stress, fatigue, physical pain, and not being able to cope with their illness. The change in self-awareness encompassed patients' increased ability to understand their body's signs and their own pattern of reactions. It also involved developing certainty about their limitations. One woman described how the awareness of her body changed throughout the program:

*Before, I was so tired, and my body was very tired. It had something to do with the psychological stress and bodily pain I had; it was very complicated. When I learned how to relax, the body could relax, rest, and breathe, and then, everything changed. I learned not to do more than I could handle. I needed to take it easy and focus on myself and my capacity. When I do, the body heals faster and doesn't hurt as much, and I don't need to go all the way down before I can get up again. It has helped me a lot to be more aware of that.*

This excerpt offers an image of how patients' systematic work on Bodyknowledging contributed to changing their lives in a positive manner. The woman above explained how being considerate of her body's tolerance limits for the magnitude and type of activity she engaged in contributed to less pain. She also pointed out that the body healed faster and was more stable when she observed these benefits. The achieved insight led the participant to cope with pain.

### **Accepting one's limited capacity**

The Bodyknowledging Program helped the participants make an active choice about accepting themselves and their condition as it was. At the same time, it allowed them to study their own capacity for coping and functioning. Even though many had been living with illness long term, it was hard to acknowledge the diagnosis and the limitations the condition imposed on their lives. Acceptance was a challenging part of the process, but it was also liberating and reassuring. Having realistic expectations was a part of this process and involved letting go of some dreams and activities while replacing them with new and more realistic ones. The participants learned how reconciling with one's capacity led to better health and increased their capacity to participate in society over the long term.

### **Making priorities and setting boundaries**

Another side of this process implied a struggle to accept the necessity of giving priority to participants' own needs in order to stay well. One of the female participants realized how important it was to be satisfied with her efforts despite a lowered level of performance compared to her pre-illness level of functioning:

*I need to say «no» when I need to, instead of trying to do something I really shouldn't be doing. I'm better at telling both myself and others that my body needs to rest.*

It was difficult for her to understand and accept that she had different needs now than before the illness intruded upon her life. Through engagement in the program, she learned how to let her body decide which activities she could achieve at a given time. She became aware of the dynamic nature of her body's tolerance limits and was able to explore and utilize her possibilities for activities and participation in accordance with her embodied knowledge and reactions.

### **Letting go of shame**

Some of the participants had been struggling with the idea of being self-centered and egoistic when focusing on themselves and their own needs. This way of thinking was connected to feelings of shame, guilt, and the stigmatization of being ill long term. Some of the participants described themselves as having withdrawn from others and feeling socially isolated, but some of them also felt a need to take a stand toward others:

*I have become stronger and better at letting others adjust their expectations toward me in accordance with my limitations. Sometimes I feel egotistic, and that's not like me, but right now, it's what I need. Sometimes I feel ashamed when I'm going to the gym even though I'm on sick leave, but that's totally wrong, because I have to go there in*



*order to recover. Other people may say whatever they want; I don't care anymore.*

While part of the program, this participant learned how to accept her situation and realized that being open and truthful about it strengthened her. She learned that other people had no right to override her decisions, because it was her body and her life that she alone was responsible for taking care of. In relation to this, participants pointed out the importance of being satisfied with their own efforts and affirming themselves as good enough as they were at that moment. They lowered their own expectations and stopped comparing themselves to others.

### **Regaining control**

According to the participants, one of the most important changes reported was the opportunity to regain control over their own lives. This seemed to be a process connected to changes in self-awareness and in accepting one's own capacity. While having an unstable health condition, the participants established control by adjusting daily activities and acknowledging how factors in their physical and social environments affected their health. They described how they structured their lives to enhance their health by building more energy and satisfaction into their experience. This approach lent clarity to a situation they formerly felt was chaotic. They reported being in this health promotion process continuously and described how it involved knowing what to prioritize in interaction with their surroundings:

*It's about choosing to avoid things I know are stressful. One day can be more painful than others, but it's about making adjustments in line with my body. Sometimes that means canceling things I really would like to do.*

Through their engagement in the new health promotion program in their own community, participants learned how to adjust their daily activities based on bodily signs of limitation and capacity in the actual moment. Through the confidence they achieved in themselves and their personal knowledge about their health, participants gained the feeling of being in control, and subsequently, anxiety and sadness aroused by illness were more easily dealt with.

### **Factors contributing to changes in perceived control in chronic illness**

Participants expressed that the frame of the program, the Bodyknowledging model, and their reflections and work on the phases were important factors that contributed to positive change. Professionals' attitudes and approaches were a part of this. They described the group leaders as calm, supportive, and inclusive and appreciated that they explained everything in a comprehensive way. The Bodyknowledging model was presented as an accessible, educational, and practical tool for gaining awareness,

acceptance, and control. Through recognition and comparison of their own situation to the model's content, they felt strengthened, supported, and comforted. Studying the different phases of the Bodyknowledging process made it easier to be aware of which phase they found themselves in and to assess their emotional reactions as a natural part of an overall health promotion process:

*I liked the composition of the phases—that it moves upwards. It makes it easier to put my reactions into words and to see that it's natural to react in that way. The model lets you know that others have the same experiences and that this is normal.*

Working with the Bodyknowledging model contributed to a feeling of unity with other users, as cited in the pedagogical tools, and between users of the program. This unification helped patients let go of uncertainty and loneliness. The model highlighted hope and focused on wellness and health in spite of living with a long-term condition. It also encouraged patients to work on their own health as an overall process in order to move to the next phase. After completing the program, participants used the model's concepts as part of their ordinary language. They argued that this was important for structuring their thoughts and that it contributed to a lowered level of stress. As a result, they had more energy to do the things they valued highly. Some experienced difficulty in working on thoughts and feelings that arose as they engaged in the program. However, they found comfort in identifying with others who were dealing with the challenges of living with illness on a long-term basis:

*Sometimes I felt completely exhausted and empty. It was in those moments [that] we got the opportunity to build each other up with positive feedback.*

Through group cohesion, support from the group leaders, and meeting with likeminded people, participants felt encouraged. The group gave rise to acceptance and comprehension of not only patients' own situations but those of their peers as well. The program offered an opportunity to express oneself, and participants emphasized the importance of honesty in the group and having someone with the same experiences and understanding as listeners. The group sessions could provide something unique that their family, friends, or colleagues could not offer—a kind of high-quality understanding that helped them trust in themselves and their capabilities:

*Others would not understand this type of situation. It felt great to have someone who had similar experiences and challenges. This helps in feeling better mentally, which also helped me to handle my physical*

In addition to promoting the sharing of thoughts, feelings, and experiences, the group was a sanctuary for exchanging positive feedback and appreciation. Users expressed it as being motivating to feel important and meaningful in each other's lives. They held the view that the Bodyknowledging program represented a new and different meeting with the health care system and recommended that all health care workers should learn about Bodyknowledging and this new way of approaching people who are living with long-term illness. However, participants had some suggestions for improvement of the program, such as longer sessions and a six-month follow-up. Others suggested revisions of educational tools, such as a bigger flip-over. One of the group completions consisted of several women and only one male participant. In the beginning, he experienced his minority status as challenging due to difficulty in opening up and sharing with the others. As a result, he recommended making sure that every group involved both genders. Participants did not agree concerning having a diagnosis-specific or heterogeneous group completion of the program. They argued that diagnosis-specific groups could be an advantage because of the similar understanding between participants, whereas groups with a variety of diagnoses also could be an advantage because such a structure contributed to the development of a broader knowledge base about health and chronic illness coping.

## **Discussion**

Our qualitative interview study suggests that people diagnosed with chronic illness have the possibility to achieve positive changes in perceived control through engagement in the Bodyknowledging Program in their community. The program represented an innovation for participants in the sense that the patients' bodily knowledge was acknowledged and utilized systematically as a source of health, independent of diagnostic categories and illness-related problems.

### **Utilizing the dialectics of body and mind to promote coping and health**

The health care system has been dominated by a dualistic approach to patients that implies a focus on deficits and treatment of affected organs, with a lack of attendance to the illness's effects on the person as a whole. The dualistic understanding of the body is a disadvantage to patients living with health problems because many of them are struggling with complex symptoms and need comprehensive attention. Therefore, a broader understanding of the body in both health and illness is needed (Leder, 1992; Svenaeus, 1999). The French philosopher Merleau-Ponty (1996) introduced a dialectical understanding of the interplay between body and soul that replaced the dualistic understanding of the two concepts as separate entities. He argued that every person's body is infused with meaning and expression and that body and mind are attached and function in holistic unity. The Bodyknowledging framework is

a contribution to the further development of this integrated perspective of body and mind in chronic illness. More specifically, the person's bodily knowledge is recognized as an important resource for prevention, improvement, and better health (Heggdal, 2013).

The results of this pilot study in the community revealed that the Bodyknowledging framework is a useful tool for health promotion in the context of chronic illness. The findings are in line with earlier testing of the program in specialist care (Heggdal, 2015a). Participants were assisted in their discovery of the connections between symptoms and levels of stress, social interactions, life events, and physiological reactions and how they could cope with many of the challenges they were facing. In our study, we saw how they learned to make sense of and utilize the dialogue between body and mind as a resource for health promotion on a daily basis. While listening to their bodily signs and reflecting on the meaning of those signs, they were coping with the uncertainty and lack of control by reducing chaotic thoughts. As a result, it became easier to focus on what they needed to handle the situation. At the same time, this approach contributed to clarity of thought gained from a less tired and painful body. In turn, stress was kept at a distance. The elevated self-awareness and the acceptance of the body's capacity enabled participants to prioritize correctly based on their needs and capacities at the present moment. These findings confirm that they utilized emotion-focused and problem-focused coping strategies, in line with Lazarus and Folkman (1984) theory, as they worked through their emotional stress and facilitated constructive changes in daily living activities.

### **The utilization of patient expertise in health care encounters**

The participants in this study shared experiences of being disregarded and not listened to in their encounters with health care systems. This sense of invisibility gave rise to a feeling of being neglected, which led to a lack of influence on their course of treatment. These experiences are often connected with the dualistic perspective, implying that the patient's body is to be treated as an object of scrutiny by health care and that the person's understanding and bodily experiences are not valid knowledge to be combined with objectively provable tests (Heggdal, 2008; Leder, 1992; Toombs, 1993). The consequence is that professional knowledge is valued as more significant than the patient's experiential knowledge and that the patient is assigned a passive role as both an observer of the work of professionals and as a recipient of care and treatment. Hence, the health care system may itself unknowingly give the patient a feeling of being helpless and out of control.

Contributions from the interviews have shown that the unique knowledge gained by chronic illness patients about their body represents a resource for practicing health promotion in care encounters. However, participants suggested some revision of the new program, such as lengthier sessions, a longer interval for the follow-up, and some revision of the pedagogical devices. Some considered it tough to work on thoughts and feelings that arose in the program and expressed a need for social support between

sessions.

### **Experiencing control in chronic illness**

Patients achieved personal knowledge of their health through individual experiences with their illness over time. By utilizing their bodily knowledge consciously, contributions were made toward better functioning. Our findings confirm the relevance of Bandura (1977) view that the individual's self-efficacy and belief in his or her own capacity for achievement and control increase his or her capacity for health improvement.

Based on earlier studies, we know that the locus of control may affect people's health (Abramson et al., 1978; Lefcourt, 2014) and that a sense of control or self-efficacy leads to better adjustment among patients diagnosed with a variety of diagnoses such as rheumatoid arthritis (Somers, Wren, & Shelby, 2012), chronic obstructive pulmonary disease and chronic heart failure (Arnold, Ranchor, Dejongste, Köeter, Ten Hacken, Aalbers, & Sanderman, 2005), cancer (Cunningham, Lockwood, & Cunningham, 1991), spinal cord injuries (Middleton, Tran, & Craig, 2007), and hypertension (Warren-Findlow, Seymour, & Huber, 2012). How can these theories and research findings shed light on the outcomes of the Bodyknowledging Program? The patterns of themes such as self-awareness and acceptance of one's capacity seem to indicate that participation in the new program contributed to a change in participants' locus of control, taking it from external to internal. Based on these findings, it seems relevant to propose that the BKP contributed to perceived control of illness-related strain and circumstances (i.e., «by making priorities, setting boundaries, and letting go of shame»). This perception happened when professionals challenged patients to get to know their bodies and utilize their knowledge of health and illness. More specifically, it transferred some of the power to the patient. The theories of locus of control and self-efficacy offer an interesting backdrop for reflection on these findings. The theory of locus of control points to a tendency in each person to attribute either internal or external control. Thus, it points to the personality as an important factor in coping (Rotter, 1966). The theory of self-efficacy emphasizes social learning as providing possibilities for change and thus seems to point to a more flexible understanding (Contrada & Goyal, 2005). The Bodyknowledging Program invites the person to engage in the study of his or her possibilities, resources, and strengths for health in a group of peers. It also challenges the person to attend to himself or herself and to his or her patterns of thinking about and handling the situation.

The content of the program represents a relevant frame for strengthening the internal locus of control and self-efficacy. It has helped patients look up and ahead by studying and taking charge of their own health and discovering their own capabilities. The professionals challenged the participants to study and reflect on the phases of Bodyknowledging (Heggdal, 2013). Their personal stance and personality were thereby given space and attention in a safe context within their own community. In addition, the other group members were present, shared their stories, and engaged in

dialogue, and social learning among the group members was evident in the findings. The group leaders' recognition of patients' knowledge about themselves and the social support, positive feedback, and encouragement from their peers they received facilitated belief in their ability to cope with uncertainty and other challenges created by the illness. In contrast, patients reported having had a passive role in their own course of treatment before they participated in the BKP. This had led to ways of acting that were similar to learned helplessness. Earlier studies have shown that learned helplessness affects people's health in a negative way (Maier & Seligman, 1976; Nicassio et al., 1985). Our study supports these findings because the participants reported their health became better when they unlearned their helplessness and regained control through active engagement in the program. Letting go of shame and being proud of oneself were important in this regard. It became easier for patients to take control by accepting their situation, making the right priorities, setting boundaries, and being satisfied with what they were able to do. The perception of control facilitated the making of better adjustments in daily living activities in accordance with participants' bodily capacities, needs, and priorities. This was in line with research findings that show how patients who believe they are in control of their illness adjust better than patients without such beliefs (Taylor, 2009; Thompson, Nanni, & Levine, 1994).

Strategies of avoidance, denial, and reduction in information-seeking were described by Mishel (1988) as actions patients used to handle both uncertainty and lack of control over their illness. Through their engagement in the BKP, participants got the opportunity to recognize their abilities to favorably affect their own health and their own life situations. They gained greater knowledge of themselves (i.e., about their own limits of tolerance), and they learned how to think and act differently and in a more constructive way. Through the program, they developed new perspectives on their own situations. They gained insight into their own strengths and possibilities, and a strengthened self brings about greater power to manage the challenges imposed by illness.

This study had some limitations. The sample was small; thus, the results are not readily generalizable to a larger population. However, the sample contained variation in terms of men and women, medical diagnoses, and communities. Moreover, the empirical material was sufficient to accomplish IPA and to reach saturation. We emphasized inter-subjectivity in the analysis and invited other scientists to engage in critical reflection on the findings. Based on the results, we would like to suggest the further implementation of BKP in community care in order to prevent deterioration and promote coping and health in patients with chronic illness. Implementation should be followed by research and should include larger samples, younger people, and testing of the program in an international context.

## **Conclusion**

In this article, we have focused on the experiences of uncertainty and lack of control in long-term illness, how they imply stress and risk of mental health problems, and the necessity for them to be attended to in health care. We conducted a pilot study of the outcomes of a new intervention that utilized the bodily knowledge of patients with chronic illness to promote coping and health (Heggdal, 2013). Interpretative Phenomenological Analysis was applied to analyze in-depth interviews from eleven men and women diagnosed with a variety of chronic conditions. Headings for the outcome were: changes in self-awareness; accepting one's capacity; and regaining control. Participants experienced being more solid and courageous after being engaged in the Bodyknowledging Program. This led to adjustment and better functioning. These experiences are closely related to the concept of self-efficacy and are in line with earlier research showing that possession of a strong self-efficacy increases progress and growth in people struggling with chronic illness (Graves, Scott, Lempp, & Weinman, 2009).

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#### Abstract

Among the main challenges accompanying chronic illness are uncertainty and lack of perceived control, both of which put the patient at risk of developing psychological comorbidities. This qualitative study explored patients' experiences with changes in perceived control while engaging in a new health promotion program in their community. Participants' bodily knowledge of chronic illness was utilized systematically in the promotion of their health during seven group sessions. Eleven men and women from the eastern part of Norway participated in the pilot implementation. Qualitative interviews were used for data collection and were analyzed according to Interpretative Phenomenological Analysis. The findings were identified as: changes in self-awareness; accepting the limits of one's capacity; and regaining control. This resulted in patients' development of a strengthened capacity to handle illness-related strain and individual strategies to prevent psychological deterioration.

**Keywords:** chronic illness, coping, health intervention, perceived control, self-awareness, self-efficacy.

**Author affiliation:** Miriam Hjeldsbakken Engevold – Department of Psychology, University of Oslo, Norway; Kristin Heggdal – Department of Health Studies, University of Stavanger, Norway.

**Contact information:** [Miriam Hjeldsbakken Engevold](mailto:miri_hjel@hotmail.com), PO Box 1094 Blindern, N-0317 Oslo, Norway. Email: [miri\\_hjel@hotmail.com](mailto:miri_hjel@hotmail.com).

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**Miriam Hjeldsbakken Engevoid**

Miriam Hjeldsbakken Engevoid has a master's degree in health and social psychology from the University of Oslo, Norway.

**Kristin Heggdal**

Kristin Heggdal is an [associate professor](#) at the Department of Health Studies, University of Stavanger, Norway.