

Denne filen er hentet fra **Lovisenberg diakonale høgskoles** institusjonelle arkiv <u>LDH Brage</u>.

'We experienced a lack of tools for strengthening coping and health in encounters with patients with chronic illness': bridging theory and practice through formative research

Kristin Heggdal Universitetet i Stavanger

Ved henvisning til <u>publikasjonen</u>, bruk fullstendig referanse:

Heggdal, K. (2015) 'We experienced a lack of tools for strengthening coping and health in encounters with patients with chronic illness': bridging theory and practice through formative research. *International Practice Development Journal*, 5(2). Doi: <u>10.19043/ipdj.52.004</u>

Rettigheter:

International Practice Development Journal er et Open Access tidsskrift som tillater publisering i institusjonelle arkiv. Les mer: <u>http://www.fons.org/library/journal-permissions</u>

International Practice Development Journal

Online journal of FoNS in association with the IPDC (ISSN 2046-9292)



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

'We experienced a lack of tools for strengthening coping and health in encounters with patients with chronic illness': bridging theory and practice through formative research

Kristin Heggdal

University of Stavanger, Norway Email: <u>kristin.heggdal@uis.no</u>

Submitted for publication: 1st July 2015 Accepted for publication: 29th October 2015 Publication date: 18th November 2015 doi:10.19043/ipdj.52.004

Abstract

Background: Healthcare personnel in specialist care in Norway took the initiative to develop their practice in order to improve follow-up of patients with chronic illness. A research project was constructed that involved a close collaboration between practice and research in the development of a new, complex intervention to strengthen patients' ability to live with long-term conditions.

Aims and objectives: This paper seeks to describe a part of the research process that involved the firststage development of the intervention. The first objective is to describe how clinicians, patients and a health researcher collaborated, and to discuss the benefits of this collaborative work for improving practice. The second objective is to outline the intervention's aspects and components.

Method: Three clinical sites were chosen for developing the intervention: a rehabilitation unit, an outpatient clinic and a centre for patient education. An interdisciplinary team of nine healthcare personnel and four patients engaged with the researcher(s) in the formative research. A list of criteria for reporting on the development of complex interventions was applied to elaborate on intervention components.

Results: An intervention was developed that entailed a person-centred approach to facilitating overall health in chronic illness. This involved a change in practice as the professionals acquired a new approach to the use of patients' capacity for health, and as patients began to function as active partners in health promotion.

Conclusions: A close collaboration between clinicians, patients and researcher was necessary for developing a theory and a research-based intervention that improved the follow-up of individuals diagnosed with long-term conditions. The intervention was designed to be applicable across diagnostic categories and in a variety of clinical settings. These patients experience a multitude of challenges that require attention in health promotion. Therefore, health professionals should be encouraged by their leaders to engage in interdisciplinary collaboration with researchers in academia in developing new interventions for improving practice. Researchers who engage in such projects should be prepared to take on long-term collaboration.

Implications for practice:

- There is a need to develop the field of health promotion for long-term conditions, and especially a need to develop interventions to strengthen individuals' capacity for health, empowerment and recovery
- An interdisciplinary project team is an advantage when developing interventions that aim to

address the challenges experienced by individuals living with long-term conditions

• Partnership with patients in the design and testing of new interventions is necessary to maximise the relevance and suitability of the intervention

Keywords: Long-term conditions, patient participation, health promotion, interdisciplinary, formative research, complex interventions

Introduction

A majority of patients who attend healthcare services today are diagnosed with long-term conditions or other non-communicable diseases that are not amenable to a complete medical cure. These patients are in need of other types of interventions that contribute to strengthening their health and their capacity to participate in society (World Health Organization, 2010; Harbers and Achterberg, 2012). Lubkin and Larsen (2013) argue that the potential for health promotion activities and overall health remains largely untapped in many individuals with chronic illness and that efforts must go beyond the individual's condition and limitations to include holistic health. There seems to be a need for more broadly applicable interventions that are independent of diagnosis and clinical setting in order to enhance the patient's health and wellbeing while living with illness. Wagner et al. (2001) argue that there is a need for improving practice in this field by means of interventions that allow for a personcentred approach that supports individuals to take charge of their own health. These interventions are typically applied by nurses and other groups of health professionals responsible for the follow-up and monitoring of persons with long-term conditions. The challenge is to ensure that these interventions are theory and research based, as well as being useful in practice.

The initiative for the present study came from interdisciplinary healthcare personnel who highlighted a lack of tools to promote coping and health in their encounters with patients diagnosed with longterm conditions who needed follow-up. The research involved close cooperation between practice and research in the development of an intervention for strengthening and utilising patients' capacity for health when living with chronic illness.

Background

The concepts of health and health promotion in the context of chronic illness are described in the literature as multidimensional and have no unified definitions. However, there seems to be a common view that people are fully capable of being healthy and experiencing a good quality of life while living with a long-term condition. Kaplun (1992), for example, has described such patients as resourceful, and health promotion in chronic illness as a process of enabling and developing potentials for healing and health. Leddy (2006) expresses a similar view, that health promotion in chronic illness entails developing the individual's strength and environmental resources to find solutions, rather than focusing solely on illness repair. Miller (2000, p 9) introduced the concept of 'patient power resources in chronic illness'. These resources include the patient's physical strength, psychological stamina, social support, positive self-image, energy, knowledge and insight, motivation and belief system. These resources should be assessed and used to strengthen coping and health in long-term conditions. This is in line with a strength-based care approach that involves consideration of:

'The whole person, what resources people have available to help them deal more effectively with their life, health and health challenges, and focusing on the person's uniqueness and not just their diseases or problems' (Gottlieb, 2013, p 1).

The question is, how can patients' resources for health in chronic illness be used in clinical health encounters? Development of educational or supportive interventions seems to be important in this regard. These interventions are often categorised as patient education, self-management or coping programmes. Research findings demonstrate that while traditional patient education increases patients' knowledge of their condition, the interventions are unsuccessful in changing behaviour, and do not

have an impact on disease control or other outcomes (Wagner et al., 2001). While these interventions often include health behaviour topics, their main focus is the control and management of the condition. This is also the main focus of Lorig et al. (2003) in their layperson-led, self-management education. Health promotion/wellness interventions hold another primary focus, which seeks to explore how factors other than disease-related biomedical factors – such as the psychosocial and behavioural – may influence the trajectory and functionality of people living with long-term conditions.

Stuifbergen et al. (2010) reviewed 190 publications on the benefits of wellness interventions in long-term conditions, and found that most interventions focused on a variety of health promotion behaviours, such as nutrition, physical exercise, psychological wellbeing and stress management. However, most interventions focused on one diagnostic group specifically. The studies reported immediate post-intervention results, but the content of the interventions was described in a limited manner and most interventions were not informed by theory.

Interventions designed for strengthening health and wellness in the context of chronic illness are multifaceted and therefore characterised as complex. These interventions are defined as health services that are not drugs or surgical procedures, but interventions that have many potential active ingredients (Campell et al., 2000). Investigators are recommended to engage with practice in the development and evaluation of such interventions to ensure they are research and theory based and relevant to practice (Stuifbergen, 2006; Kralik et al., 2010). A review of published papers on complex interventions in healthcare demonstrates that most studies report outcomes but development aspects are often poorly described (Oakley et al., 2006). The lack of reporting on how interventions were developed and on their content makes them difficult to implement in practice and inhibits further research (Clark, 2013). Möhler et al. (2012) have developed a criteria list to improve reporting of the development of complex interventions. The list contains 16 items divided into three sections:

- 1. Development of the intervention
- 2. Feasibility and piloting
- 3. Introduction of the intervention and evaluation

The focus of this article is the first stage: development of a new health promotion intervention for follow-up of individuals with long-term conditions. Pilot implementation and patients' evaluations of health-related outcomes are reported elsewhere (Heggdal, 2015).

Aims

This paper seeks to describe a part of the research process that involved the first-stage development of a new intervention. The first objective is to describe how clinicians, patients and researcher collaborated in the research, and to discuss the benefits of this collaborative work for improving practice. The second objective is to outline the intervention's aspects and components in order to establish a basis for implementation and further research in clinical practice.

Methods and material for developing the intervention

Initially, healthcare personnel working in rehabilitation independently began by using Bodyknowledging theory (Heggdal, 2003) in their encounters with patients with long-term conditions in order to support their coping and recovery. Bodyknowledging 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 researcher was invited to the field location in order to discuss the application of the theory, and was motivated by the following research questions:

How can Bodyknowledging theory be useful in practice and as a framework for developing an intervention to promote health and wellness for individuals who are living with chronic illness? How can patients, practitioners and researcher develop the intervention collaboratively, and what benefits could that realise?

Ethical considerations

The ethics committee of the Southern and Eastern Regional Health Authorities in Norway approved the study and the research was conducted in accordance with the World Medical Association's International Code of Ethics. Informed consent was obtained (orally) from participating patients and professionals to carry out the research.

Project organisation and study participants

The engagement of healthcare personnel and patients was emphasised from the beginning of the research and throughout the development and evaluation of the intervention. The researcher chose three clinical sites for the development of the intervention: a rehabilitation unit, an outpatient clinic and a hospital-based centre for patient education, the latter known as a 'Learning and Mastery Centre'. The three units were located in two general hospitals in southern Norway. An interdisciplinary project team of nine healthcare personnel from the three sites (including five nurses, one physiotherapist, and three occupational therapists) was established. The researcher was the leader of the team. The healthcare personnel recruited four patients as study participants: one man and one woman who were former patients, and two women outpatients.

Formative research

The research design for the project was qualitative process evaluation. However, the first part of the project, which is reported in this paper, involved qualitative, formative research to consider programme structure, content and pedagogical approaches. Two of the nurses in the project team worked part-time as research assistants in the first year of the development work, and seven project meetings were held during this time, at which the interdisciplinary team discussed Bodyknowledging as a theoretical framework and exchanged ideas on how it might be useful in practice. These ideas were noted and later used by the researcher in the formation of the first draft of the intervention. The methodological steps included:

- Establishing the project team
- Clinical reflection notes
- A workshop
- Development and testing of pedagogical tools
- Development of the intervention manual
- Development of an educational programme for health personnel

Establishing the project team

The formative research began as the team of health professionals gathered in Oslo for its first meeting. This was a seminar day and an opportunity to get to know one another and to form a cooperative group. The researcher introduced the project plan, invited the team to discuss it and held a lecture on the development and content of the theory and model of Bodyknowledging. The team was then invited to study the theory in more detail.

Clinical reflection notes

The clinical project team members reflected on the usefulness of the Bodyknowledging model in their work with current patients, keeping a journal of their reflections for four weeks. The following questions were used to organise the notes:

Describe a situation or the challenges you experience in an encounter with a patient in clinical practice.

Can Bodyknowledging theory be a resource for you, and in what way(s)?

The notes were sent by mail to the researcher who read them thoroughly, reflected on the experiences shared by the clinicians and formulated questions in the margin of the text. Follow-up meetings were held at each site for in-depth discussion, using the clinicians' notes and the questions as a guide to elaborate on the usefulness of Bodyknowledging. During the discussions, the idea arose to use

the phases of the Bodyknowledging framework (Heggdal, 2008; 2013) as a process tool to promote patients' health. The clinicians challenged the researcher to develop pedagogical tools to support their dialogue with patients – for example, questions that could serve to strengthen patients' coping and health promotion efforts. The researcher took notes, reflected on the ideas that arose in the discussions and incorporated these ideas into the further development of the intervention structure, content and pedagogical tools.

Workshop

A workshop was arranged to discuss how Bodyknowledging theory could be used more specifically as a pedagogical approach in the promotion of health in encounters with patients living with longterm conditions. The workshop theme was: 'Bodyknowledging as a foundation for the design and content of pedagogical tools for health promotion in chronic illness'. Members of the project team invited two former patients to the workshop. Two researchers and two university college lecturers with pedagogical and clinical backgrounds also attended. Some preparatory work was sent to the participants. At the workshop, the researcher presented the theory and model of Bodyknowledging in a plenary session. Afterwards, one of the nurses in rehabilitation shared the first experiences of using the model in practice. Then the participants were organised into three groups and given an exemplar of the summary of the main concepts, experiences and actions described in the Bodyknowledging model, and conducted a brainstorming session for one hour with the following questions in mind:

What kinds of associations does this model give? What kinds of questions would you like to pose to invite patients to dialogue on the themes described in the model? What kind of pedagogical tools do you think are relevant in this context?

Participants shared their ideas in plenum and engaged in further discussion.

Development and testing of pedagogical tools

The researcher summarised the ideas from the workshop and the reflection notes and compared them with those identified in publications on patient education and wellness interventions, to check the relevance and novelty of the ideas that arose in the discussions. The findings were used as a guide for the researcher to develop the first draft of the pedagogical tools and a framework for the new intervention. A graphic designer was engaged to produce a layout. The pedagogical tools consisted of a poster, a booklet/diary and a flipchart to facilitate participants' health promotion processes. One of the nurses reviewed the text of the flipchart with the researcher and gave her feedback. The booklet/ diary was reviewed by three of the participating patients (the fourth was not available at that point), and two experts in the field of textbook publication. The researcher incorporated this feedback in the second draft of the tools.

Piloting of pedagogical tools

One of the nurses in the project team, who worked at the outpatient clinic, had recruited two of the four patients – both women who had been diagnosed with inflammatory bowel disease – to engage in the piloting of the pedagogical tools on the same day as they had their regular appointments with the doctor for blood tests and medication. The researcher, who has a clinical background as a nurse working with people diagnosed with long-term conditions, saw the patients afterwards at the clinical site in individual consultations. This consultation replaced the regular consultation with the specialist nurse and lasted for an hour at three time-points over six months. In this way, the relevance and feasibility of the pedagogical tools and the suggestions for the intervention framework were tested in individual consultations. The patients confirmed the pedagogical tools to be useful in supporting their own health promotion efforts and recommended that steps be taken to develop a new programme to support patients who needed follow-up.

Development of the intervention manual

The researcher outlined the intervention manual as part of the formative research. The question was, how the manual could become useful as a tool for health professionals in their clinical practice? The first suggestion for the manual contained a description of the whole intervention – that is, the aims of the intervention, the structure, content and pedagogical approaches as well as the requirements for professionals' competence, and the time and the resources needed for implementation. The project team was invited to review the 100-page manual critically, and gave the researcher written and oral feedback on the organisation and content of the text as well as on the researcher's suggestions for intervention structure, content and pedagogical approaches. The researcher emphasised active listening, paid attention to the details of the feedback from the clinicians and posed questions when something was unclear. Afterwards, the researcher reflected on each part of the feedback and revised the manual accordingly, with the aim of making it relevant and useful for practice.

Development of an educational programme for health professionals

An educational programme for health professionals was developed in parallel to the formative research, and the clinical team completed 80 hours of training to prepare themselves for the implementation of the intervention. The training included studying the theoretical foundation of the programme, as well as the application of pedagogical tools and approaches. More details are provided in the description of Component D and in Table 2, below. The researcher provided the main part of the training. However, in order to cover all the topics, lecturers were hired to teach in their specialties: a psychiatric nurse specialist taught group work, a social worker taught solution-focused therapy and a physiotherapist taught the principles of body awareness therapy.

Results

The result of the formative research was the development of a new intervention for use in follow-up of individuals with long-term conditions to facilitate coping and health. This implied a change in clinical practice, which is elaborated in the discussion later in this paper. The intervention was designed to be broadly applicable across diagnostic categories and in a variety of settings. In the following text, the items of the criteria list developed by Möhler et al. (2012) are used as a basis for the reporting of the first stage – development of the new intervention.

The intervention's underlying theoretical considerations

Bodyknowledging theory (Heggdal, 2003) served as the main theoretical framework for the intervention because healthcare personnel had started to use the concepts to help patients cope and recover (Brooks et al., 2015), and found it to be a relevant tool for practice. The theory was developed using a 'bottom-up' strategy, drawing on a number of studies involving patients with different long-term conditions, such as stroke, chronic obstructive pulmonary disease and inflammatory bowel disease. Patients' experiences of their illness and health, coping abilities and health promotion resources were central to the research. Empirical evidence showed that two major concerns of people living with long-term conditions are the multitude of uncertainties they face, and the constriction of life space (the sphere to act within one's daily life) they encounter due to health changes. Patterns emerged indicating that patients' experiences and actions performed to manage their situations constituted a dynamic process of health-related change through use of bodily knowledge of health and illness (Heggdal, 2013).

Reflected in these findings is the tenet shared by Bodyknowledging theory, which asserts that people have bodily knowledge that constitutes an important but little used resource for coping and health promotion in chronic illness. This unique yet undervalued knowledge is recognised and strengthened through the patient's engagement in the new intervention.

Bodyknowledging theory is in line with the phenomenological understanding of the body as introduced by Merleau-Ponty (1994), in which the body is understood as an object and subject at the same time and as a primary source of meaning and knowledge. The dynamic dialectics of the body as subject and object are being used in the person's efforts to promote health when they observe their body and at the same time sense its reactions. The empirical basis of the theory offers examples of how patients diagnosed with chronic illness learn to know their body's dynamic limits of tolerance for the type and magnitude of activity and for factors in the physical and psychosocial environment, and how this knowledge is applied to prevent deterioration and to promote health. This is a dynamic process in which the person moves up and down and in and out of different phases as they promote their own health. Therefore, Bodyknowledging theory is closely connected to Antonovsky's theory of salutogenesis (1988) in the sense that health is perceived not as dichotomous to disease, but as a flexible continuum, indicating that the person's sense of coherence is being strengthened through Bodyknowledging.

The theoretical basis for the intervention also rests on Freire's theory (2006) of empowerment, which asserts that the person's acknowledgement of their situation and their efforts to find solutions to the challenges of that situation are important, and that dialogue is a means for the liberation of human resources. The idea of empowerment was incorporated in the Bodyknowledging framework in the first instance, as it was grounded in patients' experiences of health and illness (Heggdal, 2003; 2013). Empowerment was further incorporated as the theory's layperson-based concepts were used explicitly in the formation of the intervention content and pedagogical tools. The new intervention was named the Bodyknowledging Programme (BKP).

The components of the intervention, the rationale for their selection of components and the essential function of each one

Table 1 presents an overview of the components of the Bodyknowledging Programme.

Table 1: Components of the Bodyknowledging Programme (BKP)		
Component	Description	
A: Structure of the intervention	 Parts Seven sessions The first three sessions were held weekly, the next three sessions were held every second week and the seventh and final session six months after the programme started Group sessions (3 hours) or Individual sessions (1.5 hours) 	
B: Content	 The Bodyknowledging model: phases of Bodyknowledging, personal limits of tolerance and strategies for promoting health as described by former patients Patients' own themes of health promotion in chronic illness The social dimensions of living with a chronic condition; encounters with society 	
C: Means	 Introduction to Bodyknowledging by healthcare personnel Pedagogical tools: poster, flipchart, booklet/diary. Open dialogue and reflection individually and/or in groups. Reading of booklet/writing of diary Physical exercises inspired by body awareness therapy Challenges and support to stay active and participate in society 	
D: Healthcare personnel	• Interdisciplinary: nurses, occupational therapists and physiotherapists, who had done a 30-CPD credit postgraduate course in Bodyknowledging	
E: Patients	• Participants' engagement in the programme, their experience of the challenges of living with long-term health problems. Their bodily knowledge of health and illness, their health promotion capabilities and actions to stay healthy, and their relational resources and social support requirements	

Component A: Structure of the intervention

In order to facilitate patients' processes of health promotion, the programme was structured in seven sessions over a six-month period. The first three sessions were held weekly, the next three every second week and the final session six months after the programme started. This mode of organisation aimed

to facilitate participants' systematic work on health promotion over time. The rationale for follow-up over six months was based on research findings indicating that patients' efforts must be supported in order to be integrated and accomplished on a long-term basis (Halding and Heggdal, 2011). To maximise flexibility for practice, the programme was structured to accommodate both individual and group formats. When the programme used groups, eight to 10 people living with different health conditions participated and each session lasted for three hours with one 30-minute break to eat and socialise. Group sessions were led by representatives from two different professions; for example, a nurse and a physiotherapist or an occupational therapist and a nurse, who had completed the educational programme (BKP Component D).

In the individual format, the sessions were scheduled to last one-and-a-half hours, and patients and healthcare personnel worked together using the same content as in the groups. This way of organising the programme was applied across the clinical sites. The educational programme for health professionals and the intervention manual ensured the intervention could be applied consistently across all sites.

Component B: Content of the intervention

The programme content was organised according to the phases of Bodyknowledging; that is, patterns, experiences, actions and consequences of patients' health promotion processes, as described by former patients. However, the participating patients' experiences of their life situation and their potential and capacity for health formed the core of the content.

Using the theory and model of Bodyknowledging as a framework, healthcare personnel were trained to invite participants to engage in their own process of health promotion with the following questions in mind:

What is making your illness better or worse? What can you do to cope and recover, and what do you need in the form of support from others? How can your health and wellbeing be strengthened?

These questions were rooted in the empirical work on Bodyknowledging and came from former patients who had participated in the research to establish the model. In this way, the model was used as a tool to support the participants to search for answers to these questions as they worked systematically on their own health. This meant that professionals engaged patients in working on different phases of Bodyknowledging, such as the phase of uncertainty – denying and escaping the sick body; the phase of losing life space – grieving and anger; the phase of listening and understanding the body's signs – strengthening hope; and the phase of integrating knowledge – exploring new possibilities of wellbeing and health (Heggdal, 2013).

The rationale for the content was outlined in the theoretical section and is consistent with empowerment models of health promotion (Naidoo and Wills, 2000) in the sense that the content rests on empirical findings from lay accounts and goes beyond providing information towards facilitating action and raising critical consciousness of one's own health. It invites the discovery of factors in one's life situation that may have a positive or negative impact on health, and of which factors are subject to change and what the relevant actions are.

Component C: The means through which the content was provided

The pedagogical methods chosen were varied and included: a short introduction by healthcare personnel to the Bodyknowledging framework at the beginning of each session; patient narratives about health conditions, coping and health promotion efforts; the dialogue with healthcare personnel and peers; and individual work between sessions; and group work.

A poster, a booklet/diary and a flipchart were developed as pedagogical tools to facilitate participants' health promotion processes. The flipchart contained a collection of 30 large sheets that were twosided so the involved person(s) and healthcare personnel could see the same content when they were sitting at opposite ends of the table. It contained the same content as the poster, but added more detailed text following the headings in the Bodyknowledging process model. In addition, the text contained questions to facilitate the person's reflection work. The tools implied that patients engaged in dialogue on their health in a variety of ways, such as the dialogue with the text on the poster, flipchart and booklet/diary, the dialogue between patients (in group format) and the dialogue with healthcare personnel. The questions used were inspired by the principles of open dialogue and solution-focused therapy (Anderson and Goolishian, 1992; Freire, 2006; O'Connel, 2012).

The rationale for emphasising dialogue in this programme was also based on research findings showing that patients have embodied resources for health that are not fully employed (Price, 1993; Frank, 1995; Stensland and Malterud, 1999, 2001; Wilde, 2003; Heggdal, 2003, 2013), and on Thorne's (2005) research on the patient-provider communication in chronic illness as a health promotion window of opportunity to enable and develop the potential for healing and health.

Physical activity was also an important part of the programme's content, and health professionals introduced exercises at the beginning of each session to support the participants in the use of their bodily knowledge as a resource for health. The exercises were inspired by the physiotherapeutic method of basic body awareness therapy, which concentrates on breathing, balance and movement (Dropsy, 1988; Gard, 2005). In addition, participants were asked to choose a physical activity to do at home twice a week, and questions concerning these activities were posed in subsequent sessions to support the patients. The role of physical activity was based on recommendations by health authorities concerning physical activity as an important health promotion measure (Healthy People, 2015).

Component D: Healthcare personnel

The healthcare personnel who engaged in the development of the intervention had completed an 80-hour educational programme in parallel to their participation in the research. The training was intended to lay the groundwork for patients to be active partners in health promotion in relation to their life situations. Professionals were taught to use the pedagogical approaches and tools in a flexible way in relation to the person or group in question. Their main function was to engage with participants as dialogical partners, listen to their stories, acknowledge their experiences and ask questions in order to support and challenge participants' further work on their health promotion as a process that incorporated the possibility of change. In order to do this, the professionals studied the theoretical foundation for new interventions, including the phenomenological understanding of the body, research findings describing the experienced knowledge of patients in chronic illness, Bodyknowledging theory, salutogenic theory, empowerment theory, and principles of dialogue and group work (see theoretical section for references).

The healthcare personnel were trained to approach the patients as resourceful and knowledgeable, to pose more questions than give answers (Anderson and Goolishian, 1992; Stensland and Malterud, 1999, 2001) and to study how they could strengthen patients' health promotion efforts and empowerment (Freire, 2006; Leddy, 2006) by means of the intervention's content and the pedagogical tools. This required self-reflection concerning their role as dialogical partners with patients in health promotion. The rationale for the training was that health professionals' education in terms of patients with long-term conditions primarily concerns assessment, treatment and care, while the role as an equal partner in health promotion is less evident. Table 2 offers an overview of the main content of the educational programme.

Table 2: Overview of the educational programme for healthcare personnel in BKP		
Course	Topics	
1: Health promotion processes	 Fundamental perspectives in health promotion work The body, knowledge, illness and health Health promotion processes (research on salutogenesis, recovery, Bodyknowledging) Empowerment and user participation The significance of social relations for coping and health The law, ethics and organisational aspects of patient participation Health education (principles of dialogue, group work, narrative method) 	
2: Bodyknowledging: process-oriented approach to coping and health	 Bodyknowledging as a pedagogical health service and a tool for health promotion Health education Professional development and change work in practice 	

Component E: Patients

The patients' engagement in the intervention was a prerequisite for the programme, as their experience of their health conditions, their own themes and solutions (Freire, 2006) and health strategies constituted an essential part of its content. As the aim was to develop a widely applicable intervention, patients' experiences of living with diverse diagnoses was taken into account in the development of the content and pedagogical tools, as well as in the implementation and evaluation process (Heggdal, 2015).

Intended interactions between different components

According to Möhler et al. (2012), some components in complex interventions are designed to support or to enhance the effect of other components. The programme's structure aimed to acknowledge and facilitate participants' health promoting resources during a six-month follow-up period. The content, pedagogical tools and methods, as well as the training of healthcare personnel, had the same goal. The interactions between patients and healthcare personnel and peers (if in group format) were necessary for patients to study their health promotion resources and to move on in the process. The theoretical framework of the intervention served as an introduction in this regard and therefore the programme allowed space for patients to have an impact on its content. Figure 1 offers an illustration of the interactions.

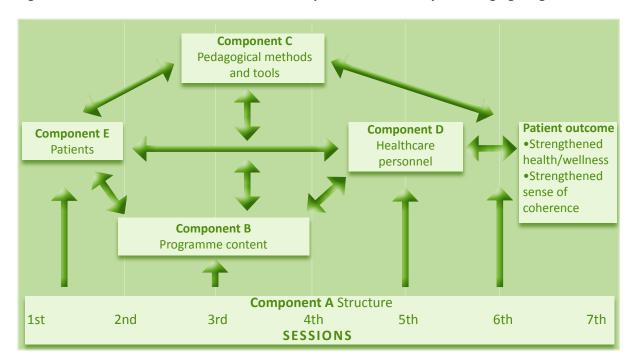


Figure 1: Intended interactions between the components of the Bodyknowledging Programme

Contextual factors and determinants of the setting in the modelling of the intervention

The Bodyknowledging Programme was designed to be widely applicable across patient groups and clinical settings to ensure that it was a flexible tool for promoting patients' health. The chosen settings for the development of the programme were described in the first part of the method section of this article. These sites were chosen because they are typical sites where patients at risk of or diagnosed with long-term conditions attend for care and follow-up consultations, and thus healthcare personnel had the opportunity to invite patients to attend the programme. The outpatient clinic holds individual consultations and the rehabilitation unit combines work with patients individually and in groups. Therefore, the new programme was designed to be applied both in individual and group formats simply by reducing the lengths of the individual sessions from three to one-and-a-half hours.

Discussion

This article describes a study initiated by healthcare personnel in specialist care who expressed a need to improve their practice with regard to follow-up of patients with long-term conditions. The research design was qualitative and formative, and required a close collaboration between practice and research in the development of a new and widely applicable intervention for the promotion of coping and health in clinical healthcare encounters with these individuals. The components of the intervention were outlined so as to lay the groundwork for successful implementation and further research. The intervention required a change in professionals' approaches in practice, from focusing primarily on managing the problems of the condition to engaging in the research to focusing on patients' resources and strengths as a part of promoting 'holistic health' in chronic illness (Miller, 2000; Gottlieb, 2013; Lubkin and Larsen, 2013).

Improving healthcare by bridging theory and practice through formative research

Healthcare personnel had chosen Bodyknowledging theory (Heggdal, 2003, 2008, 2013) as the main theoretical framework for the intervention and contacted the researcher for assistance in the development of their practice. A multidisciplinary project team was established, and the researcher, healthcare professionals and patients engaged in a shared endeavour to study how the theoretical framework could be useful as a frame to support patients in coping and health in clinical practice. This approach reflected the recommendations for the development of new interventions in the context of

chronic illness and for developing practice (Stuifbergen, 2006; Manley et al., 2014). The professionals argued that their participation in the formative research had improved their practice in the sense that it had changed their approach to healthcare encounters with patients living with long-term conditions. Before they participated in the research, their main emphasis had been on the assessment of the problems of illness and the care of the chronically ill patient. Through their engagement in the research, they experienced a change of perspective and acquired knowledge that enabled them to acknowledge and use patients' capacity for health in a much better way (Antonovsky, 1988; Miller, 2000). They held the view that the theoretical foundation for the new intervention was important in this regard, as the concepts offered a shared foundation for thinking and helped them to invite patients to study and employ their own strengths and capabilities.

A number of challenges were experienced during the development of the intervention. These concerned having enough time to engage in the study of theory alongside regular practice. This was partly overcome by means of agreements with the clinics' leadership, who offered the professionals some days each semester to study, and paid their salaries while they were attending the discussion meetings and the lectures. Another challenge was incorporation of the person-centred approach, especially in the rehabilitation unit where the medical staff were resistant. This resistance faded over time, partly because the leadership of the unit was clear about the importance of the project. The researcher visited the unit regularly, kept communication channels open, had meetings with the leaders and held several information meetings for the whole staff at the unit. This helped to create a feeling of ownership of the project. In time, medical staff could see the results of the project through the emergence of new tools.

Professionals described how their courage, assessment and communication skills developed through their systematic use of the Bodyknowledging model to reflect and to engage patients in a process of exploring facilitation of their health in spite of their conditions.

The clinicians perceived that their engagement in developing the intervention was critical for them to be able to transform their individual and collective approach to consultation and care of patients. The Bodyknowledging Programme required a change of professional functions in the sense that professionals learned to ask more questions than give answers (Anderson and Goolishian, 1992) and engage more in dialogue with patients, inviting and supporting them to express how they were and what they needed to cope and recover, confirming the validity of the patients' experiences and challenging them to employ their own abilities and strategies to facilitate their overall health (Miller, 2000; Lubkin and Larsen, 2013).

The Bodyknowledging Programme – a person-oriented and strengths-based approach

According to the healthcare personnel, the training course they underwent and the opportunity to engage as partners in research had laid the groundwork for changing their practice towards a strengths-based approach (Gottlieb, 2013). In order for professionals to consider each patient's uniqueness and whole person, and for patients to use their capacity for health, it was necessary to acknowledge the patient as resourceful and knowledgeable. This reflects a shared understanding of health promotion in the context of chronic illness, in which the patient is described as fully capable of being healthy and experiencing a good quality of life while living with their condition (Kaplun, 1992; Leddy, 2006; Stuifbergen, 2010). Bodyknowledging theory illuminates patients' health promotion processes and encompasses lay concepts that emerged from the analysis of patients' experiences of bodily knowledge as an untapped resource for health in chronic illness (Heggdal, 2013). By using the concepts and theory as a framework for the intervention's structure and content, the lay perspective was built systematically into the intervention components. Thus, the patient's perspective and capacity for health were incorporated as the main focus of the new programme. The intervention was developed to use these resources with the aim of strengthening wellness and participation in society (World Health Organization, 2010; Harbers and Achterberg, 2012). A study of the outcomes

involving men and women with a variety of diagnoses showed that participants experienced a change in their health promotion abilities by engaging in the Bodyknowledging Programme – a change in their understanding of the situations, choices and actions that make the health condition better or worse. They widened their life space and became more physically and socially active after their participation in the programme, and they felt stronger in social encounters as they were communicating more clearly what they needed in order to stay well. Patients' active engagement in the programme, healthcare professionals' attitudes and approaches, the group work and the conceptual framework of Bodyknowledging were identified as the intervention's active ingredients (Heggdal, 2015). The training of the professionals was revealed as an essential part of the intervention, and a necessary condition for ensuring a change in this field of practice.

The new intervention established a basis for productive interactions between patients and professionals in the context of chronic illness (Wagner et al., 2001). The structure and methodological approaches imply a new mode of follow-up of patients, and active engagement on behalf of the patient is a prerequisite for accomplishing the programme. This is in line with empowerment models of health promotion (Naidoo and Wills, 2000). It can be argued that the intervention contributes to a replacement of the old paradigmatic stance in which the patient was the receiver of interventions, and explicitly turns the perspective around towards regarding the patient as knowledgeable and as an active participant with a powerful part to play in health interventions (Leder, 1992; Thorne, 2005).

Methodological considerations

The reporting of the development and early piloting of complex interventions in healthcare needs to be more thorough in order to implement the interventions successfully in practice and for research purposes (Oakley et al., 2006; Craig et al., 2008). The criteria proposed by Möhler et al., (2012) have been applied in this paper for reporting the first stage of the development of a new intervention intended for interdisciplinary application in healthcare encounters. Complex interventions consist of several interacting components and the issues concern what the key intervention components are, how the intervention as a whole functions, how it is received by patients and how it can be implemented in diverse settings (Grant et al., 2013). The list of items on the proposed criteria list (Möhler et al., 2012) helped to clarify the theoretical foundation for the new intervention and its components, the rationale for their selection, intended interactions between components and the context of the intervention. Clark's (2013) theorising of the components and parts of complex interventions was useful to add more depth to the reporting, and helped to clarify the knowledge of patients as an essential component of the Bodyknowledging Programme. The practical relevance of the theoretical framework and the feasibility of the intervention were checked as part of the formative research. The evaluation of the first implementation pilot was positive (Heggdal, 2015). It is reasonable to anticipate that the thorough reporting of first-stage development of the Bodyknowledging Programme will contribute to its successful implementation in the future, as each of the intervention's components becomes better understood. This is an important part of many efforts to ensure that the programme is applied as it was meant to be, which is a prerequisite for achieving good outcomes for future patients and professionals in practice.

Conclusion

The shared research endeavour contributed to a theory- and research-based development in practice. The formative research showed how the theoretical framework of Bodyknowledging was bridged to practice and incorporated in the intervention structure, content and means. Healthcare personnel said their engagement in the research helped them acquired new perspectives and knowledge about patients' capacity for health in chronic illness and how this could be used to enhance practice. The patient's perspective was accommodated by applying a lay-based theoretical framework, and by including patients in critical discussions and the review of pedagogical tools as well as in clinical piloting. A proposed criteria list was applied and found to be useful as a guide to report the first stage of development of the new intervention and for ensuring successful implementation and laying a path

for future research. The Bodyknowledging Programme offered structure, content and pedagogical approaches for patients' and healthcare personnel to explore unused resources for health in chronic illness.

Due to political reforms in Norway, the follow-up of individuals with long-term conditions has now been reorganised and is mainly the responsibility of community healthcare. The programme was designed to be a flexible tool for practice across a variety of clinical settings, and a pilot implementation in community healthcare confirmed that it was suitable in this context (Engevold and Heggdal, 2015).

Implications for practice

The mutual dependency and collaboration between an interdisciplinary team of health professionals, patients and researcher(s) over a long period facilitated the development of a new pedagogical health service that was useful to improve practice in the follow-up of individuals with chronic illness. This formative research may serve as an inspiration to clinicians, researchers and leaders of healthcare who are concerned with ensuring theory- and research-based development of practice and the successful implementation of complex interventions.

While developing such interventions, it is important to be aware that development involves several factors: professional competence; new programmes and tools; and the culture of the whole organisation where the research is undertaken. It is important to address these levels in order to attain lasting results. Endurance, creativity and hard work over time is needed in this shared endeavour.

References

- Anderson, H. and Goolishian, H. (1992) The client is the expert: a not-knowing approach to therapy. *In* McNamee, S. and Gergen, K. (Eds.) (1992) *Therapy as Social Construction*. London: Sage. pp 25-39.
- Antonovsky, A. (1988) Unraveling the Mystery of Health. How People Manage Stress and Stay Well. San Francisco: Jossey-Bass.
- Brooks, H., Rogers, A., Sanders, C. and Pilgrim, D. (2015). Perceptions of recovery and prognosis from long-term conditions: the relevance of hope and imagined futures. *Chronic Illness*. Vol. 11. No.1. pp 3-20.
- Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A., Sandercock, P. and Spieghalter, D. (2000) Framework for design and evaluation of complex interventions to improve health. *BMJ*. Vol. 321. pp 694-696. doi: 10.1136/bmj.321.7262.694.
- Clark, A. (2013) What are the components of complex interventions in healthcare? *Social Science and Medicine*. Vol. 93. pp 185-193. doi: 10.1016/j.socscimed.2012.03.035.
- 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. *BMJ*. Vol. 337. a1655. doi: 10.1136/bmj.a1655.
- Dropsy, J. (1988) Den Harmoniska Kroppen. (tr: Body in Harmony). Stockholm: Natur och Kultur.
- Engevold, H. and Heggdal, K. (2015) Patients' experience of changes in perceived control in chronic illness: a pilot study of the outcomes of a new community-based health promotion programme. Submitted for publication to *Scandinavian Psychologist*.
- Frank, A. (1995) *The Wounded Story-teller. Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Freire, P. (2006) *Pedagogy of the Oppressed*. (30th anniversary edition). New York: The Continuum International Publication Group.
- Gard, G. (2005) Body awareness therapy for patients with fibromyalgia and chronic pain. *Disability and Rehabilitation*. Vol. 27. No. 12. pp 725-728. doi: 10.1080/09638280400009071.
- Gottlieb, L. (2013) *Strengths-based Nursing Care. Health and Healing for Person and Family*. New York: Springer.
- Grant, A., Treweek, S., Dreischulte, T., Foy, R. and Guthrie, B. (2013) Process evaluations for clusterrandomised trials of complex interventions: a proposed framework for design and reporting. *Trials*. Vol. 14. No. 15. Retrieved from: <u>tinyurl.com/Trials-complex-interventions</u> (Last accessed 12th October 2015). doi: 10.1186/1745-6215-14-15.

- Halding, A. and Heggdal, K. (2011) Patients' experience of health transitions in pulmonary rehabilitation. *Nursing Inquiry*. Vol. 19. No. 4. pp 345-356. doi: 10.1111/j.1440-1800.2011.00573.x.
- Harbers, M. and Achterberg, P. (2012) *Europeans of Retirement Age: Chronic Disease and Economic Activity*. Retrieved from: <u>tinyurl.com/EC-chronic-disease</u> (Last accessed 12th October 2015).
- Healthy People (2015) *Healthy People 2020*. Retrieved from: <u>healthypeople.gov/</u> (Last accessed 12th October 2015).
- Heggdal, K. (2003) *Kroppskunnskaping: en Grunnleggende Prosess for Mestring ved Kronisk Sykdom*. (Tr: Bodyknowledging a basic process of coping with chronic illness). Doctoral dissertation. Bergen: University of Bergen Faculty of Medicine.
- Heggdal, K. (2008) *Kroppskunnskaping: Pasienten som Ekspert i Helsefremmende Prosesser*. (Tr: Bodyknowledging patients as expert in health promotion processes). Oslo: Gyldendal Academic Publishers.
- Heggdal, K. (2013) Utilising bodily knowledge in patients with chronic illness in the promotion of their health: a grounded theory study. *Californian Journal of Health Promotion*. Vol. 11. No. 3. pp 62-73.
- Heggdal, K. (2015) Patients' experience of the outcomes of engaging in a broadly applicable health promotion intervention for individuals facing chronic illness. *Health*. Vol. 7. pp 765-775. Retrieved from: <u>dx.doi.org/10.4236/health.2015.76091</u> (Last accessed 12th October 2015).
- Kaplun, A. (1992) *Health Promotion and Chronic Illness. Discovering a New Quality of Health*. Cologne: WHO Regional Publications, European Series, 44.
- Kralik, D, Paterson, B. and Coates, V. (2010) *Translating Chronic Illness Research Into Practice*. Oxford: Blackwell.
- Leddy, S. (2006) *Integrative Health Promotion: Conceptual Basis for Nursing Practice*. Sudbury, Massachusetts: Jones and Bartletts.

Leder, D. (1992) The Body in Medical Thought and Practice. Dortrecht, Netherlands: Kluwer Academic.

- Lorig, K., Halsted, R. and Holman, H. (2003) Self-management education: history, definition, outcomes and mechanisms. *Annals of Behavioral Medicine*. Vol. 26. No. 1. pp 1-7. Retrieved from: <u>dx.doi</u>. <u>org/10.1207/S15324796ABM2601_01</u>. (Last accessed 12th October 2015).
- Lubkin, I. and Larsen, P. (2013) *Chronic Illness: Impact and Intervention*. (8th edition). Burlington: Jones & Bartlett.
- Manley, K., O'Keefe, H., Jackson, C., Pearce, J. and Smith, S. (2014) A shared-purpose framework to deliver person-centred, safe and efficient care: organisational transforming using practice development methodology. *International Practice Development Journal*. Vol. 4. No. 1. Article 2. pp 1-31. Retrieved from: <u>fons.org/library/journal/volume4-issue1/article2</u> (Last accessed 12th October 2015).
- Merleau-Ponty, M. (1994) The Phenomenology of the Body. Oslo: Pax.
- Miller, J. (2000) (Ed.) *Coping with Chronic Illness. Overcoming Powerlessness*. (3rd edition). Philadelphia: Davis. pp 9-15.
- Möhler, R., Bartoszek, G., Köpke, S. and Meyer, G. (2012) Proposed criteria for reporting the development and evaluation of complex interventions in healthcare: guideline development. *International Journal of Nursing Studies*. Vol. 49. No. 1. pp 40-46. doi:10.1016/j.ijnurstu.2011.08.003.
- Naidoo, J. and Wills J. (2000) *Health Promotion: Foundations for Practice*. (2nd edition). Edinburgh: Ballière Tindall.
- Oakley, A., Strange, V., Bonell, C., Allen, E. and Stephenson, J. (2006) Process evaluation in randomised controlled trials of complex interventions. *BMJ*. Vol. 332. pp 413-416. pp 413-416. doi: 10.1136/ bmj.3327538.413.
- O'Connel, B. (2012) Solution-Focused Therapy. (3rd Edition). London: Sage.
- Price, M. (1993) Exploration of body listening: health and physical self-awareness in chronic illness. *Advances in Nursing Science*. Vol. 15. No. 4. pp 37-52.
- Stensland, P. and Malterud, K. (1999) Approaching the locked dialogues of the body. Communicating symptoms through illness diaries. *Scandinavian Journal of Primary Healthcare*. Vol. 17. No. 2. pp 75-80. doi: 10.1080/028134399750002683.
- Stensland, P. and Malterud, K. (2001) Unraveling empowering internal voices: a case study on the interactive use of illness diaries. *Family Practice*. Vol. 18. No. 4. pp 425-429.

- Stuifbergen, A. (2006) Building interventions for persons with chronic disabling conditions. Family and Community Health. Vol. 29. No. 1. pp 28-34. Retrieved from: <u>tinyurl.com/stuifbergen-interventions</u> (Last accessed 12th October 2105).
- Stuifbergen, A., Morris, M., Jung, J., Pierini, D. and Morgan, S. (2010) Benefits of wellness interventions for persons with chronic disabling conditions: a review of the evidence. *Disability and Health*. Vol. 3. No. 3. pp 133-145. Retrieved from: <u>dx.doi.org/10.1016/j.dhjo.2009.10.007.</u> (Last accessed 12th October 2015).
- Thorne, S. (2005) Patient-provider communication in chronic illness: a health promotion window of opportunity. *Family and Community Health*. Vol. 29. No. 1. pp 4-11.
- Wagner, E., Austin, B., Davis, C., Hindmarsh, M., Scaefer and Bonomi, A. (2001) Improving chronic illness care: translating evidence into action. *Health Affairs*. Vol. 20. No. 6. pp 64-78. doi: 10.1377/ hlthaff.20.6.64.
- Wilde, M. (2003) Embodied knowledge in chronic illness and injury. *Nursing Inquiry*. Vol. 10. No. 3. pp 170-176. DOI: 10.1046/j.1440-1800.2003.00178.x.
- World Health Organization (2010) *Global Status Report on Non-communicable Diseases*. Geneva: WHO. Retrieved from: <u>tinyurl.com/WHO-ncd-2010</u> (Last accessed 12th October 2015).

Acknowledgements

Thanks to the patients and healthcare personnel at the Department of Rehabilitation, Inland Hospital, Gjøvik and at the outpatient clinic and 'Learning and Mastery Centre' at Deaconess Hospital, Oslo, Norway, for their participation in the first stage development of the Bodyknowledging Programme. Anne Mellbye, Oslo, Norway formatted the visual layout of the pedagogical material and deserves great thanks. The author is grateful to Kira Foster, PhD, and Bjørg Frøysland Oftedal, PhD, University of Stavanger, Norway, for their critical reviews of the manuscript. Research grants were received from Southern and Eastern Norway Regional Health Authorities [2005136/2008114].

Kristin Heggdal (PhD, MNSc, RN), Associate Professor, Institute of Health Studies, University of Stavanger, Norway.

© 2015 by the author; licensee Foundation of Nursing Studies, UK. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution license (https://creativecommons.org/licenses/by/3.0/)