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Kristin Heggdal

Universitetet i Stavanger

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Patient's Experience of the Outcomes of Engaging in a Broadly Applicable Health Promotion Intervention for Individuals Facing Chronic Illness

Kristin Heggdal

Department of Health Studies, University of Stavanger, Stavanger, Norway
Email: Kristin.heggdal@uis.no

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Abstract

The aim of this study was to explore the health-related outcomes of a new health promotion intervention designed to be broadly applicable among people diagnosed with chronic illness. Qualitative process analysis was applied and a purposeful sample of 52 patients, representing a variety of long-term conditions, was invited to participate in the pilot-implementation and evaluation of the program. Participants attended individually or in groups in seven sessions held over a six-month period. A lay-based conceptual framework that revealed the bodily knowledge of patients with chronic illness as a resource for health was used as the frame for the program content and interdisciplinary health professionals who had undergone 80 hours of training led the program. The pedagogical approaches were varied in order to engage patients in health promotion work. In-depth evaluation interviews took place soon after program completion and data were analyzed in-depth by means of content analysis in order to identify patterns of health-related themes and the program's possible active ingredients. The intervention was implemented successfully across clinical sites and diagnostic categories. Participants reported improved ability to manage illness-related problems and greater awareness and utilization of personal resources for health after they had participated in the program. They were able to think more positively about their own capabilities, gained greater understanding of factors that made their health condition better or worse, and became more active. Participants identified empowerment and social participation as important outcomes of engaging in the new program.

Keywords

Chronic Illness, Health Promotion, Patient Participation, Qualitative, Empowerment

1. Introduction

With the prevalence of chronic illness rising worldwide, there is a need to engage patients in health promotion work in order to prevent further deterioration, to strengthen their health and their capacity to participate in society [1] [2]. Interventions based on such work will reflect the philosophical perspective of “health within illness”, which holds that individuals living with long-term health problems are capable of experiencing health and wellbeing despite their conditions [3] [4]. Summaries of research concerning people with various long-term conditions show that they have much in common as they face the challenges of trying to live as well as possible within the context of physical, mental, or social discomfort and limitation [5]-[7]. However, patient education and wellness-interventions in the context of chronic illness are often specific to particular diagnostic groups and not designed to be applied across diagnostic categories [8] [9]. Two of the few examples of interventions that are practiced more broadly are the Chronic Disease Self-Management Education (CDSME) developed by Lorig and colleagues in the USA [10] and the Vitality Training Program (VTP) developed by Steen and Haugli [11] in Norway. Research findings showed that the lay-led CDSME program resulted in improved health status and reduced health care costs among patients suffering from arthritis [12] [13]. Improved health behavior and health status were also reported in a group of patients with serious mental illness [14]. However, a longitudinal randomized trial of stroke survivors who accomplished CDSME, showed that the intervention did not appear to impact self-efficacy and failed to influence outcomes such as mood or social outcomes [15]. This was also confirmed in a Cochrane review that focused on the outcomes of CDSME [16].

The Vitality Training Program (VTP) was led by health professionals trained (in a 30 credit continuing education program) to facilitate patients’ awareness in chronic illness [11]. Studies of the outcomes showed that patients with musculoskeletal pain reported reduced pain, increased pain-coping abilities and reduced health care consumption after completion VTP [17] [18]. A qualitative study described that participants’ awareness of emotional and bodily reactions was enhanced after VTP and that awareness of their own strategies and choices in managing their life situations with illness was raised [19]. The results are promising. However, the majority of patients involved in the research on VTP and CDSME have been women with inflammatory arthritis or other musculoskeletal pain conditions and therefore, the relevance for both men and women and a variety of diagnoses may be in question. There appears to be a need for studies on the utility of broadly applicable health promotion interventions in the context of chronic illness. The study reported here, focuses on patients’ experience of the outcomes of engaging in a new health promotion intervention designed for men and women with a variety of chronic conditions.

2. Methodology

2.1. Overview of the Bodyknowledging Program (BKP)

The intervention was based on Bodyknowledging theory [20] [21]. The theory asserts that individuals with chronic illness have bodily knowledge that constitutes an important resource for coping and health, and that patient’s bodily knowledge is developed through a dynamic, nonlinear process of learning and health-related change in interaction with the environment [22]. Theoretical inspiration for the intervention was also drawn from Antonovsky’s [23] theory on health as a dynamic continuum and Merleau-Ponty’s [24] phenomenological theory of the body as a foundation for knowledge and existence.

The new intervention was named the Bodyknowledging Program (BKP) and was organized in 7 sessions held over a period of 6 months and accomplished in groups or in individual format. **Table 1** offers an overview of the structure and content of the BKP. Health care personnel with 80 hours of training lead the program and worked in a team with patients in researching their health while using the Bodyknowledging framework as a backdrop for reflection and learning. The group format involved 8 - 10 persons living with different kinds of health conditions and each session lasted for 3 hours with 30-minute breaks to eat and socialize. In the individual format, the sessions lasted 1.5 hours, and patients and professionals worked together one to one with the same content as in the group format. The program aimed at facilitating the participants’ personal knowledge of health and wellbeing, especially their bodily knowledge of dynamic limits of tolerances for activity and the impact of environmental factors on their health as well as knowledge of their possibilities for lives unfolding within these limitations. The pedagogical methods were varied and included physical exercises, a short introduction to the Bodyknowledging framework by health care personnel at the beginning of each session, patients’ narratives about

Table 1. Structure and content of the bodyknowledging program (BKP).

Structure	Content	Purpose
Session 1	Information about program structure, content and pedagogical tools. Participants' expectations of the program. Short introduction to the Bodyknowledging Model.	Provide information to enhance security and predictability for participants. Creating a safe environment for each person to engage in the program. Establish trust and dialogue with patients as equal partners in health promotion.
Session 2	Participants' own themes about living with chronic illness. Studies of patterns of former patients' experiences of each phase of the Bodyknowledging process, especially The phase of uncertainty—escaping and denying the sick body. Introduction to physical exercises inspired by Body Awareness Therapy. Introduction to the use of the booklet/diary between sessions.	Encourage patient participation and motivation to engage in the program. Through the exercises, help the participants to attend to their body as a valuable resource for coping and health.
Session 3	Participants' own themes concerning challenges connected to living with a long-term condition and their health promotion strategies. Introduction to the phase of Losing life space—grieving and anger. The use of booklet/diary between and in sessions. Physical exercises.	Facilitate dialogue and reflection work on each participant's process of health promotion. Allowing patients to express themselves and their experiences of their reactions and challenges involved in living with health problems long-term.
Session 4	Participants' own themes and strategies concerning health promotion in chronic illness. Introduction to the phase of Listening and understanding the body's signs—strengthening hope. Acknowledging their body as a source of knowledge about health. Communicating their limits of tolerance to others. The use of booklet/diary. Physical exercises.	Support the participants to utilize their bodily knowledge as a resource to promote their health, <i>i.e.</i> helping them to discover their limits of tolerance concerning type and magnitude of activity.
Session 5	Participants' own themes and strategies for creating health within illness. How to get to know one's limits of tolerance for activity, factors of the physical and social environment. Encounters with others. The use of booklet/diary. Physical exercises.	Strengthening the participant's ability to set limits for themselves and others in accordance with their body's limits of tolerance in order to stay healthy. Training in handling the reactions of others.
Session 6	Participants' own themes of health promotion in chronic illness. Introduction of the phase of Integrating embodied knowledge—exploring new possibilities for health. Encounters with society. The use of booklet/diary. Physical exercises.	Motivation to explore their body's dynamic limits of tolerance and their possibilities for activity and lives unfolding within these limits.
Session 7	Participants' thoughts and actions on how to sustain and strengthen their health after the program. Summary of the Bodyknowledging Model in relation to each participant. Encounters with society. Physical exercises.	Encourage and help participants to make decisions on how to sustain their health and recovery, and how to sustain or enhance their participation in society.

their health conditions and health promotion efforts, dialogue with group leaders and peers about participants' themes as well as individual work on diaries between sessions.

2.2. Research Design

The research design was based on Patton's [25] description of qualitative process evaluation and guidelines for the evaluation of complex interventions [26]. The aim of the study was to get in-depth knowledge of patients' experience of health-related change, and empirical data was collected by means of qualitative interviews. The research was carried out in accordance with the Code of Ethics of the World Medical Association. With approval from the ethics committee of The South-Eastern Regional Health Authorities in Oslo, Norway, three clinical sites were chosen for the pilot-implementation of the intervention: a rehabilitation unit, an outpatient clinic, and a center for patient education, known as a "Learning and Mastery Center" (LMC). The three units were located in two general hospitals in Norway. A project team of health care personnel from the three sites (including five nurses, one physiotherapist, and three occupational therapists) was established. A researcher with a clinical background involving people with chronic illness led the project, but was not involved in the on-site delivery of BKP.

2.3. Participants

The project team used lists of patients who had been treated at the clinical sites at least six months earlier to create an opportunity to deliberately sample men and women of various ages, diagnosis and social backgrounds.

A sample of 31 men and 21 women ($n = 52$) ranging in age from 22 to 88 years of age volunteered to participate in the pilot-implementation of the new program. The diagnoses represented in the sample were chronic obstructive pulmonary disease, heart disease, chronic bowel disease, stroke, multiple sclerosis, and other functional or neurological problems without a specific diagnostic label. Participants varied in functional capacity and in time since diagnosis, but all had been ill for more than one year and faced health-related problems that were difficult to manage. **Table 2** offers an overview of the sample. The program was tested in both individual and group format at the three sites.

2.4. Data Collection and Analysis

The researcher conducted qualitative evaluation interviews with 34 volunteering participants after they had completed the Bodyknowledging Program. Of these, individual interviews were conducted with 9 patients who had accomplished the program in individual format and four group interviews were conducted with 25 patients who had accomplished the program in groups. Written informed consent was obtained before the interviews started and interviews were audiotaped and later transcribed word by word by a research assistant. Transcripts were made and data analyzed from each site (rehabilitation, outpatient clinic and LMC) and format (group or individual) in cooperation between the researcher and the research-assistant. Afterwards, the data material was analyzed across sites and formats and the project team and other health scientists were invited to engage in critical reflection on the findings. The evaluation focused primarily on whether health-related changes could be identified and what the potential “active ingredients” of the intervention were. Patton’s [25] description of “structure”, “process”, and “results” served as the main headings for the first part of the analytic process. This approach contributed to the sorting of the empirical material and offered an overview of the findings. Content analysis [27] was used to study program processes in greater depth. This implied that each interview was read through several times to obtain a sense of the whole. Then, the parts of the text that described participants’ experiences of health-related change were extracted. The text was then divided into meaning units that described the same content, abstracted into themes and subthemes and labeled with a code. Themes, subthemes, and codes were sorted, discussed, and studied again in order to develop more general themes that captured patients’ experiences of health-related outcomes of engagement in the new program.

3. Results

The Bodyknowledging Program was implemented successfully across clinical sites and participants reported that the program allowed them to work systematically on their health as a process. The findings were documented across sexes, diagnostic categories and program formats. Five themes captured participants’ experiences of change in health promotion abilities: (1) Changing perspectives on health and illness; (2) new ways of thinking and acting towards the illness; (3) understanding the situations, choices and actions that make the health condition better or worse; (2) widening one’s life space—being more active; and (3) Communicating differently about health-related matters.

Theme 1: Changing perspectives on health and illness.

A man attending individually in the outpatient clinic described his experience as follows:

I have seen a way through all the pain and anguish. When you read about the other patients’ experience, your own experience is confirmed and in this way you don’t feel so lonely. You understand that there are other people who have managed and that there is a way through it all.

Table 2. Participants by setting, gender and program type.

Participants N = 52	Rehabilitation unit	Outpatient clinic	Learning and mastery center	Total
Men	21	2	8	31
Women	7	5	9	21
Group program	17	0	17	34
Individual program	11	7	0	18
Total	28	7	17	52

A woman attending the program in a group at the LMC put it this way:

Some of my fellow participants had a very rough time, and I understood that my problems were not as big as theirs. I felt that I was not as ill as they were, and then I discovered that they did what they were able to do in order to handle their situation. It was good for me to listen to them and to understand that I am not the one who is the most unfortunate.

Sharing experiences with others who were also struggling with symptoms of illness led to changes in patient perspectives on their own health situations. Because the Bodyknowledging model and its pedagogical tools contain a description of the life worlds of those with long-term health problems, the program offered comfort and support in the midst of pain. It also relieved a feeling of alienation created by the illness. By reading about other patients' experiences (booklet) and by listening to health care personnel and peers (if in group) talking about the Bodyknowledging process, they understood and discovered something new about themselves and their own health and way of handling the illness.

Theme 2: New ways of thinking and acting towards the illness.

A woman attending the program individually at the Rehabilitation Unit described how her thinking changed and how this resulted in new ways of handling her limitations:

Bodyknowledging has helped me to think in another way and to come out and to participate in life again. If I am completely honest with myself, the things I want to do are not impossible. It just takes more time, and that was absolutely not how I was thinking before I entered this program.

A young man attending the program individually shared his experience:

I discovered that I had some sort of resistance when it comes to activity. Before I got the illness, I was quite fit and active, but after the illness hit me, I withdrew from everyone and everything, and I haven't taken it up again. I never go to parties. I've lost contact with a lot of friends and I stopped traveling. This program has challenged me to do something about it. Now, I'm asking myself: Why don't I take it all up again?

The questions posed in the program challenged the participants' understanding of their situations and urged them to question their own ways of thinking and acting. By attending to the Bodyknowledging model, participants could compare their own experience and choices to concepts and phases offered in the model's "insider" perspective. Thus, the model functioned as a process tool to assess "where they were at the moment" and to use that assessment to reflect on how they handle their situation. While still being well aware of the limitations imposed by illness, they became more aware of the risk of imposing unnecessary limitations upon themselves—how that could worsen their health—and they were able to think and act differently and more positively in accordance with their own capabilities. This created a new platform that enabled them to stay active and to resume social participation.

Theme 3: Understanding the situations, choices and actions that make the health condition better or worse.

A man attending the program in a group at rehabilitation described his experience:

I know my body better now. I listen to my body. I have learned how I feel when I am tired. Then I take a break before I begin again. It is much easier when you have a program to follow, such as this program—it works.

A woman attending individually in the outpatient clinic told her story:

It has become clear to me that I have been escaping from the illness, but this summer I've gotten a grip on the situation. I've explained about the illness in my workplace, and now I'm in a process of defining how much I should work and how. I am trying to reduce the demands I put on myself in order to prevent new relapses, because I know that when I work too much, I get exhausted and then the illness gets worse.

Discovering what they were capable of doing and how was an important part of participants' improved knowledge. Learning to listen to their bodies and take their levels of tolerance—for certain types and magnitudes of activity—seriously, helped them identify their "own standards"; that is, the level of performance of physical and social activity (including work activity) that they were able to and satisfied with accomplishing. Participants identified the ability to trust one's body and to say no, to oneself and to other people, as an important strategy for promoting wellness. As the program encouraged patients to reflect critically on their ways of

being, they engaged in a sort of “research process” concerning their own health. When health care personnel were posing questions and giving participants the time and space to reflect, it challenged them to discover their own strategies for self-care and to be in charge of their own health. A woman who was diagnosed with MS many years ago thought it was tough and challenging to work on things that after such a long time she had “placed inside of herself”. She recommended that the course leaders ensured that participants have the social support needed while participating in the program, *i.e.* contact with other group members by telephone in between the sessions or at some time after the sessions for peers to sit together as “it would have helped a lot”.

Theme 4: Widening one’s life space—being more active.

A woman attending a group at the LMC described how she learned to handle the dynamic balance between accepting one’s limits and finding new activities:

I am more conscious that I, in spite of my limitations, I can manage to have a nice time. I can’t climb mountains any more, but this summer I rode a horse at a camp in the mountains. So it’s all about compensation. Now, during the winter holiday, I was on the mountain with my friends. They went skiing and I was walking, and we had a good time together.

A woman in her forties who attended the program individually in the outpatient clinic shared her experience:

This autumn, I have started at the gym. I never liked to do the exercises, but now I feel it gives me a lot to do them. I’m impressed by how much my body can take, and to discover that I manage more and more.

Participants said that being in the program was like “coming out of a vacuum” and they used the concepts and phases of the Bodyknowledging model to sort out their chaos, find meaning in their experience, and move on to new phases. They described being more aware of what they managed in spite of the illness. The search for meaningful substitutes for pre-illness activities was a central strategy for achieving health within illness. This included the discovery of capacities that they did not know they had. These successes encouraged them to accomplish activities they thought were impossible before their attendance in the program, for example simple tasks such as going shopping for new clothes or to travel.

Theme 5: Communicating differently about health related matters.

Participants were concerned with how to tell people about their health condition and how to handle reactions from co-workers, employers, friends, and family. A man who attended the program individually at rehabilitation and whose functional limitations were “invisible” to others, described his experience:

Before, I got angry and wasn’t able to put my reactions into words. The program has helped me to say something about my experience with the illness and has helped me to have better relations with my family.

Participants appreciated the opportunity to open up and work on the difficult parts of their lives in a safe setting. Getting feedback from health care personnel (and peers if in a group) challenged their own understandings, and constituted a time for learning. As a result, participants described being stronger in social encounters, in the sense that they were learning to tell to others how they were and what they had to consider in order to stay well. This was a major achievement as many participants described a tendency to withdraw from others before their attendance in the program.

Active Ingredients of the New Intervention

The analysis revealed that the participants’ engagement in the Bodyknowledging Program, health care professionals’ attitudes and approaches, the group work, and the conceptual framework of Bodyknowledging were identified as the intervention’s active ingredients. Program participants held the view that because the Bodyknowledging model emerged from patient narratives, it was easy to understand and to use as a tool for strengthening their health and wellbeing. The simplicity of the program was emphasized as an advantage in this regard, especially by men in both individual and group formats:

I think the key is that the program is made so easy. We were eight people sitting around the table here for two and a half hours, and the relations between us were good and we had a good time together. I don’t think the relations between us would have been just as good if we had gone on a walk in the park. So I think that it wouldn’t have worked as soon as we entered another arena, but this has been done so easily and ok (man in group LMC).

Participants in the groups described how the frame constituted the conditions for social interaction and how the group work contributed to a process of learning. How initially they sat in the group with their own opinions about their life situations, and what happened when eight people began to tell their stories and share their experiences. The analysis showed that there was a pattern of change in their understanding of their health conditions and their life situations during participation in the group work. According to participants, the frame contributed to an honest forum in the group characterized by a high degree of acceptance of one another. This made them willing to share, to listen to each other and to open up and engage in dialogue about their own and their peer's life situations and possibilities for health within illness. Continuity and attendance in each session were emphasized and connected to the attainment of good results. Many participants expressed that they did not want to miss any session and made a great effort to attend. This was especially evident in the group format and can be connected to the bonding between group members and an evolving feeling of responsibility towards one another. As the content of the BKP is defined by users, this feature in groups may be particularly relevant. However, Professionals' attitudes and ways of approaching patients were identified as important active ingredients of the BKP:

The group leaders met us with a great deal of warmth and openness. I think it was calming that they were educated as health care personnel because then, they knew what they were doing, and I felt that they took good care of us and explained very thoroughly what the program was all about. After the first session, I said to myself; this is going to be very good. I think the course leaders were crucial, that they listened to us, that they were interested, posed questions and that they didn't interrupt us when we were telling our side. They were nice, because many of these "lonely" illnesses that many of us have imply that we're very much alone because we often don't have the energy to go out, and then, it's important to encounter the warm group leader. If not, I'd have been like an oyster (Woman in group LMC).

The oyster metaphor offers insight into the fact that people with chronic illness may withdraw from others due to the illness and the lack of energy they experience and that their attendance in the program helped them to feel confirmed and supported as an individual and a *person*. Participants highlighted professionals' attitudes in the program by choice of words like warmth, understanding, care and hope. They explained how the professionals invited them to engage in dialogue and helped them to use the Bodyknowledging framework as a tool for health promotion in relation to their life-situation. Professionals' competencies and the training they had undergone before the onset of the intervention was important in this regard. Participants clarified their views by contrasting their experience of the new program with their past experiences with the health care system:

For some people, it was a great transition to enter such a program, because we must remember what happens in the hospital. Often they have very limited time, and you may encounter doctors that make you freeze up because they give you the impression that they're counting the days before you can be discharged. And then, you get resentful in relation to health care. Am I just a number? Or am I just a diagnosis? And then, you enter a course like this in which you experience the warmth and the understanding. It's like balm for the soul (Woman in group LMC).

Participants used different kinds of metaphors to describe the outcomes of BKP and the healing effects of the encounters with the professionals in the program. The metaphor of "balm for the soul" was interesting as it showed that the BKP functioned as a kind of treatment for the persons involved, and was a program that allowed for attendance to the emotional and psychosocial dimensions of the health of individuals facing chronic illness. The professionals' way of posing questions was emphasized as important in this regard:

The questions posed in relation to the different phases... (of Bodyknowledging), it was a challenge to reflect on my own situation, so what I mean is that the program compels you to be open in a positive way. It works (Woman in group LMC).

Another woman expressed similar experiences:

They ask questions, and they provoke us sometimes because they want to puncture the abscess, so that we open up and tell, and that's good for us (Woman in group at LMC).

The metaphor of an abscess illustrates that persons living with chronic illness may be withholding their experiences of the illness and its consequences and the challenges involved, and that this can develop negatively and

function like an abscess. Therefore, it was fundamental that the health care personnel were not only able to create a warm atmosphere characterized by *support* and *confirmation*, but also had the competencies to *challenge* the participants to open up, share their experiences and to explore how they could promote their health in spite of having to live with health problems long-term.

4. Discussion

The purpose of this study was to evaluate a new intervention suitable for a variety of health care settings, in order to facilitate health within illness for men and women diagnosed with diverse long-term conditions by studying the participants' experience of health-related outcomes. Bodyknowledging theory [21]-[23] was used as the frame for the program content and participants were supported by health care personnel to work on their health by attending to the phases described in the lay-based conceptual framework. This approach seemed to function by establishing "a space" for person-centered health promotion that had not been available to the participants earlier on. The new intervention draws on a shared world of experience that creates a safe space for participants to research their own capabilities for health in spite of their condition. Lorig's research [12]-[14] has confirmed the importance of sharing of lay knowledge as a part of disease management and coping in chronic illness. This study adds to this by describing the outcomes of a new broadly applicable intervention that was found to be useful across diagnostic categories, sexes and clinical sites. The findings demonstrate that the intervention serves to attend especially to the psychosocial dimensions of individuals with chronic illness; hence, the new intervention takes care of important dimensions not covered by the CDSME [15] [16]. The main focus in BKP was on health as a process to be enhanced by the person him/herself and through interactions with health care providers, peers and significant others. This was in line with Stuijbergen [8] [9] who recommends that people struggling with long-term conditions and their helpers should seek to focus on "health within illness". In BKP, the problems of illness are part of the individual's process of health promotion, which implies that the painful experiences and problems created by the illness are being acknowledged at the same time as new possibilities for health are sought in each person's life. The theoretical framework [22] for the program was built on lay concepts and the professionals who lead the program were trained to use the framework systematically in order to invite the participants to express their experiences of living with the illness and to discover their strategies for promoting health. The lay-perspective was systematically emphasized and the professionals' commitment to the lay-based framework was identified as an active ingredient that facilitated the health-related changes. Patients' engagement in the program was an important active ingredient as well as those who committed themselves to attend a majority of the sessions and who took an active part in the program reported more positive outcomes than individuals who attended fewer sessions and who were more passive.

Some patients did not want to participate in groups, either because they did not want to share information about their life-situation with others or because they had just undergone major treatments, felt stressed or was emotionally unstable. Patients who attended the program individually appreciated the opportunity to do in-depth work with health professionals one to one, while those who attended groups saw the opportunity to learn from and compare themselves with peers as an advantage. In BKP-groups, there was a mix of men and women with diverse long-term conditions, and this variety was appreciated by participants because of the possibilities for sharing of lay knowledge on living healthy lives with chronic illness and the sense of community and social support given by the group.

The health-related outcomes were summarized in five themes: changing perspectives on health and illness, new ways of thinking and acting towards the illness, understanding the situation, choices and actions that make the health condition better or worse, widening one's life space—being more active, and communicating differently about health-related matters. The themes illuminate a variety of important changes, *i.e.* when patients are thinking and acting differently, this will probably have an impact on their health condition and their functioning in society. The findings also provide insight into what it means to be healthy within illness [3]. Participants' change of perspectives involved a shift from focusing solely on the disease and its limitations before they attended the program, to focusing more on and exploring opportunities for health and wellness after program completion. These shifts in perspectives were earlier described in Paterson's model [7]. This study adds to this by showing that The Bodyknowledging Program functioned as a tool to promote the shifts towards health within illness. Participants described how they were supported by health care personnel in listening to their bodies and acting on the basis of their bodily knowledge of dynamic limits of tolerances at the same time as they were

searching for the possibilities of staying active. This became an essential mode for promoting health. The approach implies that the dialectics of body and mind [24] became an important resource for health promotion in the context of chronic illness.

Findings indicate that to be healthy within illness means that the person is engaging in a type of “research” concerning their own health with the following questions in mind: What makes my illness better or worse? What are my body’s levels of tolerance for various types and magnitudes of activity? For various environments and social relationships? How can I utilize my possibilities for health and wellness within these limitations? This approach was in line with a salutogenic orientation [23], according to which each person is capable of identifying factors that promote a movement toward the healthy end of the “ease/disease” continuum. The BKP was revealed as a process-tool for individuals diagnosed with chronic illness to discover these factors and to act accordingly.

Participants described that “to be healthy within illness” also implied coming out of a vacuum and to participate in life again. This applied to different areas of life, including family life, working life, and social life. The search for alternatives to pre-illness activities was essential in this regard and to allow oneself the time needed to make changes. Facilitation of social and physical activities has been described as an important outcome of health interventions among patients diagnosed with chronic illness that also has an impact on social economy [1]. Participants described how the BKP functioned as a tool for them to cooperate with health care personnel and peers in health promotion work. This was in line with person-centered care, which implies that patients are viewed as competent and are actively involved in the planning and conducting of their own care [28]. Professional’s competence in utilizing patient’s experience and bodily knowledge of health and illness was essential in this regard [4]. However, the bodily knowledge of patients with chronic illness was not “inserted” or “taught” them by professionals, as the knowledge was created by means of a natural process that goes on within them [20]-[22]. Health professionals who lead the BKP did not teach the participant specific tasks or skills. Rather, the program draws patients’ attention to the health-seeking process that is already in progress within them.

The Bodyknowledging framework contains tools for participants to assess their own responses to long-term illness and to discover how they can alter their situation by means of their own resources. By contrast, the starting point for the lay-led CDSME program [10], and professional-led patient education, is the problem of pain or illness, which is altered by means of predefined self-management skills. Self-management programs and disease-specific patient education may be regarded as tools for health promotion in chronic illness. However, there is a need for more broadly applicable programs like the BKP that illuminates un-utilized resources for health, attends to psychosocial dimensions and promotes participation in society.

The Vitality Training Program [11] and the Bodyknowledging Program share a phenomenological view of the body as a subject and as a source of knowledge for health and well-being [24]. However, the two programs differ in their empirical grounding and pedagogy. While the VTP is grounded in professional philosophies of teaching, the BKP is grounded in lay experiences of health and illness. The BKP presents patient-centered expertise (the phases of Bodyknowledging) to be interpreted and applied by patients with different diagnoses and conditions [22]. This approach is in keeping with Paulo Freire’s [29] “pedagogy of the oppressed” in which dialogue serves as the main method for helping people understand their situations and act in new ways by means of their own resources. The findings show that BKP fits into empowerment models of health promotion [30] as health care personnel explicitly attended to patients’ bodily knowledge and capabilities. Validating (supporting, confirming and challenging) this personal knowledge systematically had an empowering outcome. In BKP patient’s experience and bodily knowledge, peers and professionals’ expertise on health promotion was illuminated as equal valuable resources in a caring context and the outcomes demonstrated that the program worked to promote health and social participation in men and woman diagnosed with a variety of chronic conditions.

5. Conclusion

The findings from the qualitative process evaluation showed that The Bodyknowledging Program worked as a health promotion intervention in the context of chronic illness. The program is user-based, interdisciplinary, and broadly applicable across different patient groups, sexes, ages and clinical sites. Its timing and structure make it an excellent option for the follow-up on individuals living with long-term health problems in the community, individually or in groups. The program can be combined with disease management interventions in order to promote the health of individuals facing chronic illness because it especially attends to the psychosocial dimensions and the resourcefulness of individuals with chronic illness. Caution should be paid to secure sufficient so-

cial support between sessions and in the follow-up after program completion. This can be done by peer-contacts. Professionals functioned as facilitators for participants to learn to recognize and trust their own knowledge and capabilities for health and the systematic use of patients' bodily knowledge was critical in order for the program to work. The Bodyknowledging framework, participants' engagement in the program and the group work were important factors with an impact on the outcome. The findings demonstrate that the BKP improved participants' ability to handle illness-related problems and strengthened their health and ability to participate in society. A potential limitation of this study was that the pilot implementation was performed in Norway, and the results may not be readily generalizable to a larger population or to other countries. However, the empirical material was extensive, and saturation was reached. The outcomes give reason to continue the implementation work, followed by research that includes other countries and other groups such as people on long-term sick leave, patients with mental health problems and adolescents facing chronic illness.

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References

- [1] Harbers, M.M. and Achtenberg, P.W. (2012) Europeans of Retirement Age: Chronic Disease and Economic Activity. Implementation Framework. http://www.who.int/medical_devices/innovation/compendium2012/en/index.html
- [2] World Health Organization (2010) Global Status Report on Non-Communicable Diseases.
- [3] World Health Organization (1992) Health Promotion and Chronic Illness. Discovering a New Quality of Health. WHO Regional Publications, European Series, No. 44, England.
- [4] Gottlieb, L.N. (2013) Strengths-Based Nursing Care: Health and Healing for Person and Family. Springer Publishing Company, New York.
- [5] Lubkin, I.M. and Larsen, P.D. (2013) Chronic Illness: Impact and Intervention. Eight Edition, Jones and Bartlett Publishers, Burlington.
- [6] Thorne, S., Paterson, B. and Russell, C. (2003) The Structure of Everyday Self-Care Decision Making in Chronic Illness. *Qualitative Health Research*, **13**, 1337-1352. <http://dx.doi.org/10.1177/1049732303258039>
- [7] Paterson, L.B. (2001) The Shifting Perspectives Model of Chronic Illness. *Journal of Nursing Scholarship*, First Quarter, 21-26. <http://dx.doi.org/10.1111/j.1547-5069.2001.00021.x>
- [8] Stuiifbergen, A.K. (2006) Building Interventions for Persons with Chronic Disabling Conditions. *Family and Community Health*, **29**, 28-34. <http://dx.doi.org/10.1097/00003727-200601001-00006>
- [9] Stuiifbergen, A.K., Morris, M., Jung, J.H., Pierini, D. and Morgan, S. (2010) Benefits of Wellness Interventions for Persons with Chronic Disabling Conditions: A Review of the Evidence. *Disability and Health*, **3**, 133-145. <http://dx.doi.org/10.1016/j.dhjo.2009.10.007>
- [10] Lorig, K., Halsted, R. and Holman, H. (2003) Self-Management Education: History, Definition, Outcomes and Mechanisms. Stanford University School of Medicine. *Annals of Behavioral Medicine*, **26**, 1-7. http://dx.doi.org/10.1207/S15324796ABM2601_01
- [11] Steen, E. and Haugli, L. (2000) The Body Has a History: An Educational Intervention Program for People with Generalized Chronic Musculoskeletal Pain. *Patient Education and Counseling*, **41**, 181-195. [http://dx.doi.org/10.1016/S0738-3991\(99\)00077-4](http://dx.doi.org/10.1016/S0738-3991(99)00077-4)
- [12] Lorig, K., Sobel, D. and Stewart, A.L. (1999) Evidence Suggesting That a Chronic Disease Self-Management Program Can Improve Health Status While Reducing Hospitalization: A Randomized Trial. *Medical Care*, **37**, 5-14. <http://dx.doi.org/10.1097/00005650-199901000-00003>
- [13] Lorig, K., Ritter, P., Stewart, A., Sobel, D., Brown, B., Gonzales, V., Laurent, D. and Holman, H. (2001) Chronic Disease Self-Management Program: A 2-Year Health Status and Health Care Utilization Outcomes. *Medical Care*, **39**, 1217-1223. <http://dx.doi.org/10.1097/00005650-200111000-00008>
- [14] Lorig, K., Ritter, P.L., Pifer, C. and Werner, P. (2014) Effectiveness of the Chronic Disease Self-Management Program for Persons with a Serious Mental Illness: A Translation Study. *Community Mental Health Journal*, **50**, 96-103. <http://dx.doi.org/10.1007/s10597-013-9615-5>

- [15] Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N. and Charker, J. (2007) Recovery Following Stroke: The Role of Self-Management Education. *Social Science and Medicine*, **64**, 735-746. <http://dx.doi.org/10.1016/j.socscimed.2006.09.012>
- [16] Foster, G., Taylor, S.J.C., Eldridge, S., Ramsay, J. and Griffiths, C.J. (2007/2009) Self-Management Education Programs by Lay Leaders for People with Chronic Conditions. The Cochrane Collaboration, John Wiley and Sons, Ltd., Hoboken, 1-18.
- [17] Haugli, L., Steen, E., Lærum, E., Finset, A. and Nygaard, R. (2000) Agency Orientation Perspective and Chronic Musculoskeletal Pain. Effects of a Group-Learning Program Based on Personal Construct Theory. *Clinical Journal Pain*, **6**, 281-289. <http://dx.doi.org/10.1097/00002508-200012000-00002>
- [18] Haugli, L., Steen, E., Lærum, E., Nygaard, R. and Finset, A. (2001) Learning to Have Less Pain—Is It Possible? A One-Year Follow-Up Study of the Effects of a Personal Construct Group-Learning Program on Patients with Chronic Musculoskeletal Pain. *Patient Education and Counseling*, **45**, 111-118. [http://dx.doi.org/10.1016/S0738-3991\(00\)00200-7](http://dx.doi.org/10.1016/S0738-3991(00)00200-7)
- [19] Zangi, H.A., Hauge, M.I., Steen, E., Finset, A. and Hagen, K.B. (2011) “I Am Not Only a Disease, I Am So Much More”. Patients with Rheumatic Diseases Experiences of an Emotion-Focused Group Intervention. *Patient Education and Counseling*, **85**, 419-424. <http://dx.doi.org/10.1016/j.pec.2010.12.032>
- [20] Heggdal, K. (2003) Kroppskunnskap—En grunnleggende prosess for mestring ved kronisk sykdom [Bodyknowledging—A Basic Process of Coping with Chronic Illness]. PhD Dissertation, Department of Public Health and Primary Health Care, University of Bergen, Bergen.
- [21] Heggdal, K. (2008) Kroppskunnskap—Pasienten som ekspert i helsefremmende prosesser [Bodyknowledging—Patients as Expert in Health Promotion Processes]. Gyldendal Academic Publishers, Oslo.
- [22] Heggdal, K. (2013) Utilizing Bodily Knowledge in Patients with Chronic Illness in the Promotion of Their Health: A Grounded Theory Study. *Californian Journal of Health Promotion*, **10**, 62-73.
- [23] Antonovsky, A. (1988) Unraveling the Mystery of Health. How People Manage Stress and Stay Well. Jossey-Bass Publishers, San Francisco.
- [24] Merleau-Ponty, M. (1996) The Phenomenology of Perception. Shri Jainendra Press, India.
- [25] Patton, M.Q. (2002) Qualitative Evaluation and Research Methods. 3rd Edition, Sage Publications, Thousand Oaks.
- [26] Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Petticrew, M. (2008) Developing and Evaluating Complex Interventions: The New Medical Research Council Guidance. *British Medical Journal*, **337**, Article ID: a1655. <http://dx.doi.org/10.1136/bmj.a1655>
- [27] Graneheim, U.H. and Lundeman, B. (2004) Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness. *Nurse Education Today*, **24**, 105-112. <http://dx.doi.org/10.1016/j.nedt.2003.10.001>
- [28] Ulin, K., Olsson, L.E. and Ekman, I. (2015) Person-Centered Care—An Approach That Improves the Discharge Process. *European Journal of Cardiovascular Nursing*. <http://dx.doi.org/10.1177/1474515115569945>
- [29] Freire, P. (2006) Pedagogy of the Oppressed. 30th Anniversary Edition, Continuum International Publication Group Inc., New York.
- [30] Naidoo, J. and Wills, J. (2009) Foundations for Health Promotion. 3rd Edition, Ballière Tindall Elsevier, London.