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The effect of a person-centered and strength-based health intervention on recovery among people with chronic illness

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Abstract

Background: Strengthening the health capacities of people diagnosed with a chronic illness is an essential part of secondary and tertiary prevention. However, research-based interventions focussed on health and recovery in chronic illness remain scarce. Additionally, these are often designed for specific diagnostic groups while healthcare workers are in need of more broadly applicable interventions that attend to personal resources for health. The aim of the present study was to trace patient recovery during an intervention designed to strengthen their bodily knowledge as an important resource for coping, recovery and health in chronic illness.

Design and methods: The Outcome Rating Scale (ORS) was applied, as this instrument repeatedly measures progress in coping and recovery. Four dimensions were assessed: (1) individual (personal or symptomatic distress or wellbeing); (2) interpersonal (relational distress or wellbeing); (3) social (patient satisfaction with work, school and relationships) and (4) overall (general sense of wellbeing).

Results: The sample comprised 13 men and 24 women who had been diagnosed with a range of long-term conditions and were attending the person-focussed health intervention in their community. Significant change was identified during the programme period. The findings indicate more improvement on the personal and general wellbeing dimensions than on the interpersonal and social dimensions. The number of participants scoring above the ORS cut-point of 25 increased by a factor of 1.7, demonstrating the programme's efficiency.

Conclusions: The results indicate that The Bodyknowledging Programme had a significant impact on the various forces driving recovery in chronic illness.

Keywords

Chronic illness, health promotion, intervention, Outcome Rating Scale (ORS), patient activation, patients as partners, person-centered healthcare, primary care, quantitative method, recovery, self-management, social and economic costs, The Bodyknowledging Programme, wellbeing

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Introduction

The increasing number of people diagnosed with chronic diseases represents a challenge for public health. Almost one-third of EU citizens report having a chronic illness or long-lasting health problem and prevalence increases with age [1]. Chronic disease can have a negative influence on social activity and labour participation, contributing to social and economic costs both for those affected and for Society as a whole [2], as patients and their families struggle over the long term with illness-related problems. Utilizing these people's resources and health capacities, while simultaneously treating their disease, is challenging and healthcare personnel need tools and interventions that can facilitate recovery and health. Alongside concepts such

as self-management, person-centered care, hope, empowerment, coping and wellbeing, recovery has become an important concept in research on chronic illness. These concepts share a common perspective that is health-centered rather than disease-centered, emphasizing the role of patients as partners in healthcare rather than positioning professional providers as the central determinants of health and wellbeing [3,4].

According to Collier [5], the concept of recovery is confusing, poorly understood, difficult to define and open to interpretation. That said, two main conceptions of recovery can be distinguished in the literature: 'medical' or 'clinical' recovery, referring to cure from an illness and 'personal' or 'life' recovery, referring to a process of personal growth and health-related change. While ideas of

clinical/medical recovery are more restrictive and are often described in terms of normalization of biophysiological functions, the personal/life approach emphasizes individual-defined parameters of recovery. In the context of chronic illness, personal recovery is not the same as being cured and/or having no further symptoms. Instead, it includes 'return to a state of wellness' (e.g., following a relapse [4-7]).

Recovery in long-term illness has been described as a process, an approach or a vision and as a guiding principle for clinical practice [4]. While Strauss and Corbin [8] were among the first scientists to study the recovery process in chronic illness, the main focus of their Trajectory Framework was not the process of recovery but the issue of how to handle challenges during different phases of the illness. Dorsett [9] argued that the person's experience and the associated learning process are the most important parts of recovery. Tobian [10] studied the recovery of patients with myocardial infarction and identified three interrelated phases of recovery that involved learning: (1) accepting what has happened; (2) establishing boundaries (to determine what one is able or unable to do following the infarction) and (3) making adjustments to re-establish normality (i.e., to resume the activities of daily living).

In a longitudinal study of recovery, Brooks [11] looked at patients with a range of long-term physical health conditions and compared the results with studies of mental health recovery. The findings indicated that participants viewed recovery as a complex non-linear and personal journey associated with resuming previously valued activities. The main difference between recovery from physical and mental health conditions seemed to relate to perceived threats on the participant's horizon. For patients with somatic diagnoses, mortality was identified as a constant background concern integral to their experience and they focused on the here-and-now while minimizing disruption and maintaining or restoring their capacity. In this regard, they differed from mental health patients, who seemed more future-oriented, focussing on hope and their awareness of a more active self [11].

Beyond the medical, interventions to facilitate personal and life recovery in chronic illness are scarce and are for the most part designed for patients with mental health problems. For instance, the Wellness Recovery Action Plan (WRAP) seeks to identify and utilize patient resources to facilitate recovery and the Illness Management and Recovery intervention (IMR) aims to help users to mitigate vulnerabilities and stressors by building social support, using medication effectively and developing a relapse prevention plan [3,11,12]. These interventions resemble the services commonly offered at Community Mental Health Centres (CMHC) in Norway [13]. Interventions to facilitate personal recovery in chronic somatic illness are often disease-specific; these include Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) and Adaptive Pacing Therapy (APT), which focus on recovery from chronic fatigue syndrome [14].

Interventions that are practised more broadly tend to focus more on managing disease-related problems than on restoring health and wellness [15-17] and there remains a need to study patient recovery during interventions

designed to facilitate health, wellbeing and personal recovery across diagnostic categories. For that reason, the overall aim of the present study is to examine the effects of a broadly applicable intervention that focuses on the patient's bodily knowledge of health and illness as an important resource for coping, recovery and health in chronic illness. Importantly, in qualitative studies of the outcomes of such interventions, patients reported changes in self-awareness and attitude to their life situation and in awareness of their body and acceptance of their limitations, as well as progress in setting priorities and boundaries, letting go of shame and regaining control over their lives [18,19]. One study investigating changes in Sense of Coherence (SOC) demonstrated increased SOC from baseline to four-month follow-up, with a larger mean change among patients attending the intervention in a community care context as compared to those in specialist care [20]. This paper further examines the effects of intervention by means of repeated measurement of outcome.

Methods

The intervention we employed was grounded in Bodyknowledging theory [21,22] which asserts that individuals living with health problems over the long term possess bodily knowledge that constitutes an important resource for coping, recovery and health. Theoretical inspiration was also drawn from Antonovsky's [23] theory of health as a dynamic continuum and from Merleau-Ponty's [24] phenomenological theory of the body as a foundation for knowledge and existence.

The Bodyknowledging model illuminates how the patient's bodily knowledge develops through a dynamic and non-linear process of learning and health-related change in interaction with the environment [25]. This unique but undervalued knowledge is recognized and strengthened through the person's engagement in the intervention and through dialogue with health professionals and peers.

The Bodyknowledging Programme (BKP) comprises 7 sessions over a 4-month period, conducted in groups of 5 to 8 participants and led by 2 health professionals (nurses, physiotherapists or occupational therapists) with specialized training in the BKP.

User participation is a necessary precondition for completing the programme and patients are encouraged to share their health-related challenges, explore their recovery strategies and engage in the group process.

The programme reported here included physical exercises that focus on breathing, balance and movement and participants were asked to choose a weekly activity and to write a diary. A textbook on the Bodyknowledging model (with questions) served as a guide to personal work on recovery. The group also reflected on the questions in the next session. A full account of the development and components of the BKP has been published elsewhere [26]. The reported study forms part of a complex intervention design involving the introduction and

evaluation phases of BKP in community healthcare [27,28].

Setting and participants

The study was conducted during the period January-June 2017 and involved 3 municipalities in south-eastern Norway. Healthcare professionals working in the community invited 50 patients with a range of long-term health conditions to participate in the study. Of these, 44 accepted the invitation, but some could not be included in the analysis, as they did not complete the measurements on at least 2 occasions (as required). The diagnoses of the 37 patients in the final sample included stroke, multiple sclerosis, muscle pain, arthrosis, chronic fatigue syndrome, abdominal pain and psychological problems such as depression and anxiety. Five of the participants had part-time jobs and 32 were in receipt of public transfer payments. The study group was representative of people with chronic illness who are eligible to attend community health programmes such as the BKP. Table 1 provides further demographic details.

Table 1 Characteristics of the participants at baseline (n=37)

Demographic factors	N	%
Male	13	35.1
Female	24	64.9
Age Mean ± SD (Years)	54.32 (11.94)	
<i>Co residency</i>		
Living with partners	23	62.2
Having Children	18	48.6
<i>Employment status</i>		
Working	5	13.5
Work assessment allowance	4	10.8
Sick leave	4	10.8
Receiver of disability benefits	11	29.7
Rehabilitation	4	10.8
Retired	3	8.1
Other (student, unemployed, fulltime housework)	6	16.2

Measures

The Outcome Rating Scale (ORS) was chosen for repeated measurement of patient progress in terms of coping and recovery throughout programme participation. The instrument has been shown to be clinically relevant, easy to use, score and interpret and applicable in various treatment contexts [29-31]. In addition, it was assumed that the ORS could illuminate connections between physical and psychosocial aspects of the patient's life situation during chronic illness. The instrument assesses 4 dimensions: (1) individual (personal or symptomatic distress or wellbeing); (2) interpersonal (relational distress or quality of intimate relationships); (3) social (patient satisfaction with work, school and relationships outside the home) and (4) overall (general sense of wellbeing). The 4 dimensions are translated into a visual analogue format of 4 10 cm lines; the score is the summation of marks to the nearest millimetre on each of the 4 lines as measured by a

centimetre ruler or template, up to a possible total score of 40 [29]. According to Miller and Duncan (2004), a change of at least 5 points in a positive or negative direction is considered reliable, as this exceeds the measurement error based on the reported reliability of the ORS and is one of 2 criteria for clinically meaningful change. The second criterion is movement from a score typical of a patient population to one typical of a healthy population. The ORS cut-off point of 25 distinguishes dysfunctional from normal functioning [32]. Scores above 25 indicate good coping, wellbeing and recovery, while scores below 25 indicate lower levels of wellbeing. In the present study, the ORS was applied on 3 occasions: at baseline, after 3 BKP sessions (i.e., after 3 weeks) and after the seventh and final session (i.e., at the end of the 4-month study period). The purpose of the study was to trace possible changes in participant scores on the 4 ORS dimensions as a measure of the outcome of their engagement in BKP and as an indicator of their recovery.

Statistical Analysis

Statistical analysis was performed using SPSS v24. Differences between mean scores at t_0 , t_1 and t_2 were assessed by one-sample t-tests and by repeated measures analysis (general linear model, Bonferroni-corrected for multiple comparisons).

Ethics

This study of the outcome of BKP in community care was a next-step study of the outcome of BKP in community care, following an earlier study of the intervention in specialist care. The research was approved by Norway's South-Eastern Regional Committee for Medical and Health Research Ethics, with due regard to the principles of the Declaration of Helsinki [33]. Participants were recruited among patients who had sought support from mainstream community care services to manage their illness. All participants received a letter containing information about the research and gave their informed written consent prior to the intervention. They were told that they were free to withdraw from the study at any time without any negative consequences for their treatment. The health professionals leading the BKP groups had no access to patient records and knew only patients' gender, age and diagnosis. The principle of confidentiality for protection of participants' integrity was explicitly referred to at the beginning of each session.

Results

The final sample comprised 13 men and 24 women (n = 37) with a mean age of 54 who had completed the ORS form on at least 2 occasions during the intervention period (Table 1). Four of the participants failed to return the ORS form at the 3 time-points; 33 returned the questionnaire at all 3 time-points and 28 completed the questionnaire on all 4 dimensions and at all 3 time-points.

Table 2 Results from repeated measures (general linear model, with Bonferroni's correction for multiple comparisons) for assessing progress in coping and recovery

Sub-scales	N	t0*	t1*	Diff	pDiff	t0*	t2*	Diff	pDiff	t1*	t2*	Diff	pDiff
Sum	30	20.697	24.12	3,423	0.001	20.697	25.463	4.767	0.002	24,12	25.463	1.343	0.205
Individual	30	4.71	6.16	1,450	0.006	4.71	6.393	1.683	0.002	6.16	6.393	0.233	1
Interpersonal	30	5.537	6.26	,723	0.445	5.537	6.54	1.003	0.073	6.26	6.54	0.28	1
Social	29	5.541	6.372	,831	0.079	5.541	6.431	0.89	0.208	6.372	6.431	0.059	1
Overall	30	4.76	5.54	,780	0.026	4.76	6.313	1.533	0.007	5.54	6.313	0.773	0.085

* ORS-averages by time-point

The results represent an overview of the BKP's contribution to participants - personally, socially and interpersonally, as well as general wellbeing within the timeframe of the programme. According to baseline measurements, the mean ORS score for the total sample (n = 37) was 21.16 (SD = 7.49), which is relatively low and falls below the ORS cut-off point of 25.

Progress and Outcome

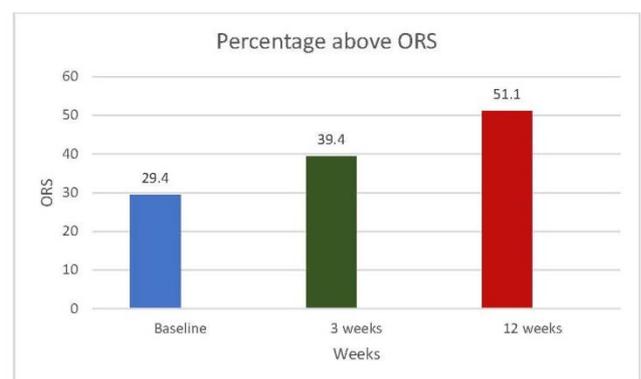
Table 2 shows pre-programme, mid-programme (after 3 sessions) and post-programme (after 7 sessions) means and standard deviations, confirming a change in ORS scores throughout. From t₀ to t₂, the total change in average ORS for the whole sample (n = 37) was 4.6 (SD = 7.57). Some patients scored lower at t₁ than at t₀ or at t₂ than at t₁. In general, however, there was an observed overall improvement from t₀ to t₁, with a mean change of 3.52 (SD = 4.83). The change did not reverse from t₁ to t₂, with a mean improvement from session 3 to session 7 of 1.34 (SD = 5.67).

We also looked for any change for each of the 4 ORS dimensions and found that the greatest change was in the personal and general dimensions. The personal dimension change was 1.5 (SD = 2.41) and the change in general wellbeing was 1.44 (SD = 2.47); changes in the interpersonal and social dimensions were moderate. Table 2 presents an overview of ORS results by time-point and dimension.

Measuring improvement by changes in mean scores over the entire BKP timespan may not provide the best estimate of the effect of intervention, or at least is not the only criterion of success. While a permanent linear growth beyond the threshold of normal functioning is a bonus, the main goal of the programme is not continuous improvement in normally functioning patients but rather movement of dysfunctional patients from below to above

the ORS cut-off point of 25. Our data show that, at baseline, 29.4% were above the ORS cut-off point of 25. At t₁, 39.4% scored above the cut-off point and at t₂, 51.1% had moved from below to above the ORS cut-off point of 25. The number of participants scoring above 25 increased by a factor of 1.7 following completion of the BKP. These findings cannot be discerned from the changes in ORS mean scores but are confirmed by the percentage change in relation to time-points and ORS cut-point. Figure 1 illustrates these findings.

Figure 1 Percentage above ORS cut-point of 25 (normal functioning) at baseline, 3 weeks and 12 weeks



Early change and clinical significance

For the repeated measures analysis of change in mean scores, the final sample was n = 28, as only this number of participants had completed the questionnaire at all 3 time-points. The change from t₀ to t₁ was 0.8676 (p = 0.005). From t₁ to t₂, the change was 1.0107 (p = 0.003), indicating

a highly significant initial effect and a further significant change from t_1 to t_2 . The total change from t_0 to t_2 was 1,8786 ($p < 0.001$). These findings confirm that the BKP contributed to positive change in participant coping and wellbeing and that recovery could be traced throughout the programme, thus answering the study's principal research question.

Discussion

This is the first study to examine the effects of The Bodyknowledging Programme on recovery among people with a chronic illness who faced both physical and psychological health problems. The average baseline ORS score for the entire sample of 37 patients was 21.16. The sample of 28 who answered all the questions at all 3 time-points scored still lower (20.69). The baseline results reveal a high level of distress among participants when entering the BKP, with a majority scoring below the ORS cut-off point of 25, as is typical of people who struggle with long-term health problems.

Participants rated the outcome at 3 time-points and the results confirm that the intervention facilitated significant change, indicating a shift from considerable distress at baseline to wellbeing and recovery following programme completion. A highly significant early change from t_0 to t_1 was followed by a further significant change from t_1 to t_2 . These results align with the understanding of recovery as a process that involves learning [9,10,34]. The findings also align with another BKP outcome study [20] which demonstrated that the intervention had a positive impact on overall SOC and, in particular, on participants' ability to understand and manage health-related challenges. These results are important in that they confirm the clinical efficiency of BKP. The early change registered after 3 sessions of BKP calls into question the need to conduct sessions 4-7. However, without the follow-up sessions, the effect of BKP may have been weakened and further recovery may have been inhibited.

The greatest improvement in ORS was on the dimension of individual-personal wellbeing, indicating that the BKP targets the person's relationship with themselves and assists them in their individual process of recovery. The observed change on this dimension from baseline to t_2 was 1.68, conforming evidence from qualitative BKP outcome studies that participants experienced health and recovery as they unlearned their helplessness and regained their strength and control through active engagement in the intervention [18,19]. The other marked change was in the ORS dimension of overall/general sense of wellbeing. Regardless of diagnosis, wellbeing is a general concept that reflects the individual's experience of health. Emotional wellbeing is an important component of more general wellbeing, implying that participants' level of wellbeing was low at the beginning of the programme. Post-programme ORS scores indicate that engagement in the BKP had a significant effect on their general wellbeing, of which emotional wellbeing is an integral part. Lamers *et al.* [35] identified emotional wellbeing as a significant

predictor of both survival and recovery for people living with chronic illness, with a stronger relationship to recovery. They argued that "positive affect may influence immune and cardiovascular systems directly by activating the autonomic nervous system and the Hypothalamic-Pituitary Adrenalin axis (HPA) thus buffering the impact of stress. Moreover, they emphasized that positive affect also had an indirect favourable effect by inciting healthier behavior and more active engagement in social networks" [35]. In other qualitative BKP outcome studies, change in the emotional component of wellbeing was elicited in areas such as self-awareness, awareness of one's body, accepting one's limited capacity, setting priorities and boundaries and letting go of shame [19].

While scores on the personal and general wellbeing dimensions improved significantly, changes in the social and interpersonal dimensions during the programme period were not statistically significant. In the interpersonal (relational) dimension, the mean change from baseline to t_1 was 0.72 ($p = 0.44$) and 1 at t_2 ($p = 0.73$); the mean change in the social dimension was 0.83 ($p = 0.79$) at t_1 and 0.89 at t_2 ($p = 0.2$). There are at least 2 possible explanations of these findings. First, the relational and social aspects of living with chronic illness should perhaps be more strongly emphasized during the intervention. Alternatively, the measurement timeframe may have been too short to accommodate any significant changes in the relational and social dimensions, as participants may need more time to work on individual issues before any such changes become statistically apparent. On the other hand, in-depth studies of BKP outcomes in specialist and community healthcare have shown how participants widened their life space and became more socially active as a result of BKP engagement, developing new ways of thinking and acting and communicating differently in respect of their illness and health-related matters [18].

In this context, recovery refers to personal recovery and life recovery, in which health as wellbeing plays an essential part, rather than to recovery in the sense of cure or absence of symptoms [5]. BKP offers the individual an opportunity to explore how they can facilitate their own health and recovery and how they can function despite their illness, continuing to participate in social and work activity and in their community. The present findings confirm that the intervention fulfilled its aims as a person-centered and strength-based approach that promotes health and recovery in chronic illness [4,36], where participants are seeking health service support and professionals are in need of efficient tools and interventions to facilitate recovery.

There is a need for interventions that address the emotional and social aspects of living with chronic illness, taking account of patients' and families' strength and utilizing their resources for health, especially as such interventions are scarce [37,38]. The BKP was introduced in community care because it was designed to promote coping, health and recovery in chronic illness and was applicable across diagnostic categories, ages and gender. The BKP represents a new approach to recovery in chronic illness, framed by the lay-based concept and model of Bodyknowledging [21,25,26]. The programme invites

patients to define their situation, supporting and challenging them to discover and utilize their own resources for recovery within a group of peers, guided by professionals [26]. In this recovery-oriented approach to health services, patients are regarded as health professionals' partners in treatment and health promotion [39], in line with recommendations to implement patient-activating interventions [40]. However, this kind of approach represents a radical shift in the position of the patient as compared to traditional care, where professionals defined the treatment and recovery criteria for chronic illness.

Outcome measures are an important means of identifying efficient treatment approaches and establishing evidence-based practice through the collection and communication of patient feedback. In addition, stakeholders such as care administrators and community funding agencies need relevant benchmarks for evaluating patient change as a basis for sound decision-making [31]. In the present study, this was achieved by using the Outcome Rating Scale (ORS) as a brief instrument for measuring BKP outcomes. The scale is a well known tool in studies of psychiatric treatment outcomes, drug rehabilitation and family therapy [29-31]. To our knowledge, however, the ORS has not been utilized to study the outcomes of health and recovery interventions in chronic illness. The scale was found to be relevant in the present research context and we contend that it should be further utilized in implementing BKP in practice. Because the instrument includes only 4 items, it is easy to administer and offers clinicians a rapid overview of the patient's situation and progress. By summarizing individual ratings at different time-points, it is possible to study outcomes for both the individual and the group as a whole. This kind of assessment offers new opportunities for adjusting the pedagogical approach according to participants' needs in facilitating the individual recovery process.

The small sample size and lack of a control group limits the study's statistical power. Nevertheless, the results indicate that BKP outcome was adequately measured by ORS and confirm the findings of earlier qualitative studies. Longitudinal studies of the recovery effect of BKP should be undertaken, as well as studies involving larger samples to allow for comparison within and across patient groups, ages and gender.

Conclusions

This study provides additional support for the growing body of evidence showing that engagement in BKP substantially improves wellbeing and the ability to handle distress during chronic illness. The intervention's multifaceted approach emphasizes hope enhancement and patient-activation strategies. Highly significant early change and positive further change was identified throughout the programme period and the results confirm that the person-centered BKP approach has a positive impact on patient recovery in chronic illness.

Acknowledgements and Conflicts of Interest

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