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Rehabilitation – lessons learned from RI world congress 2021 – moving societies

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Rehabilitation – lessons learned from RI world congress 2021 – moving societies

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Editorial: Lessons learned from the Rehabilitation International World Congress—moving societies

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Editorial on the Research Topic
Lessons learned from the Rehabilitation International World Congress—moving societies

By Escorpizo R. (2022) Front. Rehabilit. Sci. 3: 1040013. doi: 10.3389/fresc.2022.1040013.

With the rise of chronic health conditions and comorbid conditions, if there is one area in medicine and health that is more critical now than in the last decades, it is the field of rehabilitation. Rehabilitation has been defined by the World Health Organization (WHO) as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” (1). According to the United Nations, the current world population stands at almost 8 billion (2), of which about 30% need rehabilitation service (1). Yet, access to rehabilitation remains limited for those who need it the most and this disparity is more profound in low and middle-income countries (1). As an organization, Rehabilitation International (RI) has been a strong advocate for advocating for the rights of people with disability and for promoting their inclusion in society (3). RI’s core mission has been in support of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (4), which provides a universal platform to learn from and develop strategies for people with disability. A biopsychosocial framework like the International Classification of Functioning, Disability and Health (ICF) (5) proves useful in examining the effects of disability on a person and what possible interventions to promote their participation in the context of their environment. Rehabilitation and the ICF make the ultimate case for strengthening health systems.

In September 2021, RI organized its World Congress, showcasing and celebrating the work of disability researchers, stakeholders, and advocates with the theme “Moving Societies”. The theme is relevant to the aim of rehabilitation being a societal strategy and strengthening the health systems to have a healthy population (6). This research topic brings forth a collection of papers from RI’s World Congress that reflects on the importance of rehabilitation and identifying the rehabilitation needs of people and the creative and innovative thinking, and diverse approaches to addressing those needs. RI promotes empowerment, giving access to and being inclusive of people regardless of disability and background. Based on the RI World Congress, this research topic highlights the value of rehabilitation in various areas such as cancer Désiron et al. (2022), brain injury Thøgersen et al. (2022), Parkinson's disease Tonnesen et al. (2022), physical activity and sports Stolz et al. (2022), occupational rehabilitation Johansen et al. (2022) and work organization Mulders et al. (2022), weight loss program Jessen-Winge et al. (2022), peer counseling Jordan (2022), and low vision rehabilitation Øien (2022). Finally, an article from the research topic proposes strategies to further develop the rehabilitation research Aadal et al. (2022).

Long-term health conditions such as brain injury and Parkinson's disease are associated with a significant burden on people and their families and caregivers, and rehabilitation goals are crucial to recovery. Thøgersen and colleagues tested a psychological-cognitive approach to capture a holistic perspective of a person with a moderate-to-severe acquired brain injury Thøgersen et al. (2022). The approach highlighted the need for self-awareness and guiding person-centered goals as part of a holistic rehabilitation program. According to Tonnesen and colleagues, goal setting is just as important as interventions. Persons with disability are the primary drivers of their goals in rehabilitation, and developing functioning goals requires time within a continuum of care Tonnesen et al. (2022).

Employment is an important outcome in rehabilitation because it illustrates a person's productivity and well-being at the individual and societal levels. This research topic highlights the work of Désiron and colleagues who argue that healthcare professionals are in a position to facilitate a return to work for people with cancer and must be able to identify the barriers and facilitators for a successful return to work and toward a shared goal Désiron et al. (2022). Johansen and colleagues outlined a project where the ICF served as an assessment tool to facilitate communication between clinicians, the patient, and job center professionals- a multi-stakeholder partnership found to affect successful work outcomes. While the ICF provided a good framework, they found it to be challenging in terms of an increase in the time burden with its administration Johansen et al. (2022). A practical perspective was offered by Mulders and colleagues with their concept of the "Inclusive Work Redesign" Mulders et al. (2022), which proposes a unique insight into how work is organized and puts people with disabilities in the mainstream, and is intended to help sustain the return to work for people with disabilities amidst current challenges in the labor force market and social security.

Rehabilitation encompasses multiple areas identified to need crucial attention and sensory loss such as vision loss is no exception. Øien conducted a comprehensive action research project highlighting the importance of the environment which overlaps with the biopsychosocial aspects of vision loss, particularly about the person-environment relationship. In this case, addressing the environment and lighting will enable people with vision loss to participate in their environments Øien (2022). Stolz and colleagues expressed the value of using the ICF framework in their work investigating the "Sportcoach" approach which mitigates work disability by way of participation in sports activities and engaging in a sports club, another holistic look at a way to innovate the delivery of rehabilitation Stolz et al. (2022).

Jessen-Winge and colleagues tackled the issue of obesity by developing strategies for effective rehabilitation programs. The authors found that awareness, activity patterns, pacing, social relationships, and balancing life are key elements of rehabilitation in the context of sensible weight loss Jessen-Winge et al. (2022). Rehabilitation programs will benefit from effective peer counseling- a process undertaken by and for people with disabilities. Jordan discussed the role that peer counseling can play in empowering people with disabilities across different kinds of health conditions Jordan (2022). Finally, Aadal and colleagues have reaffirmed the need to ground rehabilitation research in biopsychosocial principles and adhere to its cross-setting and multidisciplinary nature Aadal et al. (2022). Their work revealed the important role of service and end users, the use of the ICF, the continuum, and the ultimate steps of dissemination and implementation of findings.

Rehabilitation is characterized by a multidisciplinary approach and tackles the complex nature of physical, mental, cognitive, and multi-aspect disability in light of health conditions or diseases. Rehabilitation uses various platforms in research, education, policymaking, and practice to make a difference in people's lives by improving their functioning in their daily lives alongside their resiliency and prevention of further disabilities so they can accomplish their full potential. These characteristics make rehabilitation a keystone health strategy of society.

Author contributions

RE contributed to the conceptualization, writing, revision, and submission of this manuscript. All authors contributed to the article and approved the submitted version.

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International partners continues as we embrace and pursue the inclusion and empowerment of all people with disabilities.

Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Psychotherapeutic Intervention for Adults With Acquired Brain Injury: A Case Study Using BackUp

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A moderate-to-severe acquired brain injury (ABI) can have tremendous lifelong consequences for ABI-survivors and their families. Despite rehabilitation practice since the 1980s aspiring to a dynamic, coherent and holistic approach, the psychological dimension still seems to be a challenge and research has revealed persisting psychosocial impairments after ABI. Therefore, we developed BackUp©, a manual based short term psychological intervention for adults with ABI. This study explores the effect of the intervention though a small feasibility study, employing a single case design. One client received the intervention. Self-report measures were collected, and a semi structured interview was conducted. While results from pre, post and follow-up measures do not show clear positive results, the interview reveals positive experiences and the participant reported achieving his therapy goal. This case study provides support for a psychological intervention to support the psychological rehabilitation after an ABI.

Keywords: pilot study, mixed method, single case, psychological intervention, acquired brain injury

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INTRODUCTION

A moderate-to-severe acquired brain injury (ABI) can have tremendous lifelong consequences for ABI-survivors and their families. Many ABI-survivors are facing challenges of physical disability, cognitive deficits, and psychosocial sequelae. It has been suggested that especially psychosocial problems can be a major challenge for people with ABI, both during and post the rehabilitation process. Some of the most common psychosocial consequences are anxiety and depression, which impacts between 19.5 and 79% of the population (1, 2), and identity reconstruction or "loss of self" (3–7). Despite rehabilitation practice since the 1980s aspiring to a dynamic, coherent and holistic approach, addressing the life changing transitions caused by an ABI, the psychological dimension still seems to be a challenge and research has revealed persisting psychosocial impairments after ABI (5). Rehabilitation originates from a biomedical field (the medical model) where identification of pathology was seen as a first step to problem solving (8). Rehabilitation practices and research are still mainly influenced by rehabilitation's origin in physical medicine. However, modern medicine has a blind spot. With its dominant focus on pathology, it ignores the existential dimension of life-changing illness and its impact on emotional wellbeing. This is unfortunate since rehabilitation is more than the rehabilitation of the body and the brain. A rehabilitation program should also enable the individual to live his or her life, in a way so it becomes possible to participate and contribute to family life, community and society (9).

Because of the complexity of physical, cognitive, and emotional impairments following an ABI, rehabilitation efforts must be comprehensive and multidisciplinary including nursing care, physiotherapy, speech and language therapy, clinical psychology or counseling, vocational and social support (10, 11). The purpose of a multidisciplinary approach to rehabilitation after ABI is defined by the ABI-survivors' symptoms and can therefore vary, but often it incorporates close cooperation, awareness of communication and sharing of knowledge within the team, in regard to the professionals involved and a two-way interactive process between ABI-survivors, their families and an interdisciplinary team of professionals (12, 13). Even though holistic rehabilitation is an international recommendation (14), no clear agreement about the content of rehabilitation interventions or programs is evident from the literature. Furthermore, the rehabilitation settings, program goals, and outcome measures vary in character and content. As well as the lack of detailed descriptions of psychotherapeutic interventions and the role of psychotherapy in brain injury rehabilitation is unclear (15–18). Despite the heterogeneity of interventions, a few psychological therapies are on the rise in the field of neuropsychological rehabilitation that offers positive treatment results on a variety of cognitive, emotional, and interpersonal changes after ABI.

To date, the most established psychological intervention that offers relief of some of the psychological sequelae symptoms after ABI is Cognitive Behavioral Therapy (CBT). A systematic review by Cicerone et al. (19) found that CBT was used to increase coping behaviors and reduce emotional distress, improve executive aspects of attention and self-reported everyday functioning. Similar findings were described in a more recent systematic review by Gallagher et al. (20) on cognitive impairments following brain injury. Gallagher and colleagues identified different types of CBT that were modified to treat post-injury cognitive and emotional problems. Their findings suggest that psychoeducation based on the CBT model is one of the most frequently used adaptations because it gives ABI-survivors the knowledge of their own changed cognitive capacities and helps to create new patterns of thinking that eventually can influence behavior. Moreover, written formulations and homework tasks, as well as coping thoughts and relaxation exercises were also commonly used. This was done to accommodate problems with attention, enhance homework compliance and reduce anxiety. The 18-item Modification-Extraction List displays the most commonly reported adaptations of CBT (20). Indeed, some of the adaptations describe the core of the CBT-model, which is based on the premise, that information received from our own bodies and the outside world can influence the experience of emotions, thought processes and behavior (21).

Within ABI therapeutic interventions, there has been a development in recent years of using "third wave" cognitive behavior therapies, which emphasize self-compassion, compassion for others and the ability to be sensitive to the compassion from others through attention-awareness and motivation. Compassion Focused Therapy (CFT) (22) focuses on self-accept using appropriate or desired value-based life strategies by means of engagement in actions that lead in those directions. Moreover, Acceptance and Commitment Therapy (ACT) (23) seeks to develop greater awareness of thoughts and feelings as mental events rather than as reflections of reality through meta-cognition and meditation. However, a review of the literature reveals a small body of evidence of "third wave therapies" effect on psychosocial sequelae after ABI so far (24). The studies to date using "third wave therapies" interventions after ABI have demonstrated an improved quality of life (25), reduced symptoms of anxiety and depression (26–28), fatigue (29) and significant reduction in measures of self-criticism (27).

The research outlined above indicates that "third wave therapies" has potential as intervention for ABI-survivors, but there is still a sparce body of research. Thus, there seems to be a need for more research in the area. Furthermore, to our knowledge, no previous studies have examined the effect of combined use of the aforementioned "third wave therapies" that potentially may give more flexibility in therapeutic interventions with the purpose of meeting the challenges, which adults with ABI may experience during rehabilitation.

Therefore, the present pilot study provides the first attempt to explore the effect of a manual-based intervention program (BackUp) developed specifically to support adults with ABI through the psychological reactions that may follow an acquired brain injury. Furthermore, the study seeks to explore a client's experience of psychological rehabilitation during the rehabilitation process after ABI.

METHODS

Design

For the purpose of the study, a single-case A-B-A design was implemented. The design involved the assessment of several measures at a baseline before the initiation of the intervention phase and then the assessment was repeated after the intervention and at 9 months follow up. Throughout intervention, consisting of 12 sessions, a measure of "daily rehabilitation progress" was implemented as an evaluation tool to assess participants' daily progress.

Procedures

Since the study involved human participants and person-sensitive data, the study was approved by the Danish Data Protection Agency (Datatilsynet). The project was also reported to the Regional Research Ethics Committees for the Region of Northern Jutland (Nordjylland) who found it exempt from full review. Informed written consent from the participant was obtained at the screening phase. The pre, post, and follow-up assessment measures were administered by the leading therapist of the psychological intervention with the help of the professional staff at the neurorehabilitation center due to the participant's cognitive challenges.

The BackUp intervention was delivered by a trained clinical psychologist with several years of experience with ABI-survivors. Each session was observed and recorded by a psychology master student from Aalborg University, to monitor treatment fidelity of the treatment (30). The intervention period was 3 months, sessions were given once or twice a week depending on participants' program agreement. Sessions were held in a therapy room at the rehabilitation center. The therapy room was used by this psychologist only.

Measures and Analysis

The four standardized self-report measures were administered during the first and last sessions of the intervention program with the purpose to provide evidence for treatment effectiveness. In a classical A-B-A design assessment is also necessary during phase B. However, answering the primary outcome measures are comprehensive and can be difficult for people with acquired brain injury, therefore we developed a secondary outcome measure, for this specific intervention program, to be used on a daily basis during phase B. The secondary outcome measure was a daily self-report questionnaire measuring rehabilitation progress. A similar design was used by Hsieh et al. (31). The purpose of the secondary outcome measure was to look for possible patterns that might suggest specific links between the intervention parts and the rehabilitation progress.

Nine moths post intervention a follow-up assessment was conducted using the same primary outcome measures and a semistructured interview exploring the participants experience of the intervention. For the analysis of the data, spaghetti plot was used for visual inspection of the data (32).

Primary Outcome Measures

Depression and Anxiety

The Danish translation of the Hospital Anxiety and Depression Scale (HADS) is a brief self-report measure (14-item) that contains seven intermixed items for both anxiety and depression. The questionnaire was originally developed by Zigmond and Snaith in 1983 to shift attention from the physiological symptoms to behavioral components of anxiety and depression and have previously been used to evaluate symptoms of depression and anxiety among people with acquired brain injury [e.g., (27, 33)]. Symptomology of anxiety and depression are rated on a scale of 0–3, on which the highest score indicates the severity. The total score is calculated for each scale and ranges from 0 to 21. For either subscale, a score from 0 to 7 is regarded as normal, 8–10 mild, 11–14 moderate and 15–21 severe (34).

Personal Growth

A Danish translation of the Personal Growth Initiative Scale (PGIS) was administered to capture change and growth in the rehabilitation process that could be facilitated by the challenges from the ABI trauma, new ways of coping with cognitive and physical disabilities as well as the psychological intervention. The PGIS is a nine-item self-report measure scored on a 6-point Likert scale (1 = "strongly disagree" to 6 = "strongly agree"). Possible scores range from 9 to 54, with higher scores indicating greater growth initiative. Items assess the three possible ways of growing: unintentional and out of awareness, unintentional but in awareness and intentional and fully in awareness. The measure has robust psychometric properties ($a = 0.87$) (35, 36).

Quality of Life

The 5-item World Health Organization Well-Being Index (WHO-5) contains five positively phrased statements about respondents' subjective wellbeing for the last 14 days. Each item is scored on the 6-point Likert scale, from 0 ("none of the time") to 5 ("all of the time") with the raw scores ranging from 0 to 25. To calculate the total score, the raw score is recommended to be multiplied by four, which represents a percentage scale ranging from 0, indicating the worst imaginable wellbeing to 100, indicating the best imaginable wellbeing. WHO-5 was first published in 1998 and since then has been translated into more than 30 languages, including the Danish language. The questionnaire has been used both as a screening tool for depression and as an outcome measure in clinical trials and has a strong sensitivity of 0.83 and specificity of 0.81 (37).

Compassion for Oneself

For the primary outcome measures, the Self-Compassion Scale (SCS) consisting of 26 items were used in the pre-test and the follow-up. It is based on the three basic components of self-compassion, which entails (1) kindness and understanding toward oneself; (2) seeing life experiences as a journey to better understand one-self, and (3) an ability to avoid over-identification with negative thoughts and emotions. SCS comprises the three positive subscales: *Self-Kindness Subscale*, *Common Humanity Subscale*, *Mindfulness Subscale,* and three negative subscales: *Self-Judgment Subscale*, *Isolation Subscale,* and *Over-Identification Subscale*. Each subscale score calculates separately with a reverse coding response to the negative subscales. An overall self-compassion score is then achieved by summing the means and dividing it by 6. The original SCS demonstrates a good factor structure as well as construct validity (38).

For the post intervention outcome measures, the Self-Compassion Scale-Short Form (SCS-SF) was implemented instead, to accommodate cognitive limitations caused by the ABI. SCS-SF is a 12-item measure of self-compassion. Despite its reduced length, it is still a reliable scale with the same factorial structure as the long version of SCS. Correlations between the corresponding subscales for the original and short versions of the SCS range from $r = 0.84$ to $r = 0.93$, the total score correlation is $r = 0.97$ (39). Both scales were translated by researchers from the Center for Development and Applied Psychological Science at Aalborg University in Denmark.

Secondary Outcome Measure

The self-report questionnaire measuring daily rehabilitation progress was developed for this study to evaluate and find patterns in the holistic rehabilitation program. The questionnaire consists of nine questions with responses given on a horizontal VAS scale from 0 to 10, where 10 is the best imaginable. A similar technique was used in a previous study by Rasquin et al. (40). The questions are presented in **Table 1**.

Interview

In relation to the follow up assessments, a semi structured interview was conducted by a research assistant, who had not

TABLE 1 | Questions for measuring daily rehabilitation progress.

Number	Questions for measuring daily rehabilitation progress:
Q1	How is your mood today?
Q2	How self-critical have you been today?
Q3	How satisfied are you with yourself today?
Q4	How well has your body functioned today?
Q5	How satisfied have you been for your life today?
Q6	How well did you sleep last night?
Q7	Did you want to be social with others today?
Q8	Have you taken the initiative to be with others today?
Q9	How well has your memory functioned today?

previously been a part of the project. The interview sought to clarify the participant's experience of the psychological intervention at the rehabilitation center. The primary interest was the experience of the individual intervention based on the BackUp program. However, it was also of interest to explore the participant's experience of his psychological rehabilitation at the rehabilitation center in general. After ending the individual intervention program following the BackUp manual, the participant received additional sessions with the therapeut and participated in a group intervention facilitated by the same psychologist and a musictherpeut. It was expected that these following interventions would also affect his experience. However, in this study, the following group intervention are understood as part of the holistic rehabilitation program.

The interview was conducted at a vocational rehabilitation center which offer users a voluntary association. The research assistant worked there, and the participant was a member.

Follow-Up Assessment

In agreement with the participant, self-report measures were sent to him prior to the interview. However, he experienced, that he needed help to fill out the tests. Due to restrictions following the COVID-19 situation, it was agreed between the first author and the participant, that the first author was to call the participant and ask the question over the phone, after the interview. A similar procedure has been used in other studies [i.e., (41)].

Participant

The participant was a 58-year-old man attending a neurorehabilitation program at a specialized inpatient rehabilitation center for people with moderate to severe brain injury. We refer to him as Lars instead of his real name. He was offered a manualized psychological intervention as a part of a holistic rehabilitation program after his ABI. Lars had suffered multiple infarcts in the right hemisphere. After having been hospitalized at two different hospitals, he arrived at the rehabilitation center 6 months post injury. At that time, Lars was in a wheelchair, but during the psychological intervention he gained the ability to stand and take small steps with support. Besides his mobility challenges, he suffered from neglect and profound executive difficulties including challenges with overview and structure. In addition, visuo-perceptual and spatial difficulties were seen. At the rehabilitation center, Lars was assigned to a team of physiotherapists, occupational therapists, educators, caregivers and a neurologist, all with special knowledge of neurorehabilitation. Rehabilitation was planned and incorporated in all parts of his daily life at the rehabilitation center. Lars's team experienced Lars as having lack of insight in his ABI which caused many disagreements between the staff and Lars. The psychologist's assessment of Lars was that what seemed to be lack of insight, was also due to a defense mechanism (42). In cooperation with the municipality, the rehabilitation team and Lars, a main goal for his rehabilitation stay was formulated; That Lars becomes as independent and safe in his home as possible, so that he can function alone in his own home. For Lars the most important goal is, that he wants to be able to go out fishing again. Preinjury, Lars had an active outdoor life and enjoyed fishing multiple times a week. Moreover, he is a very social man, with a physically active work in the service industry for 40 years.

Due to the disagreements, in relation to what was perceived by the profession team as Lars' lack self-awareness, the psychologist was included in the rehabilitation process. After initiating supervision of the team, it was hyphotized that Lars would match a manual-based intervention program based on the BackUp program.

INTERVENTION

The BackUp Intervention Program

As discussed in the introduction section, ABI-survivors frequently face emotional consequences such as anxiety and depression as well as agentic and identity issues. The aim of our BackUp intervention program is to address these issues.

Two of the authors developed the first versions for use by psychology students during their internship in clinical practice in the field of ABI (43). Based on clinical experiences, minor adjustments were continuously made, until the first author finalized the current version presented here.

Within an overall framework of 3rd wave Cognitive Behavioral Therapy [cf. (44, 45)], the program covers themes that often need to be addressed for ABI-survivors, and it comprises selected CBT and narrative intervention techniques that can be used with this client group. The rationale for these choices was alluded to in the introduction section of this article and is further elaborated in the section below. **Table 2** provides an overview of themes and techniques by session.

Design Rationale

Cognitive behavior therapy (CBT) is the most empirically validated form of psychotherapy. Findings derived from randomized control trials provide support for the empirical validity of CBT demonstrating that CBT is as effective for the treatment of depression as pharmacotherapy [e.g., (46)]. CBT has been shown to be efficacious for the treatment of a variety of psychological consequences but despite the vast literature demonstrating this, relatively few studies have focused on the development of a specific CBT intervention for improving mood and coping after brain injury (47–49). Nevertheless, in addition

TABLE 2 | Overview of interventions in the BackUp program, by session.

	Session title	Session goals and exercises	Mindfulness exercises	Homework activity
1	Pre-interview with assessment and initial case formulation	Framework Psychoeducation: brain injury, rehabilitation, transition Assessment: WHO-5, SCS, HADS, PGIS	Short body scan	
2	Psychoeducation about brain injury	Psychoeducation: biopsychosocial model of health, major rehabilitation models, cognitive sequela after ABI, (mental) fatigue		Weekly schedule planning and registration, "goal stairs"
3	Psychoeducation: emotional reactions	Psychoeducation: crises responses and grief reactions Education about identity change Depression and quality of life		Registration of activities that give or take energy
4	CBT	Case formulation and defining important issues Psychoeducation: CBT-model, education about automatic negative thoughts	Short body scan	Daily activities schedule, registration of negative thoughts
5	CBT	Continuation from the previous session Work with client-chosen topics or alternatively with suggestions from the therapist	3. min. breathing exercise	Meaning: What makes life worth living anyway (ACT worth chart)
6	Introduction to Compassion-Focused Therapy (CFT)	Education and work with Gilbert's model Topic: "You have a tricky brain and it is not your fault" Goal: treat yourself properly when you face difficulties - no matter whose fault it was	Compassionate breathing exercise	Self-compassion journal
7	CFT	Continuation from the previous session Exercise: Compassionate letter to yourself Topics, e.g., It is not fair, It was my fault Goal: Learning to let it go—inner workings with self-criticism	Compassionate breathing exercise	Self-compassion journal
8	CFT	Continuation from the previous session Exercise: Visualization with a compassionate figure	Compassionate breathing exercise	Self-compassion journal
9	CFT	Continuation from the previous session Exercise: Compassionate reminiscence Topic: Family—guilt/shame/self-criticism	Compassionate breathing exercise	"Important and most important"—What was important in your life at a different age?
10	Identity reconstruction and quality of life	Topics: Before and after ABI trauma—the quality of life, identity, values, and meaning of life Exercise: All behavior is assessed through the magnifying glass		
11	Identity reconstruction	Continuation from the previous session Exercise: 90th birthday Goal: Get in touch with personal values	Short body scan	
12	Feedback	Assessment for post-tests and feedback		

to being the empirically validated treatment of choice for a range of psychiatric disorders, there is an increasing amount of literature illustrating that CBT can be successfully adapted and applied to a diverse set of neurological and medical populations (50). Anson and Ponsford (51) evaluated the effectiveness of a CBT-based coping skills intervention for 31 individuals with TBI. The intervention was designed to improve both coping strategy selection and emotional adjustment. Following treatment, participants demonstrated a significant improvement in adaptive coping.

To complicate matters, previous research has found that issues of self-criticism and shame are frequent after ABI (52) and may interfere with the treatment. In a study from 2011, Fiona Ashworth and colleagues treated a client with symptoms of depression and anxiety with classic CBT but found the intervention to be ineffective due to the client's self-criticism. They therefore changed the approach to Compassion Focused Therapy, which led to an effective reduction in symptoms for the client (53). Mindfulness, acceptance, and self-compassion are core issues in 3rd generation CBT, and the BackUp manual suggests a number of techniques to help the client achieve this, most of them from Compassion Focused Therapy.

Moreover, recent research also emphasize that rehabilitation psychology needs to address identity reconstruction as well as emotional adjustment after ABI. A growing body of research has shown a potentially vast impact of an ABI on identity and agency that may hamper psychological and social recovery [e.g., (7, 9)]. Narrative techniques were included in the BackUp program to address identity issues.

TABLE 3 | Pre-, post- and follow-up scores on assessment tests.

Assessment	Pre intervention	Post intervention	Follow-up (9 months post intervention)
HADS depression	6	10	4
HADS angst	0	4	3
PGIS	46	54	54
WHO 5	68	24	72
SCS total	17,2	17,5	17,4

To summarize, the themes included in the BackUp program are based on previous research and clinical experiences, and to address them, techniques from 3rd generation CBT are supplemented with narrative techniques.

A recent review by Salas and Prigatano (54) argues for a integrative approach to therapy after acquired brain injury, to accommodate the specific needs of the clients (54). The BackUp program was developed before that review but seems to match its recommendations.

BackUp Structure and Use

The BackUp program involves 12 individual therapy sessions, which are delivered once or twice a week with ∼45 min each. The intervention program is manualized, and the content includes several aspects from 3rd wave cognitive therapies, such as psychoeducation, mindfulness, and compassion exercises, as well as addressing existential and identity issues with narrative techniques (**Table 2**).

Most sessions have the following structure: welcome, follow up from the last session, new topic, exercise, and homework. Considering previous research and participant's particular rehabilitation goals, different strategies are implemented to accommodate cognitive impairments; for example, changes in sitting position, different communication tactics, and presenting psychoeducation in multiple formats, such as drawing on the paper and providing relevant handouts.

Due to the heterogeny of ABI clients, the therapist is encouraged to sample from the techniques and themes of the manual as clinically relevant for the individual client's challenges and resources.

Case-Adapted Implementation of the Manual

The aim was to implement the manual so that all themes in each session is addressed during therapy. At the same time, the manual has been developed so that it must be adapted to the individual client's needs and wishes, as well as the agreed therapy goals. Overall, the intervention was given in accordance with the manual, with small alterations to the client's individual needs. For example, more time was spent on psychoeducation related to themes relevant to the client, while the client was encouraged to read about the other topics in the handouts as homework. Another change was made to the homework. The client did not do the homework exercises in the beginning of the intervention. He found registration and journaling difficult, and he was often dissatisfied with his own performance and ended up throwing out his notes before therapy. Between sessions he reported having many reflections about the exercises and he completed the questionnaires daily, so it was agreed that it was more important that he reflected upon the exercises than writing them down.

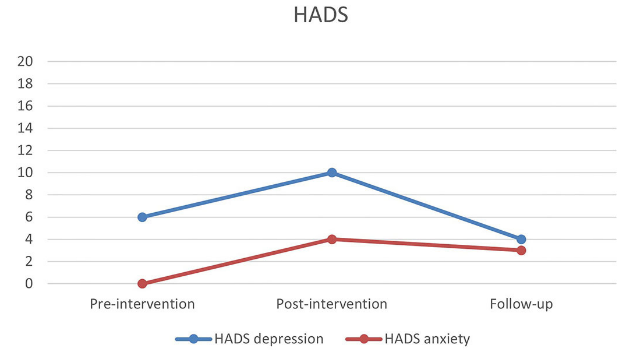

FIGURE 1 | Pre-, post- and follow-up scores on Hospital Anxiety and Depression Scale (HADS).

RESULTS

This study aimed to investigate a psychological intervention program for a person with ABI as a part of a holistic rehabilitation program at a specialized rehabilitation center. Changes was measured at three time points (pre-intervention, post-intervention and at 9-month follow-up) using the self-assessment four scales (HADS, WHO-5, PGIS, SCS). Assessment scores can be seen in **Table 3**.

Figure 1 shows changes in depression and anxiety symptoms during all three assessment points. Depression scores increased from the pre-intervention to post-intervention, from a raw score at 6–10, which corresponds to non-depression to mild depression according to applicable cut-offs. At 9 months follow-up, the raw score was 4, non-depression. Scores at the anxiety scale was at all three time points below cut-off for signs of anxiety.

An indicator of Lars' agency was obtained by the Personal Growth Initiative Scale (PGIS). **Figure 2** shows an increase from pre-intervention to post-intervention and follow-up, going from a raw score at 46 to the maximum of the scale at 56, being stable between post-intervention and follow-up measurements.

Quality of life was measured using the 5-item World Health Organization Well-Being Index (WHO-5). During the three time points of measurement raw scores interpreted by cut-offs moved from normal at pre-intervention, to lower than average and a need for awareness at post-intervention, and at follow-up scores had returned to normal (**Figure 3**).

The Self-Compassion Scale (SCS) was used to evaluate the changes in relation to self-criticism. Raw scores are seen to be stable over all three time points.

Evaluation During Intervention Period

A one-way ANOVA revealed no significant differences between the different days and the different questions. However, an

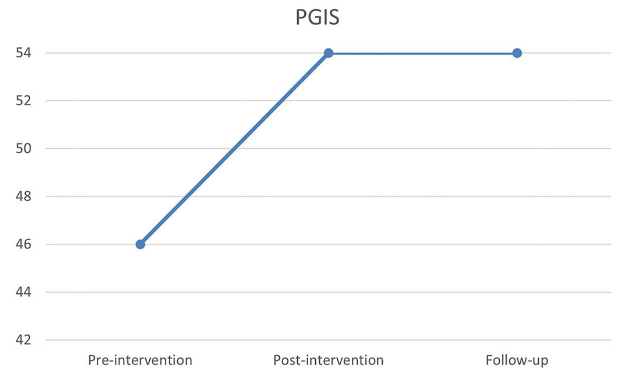

FIGURE 2 | Pre-, post- and follow-up scores on Personal Growth Initiative Scale (PGIS).

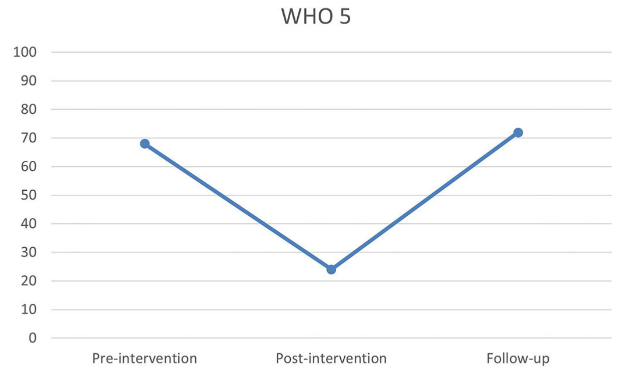

FIGURE 3 | Pre-, post- and follow-up scores on the 5-item World Health Organization Well-Being Index (WHO-5).

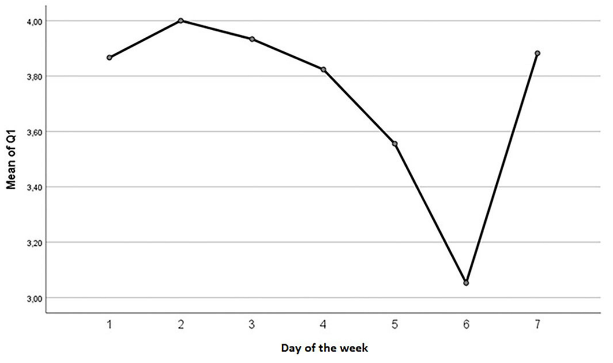

FIGURE 4 | Plotted mean scores for question one, over the course of the week, where 1 represent Monday, 2 Tuesday, etc.

interesting trend seem to show in a visual inspection (**Figure 4**). Therapy sessions were always held on Mondays.

Six out of eight questions have lowest mean scores on Saturdays, while the remaining two questions score lowest on Mondays or Tuesdays (**Table 4**). This suggests that up to and immediately after the day of therapy (Monday), the client provides highest responses, while the weekend day Saturday receives the lowest scores. No significant change was found between the difference in the highest and lowest value. For example, a one-way ANOVA showed that $F = 1.198$, $df = 33$, $p = 0.282$.

Therapist's Evaluation

The therapy goal, for Lars, was to recognize his own limitations in order to be able to participate in the rehabilitation program and to prevent conflicts with the rehabilitation team. During the last session of the intervention program, the psychologist and Lars qualitatively evaluated the intervention regarding the goal of supporting a process of self-awareness for Lars. Lars expresses that he has gained more insight into the changes of his life following the brain injury. During the therapy Lars was able to reflect on his new life circumstances and work with his values and identity reconstruction. Lars and the caregiving team no longer experienced the same degree of disagreements in the collaboration and Lars had become more independent. Lars was seen to gain more from the physical training when he had control over his own situation. It was assessed that Lars could benefit from an extension of his stay at the rehabilitation center, which he accepted.

Evaluating Interview

The interview was analyzed using Thematic Analysis (55). During the analyses of the follow up evaluating interview, the following themes appeared: *Fellowship, security, individual therapy, group therapy, Quality of Life, holistic rehabilitation, training, the rehabilitation center, inside perspective*.

Fellowship and Security

During the interview, two central themes emerged: the importance of fellowship and security. It is clear how fellowship and social interaction was an important thing for Lars, not only during the rehabilitation process, but also a central theme in his life. For Lars, fellowship had many functions. For example, fellowship with other clients at the rehabilitation center was a source of motivation:

> *"I: What did it mean you had someone to go with?*
> *L: It meant that the motivation to go was greater."*

Therefore, it was important for him to have group activities with peers at the center. During the interview, he highlighted a wish for more group activities at the rehabilitation center. In a similar vein, Lars highlighted the group therapy that he attended at the center after the individual psychological intervention. The opportunity to learn from peers and share experiences was one of the benefits he highlighted:

> *"I: Yes: So the thing about passing on the experience*
> *L: Yes*
> *I: It's something you've experienced, yes:*
> *L: That's also why it's so good – those conversations you have, to sit and talk"*

TABLE 4 | Highest and lowest mean scores for the daily questions, by weekday.

Question	Day with lowest mean score	Mean/SD	Day with highest mean score	Mean/SD
1	Saturday	M = 3.1; SD = 2.3	Tuesday	M = 4; SD = 2.7
2	Monday	M = 3.5; SD = 2.2	Thursday	M = 4.1; SD = 2.7
3	Saturday	M = 1.7; SD = 2.1	Tuesday	M = 2.9; SD = 3.4
4	Thursday	M = 1.0; SD = 1.0	Sunday	M = 1.6; SD = 1.9
5	Saturday	M = 2.1; SD = 2.3	Sunday	M = 3.5; SD = 3.9
6	Saturday	M = 6.7; SD = 2.3	Monday	M = 7.7; SD = 1.7
7	Saturday	M = 3.7; SD = 2.6	Monday	M = 4.4; SD = 2.0
8	Saturday	M = 2.3; SD = 2.4	Wednesday	M = 3.1; SD = 2.4

The fellowship is not just about how to share and learn from others in the same situation, it is also about caring for others. This relates to the second theme: *security*.

> *"L: Security, it's incredibly important"*

Lars mentions how security is important in various settings, that is in the environment, in the training, in relationships and in groups. In general, security is important for Lars and has a huge impact on the benefits he gains from different activities and relationships during his rehabilitation. Regarding the relationship with the psychologist and the music therapist Lars expresses:

> *"L: [...] I was very comfortable with them.*
> *I: Yes*
> *L: It also matters*
> *I: So you've got – you've got some good experience –*
> *L: Yes, I have."*

Therapy, Inside Perspective and Holistic Rehabilitation

Lars does not mention the outcome of the individual therapy on his own. However, when the interviewer asks Lars about the therapy, he says he has been very happy with the intervention and that he feels that it has had a big impact on him.

As mentioned in the presentation of Lars, he often experienced disagreements and conflicts with the caregivers, in relation to self-awareness or insight into the consequences of the brain injury. In the interview, Lars express how he was challenged when his deficits were in focus, rather than his potentials. According to Lars, he was aware of his challenges, but a focus on challenges was not supportive for him.

> *"L: And then there was one – I think it was the second time I was at that meeting, So – I got up and walked, I didn't, I: Uh: turned around and backed out, and then I said - what's it called – "I think you should, at these meetings, talk about what you can do for me, I know what I can't do, you don't have tell me that, I know this very well"*

The therapeutic goal of the intervention was working with insight and acceptance, this is also one of the outcomes Lars points out when asked:

> *"I: So what you're talking about now, that's some insight, and some acceptance of your situation L: Yes, my own situation, yes*
> *I: Yes. Has it had an impact that you have talked to [the psychologist] and the group?*
> *L: Yes, that it has*
> *I: Yes*
> *L: That you also come: - if one: is – accepting to oneself, that you come the furthest by being honest and then realize the things that are."*

Lars concludes that he experienced the psychologist, as well as other key professionals around him, as being very caring, and that it was very important to him. In relation to the individual therapy and the subsequent group therapy, he states that the two interventions were important:

> *"I: Yes, two interventions L: Yes: I was very **happy with them.**"*

He elaborates about the individual therapy:

> *"I: [...] And what about [the psychologist]?*
> *L: I think she went more into depth, personally.*
> *I: Yes.*
> *L: Or I think - she **did**."*
> *"L: We talked about everything. It was so nice and easy. (.) She's easy to talk to.*
> *I: Yes. How is one too easy to talk to?*
> *L: Just like we do now.*
> *I: Yes. What happens when you: uh: when you're easy to talk to. What is it?*
> *L: I think the most important thing is feeling safe.*
> *I: Yes."*

During the evaluating interview it became apparent that the intervention was feasible, and that Lars was satisfied with the intervention.

For Lars, the experience of receiving psychological rehabilitation is well-related to the physical training.

> *"L: Because, as we talked about before with the psychological and the physical, it's related.*
> *I: Yes.*
> *L: It helps each other*
> *I: Yes*
> *L: If one does not work, the other does not work either*

> *I: No*
> *L: Therefore, I believe that it: - there is too much focus on physical training. You'd have to think more about the psychological part"*

It is clear from the interview that a balance in the bio-psycho-social model is important to him. Fellowship and relationships are important to Lars as well as the need for physical training. It is seen that both biological, social and psychological factors have an impact on overall rehabilitation.

> *"L: But if the mental part is not okay, then the physical cannot be either."*

> *"L: So it's a combination. There's no point in being trained to walk, if you are not trained in: that: uh, the head - it must work as well."*

In addition to the individual therapeutic intervention, Lars participated in a group therapy during his stay at the rehabilitation center. The group therapy was facilitated by the rehabilitation center's psychologist and a music therapist, drawing on intervention methods from both approaches. The group therapy was something Lars returned to several times during the interview. It is something that has made a great impression on him, especially in relation to the social fellowship of the group. The group represented security for him, and it was important that they had something in common.

Training and Rehabilitation Center

During the interview Lars talked about other experiences he had during his stay at the rehabilitation center. Experiences in everyday life was important for the training and recognitions of changes following the brain injury.

> *"I: There was a day when I had to make soup. I had prepared it in the morning. So, for dinner, I chose to turn it on, and then I went over to train in the gym. Then came [name] over, one of the educators said "L, I've turned off your soup, I think it's finished"*
> *I: Well yes*
> *L: And then I came to think of, "L now you better, when you come home, you better get someone to come in and look, if: you've started something"*
> *I: Yes:*
> *L: For there I said to myself, it may be one of your injuries:that:that you've started something"*
> *I: Yes:*
> *L: For there I said to myself, it may be one of your injuries: that: that you do it.*
> *I: Yes. Yes, other people also experience that. That they go from something, they simply forget that they've turned it on.*
> *L: Well my problem: and what annoys me, it is: is that I knew it well, because I turn it on, and then I go*
> *I: Hmm"*

Having concrete examples of everyday challenges can help to detect them and later see how you progress in overcoming them. It opens a subsequent opportunity to work on the challenge and actively train it in everyday life and learn new strategies:

> *"L: But I have also had my [family member] to make some notes and put up "Remember to turn off" signs*
> *I: Yes. So there are some strategies you've got, to: and: help you remember to switch off*
> *L: Yes, yes, exactly. They hang so I keep watching them*
> *I: Yes."*

Not only planed exercises during the rehabilitation, but also concrete everyday experiences, have helped Lars recognize his own difficulties and take the necessary precautions.

DISCUSSION

This case study set out to explore the effect of a psychological intervention program, as well as how a client experiences the intervention after an ABI. While results from pre, post and follow-up measures does not show clear positive results, the interview reveals positive experiences with the intervention. Previous studies in the area show similar unclear results measured by quantitative parameters, while clients express good experiences of interventions [e.g. (56, 57)]. No significant fall in symptoms on the HADS assessment could be expected, since Lars did not complain about depressive or anxiety symptoms before the intervention and the assessment did not show signs of either pre intervention. However, results of the two other assessment tests, which indicated no changes for SCS and a decrease on WHO-5, is more surprising. It should be considered if the measuring tools were inadequate, or the client simply did not have quantifiable benefits—including whether the specific client is a special case. Furthermore, it can be argued that an effect cannot be expected on a client who does not experience greater symptoms of psychological distress. Why even intervene if the client does not rapport symptoms of either depression or anxiety beforehand. However, as argued in the introduction the rationale for a psychological intervention should not only be found in the prevalence of depression and anxiety among people with acquired brain injury, but also in the existential changes during a crisis. A psychological intervention is expected to not only lower symptoms of depression and anxiety, but also increase the overall outcome of the rehabilitation.

Based on this consideration, it can be argued that the intervention should be evaluated in relation to the therapy goal to a greater extent than based on symptom reduction. A previous study by Gracey et al. (57) highlighted the importance of evaluating future studies of the effect of psychotherapy for this group of clients on the bases of achieving the therapy goal. Furthermore, the third wave cognitive therapies would argue, that the goal of the therapy should not be symptom reduction but recreating a sense of meaningfulness in life (58).

The qualitative therapy goal, for Lars, was to recognize own limitations in order to be able to participate in the rehabilitation program and to prevent conflicts with the rehabilitation team. This goal was achieved as noted by both Lars and the psychologist. Furthermore, Lars was able to better collaborate with the rehabilitation team and was offered an extension of his stay at the rehabilitation center for further 3 months after the intervention, which he accepted. This allowed him to further improve in physical and cognitive functions. In this light, the intervention was effective, and it can also explain the results in personal growth (PGIS), on which Lars showed a great increase in agency. On the other hand, results from the HADS assessment showed increased symptoms of depression and anxiety post-intervention, and the results from WHO-5 showed reduction in quality of life. This apparent discrepancy may be explained by a relapse, which is to be expected when becoming aware of one's own limitations. This could further cause a grief reaction (58). Perhaps the increase of depression and anxiety symptoms can be understood as a reaction to his increased insight into own limitations, and as signs of a grief reaction. Very little is known about how people with ABI experience grief, and it has been suggested that symptoms of depression can be understood as such (59). At the time of the follow-up all scores had stabilized at a non-pathological level. From previous studies, it is known that the insights obtained during therapy for some people with ABI takes longer to consolidate (40). During the interview Lars stressed the importance of the therapeutic relationship, and a study by Zelencich et al. (60) argues for a link between a good therapeutic relationship and increased self-awareness.

If increased insight or self-awareness increases the risk of anxiety and depression, one may question why a psychological intervention should seek to support an insight process, since depression and anxiety post brain injury are associated with poorer functional outcomes (61). As reported above, lack of insight can hinder the rehabilitation process in general (58). Therefore, it can be suggested that symptoms of depression or anxiety in a period of the rehabilitation process can occur as part of a natural grief reaction (59, 62). Since reactions of grief is commonly seen in relation to increased self-awareness and identity reconstruction following the brain injury (58, 63).

During the intervention period, the participant completed the self-report questionnaire measuring daily rehabilitation progress. As seen above no significant results was found from this questionnaire. This may be due to different problems. First, $N = 1$ which means the data set probably is too small, and the scale has not been calibrated. Another problem might be in the definition of the week beginning on a Monday. From the visual inspection of question 1 it appears that had we started the week on a Sunday, a regression might have appeared.

The objective of the secondary outcome measure was to identify patterns that could link specific intervention aspects to rehabilitation progress. This was not possible, and it can be argued that another measurement would be more suited.

Future Directions for Interventions and Society

Based on the presented case, we recommend that psychological interventions should be given as an add on to existing holistic rehabilitation programs to enhance the overall rehabilitation outcome and support the client's psychological adjustment to changes after an ABI (59). Moreover, society should acknowledge the importance of psychological support following ABI, in order to support the total outcome of holistic rehabilitation. As Lars expresses the psychological rehabilitation and the physical rehabilitation are inter-dependent.

An ABI is a life changing event. An individual not only loses bodily functions, but also social and relational positions (work, network, family, etc.). The recognition of our shared humanity is crucial. Instead of dehumanizing and pathologizing ABI survivors, normalization could be an important aspect to consider further, which implies a basic mutuality in the experience of suffering. As long as there is so much stigma combined with ABI, acceptance of being a person with an ABI can be difficult and extremely shameful. We need to validate this fact much more in rehabilitation and in society. Moreover, rethink why professionals think insight is so important? Could it not serve a protective function when clients challenge the ABI? Maybe we should start validating and normalizing accounts from ABI survivors as good practice instead of confrontation and correction of reality, since this traditional practice seams to fail its purpose of leading to more insight and acceptance of difficulties and thus to a greater motivation to work with these difficulties. Furthermore, we should start reflecting on what happens to an individual's identity when they are met with disbelief in what they are saying. We should create more sameness with ABI survivors, not difference. This approach contrasts a more traditional and distanced professional/expert vs. client approach and underscores the need for a new knowledge regime in neurorehabilitation.

What seems to make the crucial difference in rehabilitation is "the way of being" of the professional. The importance of an emotional connection and of understanding the other as a complete person was underpinned by Carl Rogers, founder of humanistic psychology, years ago, but have we forgotten this valuable insight into relations? Within neurorehabilitation most educations and courses for professional focus on how we can increase our neurological knowledge on brain injuries. Rarely there are courses focusing on the relationship between professionals and adults with ABIs. Therefore, it seems important to revitalize some of Rogers valuable insight when humans are dealing with humans.

Regarding the BackUp-manual the therapist noted that the content and exercises of session number 9 could be moved forward. This would be in line with the therapy progression described in CFT (53).

Limitations and Future Directions for Studies in the Area

People with ABI represent a very heterogenous group, and thus many factors we cannot control for (31). Therefore, case studies are considered very appropriate to evaluate interventions (57). However, case studies hold some limitations, including lack of generalizability. The purpose of this study was not to produce generalizable findings, but to make a first evaluation of the BackUp-manual used as an intervention program in a single case study, and how the existing rehabilitation could benefit from a psychological intervention. The BackUp-program has not been thoroughly evaluated before and given the benefits of single case study to explore a new intervention program, the case study was assessed to be the most suited for the purpose (31). However, it is important to stress that more cases is needed to validate the effect.

The assessment tests did not show clear effect of the intervention, but the evaluating interview did. However, Lars' experienced problems remembering the intervention at 9 months follow-up, which highlights the need for follow up interviews to be conducted right after the intervention. Another factor that can affect the outcome, is that the participant in this case study tends to be motivated by participating in the study (31).

Based on the findings and limitations of this study it needs to be evaluated if inclusions criteria need to be set in regard to initial scores on the outcome measurement, or if other outcome measures are needed for future studies. The outcome measures used in this study are based on previous studies in this field (24). However, the manual was originally designed to support the psychological rehabilitation after an ABI; therefore, more qualitative measurements about obtaining a therapy goal or questionnaires on treatment satisfaction after every session could be relevant. Another assessment tool that could be suggested to befit and supplement a qualitative evaluation of the feasibility of the intervention, could be a standardized questionnaire for the therapist, evaluating the client's commitment to the therapy and the feasibility of the sessions.

As put forward by Gracey et al. (57), we recommend further case studies of psychological intervention programs as part of a holistic rehabilitation program following ABI. Future case studies should enroll more cases. Additionally, future studies should explore the link between different interventions that are part of a holistic rehabilitation in order to better assess the interrelation of various interventions.

CONCLUSION

Overall, this case study provides support for a psychological intervention based on the BackUp-manual, specifically designed to support the psychological rehabilitation after an ABI. Further studies are needed to explore the benefits of a psychological interventions as a part of a holistic rehabilitation program after acquired brain injury.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Danish Data Protection Agency (Datatilsynet). The project was also reported to the Regional Research Ethics Committees for the Region of Nothern Jutland (Nordjylland) who found it exempt from full review. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

All authors agreed to be accountable for the content of the work. All authors contributed to the article and approved the submitted version.

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Rehabilitation Through Physical Activity and Sport in Light of the International Classification of Functioning, Disability, and Health–Current Research Perspectives

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The implementation of functioning by the World Health Organization (WHO) as the third global health indicator, along with mortality and morbidity, represents a promising advancement for a comprehensive assessment of international health systems and health strategies. The description of a person's health state operationalized by both biological and lived health *via* functioning provides a holistic picture of an individual's life situation and proved to be successful in building a framework for formulating therapy goals, achievable activities, and participational aspects against the background of an individual's life situation. Furthermore, improving an individual's functional ability and wellbeing could potentially affect the health indicators of morbidity and mortality and will be codable beyond the ICF in ICD-11. This methodological perspective emphasizes the use of ICF applications on the wider and narrower level of international rehabilitation systems and highlights the incorporation of the term functioning in rehabilitation through physical activity and sport. Current research perspectives in applying the ICF and functioning in clinical and rehabilitation practices are discussed and a current explorative study is presented, which applies the holistic orientation of functioning and the biopsychosocial model to the specific case by an individualized sports coaching intervention in rehabilitation. Subsequently, a unifying ICF- oriented language in rehabilitation is considered as a powerful foundation for a consistent international research strategy concerning increased international collaborations and future research perspectives.

Keywords: exercise, functioning, ICF, physical activity, rehabilitation, sports

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INTRODUCTION

In May 2001, the World health assembly adopted the International Classification of Functioning, Disability and Health (ICF) (1), which is intended to enable internationally consistent terminology about the impacts of health problems, taking into account a person's entire background (2). One goal of the ICF is the uniform understanding of the impact of health problems on an individual's health status. Therefore, the ICF's biopsychosocial model defines a person's health state through the person's biological health combined with the person's "lived health" interacting with personal and environmental factors (3). The International Classification of Diseases (ICD) represents the international standard diagnostic classification for diseases and related health problems (4). It complements the ICF, to monitor the response of health systems to people's health needs from a bio-medical perspective with the two indicators of mortality and morbidity (5). Mortality describes the length of life of a population and its survival with health problems. Morbidity, on the other hand, describes the distribution of health conditions in the population (5). However, in order to fully describe people's health needs, a third indicator was necessary that links biological and lived health: functioning. This indicator has also been coded in ICD-11, published in January 2022, and is linked to the ICF (5). On the one hand, functioning can describe the health status of a population and the outcome of clinical interventions; on the other hand, it can depict and monitor the impact of health system services on the lived health experience of individuals (6). The result shows an increased permeability in international health care systems using ICD-11. Furthermore, this outcome enables that ICF classifications will be feasible in the future. The purpose of this article is 2-fold. First, current research perspectives are discussed in applying the ICF on human functioning in clinical and rehabilitation practices. Second, an ICF-based research approach is presented by means of physical activity and sport. The article aims to contribute to the discussion of where we currently stand in terms of functioning-orientated rehabilitation and to provide perspectives on how to improve a person's lived experience of health based on the holistic view of the ICF framework.

REHABILITATION IN LIGHT OF THE ICF

Considering aging population and the increasing prevalence of chronic health problems, world health systems face new demographic challenges. For this reason, there is a global need to invest in improving individuals' functional ability and wellbeing in addition to reducing morbidity and mortality (7, 8). In this regard, functioning is the key indicator for rehabilitation and aims to optimize the functioning of persons who have or are likely to experience an impairment in function and to change the state of disability in order to achieve activities and participation (7, 9–12). In order to compare outcomes, efficiency and cost-effectiveness of different rehabilitation interventions, differences between the change in functioning after completion of a particular intervention compared to another intervention must be discussed (13). To compare rehabilitation interventions and provide standardized reporting, the ICF stands at the forefront of the rehabilitation community (13). According to Stucki et al. (14) the ICF is a powerful health information reference system for documenting functioning in rehabilitation. Due to this importance and to counteract the demographic trend, there is a need for investment in rehabilitation systems. In order to achieve targeted rehabilitation goals, the dimensions of health, assistive devices, and accessibility must be aligned, so that people with disability can achieve participation in society and improve their quality of life. For example, by allied rehabilitation disciplines, that could enable person centered services, such as promoting health behavior in concert with mobility training and fitted assistive technology (e.g., hand bikes, wheelchairs, eHealth tools) (15).

Furthermore, it is necessary to improve existing assessment tools and to develop new ones to disseminate knowledge and to precisely depict a holistic view on a person's "lived health" in addition to their biological health for a targeted engagement of multi-professional teams in clinical and outpatient fields (10).

ICF applications have been implemented in the wider and narrower level of international rehabilitation systems in the past two decades. In this context, the ICF, with its holistic orientation, was partly used as an underlying theoretical framework, partly operationalized at the specific item level as an assessment or used to define therapy goals with patients (16). In this regard, in the US-American area, the ICF was primarily used in its conceptual approach, whereas in the European region, the concrete application in clinical practice was focused (ibid.). The ICF has been successfully integrated, for instance, into electronic health records (EHRs) in past years. Results of a review by Maritz et al. (17) showed increased comprehensiveness and interdisciplinary focus when the ICF was used in EHRs (17). Also, numerous ICF-core sets have been developed and published on the ICF Research Branch platform to provide a basis for a standardized international assessment focusing on human functioning in clinical contexts (18). Furthermore, a family-friendly ICF version for common language in communicating with parents and professionals has been developed and validated in four European countries, to ease ICF language barriers for multidisciplinary collaboration and cooperation with parents and care-givers (19). These developments provide a strong foundation for the scientific community and represent a promising future for a more functional view of patient's heath states. In this regard the central question of the 2021 Rehabilitation International Congress was therefore: Where do we currently stand and which research strategies would apply to rehabilitation practice and heath care to make optimal improvements of a person's "lived health" by focusing on functioning. Concerning this, current ICF-based applications and potential future research directions were discussed on the conference and are presented in the following paragraph.

RESULTS OF THE 2021 REHABILITATION INTERNATIONAL CONGRESS

At the Rehabilitation International Congress 2021 in Aarhus numerous ICF-based applications were presented and indicators for potential future research directions were given, that in particularly highlighted the digital processing and use of the ICF-classification. Decker (20) presented the REHADAT-ICF platform as a practical research tool to find and share targeted information about rehabilitation, vocational inclusion, and assistive technology in the cross-national ICF structure

(20). Bjørnshave et al. (21) discussed the ICF model as a communication tool with patients. Results have shown that the ICF component interactions proved promising when talking with patients about complex issues in their sphere of life. Ng et al. (22) presented an ICF application in stroke rehabilitation which enhanced communication in a multi-disciplinary team and showed promise in guiding the design of personal and holistic rehabilitation plans (22). Chan (23) also stressed the benefits of the ICF's systematic and individual person-centered service framework, which facilitated trans-disciplinary collaboration and synergy in joint professional case conferences (23). Additional innovative rehabilitation concepts were presented, such as outdoor rehabilitation programs, with no direct link to the ICF classification. Results by Alfredssen (24) indicated that an outdoor rehabilitation program empowered patients to go outside on their own. It therefore could indirectly prepare the post-rehabilitation phase and promote participation in daily life routines for patients. Autrup and Glümer (25) found that individuals had more energy after outdoor classes, and inactive, isolated, and vulnerable individuals became an integrated part of the group through these interventions. Also, results indicated that outdoor-only rehabilitation programs increased self-management and empowerment (25). In this regard, it would also be of interest to examine, on an ICF basis, to what extent these demanding environmental conditions affect activities, participation, health state, and which role physical activity and sport played in the processes.

Mentioned studies confirm the global trend that there is currently a growing number of high-quality ICF-related developments in rehabilitation contexts (26–28). However, the role of physical activity and sport represents an important variable that seems to play a subordinate role in the current discourse. As the contributions to outdoor rehabilitation have shown, impact factors of sport and exercise can make a major contribution to enhance persons' biomedical functioning, feasible activities, and social participation opportunities (29–31). In this context, aspects of training and the increase in and maintenance of physical performance play a role in the psychosocial promotion of getting active independently, self-determination, and experiencing self-efficacy (32). These are particularly important in terms of rehabilitation goals in the context of returning to work, as they enable people to regain access to working life (33).

PILOT STUDY "SPORTCOACH"

In this context, a project of the German social accident insurance institution for the health and welfare services (BGW), as evaluated by the Research Institute for Inclusion through Physical Activity and Sport, is presented. The Sportcoach-study aims to improve the quality of life, self-efficacy, fitness, and participation of persons with work-related polytrauma and occupational diseases through an individualized sports coaching approach in rehabilitation. The project runs as a pilot study in six regions in Germany. The aim is to achieve and sustain participation in social and working life of persons with occupational diseases through physical training with sports coaches and the involvement in sporting activities and participation in regional sport clubs. The sports coach advises, accompanies, and mediates persons into sporting activities and participation in sport clubs. The participants benefit from these coaching services for 18 months, in which they can try out various sporting activities and enroll in sport clubs. The selection of these sporting activities depends on numerous external and internal factors, such as distance from home and personal sport preferences. Furthermore, the coach is allocated to a person, after they have completed their medical rehabilitation at their local hospital. In the ICF biopsychosocial structure, the coach can be understood as a promoting environmental factor who guides persons with polytrauma and occupational diseases toward a healthier lifestyle post-rehabilitation to increase their global functioning capacities. The coach aims to follow the main goal of rehabilitation by a holistic approach and to optimize functioning for an enhanced health state *via* an individualized approach.

The coach's first task is to find appropriate sporting activities close to a patient's regional environment and residence; the sports are highly suited for this particular person and their individual biomedical background. As a result, the coach's approach is somewhat different from the established and widely known rehabilitation interventions. Most rehabilitation interventions focus on the increase of one particular health topic, such as the relief of dorsal pain. Furthermore, these interventions, also known as rehabilitation sport classes, are created in such a way that a wide spectrum of persons can attend these courses. This means that these classes possess a low threshold to participation and the subject matter is shortened to limited practices. However, because of this general approach, this kind of practice is effective for only a certain group of individuals and does not promote long-term involvement in sport groups close to their home. Therefore, the coach tries to find sporting activities which are highly suited to the participants' personal health needs and which promote a long-term involvement in the sport structures in their regional environment. Aside from that, the other main criterion for the coach's approach is to support individuals to participate in sport programs at sport clubs. By doing so, the effect can be 2-fold. First, participants are able to increase their health state further, since these sport activities have a higher personal binding and are guided by professionals (body functions and –structures, activities). Second, by attending sport activities at sport clubs, participants can exercise with people who share the same passion about that particular activity and have similar functioning levels in sport and thus be involved with others (participation). This effect can lead to various actions on the social level, such as building new friendships or to become a permanent member at the club. The overarching goal can be the increased participation through sports, because being involved in this sporting area may open up other potential pathways for participation in society more easily.

Since the study is still ongoing, most participants, $n = 71$, only completed two measurement points. However, preliminary results after 5 months, from t1 to t2, of the coach's approach show qualitative and quantitative effects in several areas. First, all participants reported that they were satisfied with the coaches' individualized approaches. Most notably, the participants described that they appreciated their motivational manner and their ability to recognize their personal needs. Furthermore, first quantitative results show an increase in subjective activity and health levels using the perceived physical condition scale (peps) (34). Additionally, similar effects were found, analyzing the quality of life scale (QOLS) (35). The results highlight a potential increase on the physical and social subscales. These preliminary results demonstrate that the coach's approach could be useful as a new ICF-based concept to further optimize holistic rehabilitation's aim by using a sport-orientated functioning approach. However, the above-mentioned results should be interpreted with caution, since the data only reflects the first impressions of the coach's approach. Therefore, further data is needed in order to confirm these first findings on the basis of larger sample sizes.

DISCUSSION

In summary, the sports coach approach represents an example of the concrete application of the ICF framework, which applies the holistic orientation of functioning and the biopsychosocial model to the individual case. Against the backdrop of the global situation described at the beginning of this article, individualization will become an increasingly important rehabilitation issue in the future. The establishment and anchoring of functioning in the ICF and ICD-11 was a required step in order to provide a complete set of indicators to monitor, compare, and align all five WHO health strategies (preventive, promotive, curative, rehabilitative, and palliative). In addition, it is important to compare and contrast data in international research collaborations, in which physical activity and sport play a significant role (12). The revision of ICD-11 has also greatly simplified the usage and improved the user-friendliness of the classification. There are now also online platforms available, where international contribution has been made possible (36). In addition, consistency between language versions has been improved and a Unique Reference Identifier (URI) has been developed, which for the first time represents a unique string of characters for individualized cases. This URI enables connectivity and linkage to holistic rehabilitation concepts (ibid.). The ICF has brought a new perspective to the health condition of a person, which, on the basis of the findings presented, can be depicted more and more precisely and better linked (37). Through the increasing implementation of digital health records, the ICF-holistic view of a person's functioning can build a basis to realize the optimal treatment for a certain health condition in multi-professional teams. As Wenzel and Morfeld (16) point out for rehabilitation teams working with ICF checklists, the participative orientation of their work as well as interdisciplinary collaboration and a generally more systematic way of approaching work improved. Furthermore, ICF applications proved themselves to be suitable in examination schedule, the identification of relevant functional areas and therapy target formulations (ibid.). Prospectively, there will also be an increase in assistive technologies and devices in rehabilitation; for example, for barrier-free movement, individualized physical training strategies or complementary eHealth Coaching. In this regard, the professional field in rehabilitation is becoming more diverse (including bio technicians, engineers, sports scientists) and it is becoming increasingly important that functioning goals and outcomes are defined precisely and comprehensively. Statistical mapping and structural equitation modeling could also provide further insights in the complexity of ICF-interactions in regard to human functioning (37). In this regard, a unifying ICF-oriented language in rehabilitation provides a powerful foundation for consistent international research strategies and common efforts of the creation of new knowledge (ibid.). The use of functioning as an indicator for health can be a guiding principle in this respect, as it focuses on enhancement of the person's lived health, which could be realized by tailored and functionally supportive environmental factors such as tech devices and assistive technologies in a targeted way.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary files, further inquiries can be directed to the corresponding authors.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee German Sport University Cologne. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

IS and EW devised the article structure and the conceptual framework. RV contributed to the conceptual idea and discussed study findings in this work. VA supervised the manuscript process. All authors discussed the results and contributed to the final manuscript.

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Toward More Inclusive Work Organizations by Redesigning Work

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Inclusive Work Redesign (IWR) is an innovative strategy to create feasible job opportunities for job seekers from vulnerable groups at the labor market, in particular people with disabilities, in such a way that it contributes to sustainable employment for all staff and to the organization's performance. As an element of active labor market policies (ALMP), in the Netherlands, IWR is used as an instrument for Public Employment Services (PES) and professionals in occupational rehabilitation to support employers, using a demand-oriented approach. IWR is also a potential valuable asset for strategic human resource management (SHRM) aimed at inclusion and sustainable employment. The article describes IWR in the context of social security and staffing problems of organizations, and the application of IWR in the Netherlands and Germany.

Keywords: inclusion, work redesign, rehabilitation, disability, vulnerable labor market groups, PES, ALMP, SHRM

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INTRODUCTION

Including people with disabilities into the world of work is still a great challenge for work organizations all over the world. Nevertheless, organizations should seriously consider all options to become more inclusive, for their own sake and that of society at large. People with disabilities often do not fit into regular jobs that are becoming too demanding even for an increasing number of workers without disabilities. In order to promote sustainable employability for all people, both workers and job seekers, there is a need for innovative work redesign, aimed at a better fit of work to individual abilities and ambitions.

Efforts of occupational rehabilitation professionals to (re)integrate people with disabilities into regular jobs still are predominantly "supply-oriented". They are supporting people individually in their search for a suitable job, their integration or return-to-work. These efforts are in need of a complementary "demand-oriented" approach, supporting employers to create suitable jobs (1, 2). For this purpose, the method "Inclusive Work Redesign" (IWR) was developed[1] in the Netherlands. During the past decade, this approach has been applied within the context of social security in "inclusive consulting" a great number of Dutch organizations (both public and private) in many different branches. Supported by the European Social Fund, researchers and social security practitioners from Germany and the Netherlands recently started a transnational co-operation to explore the practical suitability of IWR in the German context.

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[1] https://www.youtube.com/watch?v=gXnEnWZ5MX8&t=8s

THE RISE OF ACTIVE LABOR MARKET POLICIES

Starting in the 1980s, governments in many countries with a developed social security system adopted new policies in reaction to a steadily growing number of people dependent on allowances and as an essential element of austerity. They introduced all kinds of measures in order to limit expenses and encourage jobless people to (re)enter the labor market, that became known as Active Labor Market Policies (ALMP) (3). Important components of ALMP are public employment services and public human capital investments [assessment, vocational guidance, education and training, and recently "up-skilling and re-skilling" (4)]. For people with disabilities, a "paradigm shift" was proclaimed by the OECD (5), "from compensation to participation". This was followed by intensification of ALMPs for this particular group of people in member states (6). In fact, this led to a profound change in the nature of social security. From now on, the adage was social security by employment: anyone able to work, has to work and stay at work; allowances are only for fully incapacitated persons.

As a result, people with disabilities not only have the universally proclaimed *right* (7) to participate in work, but many of them nowadays also have an inevitable *duty* to work. This makes the need for suitable jobs for them even more urgent. This shift in social security also places the employers at the center of the social security system as the ones who are supposed to be able and willing to provide those suitable jobs. IWR was developed to support employers in pursuing this role.

Work Organizations and Their New Role in Social Security

The vast majority of employers still turns out to be reluctant to hire people with disabilities (8, 9). There is a complex of different reasons behind this negative attitude that does not match their supposed new role in social security at all. Doubts about the employability of people with disabilities, supposed lower productivity, higher absence rates, and aversion of co-workers are amongst the most frequently documented reasons for not hiring them (10). Most prominent, however, is the argument that there are *no suitable jobs* in their organization for jobseekers with disabilities (11). Because this is a final argument, "it is not possible at all", it is very important to take a closer look at the way work is organized nowadays.

Division of labor (functional differentiation, specialization) and coordination (integration of effort) are important determinants of a work organization, resulting in particular jobs, roles and responsibilities (12, 13). These actual work design features are the result of human decisions based on practical and theoretical considerations, under the strong influence of social, economic and technological developments and institutional context (12, 14) and long-standing evolved work (re)design traditions (15). Apparently, these features are unfavorable to people with disabilities as well as other jobseekers whose knowledge, skills and abilities (KSAs) do not match the qualifications asked for in the labor market.

Opposite Trends, Toward More Exclusive Organizations

Profound changes in the nature of work over the past three decades had great consequences for people at work and job seekers. Cognitive and social skills are becoming predominant in future work. There is an increasing need for the *combination* of problem solving skills and interpersonal skills (16). Overall, work has become more and more demanding. Traditional branches of agriculture and industry had to give up their long-standing predominant position, in particular in favor of the public and private service sector and healthcare. Global competition and technological developments acted as main drivers for highly efficient workplaces. Quality of work and working conditions were not primary goals in this course of events, and were put under pressure (17, 18). On one hand, task complexity increased, tasks became more flexible (job rotation), more individual responsibility was needed (task autonomy) and there was a higher need for social skills in teamwork, in contact with customers in service work or with patients in healthcare. On the other hand, low skilled jobs were subject to rigorous monitoring and control and intensification of work pace. Moreover, there is an overall tendency to longer and flexible working hours.

As a result, many organizations have become more and more exclusive. They are designed and managed in a way that they are only accessible for people *without* disabilities and *with* the right qualifications, and only as long as they do meet the demands of the regular jobs. A growing number of people is not able to meet, or to keep up with these demands. They are referred to as "people with a distance to the labor market" or "vulnerable labor-market groups" (19). People with disabilities and/or no actual or currently requested professional qualification are part of this large and heterogeneous group that is growing in many countries (20).

A STRATEGY FOR CHANGING THE ORGANIZATION OF WORK: IWR IN A NUTSHELL

IWR is a strategy for changing the organization of work. Participative work redesign which implies active involvement of current employees, results in a redistribution of tasks in such a manner that job seekers with disabilities and/or lacking qualifications can support professionals in performing their key tasks, thereby contributing to the effective and efficient operation of staff as a whole. Both the resulting new jobs and the redefined jobs of incumbent staff should meet quality standards that guarantee health, safety and wellbeing.

The business logic behind this strategy is capitalizing on the widespread underutilization of skilled staff, who are a substantial amount of their working time engaged in tasks that do not need their qualification. Previous cost-saving reductions of "headcount" were often achieved by layoffs of lower qualified staff. The routine tasks they used to perform where at -least partially- transferred to the remaining higher qualified staff. For instance, in the Netherlands yearly nation wide surveys during the last decade reveal that one third of respondents are performing tasks below their qualification level (21). This phenomenon was confirmed in many IWR-consults by UWV[2]-professionals in such diverse branches as industry (wood, metal, leather, chemical, machine, bakery, meat processing, packaging), technical installation sector, temporary employment agencies, cleaning companies, waste disposal, whole sale business (vegetables, fruit, flowers), retail (department stores, supermarkets, distribution centers), hospitality (hotels, restaurants, catering), recreation (swimming baths, sports halls, amusement parks), health care (general hospital, mental hospital, home for the eldery, nursing home, sheltered home), public services (municipalities, counties, state), education (primary, secondary, higher, university). Despite labor shortage and unfilled vacancies, there is a substantial proportion of the population of working age that is still *not* engaged in work: *people with disabilities and/or mismatching skills.* However, given the proper conditions, work can be organized in such a way that these people can also make valuable contributions to any work organization. IWR originally was developed for people with disabilities and with little education, to organize assistant jobs based on elementary tasks. Later, the scope was broadened to all people with qualifications that have become deficient or even obsolete, or are at risk of becoming so: this gave rise to the development of IWR 2.0.[3]

IWR is a generic demand-oriented strategy for organizations to become more inclusive. The initial diagnostic phase consists of organizational analysis and inclusive work analysis. The organizational analysis results in a problem definition and a plan of action that embraces the challenges of the specific organization and that management is willing to adopt. If management believes the plan of action for redesign to be a possibly viable way to create additional staffing options, an inclusive work analysis of designated departments is performed. The results of this diagnostic phase are the input for participative work redesign. In collaboration with staff members and line management, redesign options, benefits and the preconditions for successful implementation will be discussed, preferably in work sessions. During these sessions, there is room to explore proposals of various kinds; they may concern redistribution of tasks to engage new colleagues with different qualifications and to make changes in existing jobs, as well as redefining roles and responsibilities, and alternative ways of onboarding, training, coaching, coordination and management. Based on these proposals, management has to establish the final setup of the redesign and the way it will be implemented.

Organizational Analysis

Organizational analysis starts with exploring a company's or institution's mission and goals, its strategy to pursue these goals and the contextual factors the organization has to deal with (14). Focus of the analysis is on identifying existing or potential future bottlenecks in staffing vital to the organization's strategy.

Efforts necessary to guarantee sufficient qualified staff are dependent on changes in the external and internal labor market. Recently, despite pandemic related economic turmoil, many organizations in The Netherlands, Germany and several other countries are experiencing difficulties in attracting and retaining qualified staff due to tight labor market conditions. The shortage of qualified labor complicates recruitment of new staff and facilitates "job hopping" of current staff. In addition, organizations have to cope with threats to the employability of current staff. One important issue is advancing quality of work using countermeasures to the known work-related threats to the resilience of an aging population of workers facing higher retirement age. Organizations also need to keep their staff's skills and knowledge up to date and in line with innovations of products and services and keep their staff motivated and happy to increase retention. Most organizations are confronted with several of these challenges and have already tried to deal with them in their own way. It is important to connect to these ongoing activities and to explore if and how IWR can be of additional value. If IWR may be helpful and management is prepared to adapt work processes and change existing task distribution and work context, then the next step is inclusive work analysis.

Work Analysis

Organizational analysis yielded the scope for work analysis, the units that will be involved in this phase, and the specific personnel issues that need to be addressed. First, a clear picture of the present situation ("ist-situation") is indispensable. It is needed in order to explore the opportunities for reallocating tasks to less qualified new staff, so that work pressure for current staff may be alleviated, or to create chances for their career development or the introduction of technological innovations. Traditional job analysis concerns critical tasks and responsibilities (roles) of a job holder, and the critical KSAs needed (22). Usually, this does not yield a complete inventory of the actual daily activities of the job holder, as that only becomes obvious in the analysis of work processes, as also performed in IWR.

Document study, observations and interviews are performed to identify the work processes, and the activities (tasks) of which they consist. For each task, frequency and duration are assessed, as well as who is (are) performing the task, what qualification is demanded, and if it is possible and desirable to transfer this task to someone less qualified. Finally, the conditions for transferring tasks are specified ("soll-situation") in participative work redesign sessions.

CASE: NURSING HOMES

Persisting shortage of staff in nursing homes is undermining both quality of work and quality of care. In the labor market, there are not nearly enough professionals who qualify for the great number of vacancies. Turnover is high, due to work pressure and lacking prospect for improvement, putting the burden on the remaining staff, including a substantial part of senior workers (over 55 years). There is not enough time for necessary professional

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[2] UWV, the Dutch Employee Insurance Agency.

[3] https://www.inclusiveworkredesign.com/methods-instruments/inclusive-redesign-of-work-20

development to deal with growing complexity in the demand for care, and for the introduction of new assistive technology.

This self-perpetuating spiral induces nursing homes to reconsider their traditional job structure and its relation to the actual demands in work processes. During the past decade, IWR has been successfully applied in general hospital settings to redistribute tasks and compose supporting jobs to make better use of professional staff capacity. Recently, IWR was applied in the setting of nursing homes to explore opportunities for organizational innovations that could contribute to the solution of the staffing problems.

In psychogeriatric units of a nursing home, inclusive work analyses yielded 72 different tasks, varying in size, that do not require a healthcare qualification at all. Nevertheless, professional nurses and caretakers spent some 245 h per week carrying out these duties, amounting to 30 percent of their working time. These tasks were part of 4 work processes: care, nutrition, wellbeing and domestic work. Redistribution of tasks in participative work redesign sessions with representatives of unit staff resulted in the definition of 3 new support functions (**Table 1**) in order to provide professional nurses and caretakers with the opportunity to focus on their core tasks.

- The "General assistant" role: assisting in keeping general residents areas clean and hygienic, escorting clients, and transport activities.
- The "Living assistant" role: paying attention to residents wellbeing, supporting and encouraging residents drink and food intake and supporting residents activities.
- The "Domestic assistant" role: ensuring the cleanliness and hygiene of the personal livings spaces of residents and the department in general.

The general assistant serves as entry job for new employees with low level KSAs. With sufficient training on the job, they can progress to one of the other assistant functions.

IWR IN GERMANY

In 2020 we started a project for a "proof of concept" of the inclusive redesign method in Germany. We wanted to learn if and how this approach could be applied in the German context of work organizations, as well as the social security system (23). The 10 students involved in this project were professionals employed by organizations of social security in Germany. They participated in the project as part of their course in work and organizational psychology at the HGU, the University of Applied Sciences of the German Social Accident Insurance (DGUV).

After receiving an introduction in theory and method of inclusive redesign, they started developing their skills at the campus by performing an inclusive work analysis of the university's restaurant staff. Next, they performed a redesign project at a local administrative agency of the DGUV. They performed an inclusive work analysis by observing and interviewing 30 staff members, and developed a proposal for redesign. In short: the redesign is aimed at redistributing tasks in such a way that at each level, functions are concentrated around their core duties, and that it creates job openings for people with disabilities and/or no or (currently) irrelevant professional qualifications. Unfortunately, the final phase of a participative redesign session together with the staff could not be realized, due to the start of the pandemic. The project report of the "ist-situation" describes the actual state of work processes, tasks and responsibilities, as well as staff's perceptions of workload, bottlenecks, ambitions and desirable changes in work and work context. For the "soll-situation", a series of recommendations has been formulated.

The concept of inclusive redesign proved appealing to all involved: students, management and staff. The method proved to be well applicable in the context of a German work organization, and yielded useful results and recommendations, according to this organization's management. The results and the experiences in this feasibility study were encouraging for the next step ahead: a pilot in a German hospital struggling with staff shortages, especially of nurses. This pilot will start as soon as the Covid-situation allows.

DISCUSSION

In the Netherlands and Germany, but also many other countries growing demographic imbalance is responsible for structural labor market shortages and a structural more vulnerable aging workforce. Work organizations are challenged to develop new

TABLE 1 | Three new assistant functions, examples of tasks.

Work processes	General assistant	Living assistant	Domestic assistant
Care	Escorting or transporting clients to and from living room and organization's restaurant	Supporting and encouraging residents' drink and food intake	Making beds, cleaning beds, collecting and transporting dirty laundry
Nutrition	Setting and clearing the tables Washing dishes	Preparing breakfast, serving coffee and tea	Cleaning living room and kitchens
Wellbeing	Socializing with clients	Activities with individual clients, e.g. reading, playing games, listening to music, taking a walk, supporting clients in the use of technical devices like "Braintrainer" or "ExperienceTV"	Socializing with clients
Domestic work	Daily cleaning of toilets, bathrooms, halls and corridors, doors and door handles Thorough cleaning of wheelchairs and rollators, hoists	Mopping floors of common areas like living rooms and kitchens	Vacuuming and mopping of clients' personal living spaces according to a fixed schedule

Our organizations are cooperating in a transnational project on inclusive redesign, supported by the European Social Fund (project 2019EUSF2013).

strategies in response to the resulting quantitative and qualitative staffing problems. One of the obvious directions to look for solutions are the large numbers of still unemployed people with disabilities and/or with qualifications not (longer) matching regular job vacancies. However, these job seekers are dependent on suitable jobs that enable (re)entry in organizations, and chances for professional development, that most organizations do not yet offer. To be able to make productive use of this growing labor market reserve and thus to create also better working conditions for current staff, a definite change in the way work is organized is necessary.

In the context of Social Security in The Netherlands IWR during the past decade has proven to be an effective instrument in demand-oriented service for employers, who want to include people with "a distance to the labor market", in particular persons with disabilities[4] Recently we have explored the applicability of IWR within the context of German Social Security and work organizations. The results and the experiences in this feasibility study were encouraging for the next step ahead: a pilot in a German hospital struggling with staff shortages, especially of nurses.

Inclusive work redesign (IWR) is a change strategy for organizations interested in an attractive business solution: the combined use of internal and external untapped human resources. Recent publications on human resource management (HRM) are calling for "Inclusive HRM" (24) and "Employer Engagement" (19) as "the active involvement of employers in addressing the societal challenge of promoting the labor-market participation of vulnerable groups". Inclusive work redesign as a generic participative change strategy can be a valuable asset in pursuing these goals.

DATA AVAILABILITY STATEMENT

Publicly available case studies used or this study will be accessible on request.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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[4] https://www.inclusiveworkredesign.com

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ORIGINAL RESEARCH
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Five Vital Components in an Occupational Therapy-Based Municipal Weight Loss Program Obtained Through Research Circles

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Introduction: Currently 1.9 billion adults worldwide are estimated to be overweight or obese. Weight loss sustainability is difficult, and weight loss rehabilitation programs have been criticised for having an individualistic approach. It has been suggested that occupational therapists could be used as part of a transdisciplinary approach because of their holistic perspective. During the development of an occupational therapy- based weight loss program five components arose as essential from earlier interviews with health professionals and citizens with obesity: diet, physical activities, social relations, habits and balancing everyday life. Before developing the program, we needed a clearer picture of which strategies should support the five components. The aim of this study was to obtain a description of strategies related to the five components that could support weight loss to become part of everyday life of people with obesity.

Methods: This study took a participatory design by using research circle (RC) methodology. Two RC groups were created, one with occupational therapists and one with citizens with obesity. Researchers participated in both RC groups. Data was obtained through democratic principles. The two RC groups met four times over a period of 4 months. Qualitative content analysis was conducted.

Results: Five themes arose: (1) Diet—Find the line between either-or, (2) Physical activity—Break the comfort zone, (3) Social relations—Stand strong together, (4) Habits—Focus on possibilities instead of bad habits, and (5) Balancing everyday life—Handling life's bumps.

Conclusion: The strategies for a weight loss program including the five components should include awareness of senses and activity patterns surrounding meals, taking one step at a time when focusing of physical activities and be conscious of values, include family and friends in the program to find common ground and self-confidence and use re-placement activities. We suggest that the component of balancing everyday life should be seen as an overall component as all strategies are related to finding meaning and variation in activities which is part of an ongoing weight loss process.

Keywords: obesity, overweight, danish obesity intervention trial, DO:IT, everyday life, rehabilitation

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INTRODUCTION

Obesity has been labelled "the greatest public health challenge of the century," and has been acknowledge as a chronic disease by the World Health Organization (1). The prevalence of people living with overweight or obesity was 1.9 billion and of those, 650 million were obese in 2016 (2). This is a challenge because living with obesity affects a broad spectrum of life (3). Obesity is associated with health conditions such as cardiovascular disease, cancer and diabetes mellitus (2). Moreover, physical and psychological consequences of obesity (e.g., pain and feelings of being less valued) have an adverse impact on everyday life understood as components of activities and participation (4–6). Activities such as playing with children, buying clothes and going for a swim that are taken for granted were found to be adversely impacted by obesity (3).

Rehabilitation programs that combine physical activity, diet, and behavioural therapy can result in significant weight loss (7, 8). However, maintaining weight loss remains elusive (7). Some have argued that existing programs have failed because they treat the process as a problem of individual agency that is addressed outside of the individual's everyday life (9). This approach stands in contrast to an occupational therapy perspective advocating for a more holistic approach (10). The holistic approach within occupational therapy attend to the link between person, activities and the environment and how these factors all influence participation in everyday life (11, 12).

The Danish National Board of Health recommend that weight loss programs should include a combination of diet exercise, behavioural therapy and everyday life (13). This is further detailed in earlier studies with the aim to understand wishes for the content of weight loss program both from the health professionals and the citizens with obesity (descripted only as citizens in the following). The studies, based on 66 individual interviews, showed that both groups wanted to focus on meaningfulness rather than narrow components like sports and calories, and that it should be implemented in everyday life if sustained weight loss and increased well-being were to be realistic outcomes. The two groups agreed that five components of a trustworthy program should be diet, physical activities, social relations, habits and balancing everyday life (14, 15).

Obesity is a complex phenomenon wish needs to be addressed from a transdisciplinary view. Health professionals conducting weight loss programs should be medical doctors, dietarians, physical therapists, nurses, psychologists and occupational therapists (13). Despite the recommendation and potential benefit of applying an occupational therapy perspective to a transdisciplinary weight loss rehabilitation program with their focus on participation in everyday life, the research is sparse (10). To address this knowledge gap, we wish to develop an occupational therapy-based weight loss program as an ad-on to existing weight loss programs for municipalities. The municipalities in Denmark are responsible for conducting weight loss programs for its citizens. One of our earlier studies, a survey of all weight loss programs in the municipalities, showed that the programs primarily included one or two health professionals (most often dietarians) and that the programs were heterogeneous in length and content (16).

In the developing phase of the occupational therapy-based ad-on weight loss program we wanted to understand the role of occupational therapists more deeply. This was done by understanding strategies that could support the five components from the view of occupational therapists. As the focus for occupational therapists are the everyday life of citizens the perspective from occupational therapists should be understood in relation to the perspective of the citizens. Therefore, the aim of this study was to obtain a description of strategies related to the five components that could support weight loss to become part of everyday life of people with obesity from the perspective of occupational therapists and citizens.

MATERIALS AND METHODS

Research Design

Based on the roots of Gadamer's hermeneutic understanding this study took a participatory design by using a research circle (RC) methodology (17). The methodology emphasises collaborative cooperation between researchers and participants to develop knowledge through discussions and reflections. We applied the principles of RC methodology with the aim of discussing strategies relating to the five components obtained from the previously conducted 66 interviews (14, 15). In accordance with the Danish National Committee of Health Research Ethics, ethical approval is not required for studies that include only interviews.

Participants

Participants were recruited to two different RC groups representing occupational therapists and citizens. The researchers who participated included a PhD student and two master's degree students were all occupational therapists. They had the role of moderators. The target sample size was five – eight participants for each group to make sure that everybody would be heard (18).

A purposeful sampling approach was used. Citizens were included if they self-reported a BMI +30 and had experiences with weight loss attempts. Exclusion criteria was if the citizens did not speak or write Danish. The citizens were selected from waiting lists for weight loss programs offered in one of the Danish municipalities. Health professionals from the municipalities helped the research team by phoning citizens on the waiting lists and presenting the study information to potentially interested citizens. We introduced the health professionals to the project by phone and thereafter emailed them a detailed description which they used to inform the citizens.

In our previous finding content for a transdisciplinary collaboration was included, however specific knowledge about the role of occupational therapists in the collaboration seems to be missing (15). Inclusion criteria for the occupational therapists were that they had worked with group-based weight loss rehabilitation programs in a municipal setting at least three times before. To ensure that the focus was only weight loss, programs combining weight loss and a diagnose such as diabetes

TABLE 1 | Procedure of the research meetings.

	First meeting	Second meeting	Third meeting	Forth meeting
Content	Diet and physical activities	Habits and social relations	Occupational balance and sustainability	Validation
Procedure	Presentation of results from previous studies	Validation of manifest content from the first meeting	Validation of manifest content from first meeting	Presentation of results from the previous meetings
	Recommendations about diet and physical activities	Presentation of results from previous studies	Presentation of results from previous studies	Discussion and validation
	Working in pair with questions and reflections about how the components should be part of a municipal weight loss program	Presentation of research of habits and social relations related to weight loss	Presentation of recommendations about weight loss and weight loss maintenance	Evaluation of the entire process including all four meetings
	Supporting and building on each other's ideas by saying "Yes-and-then" Evaluation of this day's research circle	Discussion about habits Video sequences of a couple talking about how they support each in doing nothing Discussion about the video and social relations Evaluation of this day's research circle	Theory about occupational balance Discussions about the content Evaluation of this day's research circle	

were excluded. They were invited by a snowball method as we contacted occupational therapists which we knew could be included and they helped the further process.

Signed informed consents were obtained from all the participants who agreed to participate in the project in accordance with the Declaration of Helsinki.

Data Collection

The two RC groups met four times in the period from February to May 2020. The meetings were planned to be conducted every third week in a meeting room at the University of Southern Denmark. However, because of the Covid-19 pandemic the last two meetings with each group were virtual Zoom meetings. Each meeting lasted 2 h. Diet and physical activity were discussed in the first meeting, habits and social relations in the second, and balancing everyday life and sustainability in the third. In the fourth meeting, we validated the preliminary results. All meetings started with a presentation given by one of the researchers, based on the knowledge from previous studies (14–16, 19) and meetings 2–4 also included a summing up of the previous meeting, with time for comments and reflections. Activities and debate questions to facilitate discussions and secure equal participation were prepared for all four meetings (**Table 1**). The researcher had the role as facilitators, however in accordance with the RC democratic principles knowledge from all participants was discussed on equal terms (18). All meetings were conducted in Danish, audio recorded and transcribed into 312 pages. All data were stored in a safe database provided by the University of Southern Denmark and all participants were anonymised in the transcript material.

Data Analysis

The data was analysed using qualitative content analysis on a manifest level between the first three meetings separately for each RC group (20). This analysis consisted of four steps. In the first step, all the data material was read by the researchers. In the second step, content relating to the component of the meetings was identified and divided into meaning units. In the third step, the meaning units were condensed and labelled with a code. The codes were then aggregated into subcategories and categories. Between the third and fourth meeting, the categories from each RC groups were discussed between the researchers to be merged into 12 final set of categories. The 12 categories were discussed with the participants for validation in the fourth meeting. Knowledge from the last meeting was discussed between the first two authors and the master's degree students in order to refine and modify the merged categories until five themes emerged which seemed to fit the data in the best possible way (see **Table 2**).

RESULTS

Thirteen participants were represented: three citizens, seven occupational therapists and three researchers (**Table 3**). In the findings, the citizens will be represented with a C and a number and the occupational therapists with an O and a number.

Diet—Find the Line Between Either-Or

The two most significant strategies discussed was addressing consciousness and satisfying the senses. One central element from both RC groups when discussing consciousness was that prohibition and registration of what to eat should be avoided. O1 stated this very clearly by saying:

> *O1: "it is very, very important that it doesn't become a prohibition. Above all, it must not be a prohibition. Now you must never ever eat cake, or you may never again eat cake."*

C2 agreed that there was nothing called forbidden food. She explained that if she failed to eat healthy when following a diet, she felt bad and suffered from a bad conscience.

TABLE 2 | Themes and categories.

	Physical activities	Diet	Social relation	Habits	Occupational balance
Themes	*"Break the comfort zone by finding positive value"*	*"Find the line between either or"*	*"Stand strong together"*	*"Focus on possibilities instead of bad habits"*	*"Handling the bump in life with adaptability"*
Merged categories	Everyday life instead of recommendation Crossing boarders slow through doings Find physically, social and mental values and rewards	From restrictions to enjoyment Easy to relate to everyday life Focusing on culture regarding food Conscience about actions and feelings before changing	Focus on secondary relations both under and after weight loss The family both influence and are influenced Strategies to meet the world	Strategies into the everyday life in a never-ending story Learn to stand strong alone The context is a central part of the changes	Weight loss should be one activity goal out of many Variable structure Raise self-conscience through experience and meaningfulness
Categories Citizens Group	Use the opportunities at home Involve other Do not follow the recommendations	No restrictions Relate it to everyday life Focus on the feelings	Managing conflicts in social connections Information to nearest network to stop negative support Support after the program for sustainability	Fighting the bad habits Implementation in everyday life Repeating small changes Record changes	Balance in activity goals Increase self-conscience through different activities Find structure through doings
Categories occupational therapist Group	Start where they are Cross boarders Focus on values	Senses instead of restrictions Consciousness about eating habits Practical implementation	Navigate in a mutual influence Use relations for sustainability Different needs	Learn to stand strong Handling an ongoing process The context is part of the habits	Life is in focus, weight loss is a positive side effect Experiences should be the starting point Small variations are the way to success

TABLE 3 | Participants included in the study.

Participants	Gender	Age	Employment	Part of meeting
Citizens				
C1	F	34	Unemployed	1, 2, 3, 4
C2	F	64	Senior citizens	1, 2
C3	F	52	Healthcare worker	2, 3, 4
Occupational therapists				
O1	F	34	Health centre	1, 2, 3, 4
O2	F	42	Health centre	1, 2, 3, 4
O3	F	42	Occupational therapist education	1
O4	F	32	Day offer for young people	1, 2
O5	F	41	Health centre	1, 2
O6	F	48	Privat company	2, 3, 4
O7	F	31	Health centre	3, 4
Researchers				
R1	F	27	Master student	1, 2
R2	F	25	Master student	1, 2
R3	F	47	PhD student	1, 2, 3, 4

However, all the participants agreed that the path to taking a decision without bad conscience was difficult. According to O3 consciousness should be the first step:

> *O3: "I think it's got something to do with – as far as citizens are concerned – it has something do to with consciousness of the choices they make before they change them."*

The occupational therapists said that the way for the citizens to realize what and how much they ate should be by asking about their everyday life. O2 gives an example:

> *O2: "I can see that when I ask them about their diet, they say but I don't eat anything, and they turn up and have a BMI of 49. But I don't eat anything [.......]. And you get the urge to say: 'How's that?' and you don't of course but you get the urge to say well now, please listen carefully, what exactly is that's happening?.... Well, then you hear them say: 'Well, I love rice'. Well okay then [....] Well and in that way, you start to get the true picture. So, I also think there's lots of things like that; asking and narrowing it down with the different things in everyday life."*

The participants connected consciousness to the patterns surrounding food. O3 pointed at the shopping pattern, while C3 pointed at the eating pattern and explained that her eating patterns was unsuitable because she ate in front of the TV, but she didn't know how to change it. C1 suggested using a sort of diary to write down what happened:

> *C1: "...get some kind of form you can use at home so you can write it down there. In other words, I become aware of when I do something. And perhaps you do it simply by writing it down, on an ongoing basis."*

The citizens also connected consciousness to senses. C1 said that instead of just "eating with the eyes" one should use several senses. The occupational therapists believed that changing the line between either or should be found in the senses like taste, colour and odour. Senses should be used instead of talked about. O2 said:

> *O2: "There is something about the senses that might work. I mean all the stuff about sensing and especially tasting. "*

Physical Activity—Break the Comfort Zone

All the participants agreed that being obese made it unrealistic to follow recommendations from health authorities about spending time being physical active. Nevertheless, all of them found it important to carry out more activities in everyday life by using the strategies small steps and value. The citizens pointed at integrating physical activity with activities done at home instead of going to the fitness centre. C2 explained how she structured doing her laundry to get more physical activities:

> *C2: "It's because we live on the first floor. I've organised it so that when I fold clothes, I fold piles with tops, piles with socks and piles with trousers, etc. Then I carry each pile up. That way I don't carry everything in one go. Before, I would put every pile in a single basket and carry the whole lot up."*

O5 said that instead of giving a lecture about recommendations they should talk about all the things they already do at home, like vacuuming or gardening. C1 stated that understanding physical activity as home activities made it more manageable. However, doing things at home did not make up for the lack of physical activity in the long run. The occupational therapists especially emphasised the importance of leaving one's comfort zone. O2 explained that it is important to start with small steps and then to build on the process:

> *O2: "I completely agree that they need to start on a small scale and build things up from there, so that they are not frightened off. But at the same time, making sure they are not in their comfort zone all the time. Otherwise they will go back to doing what they usually do."*

Crossing new lines, small victories was experienced. O1 recommended bringing the citizens to sports clubs to overcome practical barriers like going to the dressing room, overcoming the feeling that your heart is beating too quickly and to get introduced to different sports. This gave the citizens the opportunity to find value with physical activity. Values were highlighted in both RC groups. O5 explained that the value could be both physical, psychological and social but the point was to make the citizens realize there were different possibilities with physical activity. O2 suggested using narratives:

> *O2: "....what things did you do when you were young? And what did you do during your active adult life? Well now, three years ago myself and my husband would go dancing and we don't do that anymore. Well then, why don't you start that again?"*

Social Relations—Stand Strong Together

The strategies that were emphasised were self-confidence and common ground. Both RC groups divided social relations into two groups; a primary group, which was families and a secondary group, which was friends, peers and health professionals. The primary social relations are more complex than the secondary group. Peers seemed important because of the possibilities of including new activities in everyday life and by exchanging experiences. For the citizens, professional advice was stated as essential. C1 wanted advice when starting something new or felt physical pain and suggested Facebook to get prolonged advice. The occupational therapists used Facebook but seemed sceptical about a prolonged advice period because they pointed out the importance by learning to handle changes and stand strong alone. As stated, the primary group's social relations are more complex because changes here might affect the whole family. O6 puts it like this:

> *O6: "You must never underestimate how often it can create major conflicts if you go in and set up some goals or create major changes in a family structure."*

According to O5, the citizens should handle these potential conflicts as they should decide what changes are necessary to reach their goals. It could be major changes, for example divorce or minor changes, for example, cooking food differently. O2 said that taking the power boosts self-confidence:

> *O2: "You can certainly involve close family members in one way or another but for some people being able themselves to come home and say 'You know what? We can do things this way' – it's a real boost. So, they themselves reclaim power and so you can say that it isn't us who have the power."*

The most important thing for C1 was to include her partner in the program to find common ground. She wanted him to understand how her overweight made her feel physically and psychologically deprived. She explained how she had experienced that her partner opposed her project if he did not understand it or did not find the changes important. C3 found it difficult to integrate a partner but very important for avoiding a conflict. She worried how life could be if they should eat different food or even eat separately at different times or places.

Habits—Focus on Possibilities Instead of Bad Habits

Habits seemed essential with strategies turning to resources and action. The citizens first reaction on this subject were bad habits. C1 simply said:

> *C1**:** "Well now, I also quickly think bad habits. And I think it's slightly because the thing that I wrestle the most with, is bad habits."*

The occupational therapists found working with bad habits important because this "*fight against bad habits*" was attractional and led to negative feelings about their ability to change. O6 used a metaphor as a backpack filled with good and bad experiences, but the only thing in focus were the bad experiences.

> *O3: "But because they have completely succumbed to "I'm no good for anything. I can't do anything, and I gain weight every time I drive past the bakery!"*

Both RC groups highlighted the need to change these feelings to achieve positive attitude and success. Overall, the occupational therapists expressed the importance of using conversations to find resources there could bridge to habit changes, while the citizens focused on carrying out activities. The OTs used positive thinking to break the vicious circles, dreams to understand feelings and resources from earlier successful attempts to change habits. Talking about feelings and resources was done to show how to transfer these actions to the next action. O2 explained:

> *O2: "Is there a way you can find calmness in some other way rather than eating four Victoria sponge cakes? I get to grips with the feelings and find out what it is that you get when you carry out this action even when you don't want to do it because it's you who carries out the action and you do it because you get something out of it. Well okay. It gives me calmness, or it gives me pleasure or it gives me something or other. It comforts me. Okay, can you call someone and get comfort that way instead of...."*

The citizens agreed that feelings and habits were connected because they often felt sorry for themselves. However, they all stated that carrying out activities was the way to achieve success. C2 said that anything is better than the couch and even carrying out minor activities gives you energy to move on. C3 followed this by explaining how activities can lead to positive thinking:

> *C3: (Smiling) "That's precisely how it works. And then they gradually realise: 'God. I bloody well have some backbone...."*

Balancing Everyday Life—Handling Life's Bumps

Weight loss was understood as a never-ending process incorporated into a changeable life with bumps along the way. This should be handled with the strategies of finding meaning and including variation throughout everyday life. Bumps were explained as multiple situations such as starting to gain weight again, having an argument with a friend, divorce or being fired. Often, the way this was handled was by eating or going back to the couch. The central way to change this is to find meaning and incorporate it into everyday life:

> *O4: "The phrase that pops into my head is actually meaningful everyday life. That it should be meaningful for the individual person to make these changes and carry out these initiatives. Not just do them. But that they should have meaning and build further on them."*

Meaning was experienced differently by C1 and C3. C1 found weight loss to be meaningful because she was in a place where she had to lose weight to do the things she wanted to do. Conversely, C3 had accepted her weight, and was focusing on walking long distances because she loved doing it. She explained the importance of being adaptable in the process:

> C3: "*... you must be very open to change, and I have to say that's the first thing I have learned after having walked on the pilgrimage. It helps that changes have happened and at last I could be part of this. And it was a long time before I finally understood that you have to be willing to change."*

Even though C1 found weight loss meaningful in her life, she wanted her activities during the day to have different meanings. She knew this could be difficult:

> *C1: "And that's something I'm working on, sometimes you have to leave off thinking I'm doing this because I have to maintain my weight, or I have to lose weight. I take the dog for a walk simply because I think walking the dog is really enjoyable."*

This quote indicates that being open to change was linked with variation in everyday life. Achieving variation and finding meaning was understood to be a difficult process which could be supported by structuring the days for a period. The occupational therapists thought that a flexible structure could be part of a weight loss program, but having too much structure is the same as overly focusing on diet again:

> *O2: "Well, I believe that structure can provide meaning. But you can also have too much structure, if you can put it that way. So, you become a slave to structure. You're helpless without it. No. Now maybe it's too...... well that is, you can easily have a structure from the beginning, where you say okay for the first three weeks, since I want to try to do things this way but in my world, you need to have it as a learning experience. Okay. It worked for me or it didn't work for me. So, in terms of structure for structure's sake, I only have a little remaining, relating to diet."*

DISCUSSION

The aim of this present study was to obtain a description of strategies related to the five components and how they could support an occupational weight loss rehabilitation program. The participants found it feasible to work with all five components connecting several strategies to them: For diet, the strategies were senses and consciousness, for physical activities, values and small steps, for social relations, self-confidence and common ground, for habits, resources and actions and for balancing everyday life, meaningfulness and variation. In the following the strategies will be discussed and specified.

Diet—Find the Line Between Either-Or

The participants found that strict diets were unsustainable as it made the citizens feel that they were either trying to lose weight or not. Therefore, it was pointed out that prohibition and registration of what to eat should be avoided when changing eating behaviours. Instead, they focused on awareness related to activities and senses surrounding the food. This invites to a more holistic approach understood as involving both the person wanting to change and activities (10).

More specific the occupational therapists connected the person and the activity of eating by focusing on the senses. They highlighted that they met citizens who often ate without being aware about what they ate or how it tasted. To enable the citizens to stick with a diet conductive with weight loss the occupational therapists believed a strategy in weight loss programs should be encouraging awareness of the specific activities of eating by the utilisation of the sense such as taste, smell, texture, colours, and sound. This strategy is in line with a successful non-diet program called "Health at every size" valuing eating by empowering citizens to eat based on hunger, nutritional needs and pleasure instead of regulations. In this programs the importance of nutrition topics are addressed for weight loss (21). This is an important example of how the strategies from an occupational therapy perspective should be connected to knowledge from other professionals about nutrition in a transdisciplinary collaboration.

However, according to the participants the activity of eating should not only be connected to the person and the senses but also to an understanding of the patterns of activities related to eating both before, during and after, e.g., a shopping pattern or the pattern of watching TV during eating. Patterns are seen as a regular way of acting or doing something and therefore an activity pattern could be understood as activities performed during a day, a month, a year or a life (22). Activities during everyday life influence each other in a dynamic system like every time I watch TV, I eat chocolate. Therefore, to understand the patterns we suggest that citizens wanting to lose weight should write down what they do in relation to the activity of eating as suggested by one of the citizens in this study.

Physical Activity—Break the Comfort Zone

The overall goal with this component according to the participants is to support citizens with obesity integrating more physical activity in everyday life. The literature describes physical activity as an important component for losing weight and recommendations vary from 20 to 30 min five times a week, to 1 h every day (23). These recommendations have been criticised for not being feasible because of physical limitations caused by obesity (24). The same understanding was seen from the participants as they meant that these recommendations were unrealistic. They pointed at two strategies for integrating more physical activity: taking small steps and finding a way around individual values.

The Danish National Board of Health recommend implementing small steps in any weight loss program (25). The occupational therapists in our study found this recommendation useful, especially in relation to changing physical activity. Small steps could be understood as part of an activity analysis with the purpose of understanding tasks and environment related to physical activities (26). This analysis should result in finding the right level to start and then building opon this knowledge. This strategy was explained by our participants as they recommended increasing physical activities in the home environment, by extending activities which were already implemented in everyday life.

However, to implement sustainable physical activities in everyday life the participants pointed at the importance of values. Focusing on values are in line with a study from Toft et al. (27) describing individuals need to find the way around physical activities based on values and possibilities instead of "drifting along with others' choices of living" (27). Values are individual and need to be developed though discussions and experiences (27). To support the discussion the citizens need to be aware of earlier experiences with physical activities like suggested by one of the participants in this study. This could be done by telling the story of physical activities and its value throughout a lifetime. This method has been developed by Clark et al. and is named "activity—story—telling" (28). By combining "activity—story-telling" with experiences though doing physical activities in e.g., the municipality setting, the telling could be turned to "activity—story—making." Combining the telling with experiences could then turn to "activity story making" with new perspectives on values and meaning and might then be transformed to a future story including physical activities (28).

Social Relations—Stand Strong Together

It has been pointed out that group-based weight loss programs are more effective than individual programs because of the relationships between participants, peers and health professionals (29). In our results, these social relations are called secondary relations and seems easier to include compared with primary relations. The primary relations were understood as complex but interestingly, there seemed to be a discrepancy in how to handle this complexity. The occupational therapists highlighted the importance of standing strong to achieve confidence, while citizens found it important to integrate the changes with the nearest network. Learning to stand strong by working with self-confidence and self-efficacy could be done through behavioural therapy, which is recommended in weight loss rehabilitation programs (30). This perspective is related to an individual approach, where every person has the opportunity to fix the problem by themselves (11).

The citizens perspective showed that the social relations need to go beyond support. Family members or close friends should do things together with common value and meaning in the activities they engage in during a weight loss transition. Finding common value and meaning in activities could be explained as co-activities describing activities done together more than one person with shared physicality, emotionality and intentionality (31). To implement this and support sustainability family and friends need to be seen as an important part of a weight loss process because citizens are embedded in and influenced by the social context of their everyday life (11).

Changing Habits—Focus on Possibilities Instead of Bad Habits

The participants talked about bad habits pointing out that the negative things in their life influenced their belief in achieve weight loss. The strategies recommended by the participants were focusing on possibility through their resources and by doing activities. This is in line with the thoughts from Dewey about learning-by-doing. According to Dewey, the connection between one's activities and the consequences becomes, with experience, embodied within the person as habits. The habits will be deeply rooted by doing the activity related to the habit (32). Habits are complex because they contain several levels. Gardner (33) distinguish between (automatic) initiation and (conscious) performance of behaviour and suggests that one activity will include both, e.g., going to the gym might be a

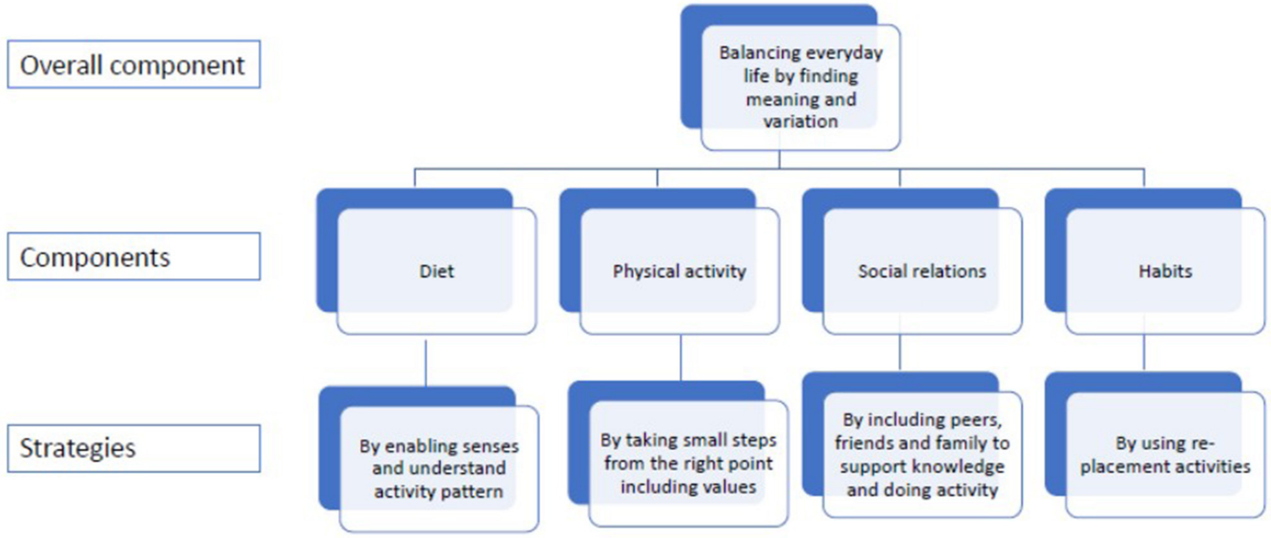

FIGURE 1 | The relations between components and strategies.

conscious decision, while exercising at the gym and showering afterwards might be an automatic action (33). Habits are by this understanding operating below conscious and are triggered by environmental cues. Implementation intervention has been suggested as one way to develop new habits (34). Implementation intervention could be described as re-placements-activity and has been shown to be successful in weight loss maintenance (14, 35).

We thereby suggest that replacements-activities should be part of the strategy of using the citizens resources and activities to understand and navigate in the complexity of habits.

Balancing Everyday Life—Handling Life's Bumps

Weight loss and weight loss sustainability are often seen as two different phases, with the sustainability phase understood as an extended care model (7). One way of going through these phases is by structuring everyday life by doing the same activities at the same time almost everyday day (14, 15). This is extended in this study by using the word "a flexible structure" including words like variation and meaning indicating an integration of the two phases. A similar approach is recommended by Greaved et al. (36) who suggested that phycological strategies like motivation and self-esteem should be included in both weight loss and weight loss sustainability. The participants in our study wanted weight loss to be part of everyday life, however not all activities should be related to weight loss. The activities related to weight loss should be part of a variated life filled with activities having other meanings and purposes. However, participating in for example physical activities could change meaning along the way, like the story from the citizens about how taking a walk could change meaning from weight loss to experiencing the nature.

For the citizens to find balance and understand the meaning and variation the activities in everyday life need to be in line with the person's resources of time, energy and ability (37). We suggest that the citizens need to identify barriers and opportunities to implement changes in line with their specific circumstances in life. Identifying barriers and opportunity related to activities could be addressed in all components presented her; diet, physical activities, social activities, and habits. We therefore recommend that balancing everyday life should be an overall component that need to be reached through the other four components and their strategies (**Figure 1**).

Limitation of the Study

A limitation in the study was the number of citizens which might have been influenced by two issues. The first issue being that the study was conducted at the university as it might be a barrier for some people who are not familiar with the higher education system and its institutions. The second issue was the fact that we did not use snowball principles as we had done when searching for the occupational therapists. However, as this study builds on our previously study with 34 individual interviews with citizens, we find this work to be valid. All the participants were women and even though knowledge from our previous study were found from both men and women the fact that only women discussed strategies might have influenced the results.

In relation to the participants in the RC it is a limitation that only 1 citizen, 2 occupational therapists and 1 researcher participated in all four meetings. However, to overcome this limitation every meeting started with a resume and a discussion based on the previous meeting to obtain the perspectives from the once who had not been represented in the previous meeting.

The fact that we had to conduct two Zoom meetings because of COVIDE-19 might be a limitation too. Conducting workshops online is challenging and even though we used discussion rooms provided by Zoom, the researchers' role became more like an interviewer rather than participants in the discussion. Despite this, we still describe this study as RC methodology because we met four times and the two first was done face-to-face indicating that the participants knew the procedure for RC methodology.

CONCLUSION

Strategies assisting citizens with obesity to embrace to the five components of a holistic and sustainable weight loss program, should include utilizing the senses—such as taste, smell, texture and vision (colour)—when preparing and enjoying a meal; to be conscious of the patterns of activities surrounding the meal; to take one step at a time, not being overwhelmed; to find value in activities; to build self-confidence together with others and find common ground through participating in activity with family and friends and find re-placement activities. All of these strategies are related to everyday activities and participations, and we therefore suggest that the component of balancing everyday life through variation and meaning should be an overall component to provide encouraging support in day-to-day activities to stay healthy and reach weight loss goals.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CJ-W and JRC designed the study and wrote the first draft. CJ-W, KL, and SS were involved in the data analysis. All authors were involved in interpretation of the findings, involved in the drafting the manuscript, read and revised subsequent drafts, and approved the final manuscript.

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A Study of Environmental Factors in Low Vision Rehabilitation

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Healthcare has the past decades shifted from a narrow medical perspective to a more holistic, biopsychosocial perspective. Disability understood as a contextual condition constituted by the relation of the individual to their social and physical context. The disability model of the International Classification of Functions (ICF) contextualizes activity, participation, body functions and structure by including environmental and personal factors. However, illustrated by the consideration of the environmental factors as a neutral dimension, the dynamic interrelation of the individual parts of the system is rather unchartered. In 2017–2019, a lighting assessment was developed and tested on 60 participants in low vision rehabilitation. An action research project accompanied the pilot study from 2018. Ethnographic participatory observations of the low vision consultants in 15 consultations, semi-structured interviews, and a document analysis of the project material of the pilot project has been analyzed using the theoretical framework of science and technology studies. Mapping the physical environment showed a range of factors from spatial organization to luminaires and light bulbs. Moreover, in relation to specific activities, relevant factors were identified and assessed, and in the intervention adjusted to relevant personal and social factors. Identifying overlapping personal, environmental, and professional spheres illustrates the complexity of practicing rehabilitation in people's everyday lives. Acknowledging and coordinating different versions of lighting enabled low vision consultants to work across these spheres relationally. ICF was embedded in the practice of low vision consultants as a frame of reference, however, implementing this framework occurred through an assemblage of tools from different fields. The focus on lighting as an active element in low vision rehabilitation demonstrated a way to work across the personal and environmental to reduce the gap that caused disability. In everyday life, the physical environment was pivotal in the person–environment relationship and in enabling or disabling the individual. However, the physical environment was also key to the rehabilitation process, facilitating the individual's learning and change processes and reconfiguring their understanding and use of the environment. Consequently, the physical environment was not a neutral background to the other factors but rather enabling the rehabilitation and recovery processes.

Keywords: physical environment factor, holistic approach, low vision rehabilitation, lighting assessment and intervention, interdisciplinary collaboration

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INTRODUCTION

The theory and practice of rehabilitation as a field are continuously developing. The introduction of the International Classification of Functioning, Disabilities, and Health [ICF, (1)] in 2001 illustrated a shift from understanding health from a medical model perspective to a biopsychosocial model. "A holistic approach to patient care" (2) comprised a shift from understanding disability as a condition of the individual to a condition of the individual situated in a specific social and physical context, associated with new views and valuation of human nature. By placing the individual at the center, expertise has changed from being solely a professional and medical matter to rehabilitation being acknowledged as a collaborative process occurring within the lived life of the patient and bringing their perspectives and expertise into play. Rehabilitation is conducted as a joint problem-solving process in which identification, investigation, goal setting, implementation, and assessment focus on hope, coping, positive self-perception, and the individual's perception of a meaningful everyday life to support "the mastery, learning, and change processes that characterize the work of rehabilitation" (3). The individual's process is known in the field of psychology as recovery and supports the individual in becoming more self-reliant, returning to working life, or living with a disability or impairment. Departing from the belief that all people have the potential for change and development, the recovery-based approach does not focus on the medical understanding of the patient as a passively disabled individual but rather the universal aspect of facing and coping with the situation to change and develop (4). The notion of holism is present in the new paradigm of rehabilitation in several ways, including the understanding of a *whole body* where conditions are related to both body functions and structures (1); the individual being situated in a *social and physical context* as part of the contextual factors in the ICF (2); and that the *rehabilitation process* is holistic regarding goals, duration, and results (5).

However, the contextual factors have not been adequately conceptualized and have consequently been difficult to measure (6) and operationalize in practice (7). Furthermore, meaningful application of the environmental factor component has been elusive. Hence, the environmental factors of ICF include the "physical, social, and attitudinal" environment, the physical seems to be absent or less implemented in the classification system. It is not mentioned in the three levels of functioning and in the qualifiers, it is reduced to standardized environment: A test setting or an environment "with uniform impact," or "with precisely defined parameters based on extensive scientific research." A generalized approach introduced to "neutralize the varying impact of different environments on the ability of the individual." The interaction between a health condition and an environment has in ICF been interpreted as the effect of one on the other, while the interactive joint effect cannot be predicted from the sum of the individual effects (6). The version of holism embedded in the classification of functions still largely represents a medical understanding, a monistic materialistic view "where a whole is described as the sum of its parts" (8). Quantitatively assessed, reduced, and biomedically described parts, illustrated by the ICF's description of psychology as "functions of the brain," exclude the interrelation between the body and psychological functions. Seen in this manner, disability or disease are understood in relation to a concept of normality, which falls short when addressing more complex or highly individualized psychological phenomena as Alzheimer's, anxiety, or chronic pain syndrome. The hierarchical system of codes reduces the complexity of the dynamic relationship between the individual and the environment, consequently limiting the holistic biopsychosocial perspective. To grasp the human–environment interaction holistically, Solli and DaSilvia argue that we need to acknowledge multiple spheres of reality (ibid.). The health impact of the environment, by increasing the experience of health or decreasing the experience of disability, is embedded in tacit knowledge more or less hidden from the traditional ICF perception of knowledge, why acknowledging health not only as a product of human function but also human experience would offer "a more inclusive, comprehensive, and holistic environmental factors component" (7).

Disabling and enabling environments have been a focus of universal design (UD) for the past 25 years. Parallel to rehabilitation, UD evolved from accessible design with special solutions for special needs to focus on abilities and inclusion from the mid-1980s onward. UD embodies a relational understanding of disability as a complex interaction between the individual and the social, cultural, and physical environment (9). Embracing the human experience and condition of living with disability, the relational gap model conceptualizes a more comprehensive understanding of disability as "emerging from the interaction between individuals and their social-material environments" and integrates knowledge from the social sciences, medicine, and the humanities (10). The gap model focuses on the interaction between the individual's abilities and the environmental demands in a specific situation, where the gap between the two creates the disability. A gap is prevented or handled by strengthening the individual's abilities and/or changing the environmental demands.

By embracing the role of the physical environment in enabling people with disabilities, UD holds a transactional process perspective acknowledging the interaction of the individual and their environment, including the wide variety of individual capacities that change over time (11). The holistic approach in UD has included the diversity of human interactions with the environment "fostering a more holistic understanding of the built environment" (12). Universalism is understood as "what is held in common by people," not as a normative body, but "a universal human ethic that is simultaneously responsive to the specific, situated, nature of human subjectivities" (13). UD is not limited to buildings but rather includes, according to the UN Convention on the Rights of Persons with Disabilities, products, environments, programs, and services usable by people of different ages and impairments (14).

Acknowledging the different fields of knowledge and the limits of each professional field, UD emphasizes interdisciplinary collaboration. Rehabilitation professionals and user representatives provide important knowledge of the human diversity informing UD (9) and UD can facilitate and support rehabilitation with designs that are flexible, equitable, adjustable, and intuitive to use (13).

Another aspect adding to the complexity of rehabilitative practices, beyond the holistic and interdisciplinary, is the interaction between theory and practice. This interdependent relationship has been reinforced over the past decades as the practice becomes more professionalized and research aims to be more practice-based. However, the double move toward more holistic and interdisciplinary practice and the persistent silos predominating in research constitutes a paradox of the evidence-based practice. Environmental factors and especially the physical environment remain unknown territory for many rehabilitation professionals. In a Danish textbook on rehabilitation (15), the physical environment is represented by the different types of environments (home, neighborhood, workplace, and local environment) and by underlining accessibility and the use of assistive technology. "Very specific environmental factors can be taken into account and tailored specifically to the individual citizen's situation" (ibid.); however, these factors or their role in the rehabilitation are not further explained. Consequently, scholars call for knowledge concerning the "meaningful involvement" of the patient's knowledge of their life and preferences, their environments, and the mutual relationship between people and their environments (3).

Nevertheless, how do these paradigmatic shifts look in practice and how are holistic and interactional frameworks understood and enacted? Moreover, is it possible to bridge the fields of rehabilitation and UD to justify a study of the role of the physical environment?

Within the changing landscape of rehabilitation, innovative approaches have been mobilized, however the valuable practice knowledge associated to these efforts is often omitted in scientific representation and dissemination. The tacit practice knowledge includes both the translation of generic guidelines to specific settings and situations and the translation from specific situational conditions or considerations into explicit knowledge (16, 17). Because these knowledge translations are not made explicit, gaps in and resources for creating evidence and barriers in applying the evidence in practice arise (18). The application of knowledge and how it is accumulated differs by time, place, and culture, and a given profession has its own "disciplinary perspectives" that affect the understanding of problems and their solutions (13). Randomized controlled trials, which work well for well-defined groups of patients undergoing a well-known and described treatment under highly controlled conditions, are seldom available and not the ideal research design to study rehabilitation practice, which involves more complex and dynamically changing conditions in the patient group, the treatment, and the conditions (19). To relate to the lived experience of their clients "...much more information (than the diagnosis) is needed to understand the world in which people with visual impairment inhabit" (20). Meta-analyses, technological analyses, practice guides, and databases would be more appropriate to operationalize the current knowledge of rehabilitation practices, and richer descriptions and explorations of treatments, subjects, and physical environments would further improve rehabilitation practices (18).

The WHO states that the ICF "acts as a catalyst for change management as educators start modeling a holistic approach to patient care" (2). However, how can we move beyond the "neutralized environment" to recognize and work with the enabling and disabling aspects of our environments? How can this knowledge be operationalized in rehabilitative practice?

The Context of Low Vision Rehabilitation Practice in Denmark

Lighting has been a key element of low vision rehabilitation for decades and innovations in the field of low vision and lighting have encompassed new lighting technologies and supportive aids; however, lighting assessments have traditionally been based on specifications tied to specific diagnoses, much in line with the medical model. Moreover, lighting interventions have been conducted in clinical settings and involved visual assessments combined with adjustments of the overall lighting to find the best lighting level for an individual positioned at a specific distance from a vision chart. Home assessments and smaller lighting interventions have been conducted but they have been unstructured, and the effects have been largely unknown. The small number of research studies on home lighting assessments in low vision rehabilitation that have been disseminated in the scientific literature include near-task lighting (21), lighting prescriptions (22), interventions with improved lighting (23), or the performance of and preference for different lighting levels (24). These studies have been limited to specific variables such as specifically pre-selected lighting or lighting levels, activities, spaces, or diagnostics, and guided by expert knowledge. Consequently, qualitative research of a "multifaceted approach to lighting intervention" that explores the experience of lighting environments has been needed (21).

In Denmark, rehabilitation has been a political focus and included in the Danish Executive Order on Social Services Act since 1998, and in 2015, a revision stated that rehabilitative initiatives for citizens with impaired functioning should be "organized and performed in a holistic and interdisciplinary manner" (25). Responding to this call, the Center for special education (CSU), Slagelse, initiated a pilot project entitled "Better Light, Better Living" (BLBL) in 2017 to test and assess a methodology and approach for a systematic lighting assessment and intervention. From 2017–2019, BLBL was tested with 60 visually impaired participants in three stages: a baseline assessment of lighting and activities in the home, lighting intervention in the lab, and a follow-up visit or phone call (26).

From 2018 to 2022, an action research project has accompanied BLBL, framing the pilot project as a case for investigating low vision rehabilitation and, particularly, the tacit embodied and embedded knowledge within the practice. The research project has involved sub-studies exploring the different types of contextual knowledge, including embodied knowledge of the individual, knowledge embedded in participants' routines and their interactions with environments, and knowledge embedded in the practices of the low vision consultants (16). The situated knowledge was identified, translated, and coordinated throughout the three stages regarding lighting in specific situations or activities, "linking the individual impairment and visual function to the physical and social context" (27). The light formed a boundary object of the physical environment, an embodied experience, and a shared social parameter, relational in all three matters (16). Within the BLBL approach, lighting design and implementation covered a wide range of the physical environment, from the geographically determined dynamic seasonal changes of daylight (17) to different arrangements, luminaires, and light bulbs. Even though the physical environment has played a key role in each of these analyses, the research objectives have been related to a rehabilitation process, recovery process, or co-design process. What can we learn about the environmental factors from a case like this, and how can it support the holistic effort in rehabilitation?

THEORETICAL FRAMEWORK

Exploring the role of the environment in professional rehabilitation practice has, due to the interdisciplinary character of the action research project, been informed by fields beyond traditional health research. Drawing on the social constructivist approach of science and technology studies (STS), and actor-network theory (ANT), the human-environment interaction is emphasized as the core of these approaches' acknowledgment of socio-material interaction and actor-networks as wholes constituted by human and non-human actors (28). These studies do not aim to provide deterministic causal explanations of how science or technology influence society but rather to "make available resources for thinking systematically about processes of sense-making... reintegrated into explanatory projects that conform more accurately to the lived experience of modern societies" [(29), p. 38]. In this process, there "is no social order … [but] endless attempts at ordering" (30). Material artifacts, humans, and conventions are mutually interdependent in effecting and affecting one another. Unlike the reductionism of the medical approach, this could cause issues of the overwhelming proportions of holism (29). Therefore, mapping these actor-networks requires attention to the relevant actions taken and identifying and following the relevant actors, which allows the study of complex and dynamic relations. In her study of atherosclerosis and the different versions of this phenomenon enacted in different practices at a Dutch hospital, Annemarie Mol developed the notion of the "body multiple" (31). This approach acknowledges that different ontologies coexist across professional and personal practices as different versions that, in each of the different settings, are ignored, excluded, acknowledged, included, distributed, or coordinated. These enactments involve entanglements of methodologies, treatment paradigms, and knowledge, but also instruments, representations, blood, flesh, and, not least, how "people live with diseases" (ibid.).

MATERIALS AND METHODS

Ethnographic studies in healthcare can help us illuminate "the organizational and interactional processes through which health care is delivered" (32). BLBL has been studied as an ethnographic, mixed- methods, prospective, and longitudinal designed "in-depth, detailed, holistic case study" (33). The empirical material have included *fieldnotes and visual material* from participatory observation of 15 consultations (8 home visits and 7 lighting lab sessions) following one of the two low vision consultants, a visually impaired participant and his/hers accompanying family member in the home environment or in the facilities of the low vision services; *project documentation* from all 180 consultations (home visits, lighting lab sessions, and follow up with the 60 participants), and *transcriptions and fieldnotes* from a series of semi-structured interviews with the two low vision consultants. The 15 consultations have been considered as sufficient for investigating the role of the environmental factors and its dynamic interactions within the intervention. Sample size calculation or other defined robustness have not been considered.

Observing and identifying the practical knowledge of the professionals included their approach to the participants, their use of the schemes and technologies within the project framework, the involvement of the individual, and the social and physical context. Beyond the work of the low vision consultants, the observations involved the spaces, physical traces of the participants' use of the space, and adjustments or adaptions of spaces or arrangements. Observations also included the dynamics and interrelation of the users, the space, and any material artifacts relevant to the specific activity. As lighting is most often used in "tacit, normally unspoken about ways to make, maintain, and improvise atmospheres of home" (34), observations of the consultants and participants moving around the home environment focused on their interaction with and articulation of the lighting and the environment. The research focus on the role of the physical and social context in the intervention has been informed by architectural anthropology, recognizing the home environment as "part of wider socially situated practices [that] helps us understand the shifting dynamics at play" and located between "the technical, social, and individual, insisting on a holistic understanding" (35). The initial findings of the project have been addressed and discussed in a series of qualitative semi-structured interviews with the two low vision consultants of 1–2 h discussing outcome, measures, intervention design, tacit knowledge, and dissemination. The interviews have been recorded and transcribed.

Thorough descriptions have been drafted from the observations based on field notes, transcriptions, and visual materials. An analytically focused sampling was conducted to identify and describe (a) the active environmental parameters of the intervention and (b) patterns and themes of the interactions and change processes. Finally, a theory-focused concept sampling was conducted to analyze and discuss the relation and fit of these results and the framework of ICF, depicted in **Figure 1**.

The BLBL pilot study was conducted as a quasi-experiment without a control group, where all participants received similar and non-invasive interventions. The comparison of baseline and endline measures was included as a quality assurance of the intervention, and consequently it did not require review, approval, or permissions from Ethics Committees or Institutional Boards. For storage and use of personal information the trial was conducted according to Danish legislation and adhered to requirements of the data monitoring committee. Informed consent was collected from the 60 participants as part of the overall BLBL framework, the participatory observation was announced to and approved by the participants before our visits, and the focus of the observations on the work of the low vision consultants and the overall BLBL project was repeated when we arrived. Personal information of the participants has not been used in the ethnographic research study. Moreover, the framework for the research collaboration with CSU was defined in a legally binding cooperation agreement between our institutions, where dissemination of research results has been shared and reviewed within the project group before disclosure.

As an outsider to the health profession, I lack the professional understanding of how health is practiced and privileged focus on the process of recovery or rehabilitation. Conversely, as an architectural researcher equipped with anthropological and socio-constructivist frameworks, the attention has been paid to the role of the physical context, however entangled and situated in the everyday lives of the participants and the professional practice of the low vision consultants: As a way for my position to contextualize the 'usual suspect', the built environment, in social and professional overlapping spheres. One of the gifts of qualitative empirical studies, as a case study or an innovative project, is that it can enable us to recognize the different spheres, and how they interact and affect one another. Making the know-how from the "other" discipline explicit, here discussing the ICF framework in a metatheoretical matter within a rehabilitation journal, is also perhaps an outsider-position, however inviting for a joint exploration of the field of rehabilitation.

FINDINGS

Where the overall objective of the low vision consultants in BLBL was to improve the participants' quality of life, the interest in this paper has been to identify interactions within the processes and, more specifically, the role of the environmental factors.

Identifying Contextual Factors and Actors of the Physical Environment

Identifying the relevant environmental factors to BLBL starts with the seasonal changes. Based on their prior practice knowledge, the consultants knew that the issues regarding lighting primarily arose in the dark winter months, and why the pilot study was conducted in this period of the year. Being located in the northern hemisphere, these seasonal conditions affect our everyday lives and several participants mentioned natural lighting and daylight as important for their functioning (17); many described individual preferences regarding natural lighting, whether daylight, overcast, sunlight, or twilight (27). Furthermore, at a *building scale*, the typology, structure, and orientation of the building as well as the dimensions, size, and position of windows in the façade influenced the amount of daylight present. Additionally, obstacles outside the building, the floor number in a multi-story building, and the spatial distribution of the apartment affected the distribution and amount of daylight available. The overall composition, dimensions, proportions, and organization of *spaces* affected each specific space. Ceiling height and depth affect the experience or atmosphere of a space, creating different characteristics (small, large, intimate, formal, etc.), while interconnected spaces, thresholds and openings, and the fixed interior provide coherence or contrast. At the next level, were material artifacts such as furniture of different shapes, materials, and colors and the amount and position of furniture, leaving more or less free floor space to move in. Some living rooms were equipped with sofa arrangements in dark leather, combined with long, dark curtains, while other living rooms were sparsely furnished and kept in pale colors. Different wall paints, wallpapers, panels, different finishes, and amounts of pictures and other artifacts on the walls affected how light was reflected from the surfaces. Likewise, the color and finish of the floor and ceiling, curtains, and other types of stationary or flexible shading, overhang, awning, film, or blinds also affected the environmental context.

The main lighting parameters can be divided into *light space*, *luminaire*, and *light bulb*. As this was the focal point of BLBL, the aspects within these categories were thoroughly explored and mediated throughout the stages of the program. *Light space* can be described as the illuminated space established in a darker surrounding: the overall space conditioned by size, form/distribution, and orientation/direction, comprised of daylight or artificial light, direct or indirect light, and its interplay with shadow. Different light spaces can be arranged to integrate or create isolated isles of light and can be coordinating or contrasting if there is a large difference in luminance. The *luminaire*, or what we know colloquially as a lamp or lighting device, includes the electrical device, the fixture that holds a light bulb, diode, or tube, and often a system of shades, screens, and/or diffusers. A range of different shapes, sizes, and proportions were represented in the homes, differences that influenced how the light was emitted and illuminated the close surroundings and surfaces. Consequently, the position and orientation of a luminaire affected the light space, the material of the shade or screen was another important variable of how the light was distributed. A translucent material, such as an opaque or frosted glass lamp, spread the light and made the lamp appear as a luminous object, while a metal shade concentrated the light and directed it and provided more light on the surface of, e.g., a table. Luminaires was represented in many different typologies,

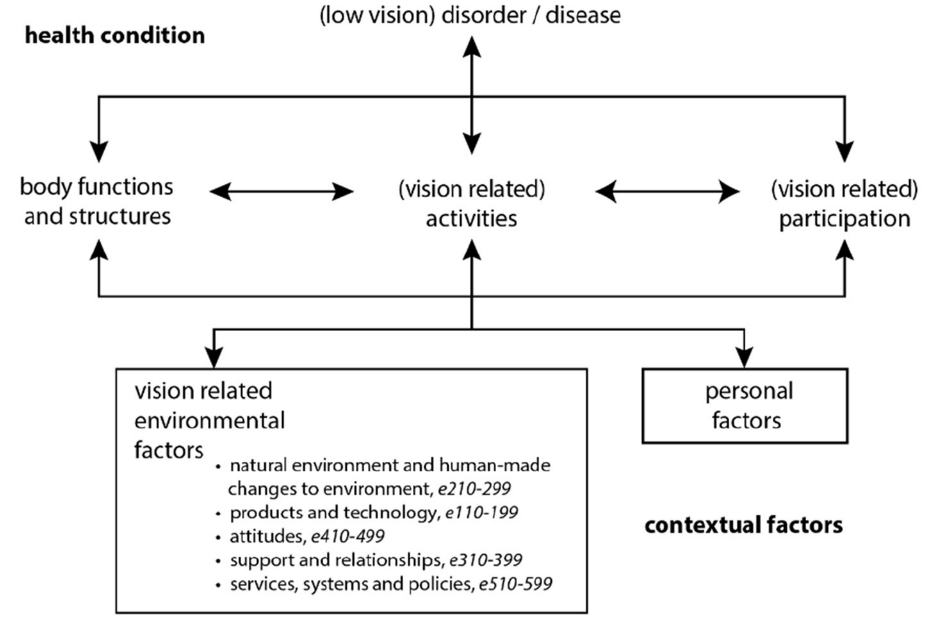

FIGURE 1 | The ICF disability model [(1), p. 9] adapted for low vision rehabilitation, including the classification's further subdivision of environmental factors.

ENVIRONMENT	BUILDING/ SPACE	INTERIOR/ MATERIAL ARTEFACTS	ILLUMINATED SPACE	LAMP	LUMINAIRE
e2255 *e245*	*e155*	*e115*	*e2400-01*	*e115*	*e115*

FIGURE 2 | Mapping of the physical parameters and its corresponding classification codes in ICF.

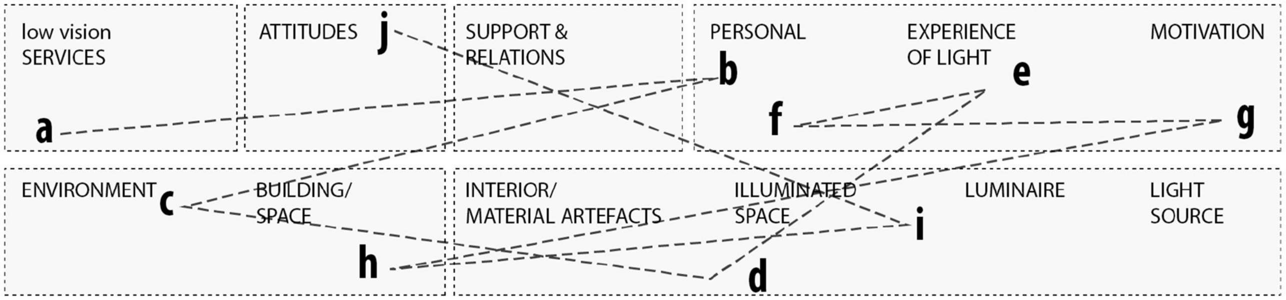

FIGURE 3 | Mapping of the trajectory of the implicit and explicit sequences of the assessment in the home environment placed in relation to extended ICF categories.

styles, and designs from industrial, ceiling-mounted light panels to traditional designs or aesthetic, neatly geometric or organic and sculptural lamps. These was either mounted on the ceiling or wall, standing on a table or on the floor, was either fixed, flexible, or mobile and could be switched on and off by switches on the lamp or wall or by remote control. Finally, the *light bulb* (or diode and tube) was pivotal for the light space, especially the relation of the light source's intensity to the overall luminaire and its close surroundings. Also, the bulbs came in different shapes, size, and lighting technologies, dimmable or fixed, and of different intensity, color temperature, and rendering.

Two spatial categories have been added to the ICF framework for the environmental factors, building/space and illuminated space. Building/space as an intermediate between the environmental (daylight, location, and orientation), and the products and technology of daily use, including interior/ material artifacts. And illuminated space as subcategory to building/space, as an intermediate between the luminaire, light source, and

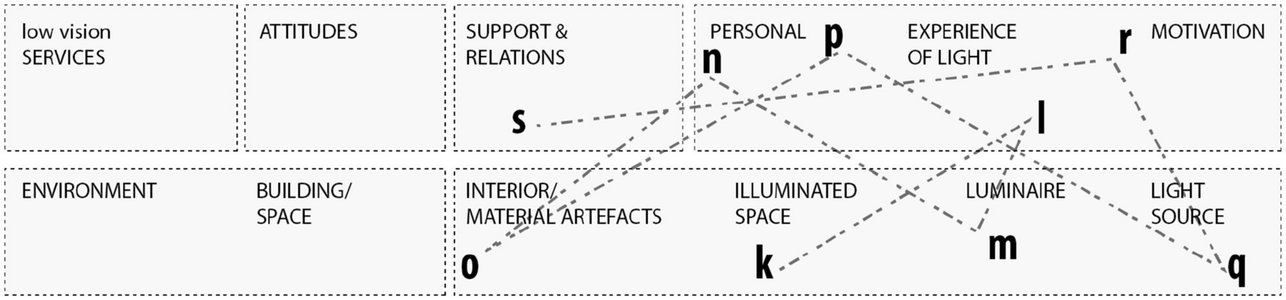

FIGURE 4 | Mapping of the trajectory of the implicit and explicit sequences of the assessment in the lighting lab placed in relation to extended ICF categories.

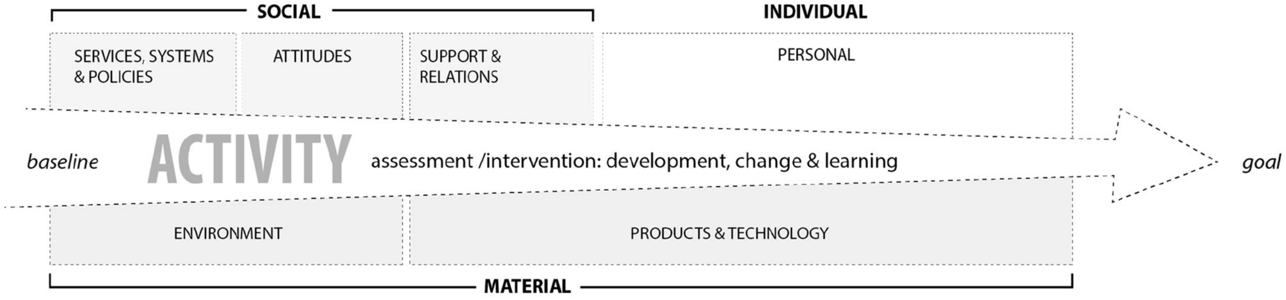

FIGURE 5 | The assessment and intervention with basis in the situated activity work as a trajectory for the change and learning processes across the different parameters, across the social, individual, and material.

the overall physical setting. As seen in **Figure 2**, these physical parameters have corresponding ICF classification codes: seasonal changes (e2255; e245), building scale (e155), and the illuminated space (e2400-01). The interior, lamp, and luminaire share the same code (e115).

The Professional Navigation and Coordination of the Environmental and Personal in the Rehabilitation Process

In the Home Environment

> *When I enter a house, I look around. "Okay"... As soon as I enter, I scan the room for any glare, flicker, large contrasts—how does my eyes adjust. Moreover, the shape and design of the lamps, the light bulbs... This just happen automatically, no matter whether the light is good or bad...*

Typically, the consultant would have some impression and expectations of the specific case before the first visit. This would include prior knowledge from the participant's journal concerning their vision (a), including impairment as well as knowledge of the residential area, and brief knowledge of the situation from an initial phone conversation and a self-reported visual function questionnaire (VFQ39) (b). Furthermore, the subconscious scanning described above would often start before entering the home: Recognizing the building and typology of housing and the close surroundings would form initial impressions and input that constituted a baseline (c). The first impressions of the interior space provided further input of the specific participant's everyday life (d). Because, as stated by one of the consultants: "...then we explore the challenges of the visually impaired individual... because sometimes their issues are far from my initial personal guess." The narrative interview focused the conversation on the personal (e), in which the participant was encouraged to share their experiences with activities where the current lighting condition and their visual impairment were misfit and disabled them. The personal could involve psychological, neurological, spiritual, cognitive, physical, and biological concerns as well as aspects regarding their vision that arose during the conversation such as light sensitivity, eye strain, contrast vision, or issues regarding adaption, color appearance, and the stability or flux of their condition. Furthermore, more practical issues regarding their use of optics and aids such as glasses, magnification, or distancing were discussed. Three activities were selected for further assessment, where the participants specified personal aspects such as handling self-care, preparing or consuming a meal, or hobbies and social aspects such as communicating or socializing (16) (f). Activities were situated in different specific parts of the home environment and concerned specific illuminated spaces. The participants rated their performance of each activity by importance, performance, and satisfaction on the Canadian Occupational Performance Measure (COPM), shifting the focus to motivation (g). The motivational aspects were both internal, related to the individual's hopes, dreams, and aspirations regarding the implications of potentially being able to resume to these activities in general or with less effort, and external, linked to specific social and physical activities. The actual relevance of the social context differed by case, as some family members were more actively involved than others; however, in general, the social context constituted an external motivation.

Subsequently, the assessment continued in the specific physical setting of each activity (h), enabling the participants to get more specific regarding the difficulties and workarounds for handling an activity. These situated conversations often involved narratives of attunements, culturally and socially informed aspects of settings such as wanting to create a specific atmosphere for social occasions like "hyggebelysning" [cozy lighting] for a family dinner or as part of an evening ritual (17). Situating the activity within the interior arrangements, material artifacts, illuminated space, and with the specific luminaires and light bulbs (i), the visual function was assessed by two measures representing a baseline.

With the participant positioned in their activities, the consultants proceeded with the lighting assessment. Often initiated with an implicit scan of the close surroundings: noticing the illuminated space, the distribution and direction of light, the relationship of natural and artificial light, and the relationship of direct light, indirect light, and shadows. The activity further enabled a situated experience of light, shared by the participant, the family member, and the low vision consultant. The walkthrough, demonstrations, and practical performances enabled reflections and discussions as frustrations or comments on their own feelings or performances were shared and discussed. Observing from the position and field of vision of the participant, the consultant could note whether glare, from reflections of the luminaire or a directly visible light source, was an issue, or observe the specific luminaire, its type, shape, material, dimensions, proportions, location, orientation, and mobility, in relation to the participant and the activity. The characteristics of the light source were also assessed, including the type, material, luminance, and relation to the overall luminaire, and again the relation to the participant and activity. Furthermore, the consultant could consider the lighting demands in relation to other activities in the same setting, whether it was appropriate across activities or there was a need for adjustable or different types of lighting. The relevant aspects of this implicit scanning were addressed and discussed with the participants during the assessment.

Beyond the subconscious scanning and positioning to detect potential issues in the home environment and possibilities for improvement in the overall and specific settings, different tools and measures were applied to assess the light (i). Luminance was measured on surfaces with a light-meter or the spectral distribution of wavelengths was measured with a spectrometer. These devices were also used during the dialogue to demonstrate, e.g., the features of an energy-saving compact fluorescent lamp (CFL) or an insufficiently illuminated dining table. The CFL's spectral distribution—illustrated by a range of peaks in the display of the spectrometer—was compared with the more even distribution of natural light or an incandescent bulb or LED. The illumination in a specific location was illustrated by comparing the lux measurement to a measurement in a setting with more sufficient lighting or to the general recommendations for lighting in work environments. The explicit measures of the lighting levels (lux) in the central positions of the settings were recorded on a provisory sketched plan showing the simple spatial layout. Along with photos taken of the different situations, this constituted the documentation of the home environment.

Often conducted as the last element of the first visit, the accompanying family was offered a guided simulation of the visually impaired person's visual experience (j). An application for simulating different diagnostics and conditions enabled the consultants to recreate visual acuity and impairment similar to the individual, and by adding filters to the settings sequentially they could specify and explain the different conditions. In a pair of VR/AR goggles, the family member had the visual condition explained in a virtual reality representing the lighting lab of CSU, followed by an exploration of the home environment in an augmented reality setting situating the visual condition to the specific home environment and lighting condition. Furthermore, the demonstration often inspired engaged conversations between the visually impaired person and the accompanying kin and, thereby, another processual loop linking the individual, social, and environmental.

Figure 3 shows the trajectory of the typical home visit, regarding the distribution and diversity of the relevant actors, that beyond the parameters of the physical environment involved personal and social parameters. In addition to the categories of the ICF classification, the spatial characteristics of the home found in the living spaces and the illuminated space, included both material artifacts (walls, surfaces, furniture) defining the space and human and non-human substances inhabiting it. In these first steps of the assessment, the interaction with the participants focused on the visually impaired person's overall experiences with and use of lighting in their everyday routines, relating this to both their social life in the household and their overall feelings about their impairment.

Lighting Lab and the Clinic

Moving on to the lighting lab, the lighting intervention was framed as a collaborative process between the low vision consultants and the participating visually impaired and his/her company. The lighting intervention was intended to recreate a lighting condition similar to the specific settings from the activities in the home environment. The consultant would have "prepared the stage" before the participants arrived and, with the visually impaired person positioned in the scenario (k), different lighting, lamps, and arrangements could be tested (l). If the low vision consultant considered a different luminaire as part of the solution, an alternative was compared to the original by demonstrating one and then the other (m) with the participant seated in the same position. This allowed the individual to pay attention to nuances of how the two conditions affected their visual perception and ability to perform the activity (n). In this testing phase, different relevant attributes (o) were involved such as food on a plate, crossword puzzles, magazines, or if the activities concerned using appliances or furniture such as the kitchen surface, washbasin, or wardrobe, these were incorporated into the practical testing. Some participants were encouraged to bring own relevant artifacts to the lighting lab. One woman, who had faced difficulties perceiving form and substance in her current lighting, brought samples of clay, as she wanted to test whether a different lighting could help her distinguish different material characteristics (p). Similarly, differences in lighting quality by color or intensity, were tested and compared by introducing different light sources (q). The line of tests was informed by the embodied experience of the participants, managed by the tacit knowledge of the consultant adjusting to the individual's interest and mental or physical energy (r).

Leaving the clinic and the lighting lab, the participants left with a specified lighting prescription for the suggested lighting adjustments for each activity, including printed photos from the home environment where the consultant had outlined the shape, position, and direction of the luminaires or outlined if any of the existing lighting should be moved or removed. These contextualized recommendations eased the involvement of support and relations (s) to implement the recommendations. Both by the participating family or friends, but also personal assistants, electricians, or lighting professionals.

The lines mapped in **Figure 4** represent the sequences of the lighting intervention in the lighting lab. As a continuation of **Figure 3**, the trajectory show that the consultants continuously worked across personal and environmental issues, aligning them to the situated activity.

Relational Understanding of Light

The empirical material of the processes in the BLBL program demonstrates a multifaceted and relational understanding of light. Where the assessment in the home environment facilitated the individual's reflections on their own current performance of daily activities, the intervention focused on the embodied knowledge and new or resumed abilities enabled by the adjusted lighting. Beyond physics, the lighting was related to the specific activity and experienced by the individual through their visual abilities and affected by their hopes and desires, and change could be enacted in the individual by adjusting the social and physical context.

However, in many cases, the changes occurred in all three aspects. It was close to impossible to say what started and what affected which aspect. In some cases, no changes were made to the light but rather to the way the light was used. For others, the family or kin accompanying the visually impaired person gained a better understanding of their issues and were motivated to implement the changes. The problems identified were related to specific activities and visual functions and supported different interpretations and uses of light (16).

The consultants have highlighted the importance of active involvement as one of the main findings of BLBL; rather than just telling people what to do, the assessment and one-on-one testing enabled the participants to take action and make changes:

> *When we started the project, we were not at all aware of the extent of the education or coaching in BLBL. However, it is a great deal, for them to really understand it.…I think that is one of the pivotal differences from our previous practice regarding lighting, that earlier we [as the experts] made the decisions for them, now we enable people to make their own decisions.*

DISCUSSION

Enabling and Disabling Environments

Within the ICF classification, the "physical, social, and attitudinal" environmental factors are recorded and coded individually as facilitators or barriers to human functioning and their effects are assessed by the functioning of "the person overall, to each ICF component, or to performance and capacity" (2). Even though several of the parameters are described in the ICF classification codes, it is often related to isolated variables, as for e155 where design, construction and building products and technology is specified to "entering and exiting" (e1550), "gaining access" (e1551), "wayfinding" (e1552), or "physical safety" (e1553). However, the study expands the understanding of these factors beyond a neutralized environment and shows that these components are interlinked and dynamic: The physical environment has a huge effect on the social and the personal, and in the process of BLBL they are operationalized in relation to one another.

Whiteneck and Dijkers (6) suggest that to operationalize the environmental factors of the ICF, we should abandon the traditional tests and rather ask two questions: First, the level and type of functioning the individual desires and second, whether there are environmental barriers impeding them (nuanced by quality, quantity, or ease). This has more or less been the BLBL approach, embedded in the narrative interview, COPM, and lighting assessment and intervention. The interview was focused on lighting; however, this environmental parameter was operationalized and used as an active part of low vision rehabilitation to support the personal recovery process of the individual participant. In this manner, activity issues and the related lighting problems were aligned with the individual's perception of a meaningful everyday life and focused on the support of the mastery, learning, and change processes at stake (3). The environmental factors and the individual were considered active and dynamic aspects responsive to change (4) and lighting was a key actor in the rehabilitation process that was used to facilitate rehabilitation and change processes for the individual's recovery.

The focus on activity and usability throughout the problem-solving process made the environmental factor of lighting operationalizable, allowing for solutions that fit the principles of universal design (UD): *equitable*, *flexible*, *simple and intuitive use* with *low physical effort* within the required *size and space*, providing *perceptible information* and forecasting the potential *tolerance for error* (12).

Holistic

Both the ICF and UD are models aiming for a more holistic approach to rehabilitation or design. The holistic approach in UD prioritizes the human impact of design decisions (12), the role of the physical environment in transactional processes where the relations and interactions between people and the environment are seen as universal conditions of life (11). This whole comprises complexity in several ways—a wide variety of individual capacities that change over time and a diversity of human interactions with the environment (12). Where scientific or medical knowledge is reductionist by nature, a challenge for the relational and holistic methodological framework is to manage the extent of details. A strategy for not "falling into a mind-numbing holism" (29) is to follow the relevant actors. One of the main contributions to the understanding of holism derived from the action research project is the frontloading of the tacit knowledge implicated by the rehabilitation processes and embedded in personal, environmental, and professional spheres or subnetworks. To follow the change processes within BLBL, the individual or personal, the environmental, and the social/professional aspects, were investigated as relational and dynamic characters. Within a small section of the participants' everyday lives, the BLBL's limited scope of lighting + activity + issues allowed an exploration of their interactions and entanglements as a whole constituted by human and non-human actors (28).

The mapping of the parameters in **Figures 3**, **4** was done with the ICF framework and components in mind. All environmental factors were included in the intervention, however the two intermediate spatial categories introduced in this analysis, building space and illuminated space, encompass the entanglements of environmental factors, but also personal aspects, as motivation and change processes. The activity was the core in both the lighting assessment in the home and the lighting intervention in the lab, and as shown in **Figure 5** this core was surrounded by social, individual, and material. Furthermore, the relational mapping incorporates the temporal and processual scope of the GAP model. The findings show that material artifacts are crucial in order to facilitate and support the rehabilitation and recovery processes. The process of identifying, assessing, and weaving together the components and parameters and the relevant actors across the personal and environmental, is embedded in the professional practices. By supporting changes in the home environment or changes in the participants' approach to and use of their environment, the low vision consultant helped enable the abilities of the visually impaired.

However, complexity is difficult to categorize. Identifying the parameter of "social environment" as an environmental and not a personal factor in the framework is a reduction. The field observations showed that the social context, the family or kin, was entangled with both the personal and the professional as an important aspect of how the lighting was enacted as a personal and social routine (34). Another problematic element of classification is how to consider assistive aids such as a pair of glasses, magnifier, or white cane. In many STS studies, assemblages of human and non-human actors are seen as "hybrids," where an either/or classification would be problematic. In a socio-constructivist framework, all these categories and components are constructed entities that by nature do not encompass hybrids, transitions, or changes.

In other organizational or institutional contexts, new relevant actors will be revealed. When discussing BLBL across the community of low vision consultants, the local management and local political environments highlighted differences. In these contexts, the evidence in the evidence-based practice makes an even larger impact to mobilize moral and economical support for initiating change. In contexts of different professional fields than occupational therapy, the methodological freedom of choice has been a core case of interest. Consequently, the socio-constructivist approach acknowledges the act of balancing the practical expertise of navigation and the structural framework assuring non-discrimination.

Generalizability

> *The definitions used in the ICF have inclusions that provide specifications, synonyms and examples that take into account cultural variation and differences across the life span. It is therefore suitable to be used in different countries and cultures. The ICF can be applied across the entire life span and is suitable for all age-groups (2).*

The very nature of the classification and its codes, one could argue, is to de-contextualize and systematize, and there is consequently a paradox in evidence-based practices, regarding the holistic. One of the challenges lies in the scientific approach: To grasp the role of the environment as part of the participants' everyday lives, we must acknowledge the specific interaction and the very specific environment. The personal and accumulated relationship holds an entanglement of perceptions, values, materialities, and affordances that is completely omitted in a neutralized environment. The importance of a standardized environment was emphasized in relation to the capacity qualifier, which indicated that the environmental factor in this context provides a narrow and mechanical backdrop to a performance or an activity. Similar to the "naked person assessment," it does not acknowledge the social or personal aspects:

> *The Capacity qualifier assumes a "naked person" assessment, that is, the person's capacity without personal assistance or the use of assistive devices. For assessment purposes, this environmental adjustment has to be the same for all persons in all countries to allow for international comparisons. For precision and international comparability, features of the uniform or standard environment can be coded using the Environmental Factors classification (2).*

Assessing interactions and relations within BLBL has enabled an analysis across everyday and professional practices, including the role of the schemes and measures applied in the pilot study. None of the measures related to vision were, in their core structures, related to lighting or the rehabilitation process. The Farnsworth Dichotomous test (D15) and Groffman Visual Tracing Test (GVT) as performance measures represent more scientific and validated schemes developed from the field of ophthalmology and tested over decades. However, they are limited to visual performance and, along with the VFQ-39, these measures represent specific points of time, baselines or endlines, and not the intervening processes. None of the performance measures were specifically developed to assess the impact of lighting or changes in lighting but rather the performance of the participant under the environmental conditions.

The COPM does not directly relate to lighting; however, its focus on activities in combination with the narrative interview and the lighting assessment actively facilitated the process of rehabilitation and recovery. Originally belonging to the fields of psychology, occupational therapy, and lighting theory, these three schemes and methodologies were translated and adjusted to fit the purpose of the pilot study, focusing specifically on the role and use of lighting. Furthermore, they were improved and adjusted within the project as the framework was tested in the individual trajectories of the 60 participants. This can be seen as a classical iterative design process of testing, evaluation, and improvement: How does the framework fit the different needs and processes of the participants and what feels natural to articulate and frame; in what order should the different schemes or questions be introduced? During the conversations with the low vision consultants, it was obvious that, despite the comprehensive design of the COPM and the guidelines for the narrative interview, the application of these schemes differed both due to their application to different types of participants and contexts and the two consultants' different nuances of application. This resembles the complex lived experience of the clients (13, 18–20) and their practices in the recovery process and touches upon issues of rigid schemes not fitting their purposes vs. a lack of structure causing discrimination or incongruities. To acknowledge and accommodate diversity, the framework requires a methodological elasticity or flexibility, while to share and validate practice knowledge, common denominators in schemes, frameworks, and models can help evaluate and make individual practices equitable. In BLBL, a consistent COPM developed quite early in the project, perhaps due to the low vision consultants' existing understanding of the tool from occupational therapy. The test-evaluate-adjust-retest process of the narrative interview and lighting assessment lasted longer, as their role and how they were used and best embedded in the overall process were still being configured throughout the pilot study. As in most innovative processes, closure involves some level of generalization, and the vision consultants found the level of elasticity that worked for them. Subsequently, to transfer their knowledge from the pilot study to their regular practice or across the community of practice, their understanding of the narrative interview and lighting assessment must be specified and translated for the knowledge to be recontextualized (17). A possible next step could be to test these in other contexts to verify their scientific robustness and practical usability.

Interdisciplinary

In this analysis, a relational model of the physical environment was constructed from the parameters and aspects identified as relevant actors in BLBL, observed or assessed in real life and the associated documents of the 60 cases. The model represents the potential actors (or factors) that could be relevant in future cases but, rather than a checklist of a neutral environment, it works as a framework, a game board, or arena where the collaboration, learning, and change processes occur.

Some scholars accuse the ICF of remaining too closely aligned with a medical understanding of disability and identify universal design (UD) as a more appropriate framework for interdisciplinary collaboration: "Understanding disability from the perspective of the interaction between the individual and the social, cultural and physical environment" (9). Others acknowledge the ICF's support of cross-disciplinary collaboration across different paradigms and individual-social or ideal-material ranges in the field of disability (36). This article was not intended to test either of these but rather to investigate the different frameworks. One of the commonalities is the focus on situated actions in activities, participation, and usability. In one of our conversations on rehabilitation and recovery, the consultants described the ICF as a frame of reference that was embedded in their overall approach and schemes. They had previously used parts of the classification to assess new citizens in their databases; however, in their current practice and BLBL, the ICF was an underlying frame of reference.

One of the ways the ICF is embedded in their practice is through their professional backgrounds as occupational therapists. The complex dynamic relationships between people, occupations, and environments have been a core interest of occupational therapists and the Person-Environment-Occupation (PEO) model was introduced in the 1990s as a practical analytical tool to assist problem analysis, intervention planning and evaluation, or to communicate occupational therapists' practices (37). Similar to the GAP model, PEO holds a processual focus that, in addition to the person–environment, focuses on the occupation on the relational development of the spheres, being more or less congruent within a temporal scope. The PEO model has not been articulated within the framework of BLBL but has been used as an analytical framework for investigating the practice knowledge of low vision consultants in Øien (16), showing that the elasticity of the framework enabled interventions in the more complex settings of the home environment and that it depended on active collaboration between consultants and participants. PEO is distinct from the ICF and UD as a highly practical tool not for classifying or conceptualizing but rather for facilitating evaluation, interventions, and assessments (37).

In their preparations for scaling BLBL to other colleagues across their community of practice, the consultants have been facing the need to generalize and make guidelines for sharing their knowledge, especially their more implicit knowledge. After the pilot BLBL study, the low vision consultants have adjusted the framework for their narrative interview, specifying the ICF components within the questions of the guidelines: *Activity*, *participation*, *personal factors*, *health condition*, *body function and structure*, and *environmental factors*. By stating the ICF affiliation of each question, the environmental factors were specified in relation to the two main questions: "In what situations do you need to turn the light on?" and "Are there situations where you prefer not to turn the light on?" and the two sub-questions: "When did you last succeed [in performing the specific activity]?" and "What do you think enabled the performance?" The reconfiguration of the interview guide has made the use of the ICF explicit and operationalized it in this specific intervention. The main questions illustrate the relational character of the approach as they include *activity*, *participation*, *personal factors*, and *environmental factors.*

Like involving psychologists in the use of the narrative interview to learn the personal aspects, the involvement of an architect and researcher in the field of the built environment has highlighted the role of the physical and material environment and rendered it visible for the low vision consultants. Already part of their tacit knowledge but now articulated and made explicit, they have been able to actively reflect upon its role, enabling a less uniform and neutral understanding of the environmental factors. A shift similar to the understanding of the human body from the medical to the biopsychosocial approach, from a uniform and neutral understanding of the human body to acknowledging the situatedness of lived experiences and human function. As part of the BLBL, the two low vision consultants have acquired both theoretical and hands-on knowledge of lighting, refining the environmental asset in their approach. The analysis explicates this otherwise tacit practice knowledge of acknowledging, recognizing, assessing, relating, and supporting the transformation of the abilities and disabilities of the participants' everyday lives by putting the biopsychosocial approach in motion. Consequently, mapping the interaction as presented in this article enables us to recognize entanglements across the parameters and to identify the relevant human and non-human actors in the rehabilitation processes at stake.

Both in theory and in practice, we address different contexts: the everyday context of the citizen, the professional context of the practitioners, and the political context of systems and legal frameworks. Acknowledging these overlapping contexts would, in Annemarie Mol's understanding of the multiple body (31), allow for collaboration and coordination across practices. Her study was situated in a hospital setting with patients and relatives visiting, while in this study, the professionals visit the home setting. Moreover, where her study investigated several different practices enacting different versions of atherosclerosis, BLBL shows how different versions of lighting can be enacted through one approach. BLBL was originally mobilized bottom-up by practice and informed by ophthalmology, occupational therapy, and psychology but as demonstrated in the action research collaboration, its implementation has been further supported by lighting, architectural anthropology, and socio-material frameworks. Recently, the project group has recognized the potential of refining the participants' knowledge of the learning and change processes by addressing the didactical and collaborative aspects. The methodological and theoretical reflections within our interdisciplinary collaboration have primarily been based on acknowledging these multiple understandings as in the iterative processes within BLBL of recognizing and incorporating the relevant actors in the process, allow us to relate, navigate, and coordinate between the different fields of interest.

When the ICF was launched, the environmental factor classification was highlighted as one of the major innovations within the framework (1), yet today, two decades after its introduction, we argue that operationalizing this factor in practice is pivotal for reducing the gap between the person and the environment to enable disabilities. Several initiatives are working on this issue from different perspectives and in slightly different scopes and we must consider several versions of the ICF as well to use it as classification, as a point of shared reference, and embedded in practical and profession-adjusted tools. We believe that the best way to reduce the gap is by the effort of several forces including the individual and their rehabilitative support and by combining the experience-based tacit knowledge of these with interdisciplinary knowledge of science and technology. One way to approach a common denominator for the human–environment relationship is to acknowledge the physical environment not as a neutral parameter but as a key actor that can enable change.

SUMMARY AND CONCLUSION

Mapping the role of the physical environment in practice shows that different aspects of it can disable an individual; however, by investigating their abilities via the interrelation and interaction between the individual and the environmental aspects, the relationship can be reintegrated, and abilities regained. By incorporating the participants' experiences in specific activities and specific lighting scenarios and involving embedded and embodied situated knowledge, the low vision consultants supported the process of operationalizing and transforming the person–environment relationship.

The analysis shows that the nature of a model depends on how and where it is used. The physical environment is neutral in randomized controlled trials, standardized in classifications, and yet interdependent and dynamic as part of our living entanglements. In this sense, the context of the classification and the practice of classifying hold different logics and objectives than the context of the rehabilitation process and the way the model informs and operationalizes the practice of facilitating and supporting a change process. In practice, the personal, social, and environmental spheres are not isolated but entangled and, in the rehabilitation process, the professional sphere is also involved. Aspects of the individual of importance to the intervention were their experience of the situation and the lighting scenario, and their motivation. Behavior patterns and experiences are mentioned as personal factors even though this category, due to large societal and cultural variance and lack of clarity are still to be developed in ICF. The level of motivation, which could be argued is particular to the individual, is however classified as a body function, as temperament and personality, which also was persistent in the intervention. Similarly, coping, or managing is discussed in relation to participation, but not classified as a factor as such.

For the contextualized individual, in a specific social and physical environment, the different parameters isolated in factors in the classification, is entangled and interrelational. They are often contained in one another in a way the hierarchical system cannot embrace. The nature of humans and our technologies and environments contains hybrids, where the right adaptions and changes make the individual take on new grounds. The ANT approach enables us to recognize the dynamic and collaborative processes of the intervention as well, where the consultants and the participants identifies, assess, and adapt both the individual and the environmental factors in a joint process.

The understandings and intentions embedded in the ICF, such as the holistic interpretation of health or a focus on functions and abilities, are shared by other scientific and technological approaches such as universal design, that can help us refine our understanding and active involvement of the physical environment. Furthermore, the multiple understanding of the interrelation of people and the environment allows the tacit knowledge of this project to be shared and disseminated not only for low vision rehabilitation and rehabilitation overall but also to the makers of future enabling environments.

Adding new notions of the holistic to the paradigm of rehabilitation includes the dynamic and elastic relationships of spheres in the rehabilitation process and that working across multiple versions enables close collaboration with the participants and interdisciplinary collaboration.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

TØ: concepts, design, data analysis, interpretation, and drafting the article.

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ORIGINAL RESEARCH
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Practice-Based Evidence to Support Return to Work in Cancer Patients

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Background: International research emphasizes the importance of providing early, hospital-based support in return to work (RTW) for cancer patients. Even though oncology health professionals are aware of the scientific evidence, it remains unclear whether they implement this knowledge in current practice. This paper presents the knowledge and viewpoints of health care professionals (HCPs) on their potential role in their patients' RTW process.

Methods: Semi-structured interviews with oncology HCPs were used to describe current practice. Results of these interviews served as input for focus group discussions with managers in oncology hospitals, which led to an agreement on of best practice.

Results: This research had the participation of 75% of Belgian institutions involved in oncology health care services. Five themes were identified that influence care providers and staff to implement scientific evidence on RTW in cancer patients: (1) Opinions on the role that care institutions can take in RTW support; (2) Current content of RTW support during oncology care; (3) Scientific bases; (4) Barriers and success factors; and (5) Legislation and regulations. The key elements of the best practice included a generic approach adapted to the needs of the cancer patient supported by a RTW coordinator.

Conclusions: Health care providers include RTW support in their current care, but in very varied ways. They follow a process that starts with setting the indication (meaning the identification of patients for whom the provision of work-related care would be useful) and ends with a clear objective agreed upon by HCPs and the patient. We recommend that specific points of interest be included in regulation at both the patient and hospital levels.

Keywords: return to work, hospital-based support, cancer, evidence-based practice, practice-based evidence

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INTRODUCTION

The recognition of cancer as a chronic disease is associated with the need to develop a corresponding approach to the long-term recovery process (1–4).

Globally, 5–year survival rates have increased, which is confirmed by the decrease in mortality rate over the past 20 years (5, 6). Belgian patients have a relatively good prognosis, with 5–year survival rates of more than 85% and a 10-year survival rate of more than 75% (1, 7, 8).

For cancer patients of working age, this implies that RTW support deserves to be implemented as part of the care provision. More than 40% of BC survivors do not succeed in resuming work (9–13). For the other 60 %, maintaining labor participation remains far from easy and may lead to job loss (14–17). Pauwels et al. underpin BC patients' needs for support regarding return to work (RTW) and indicate that, following patients' and caregivers opinions, those needs are insufficiently met (13). Patients' needs for RTW support should be addressed and integrated in healthcare services early in the treatment process (11, 13, 18–27). Research provides insight into the needs of cancer patients and the extent to which these – with regard to labor participation – are currently unanswered (3, 28–31). The literature also makes it clear that maintaining employment/resumption of work is an important element in the lives of working cancer patients (14–19) and that it is advisable to implement this in the provision of care (32–36).

The available scientific evidence on this subject seems to be insufficiently implemented in practice, creating a gap between "evidence-based practice" and current care practice. The concerns about the relevance of scientific research to practitioners in routine clinical settings motivate enhancing treatment quality takes a quite different form, namely practice-based evidence (37). Despite this trend in oncology health care, some efforts have been made to pay attention to RTW, with a certain level of 'practice-based evidence' as results of those efforts. As a consequence, this way of implementing available scientific evidence appears to create a gap between evidence-based practice on the one hand and (experience-based) practice-based evidence on the other (38–42).

By examining the opinions and experiences of HCPs in this field, the primary objective of this study is to investigate the extent to which Belgian oncology caregivers include RTW as part of hospital care for cancer patients of working age. The second objective is to determine whether specific hospital-based guidelines could be beneficial for HCPs on how they can contribute to early support for RTW in cancer patients. Such guidelines could facilitate the process of RTW for individual cancer patients.

This study is structured to address the following research questions:

- What (science-based) approach is used to support RTW by HCPs in oncology care?
- What are the facilitators and barriers that affect success in support of RTW within the chosen approach?
- What do HCPs see as "hospital-based best practice" to provide support for cancer patients' RTW?

METHODS

This study, with its grounded theory framework, follows a quality characterization structure as this allows for the detection of non-group or situation-specific patterns and a detailed understanding of the practice-based perspectives of occupationally active cancer care providers and patients (42–46).

This qualitative characterization study was designed using semi-structured interviews and focus group discussions. The study was carried out in collaboration with the Bachelor of Occupational Therapy courses (NL: university college PXL Hasselt/ Belgium; FR: university college CeBxl, Brussels/Belgium) and the master's course in occupational sciences (UGent/Belgium). **Figure 1** visualizes the design of the research project.

Oncology services' websites, telephone contacts and email communications were used to recruit participants for the semi-structured interviews. These participants were care providers directly involved in the care of cancer patients (doctors, nurses, care coordinators, physiotherapists, occupational therapists, social workers, psychologists, onco-coaches, etc.).

When preparing the topic list for the interviews (see additional material for the interview topic list), the research group also took into account reflections obtained during the telephone recruitment from people who expressed that they did not see any use in including RTW support into the care programme and that they therefore did not wish to participate in this study. This recruitment procedure allowed the researchers to gain insight into which of the contacted HCPs provide hospital-based support for RTW in cancer patients in the hospital where they work. It also provided brief feedback on what approach is offered when the response was affirmative and, if the answer was negative, why certain professionals choose not to offer RTW support.

The interviews were carried out at the participants' workplace by specially trained pre-graduate occupational therapy students, who also transcribed the recordings. Analysis of the material was conducted by the researchers (B.S. and H.D), then supervised by the co-authors during regular research meetings. The interview guide that was used to structure the four focus group discussions was developed based on the analysis of the interviews (see additional material for the focus group guideline). This was carried out by the researchers with the assistance of a student preparing her final paper for a master's in occupational science.

The meetings for the focus groups took place in regional venues to avoid long travel times for the participants. The researchers took the role of moderators, while the collaborating student and the co-authors were responsible for written record keeping.

For both sets of data, NVIVO 12 software was used for encoding. Following the reasoning of 'grounded theory', a code tree was developed by the researchers as the start of an open coding process. The concepts that were derived from the

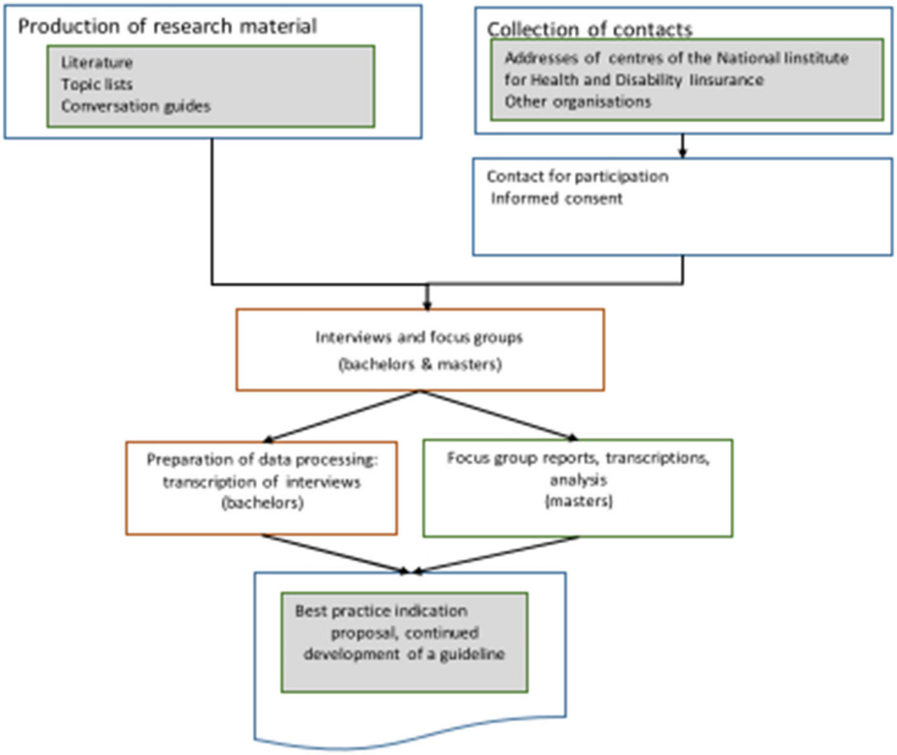

FIGURE 1 | Practice-based evidence: research design.

data were discussed with the co-authors and the participating students. They also collaborated in further analysis of the data using axial coding.

In addition to answering the study questions, the results of the analysis were used to make recommendations for implementing the findings and to develop proposals for a follow-up study targeting the development of a practice-based guideline.

RESULTS

Recruitment

Seventy-four HCPs were willing to participate in the semi-structured interviews that took place at their workplace. The disciplines that participated in the research (interviews and focus group discussion) and the numbers per discipline are given in **Table 1**.

Qualitative Analysis

The analysis of the results was carried out on the records kept during the recruitment phase, ad verbatim transcripts of the semi-structured interviews, and ad verbatim transcripts of the focus group discussions. In total, 40 people participated in the focus group discussions.

Analysis of the notes kept during the recruitment made clear that a large majority of the care providers contacted for recruitment (more than 70%, or 122 people) believed that support for RTW should indeed be on the agenda, although they had not yet undertaken any initiatives as they were not sure how to address the matter. Ten per cent of the contacted HCPs believed that the care institution plays a real role in RTW and, as a result of this belief, were developing initiatives in this area. Thirty-five people from the contacted HCPs were convinced that promoting RTW support in the hospital setting is not one of the objectives or roles of a hospital. In the following text, the "italic" written text refers to input by participants of the focus group members.

Current Role of the Care Institution in Supporting People in Work or in Returning to Work

There was a broad consensus that a hospital can/should play a certain role in cancer patients' RTW. This consensus provided the impetus for a reflection, with the participants, on the current interpretation of the care offer. Providing information to patients on RTW seems to be a significant and frequently applied part of care. The participants made it clear that they consider broad dissemination of information to be important. This is usually done in individual consultations and/or by encouraging patients to participate in information sessions at group level but a more multidisciplinary approach is estimated to be beneficial: *"My ideal is a meeting, a multidisciplinary consultation of all the stakeholders at different times of the care to take stock, but this is the ideal world"* (FF2, 316-318).

TABLE 1 | Number of participants in semi-structured interviews and focus groups by discipline (ordered by location of the focus-group discussion).

Discipline	**Interviews**	**Focus groups**				
		Brussels	**Ghent**	**Namur**	**Leuven**	**Total FG**
Doctors	**13**	3	1	4		**8**
Oncology care coordinators	**17**	1	2	2	2	**7**
Occupational therapists	**4**					**0**
Physiotherapists	**3**	1				**1**
Social workers	**14**	1	3	3	5	**12**
Psychologists	**7**	1				**1**
Nursing staff	**9**		1	2	3	**6**
Others*	**7**	2	2		1	**5**
Total	**74**	**9**	**9**	**11**	**11**	**40**

**FG, Focus group.*

Scientific Basis for the Information

In general, participants made little or no reference to the scientific evidence available to support the current method. However, they made reference to instruments used in the approach they followed., though it was not clear on what basis these instruments were selected.

Facilitators and Barriers in Practice

Concrete experiences from the participants' practice as well as their opinions and convictions on different points that they considered significant were discussed. As explained below, participants perceived several elements simultaneously as an obstacle and a success factor.

Lack of Knowledge

The participants were aware that they lacked knowledge about the legal and regulatory framework for occupational reintegration. This lack of up-to-date knowledge is particularly frustrating for the social workers but also for the other participants, and it has a negative impact on the quality of care they can provide. It was also mentioned several times that the lack of knowledge about the competences of other professionals led to a form of compartmentalization.

Presence of a Specific 'Work Specialist' in the Team

Although the analysis reveals the need to assign tasks to care providers who have specific competences in a field, it turns out that participants also consider it important to be able to assign the topic of "work" to a specific care professional who can then be responsible for coordination: *He's someone who … brings together the elements of the file, there is the bridge, and there is the implementation, and.. By saying, trust, someone, a person of trust* (FF2, 263-265)

Being responsible for this part of the care, this provider could then also refer to other team members for the treatment of specific points in the RTW pathway. However, the analysis also reveals a wide range of opinions as to which discipline within the team could or should be designated for this task.

Common Plan and Tailored Support

Participants agreed that a targeted approach to RTW support for occupationally active cancer patients should follow a stepwise plan that is the same for all patients as they progress in their recovery. There was also relative unanimity that such a "common step plan" must allow plenty of space for "tailored work" This should allow for different stages of the common plan to be carried out according to the patient's individual situation.

Participants who have experience with a concrete working method that has been in place in their hospital for some time note that some form of structure that sets out a modus operandi within the team is essential: "*But I think f… with these patients, we have to take it from the beginning. And one day you go back to work, one day you are expected to return to your workplace.*" (FN, 356-358)

Input from other participants also revealed that a structural approach that takes multi-disciplinarity into account is considered a success factor.

Case Management

There was a lot of vagueness about the criteria to be used to set the indication, who should take the final decision, who should monitor the follow-up and how this should be put into practice. There are also differences in opinion regarding the point at which such an indication is integrated into the patient's treatment pathway.

On the one hand, it is important that all stakeholders, including the patient, personal and professional network, health care providers and others, adopt the same point of view as soon as possible. On the other hand, there is a fear of frightening the patient by immediately broaching the subject of work in parallel with explanations about the therapeutic pathway. Providers feel that the ability to determine when it is still too early to mention RTW based on their assessment of the patient's condition is part of good care.

Factors of Influence

A clear distinction was made between when it is possible to talk about or provide information on RTW and when to start actions related to it. In both the interviews and the focus group discussions, providers indicated that a number of elements that influence the success of actions targeting RTW can be attributed to the attitudes, knowledge or beliefs of cancer patients. Providers particularly consider the following points:

- The Motivation of HCPs and Patients to Engage in RTW Therapies
- An understanding of HCPs' own abilities, which is (among other things) influenced by the importance of self-knowledge and self-confidence, to the extent that the wish to return to work corresponds to what is possible
- Practicalities Regarding Participation
- Information about possibilities, such as affordable and easily accessible care provision, information about and understanding of the legal measures that can be used
- The patient's relational network, where (among other things) there is social pressure or a lack of stimulation
- The extent to which patients can feel heard, which seems to be as much a barrier as a factor for success

Contact Between the Hospital and External Services

The particpants in this study are clearly convinced that collaboration with professionals outside the hospital is necessary to achieve good results: *And it is not only the hospital that must invest, it should be a collaboration between the hospital and external organizations* (IF5, 109-110).

The participants were also aware that maintaining contact with the working environment during the patient's recovery is a particularly strong success factor. At the same time, they indicated that they did not have a clear view on how they could play a role as care providers.

Regarding the necessary transmission of information from the care setting to the workplace, participants were very careful to respect the professional confidentiality and duty of discretion that is imposed on them.

Although participants reported that they rarely had the opportunity to make direct contact with the workplace of their cancer patients, there was disagreement about the extent to which this can (or cannot) be considered a component of care aimed at RTW. The analysis shows unanimity that the employer ultimately holds the key to achieving RTW.

The gradual implementation of RTW includes measures that–for both cancer patients and their employers–allow for the adaptation of the working environment, the reorganization of the content of tasks, the modification of working hours or the request for compensation for reduced performance, seem to be little known and are still rarely communicated as advice from the care providers to the patient.

Other Points of Hindrance for RTW

In addition, there are also several references to the problems that many cancer patients have with administration: "*But I think f… with these patients, we have to take it from the beginning and help them to be aware that one day they might go back to work, one day they are expected to return to their workplace.*" (FN, 356-358).

Preconditions

One of the aspects that participants with experience in supporting RTW found to be very relevant but which also often caused difficulties was the status under which patients were engaged. A wide range of different organizations in the field (e.g., home care, regional initiatives, patient advocacy organizations, self-help groups) also target "labor market participation" to a greater or lesser extent. Care providers find that consistency and collaboration in this area is far from optimal.

Moreover, from the hospital it is far from easy to get a good idea of who is best to contact in the company where their patient works. Presenting oneself as an oncology provider with a question about a worker has the consequence of informing the employer about the condition of the worker. This implies that the matter must be properly discussed with the patient beforehand and that an informed consent is signed. Without such consent, care providers cannot contact any other stakeholder.

Information on Best Practice and an Ideal Scenario

The responses of the participants in the interviews and focus group discussions on the ideal way of working were very diverse. However, two aspects emerge from the analysis of the responses:

- An ideal working method is an integrated process with good internal communication and a well-designed electronic patient file that is produced according to a general roadmap while also offering room for individual customization.
- A crucial role is assigned to a central figure who has a coordinating function and takes responsibility for the RTW process. This coordinator initiates the internal communication between care providers, manages the start and end time of the process, liaises with the workplace, leads the collaboration with intermediaries and is responsible for the management of measurement data regarding quality control and the effectiveness of RTW support.

"*In my ideal world, a kind of information desk would be associated with people who have received a specific education to be able to bring. …… from there we could get information about resumption of work and there could possibly still be a referral and where an extensive conversation is possible.*" (FN4, 445-451).

DISCUSSION

Interpretation of the Concept of Role

Differences in participants' views on the extent to which cancer care providers or the organization can contribute to RTW can be indicated as follows (using the model of International Classification of functioning, disability and health; see **Figure 2**):

- Care is primarily aimed at restoring health. Restoration of quality of life is a different priority, and the focus is on the functional level, represented by **F** (**blue area)** in **Figure 2**.

- Care should have quality of life as its goal, which is reflected in the results of this study in the form of referral to additional care or services, such as psychological support, cosmetic advice and dietary advice. Special attention is given to the ability to function in daily life, represented in **Figure 2** by component **A (red area).**
- The participants demonstrate that the purpose of care for cancer patients must also consider the restoration of their involvement in society. The participants see this as an important component of the quality of life of these patients, as seen in component P (**green area**) in **Figure 2**.

Interpretation of the Role of the Hospital and Care Providers

What the participants presented as the current approach in their hospital consists of a variety of in-hospital actions and collaboration with other stakeholders. Some of the approaches that appear in the analysis are ad hoc while others are part of a more formal process; most participants considered their approach as a work in progress.

The schematic visualization of their input in **Figure 3** indicates that the current way of collaborating does not implement direct and well-organized communication between the care (red circle) and workplace (blue circle) settings. HCPs refer to this situation as complex and confusing. The shape and the marking of the arrows in **Figure 3**, which refer to the contacts and collaboration between different stakeholders, indicate the intensity of the interactions.

Almost all hospitals offer concrete information and assistance to cancer patients regarding administrative formalities (e.g., forms to fill in for social insurance matters or notes to establish sick-leave periods).

The people indicated in the red circle may be part of the service provision within the hospital or may, as external participants, offer input in supporting the RTW journey of individual cancer patients provided by patient organizations or fellow sufferers.

The focus on restoring physical capacities (e.g., fighting fatigue, increasing stamina, giving dietary advice) is given attention in some institutions, while others put more emphasis on emotional and psychological well-being. Very often, work-related issues are only put on the agenda after an explicit request from the patient.

In programmes where work is one of the components, the direct contribution of the hospital is limited, and external intermediaries are more often used. Direct contact with the employer, although desirable, rarely takes place.

Indication

The indication[1] to initiate or attend to work-related support is usually made in a non-systematic way and mainly on the basis of a direct request from cancer patients. The participants mainly refer to their own involvement in the patients' practical situation. However, the fact that they have too little information to gain a clear overview of the elements that are important in the complexity of the problem increases the risk of a mismatch.

Best Practice

Innovative thinking about a more fitting approach results mainly in the need for more staff, resources and possibilities. The steps implemented by care providers in some hospitals to facilitate cancer patients' journey toward promoting RTW are shown in **Figure 4**.

Monitoring the maintenance of functional recovery (see also red circle of **Figure 3**) and attending to the balance between the person's capacity and the burden in the person's life seem to be essential to a successful RTW journey. These components are the basis for the development of work-oriented goals, which requires collaboration with all stakeholders.

It is these people who, during Phase 4, will shape the content of the RTW action plan and decide who will be involved and when. This should ensure that medical–functional problems are dealt with in a timely manner while avoiding any risk of dependency on the hospital.

The approach developed, implemented and by Désiron et al. was used in the KOTK-funded BRUG study project (47–50). It incorporates the above-mentioned elements and shows that the implementation of the listed components can offer significant benefits to oncology through attention to the restoration of participation.

Both parts of the study highlight the need to eliminate the disadvantages of the current shared responsibility, where it is unclear, for example, who does what and when, where the contributions of different disciplines overlap and where gaps exist. Clarity can be achieved by creating a coordinating function responsible for, among other things:

- Monitoring the RTW process
- Coordinating internal communication
- Drawing on the knowledge of others
- Ensuring that the necessary knowledge is available and up to date
- Putting together the RTW file
- Respecting privacy and medical confidentiality
- Providing functional information
- Managing administrative formalities
- Establishing contacts/collaboration with external parties (intermediaries and/or stakeholders).

The international literature on RTW support explores the possibility of utilizing different disciplines among care providers and the extent to which the RTW care needs of cancer patients are met (33, 49, 51–55). Although each of the care providers mentioned can make a relevant contribution, the literature shows that none of these disciplines has the full range of competences needed. In this study, care providers state that they assign a person to a coordinating function if they feel the need, while they refer directly to

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[1] The term "indication" here refers to the identification of patients for whom the provision of work-related care would be useful. It is important to be able to offer patients for whom this is not yet on the agenda (e.g. those who are willing and able to consider a return to work of their own free will) adequate and tailored care based on rigorous follow-up.

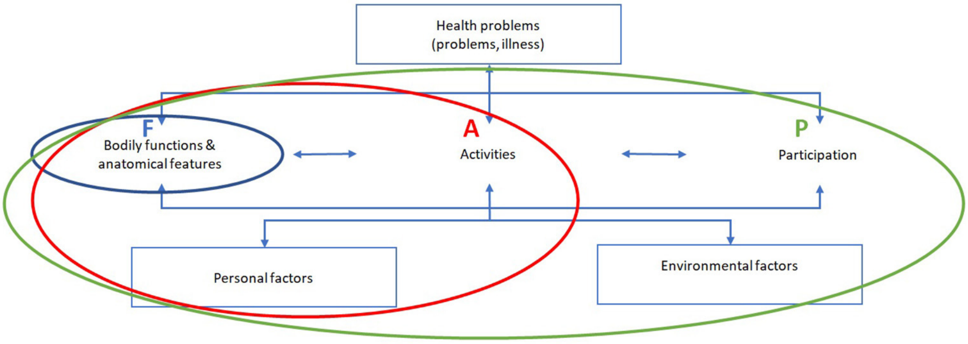

FIGURE 2 | Differences in the purpose of care regarding RTW for cancer patients based on the ICF model.

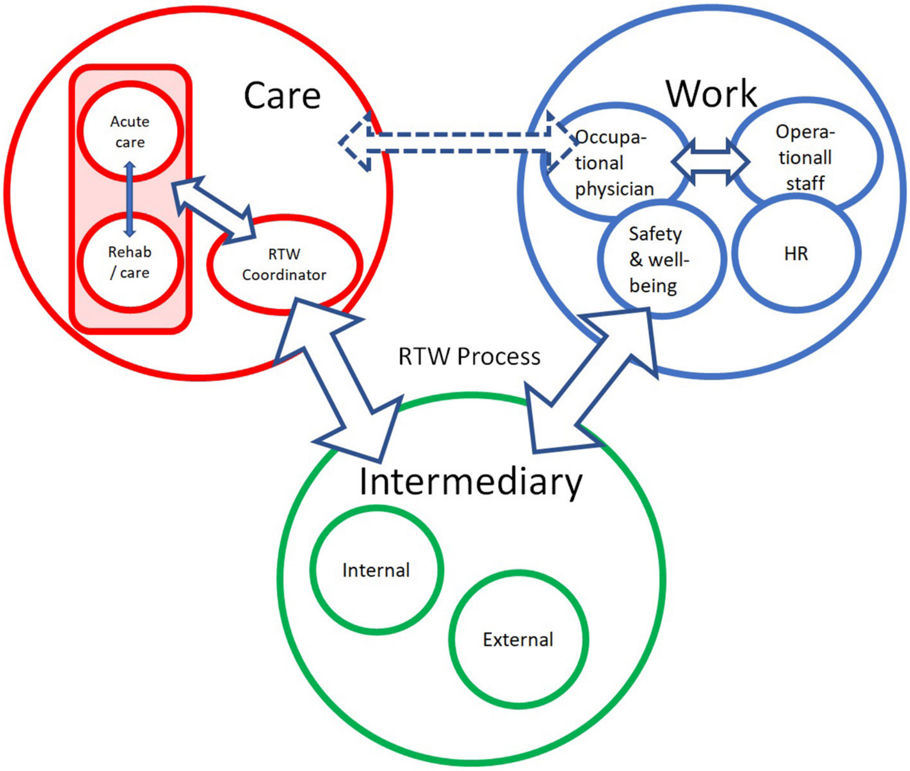

FIGURE 3 | Schematic representation of the overview of the current meaning of the work-oriented approach. HR, Human Resources Department; Red circle indicates who within care is involved in RTW support; Blue circle refers to the stakeholders in the workplace; Green circle refers to specialists who play a role in the RTW process but are not part of the care team of the oncology or revalidation department.

the need to prioritize the necessary time and resources for this purpose.

Based on the input by the HCPs about their current practice regarding their efforts in support of RTW (see **Figure 3**), **Figure 5** represents the conclusions that emerged from discussion of these findings with the research group at the end of the analysis process. The figure visualizes an ideal scenario for fulfilling the role that hospitals could play regarding RTW support for cancer patients and will be used as basis for further development of the RTW guidelines, to which this study aims to contribute.

The RTW coordinator, who is a member of the team and as the person responsible for the patient's file has legal access to the entire patient file, is responsible for coordination and internal communication with the patient, their relatives and other members of the team (see red circle). Direct access is necessary to initiate smooth collaboration between the professionals involved in the

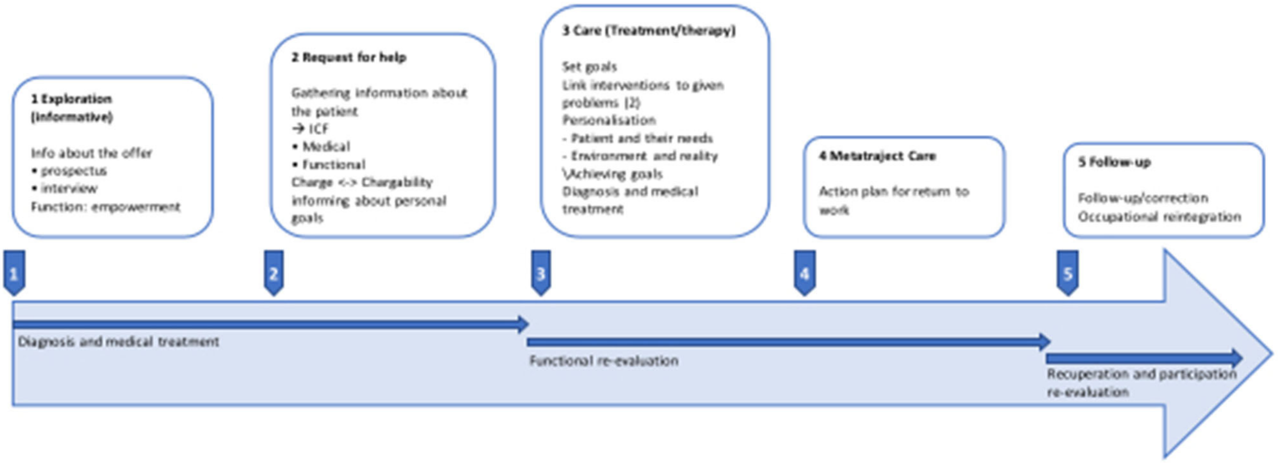

FIGURE 4 | Step-by-step plan for work-oriented care during the cancer patient's care journey.

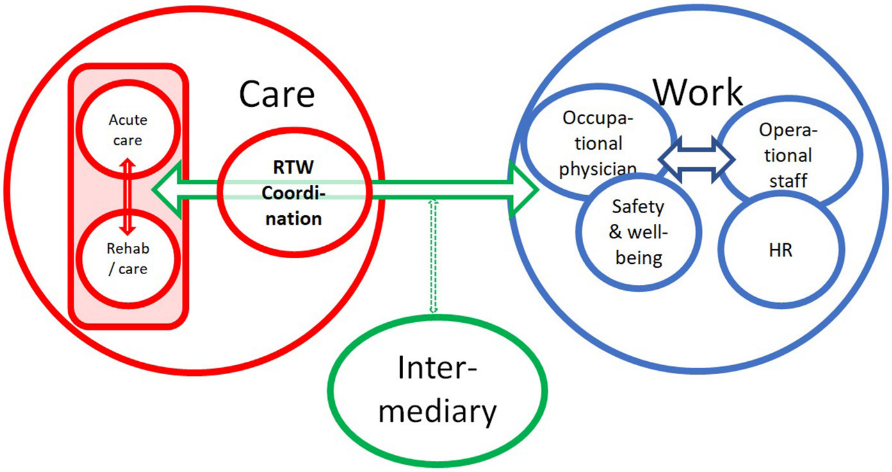

FIGURE 5 | Schematic representation of best practice for the role of hospitals in RTW support for occupationally active cancer patients.

shared confidential medical information. It also facilitates smooth and correct communication with professionals within the team who cannot legally have direct access to medical information.

The RTW coordinator assumes responsibility for the process and therefore supports the team members in their contribution according to their function. The coordinator is also the fixed point of contact for other workplace stakeholders (see blue circle) and is responsible for establishing contacts and consultations with intermediaries (see green circle), such as medical advisors for mutual societies or specific service providers.

The large green arrow indicates that direct communication with workplace stakeholders is a priority and that the involvement of intermediary partners in this area can make a significant contribution.

Methodological Considerations

In absolute numbers, the number of participants ($n = 103$) in relation to the number of cancer care providers is not high, in contrast to the number of care institutions represented. Of the institutions providing oncology care in Belgium (85), more than 75% ($n = 63$) delegated one or more persons. The relative advantage of the telephone approach compared to email recruitment is that it provides a view on the reason for non-participation. The disadvantage, however, is that the discussions left virtually no opportunity for further exploration of the reasons given by these individuals for not attributing a role to hospitals in this matter.

The variety of disciplines among the participants in the interviews and focus group discussions gives an overview of the disciplines that currently engage with work as a component of care or are delegated to do so by their institution, at different levels of direct involvement. Though the topic of this research is supporting BC patients to maintain / regain occupation (in casu work), it is remarkable that so few occupational therapist were participating in this research project. This can be partially understood by the fact that – in Belgian oncology care – occupational therapy is not structurally prescribed, even though scientific research support the input of this paramedical discipline in many domains of onco-care (35, 47, 56–62). From the viewpoint of the "evidence based practice" that is presented in literature, the poor representation of occupational therapists might increase risk of selection bias. That might also be the case for all other participating disciplines but this qualitative research project did not focus on representativity of HCPs' disciplines. As stated in the introduction to this paper, the primary objective of this study is to investigate the extent to which Belgian oncology caregivers include RTW as part of hospital care for cancer patients of working age. The phased approach of this PBE-research project provides information on the state of play in the field through the interviews but also, through the focus groups. This gives an insight into the context and policy decisions taken by institutions and care providers regarding the provision of care (in which they indicate RTW might/should be integrated).

In line with indications by the participants in our research, Bilodeau et al. state that a RTW-intervention would need to focus on both creating the conditions to change practices in favor of the intervention and making the intervention an integral part of professional practices and the organization of existing services (63, 64).

Regarding the first research question of this PBE-project on having access to scientific literature, participants indicate that is very difficult (e.g., no online access, few opportunities to participate in congresses on RTW, not enough time to read an discuss scientific information,…). The participants' input aligns with the point of view of Gabbay et al., who state that practitioners in health care found their knowledge on more than scientific literatures' information: the use of their practical skills, soft skills, technical skills, illness scripts, heuristics, rules of thumb, embedded science, guidelines, peer values, institutional culture, roe models' behavior, local norms/routines, trainers'/teachers' norms and tacit and experiential knowledge (40).

CONCLUSION

With focus on what (science-based) approach is used to support RTW by HCPs in oncology care, this project lead to the conclusion that in most care institutions, work is an issue that receives attention through very varied approaches, although in a small number of hospitals, the approach is systematic and structured. Although the input of participants aligns with evidence provided by literature, our result shows

There is also a great diversity in the provision and an equally great variation in the intensity of actions focused on work. The contribution of health care providers in supporting the re-establishment of work participation usually takes place when the patient asks concrete questions about it, and the contribution is currently mainly reflected in the efforts of social workers to inform their patients about the administrative formalities related to work incapacity and consequent benefits. This input is generally not based on a scientific model. Their visions of best practice provide a concrete form and content for actions targeting the cancer patient and solving organizational and administrative problems.

Following the input of the participants, facilitators and barriers that affect success in hospital based RTW support often form a clear 'mirror image' of each other, e.g., knowledge is seen as a strong support, the lack of it is indicated to be an important barrier. The same "mirror image" is named for issues such as (lack of) presence of an "work specialist" in the team, common and patient-tailored support in the organization of the care and in the organization of work oriented services in the hospital, implementation of case-management, contact between hospital and external services that offer RTW support… Our results show that avoiding the barriers mentioned is very much congruent with the mentioning (by other participants) of success-factors.

HCPs see implementation of those success factors / avoiding the barriers mentioned as "hospital-based best practice" to provide support for cancer patients' RTW. More specific, this means:

- Monitoring the RTW process
- Drawing on the knowledge of others
- Ensuring that the necessary knowledge is available and up to date
- Putting together the RTW file
- Respecting privacy and medical confidentiality
- Providing functional information
- Managing administrative formalities
- Establishing contacts/collaboration with external parties (intermediaries and/or stakeholders

Recommendations from this study to both policy-makers and practice therefore relate to the development of a concrete and usable guideline that provides clear information on the following topics:

- The process that can be used for patients to explore and realize their chances of returning to work.
- Essential elements for organizing the optimal integration of care provision into the hospital's operation. A key point highlighted was the need for organized coordination of support for RTW, which could possibly be organized at the hospital level (i.e. across pathologies).

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because application was not agreed upon in the informed concent. Requests to access the datasets should be directed to huget@act-desiron.be.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Sociaalmaatschappelijke Ethische Commissie (SMEC) of KULeuven, Belgium on 04/05/2018 (code: G-2018 04

1218). The participants (all healthcare professionals) provided oral and written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

HD, BS, and LG contributed to conception and design of the study. All authors participated in the elaboration of the study and contributed to manuscript revision, read, and approved the submitted version.

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What Does It Take for Research to Be Rehabilitation Research?

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Six recommendations to facilitate rehabilitation research and supplement existing research practices were identified. Rehabilitation practice requires research addressing different long-term multi-faceted needs and perspectives of end users, including service users, professionals, politicians, and administrators. Research in rehabilitation should therefore integrate different research traditions and methods. Rehabilitation research with a broad focus is sparse, and most of the research takes its starting point in the biomedical research tradition. Through a nominal group process, we developed recommendations to emphasize important issues in rehabilitation research.

Keywords: nominal group process, recommendations, rehabilitation, research, ICF

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INTRODUCTION

A growing recognition of the potential of rehabilitation has led to higher prioritization and acknowledgment of the need for high quality rehabilitation research (1, 2). Rehabilitation is, in essence, composed of a number of complex interventions (3)changing along the disease and recovery stages and involving shifting professionals. Thus, it is pivotal that rehabilitation research mirrors this complexity.

The benefits of a biopsychosocial approach in rehabilitation to reduce negative consequences of health issues has attracted growing attention and recognition (4). An increasing number of people need rehabilitation due to better medical treatment and demographic changes (5, 6). Worldwide, more than 2.4 billion people would benefit from rehabilitation (7). It has been established that rehabilitation may enhance self-efficacy and autonomy among people with disabilities (8) leading to decreasing health care needs. Consequently, rehabilitation may increase quality of life (QOL) and reduce the burden on health care systems and societies (5, 8).

According to WHO, rehabilitation addresses different aspects of the lived life and is "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" (7). Thus, rehabilitation ranges from simple training that supports the individuals (here referred to as service users) to resume previous levels of functioning, to complex interventions for service users with multimorbidity and permanent loss of functioning that negatively affect several aspects of their everyday lives. The simultaneous parallel and linear interventions may take place over time and be considered as a continuous process involving physical, psychological and social aspects, especially for service users with limited resources, complex problems, and evolving needs. These aspects are reflected in the biopsychosocial understanding of the International Classification of Functioning, Disability and Health (ICF model) (9) and in established definitions of rehabilitation (7, 10). If rehabilitation is intended to improve functioning and facilitate recovery toward better QOL, autonomy and a meaningful life, then targeted coherent efforts are required, based on the service users' perspectives and life situations. Rehabilitation should thus be seen as a continuous collaborative process between the actively involved service user and an interdisciplinary group of social, vocational and healthcare professionals (11, 12). This complexity of independent variables and individualized approaches happening at different times makes 'rehabilitation research' complex and may explain why rehabilitation efforts are challenged by a limited knowledge base (2, 8). For example, in patients with low back pain, lack of rehabilitation research that covers broad aspects of functioning, QOL, autonomy and a meaningful life has been claimed (13). Similar problems have been described in stroke rehabilitation research (14). The lacking knowledge has implications for how rehabilitation research must be planned, executed and evaluated, if rehabilitation as evidence-based practice shall improve functioning, personal independence and a meaningful life. Thus, rehabilitation research must mirror the full rehabilitation process. Additionally, societal needs to optimize health-related costs imply that rehabilitation research should examine and test the effect of rehabilitation efforts as well as the individual service users' experiences of how the efforts contribute to increase and maintain functioning, QOL and autonomy. Complex rehabilitation interventions call for application of multiple research methods and designs from different scientific traditions to cover wider perspectives than traditionally explored by the randomized controlled trial (RCT) (2, 15). Moreover, long-term studies of multifaceted interventions are needed to examine all elements of a specific rehabilitation trajectory (2). Therefore, it becomes the responsibility of rehabilitation researchers to consider, optimally in collaboration with the service users, how rehabilitation research best meets the needs of the end users including service users, professionals, politicians, and administrators. The aim of the present paper is to offer recommendations for the broad field of rehabilitation research emphasizing the special characteristics of complex rehabilitation interventions that researchers should use to supplement established generic health-related research practices (16).

METHOD

The Nominal Group Technique (NGT) was used to identify recommendations for rehabilitation research practice. This method is designed to explore opinions, generate ideas, and determine priorities in e.g., the health sector (17–20). Our group process followed the five steps process: (1): Introduction and explanation; (2): Silent generation of ideas building on individuals' knowledge, perspectives, and experiences; (3): Sharing individual contributions (round robin); (4): Group discussion for clarification; and (5): Prioritization of ideas (individual ranking).

The take-off of the nominal group process was a collaboration initiative between research, education and clinical practice in Central Denmark Region with focus on rehabilitation development in the region (21). Discussions were initiated at two meetings attended by a group of two representatives for service-users and 33 experts in rehabilitation (the expert group) from four independent sectors: hospitals; health and social care services; university, and university college. The expert group represented different backgrounds in relation to gender, education, role as clinician or researcher or patients' representative, organizational affiliation, and research tradition. From this expert group, six researchers with health and social care professional backgrounds representing the direct users were appointed to a working group to formulate targeted recommendations for rehabilitation research. The working group met four times from May to October 2019 to form the recommendations and at additional meetings to describe the final outcomes. The entire working group took part in all the five steps described below.

Introduction and Explanation

The nominal group-process was initiated through the chairperson's presentation of the framework for rehabilitation, research obligations, and existing research within the field. Common challenges to rehabilitation research addressed at the inaugural meetings were presented.

Silent Generation of Ideas. Individuals' Knowledge, Perspectives, and Experiences

Participants were asked to individually consider what they perceived as appropriate and high-quality rehabilitation research. All ideas were documented and accessible to all group members.

Sharing Individual Contributions (Round Robin)

To elaborate and clarify the ideas, each member presented their ideas to the group, who posed in-depth questions.

Group Discussion for Clarification

Structured discussion of all ideas from the common document. Large variations were identified, explained by the participants' different theoretical and scientific foundations. In-depth discussions led to a common understanding and nuancing of possible ideas related to complexity and processes in rehabilitation (19).

Prioritization of Ideas

In this step, our process deviated from the NGT, as we omitted individual ranking of the generated ideas; instead, ideas were discussed until reaching consensus. This process led to a synthesis of recommendations of special importance within rehabilitation research. It became clear that some of the identified recommendations coincided with established, generic research practice; they were therefore deemed unnecessary to include. To avoid group processes and dominance influencing recommendations, and to consult the end users, the recommendations were subsequently discussed and amended at an expert group meeting also involving the service users.

RESULTS

The NGT process resulted in six recommendations for rehabilitation research as presented in **Table 1** and explained in detail below.

Service Users Should Be Involved in the Research Process

In a number of countries, service-user involvement is required or recommended according to national health policy and legislation and is expected to improve healthcare-services (22–24). It secures democratic representation and empowerment of disadvantaged groups and presumably increases the quality and integration of research in clinical practice (24, 25). Two approaches for service-user involvement have been identified: The managerialist/consumerist approach aiming to "improve the product" and the democratic approach linked to organizations and movements. Both approaches strive to increase service-user influence in healthcare organizations and institutions, enabling them to gain better control over own lives (26, 27). Patient- and public involvement (PPI) in research is research carried out *with or by* the public (including service users) who act as participants, rather than research *on* the public/service users as subjects (28). The purpose with service user involvement is to ask relevant research questions about relevant issues. The extent of public involvement in rehabilitation research ranges from consultation to collaboration and co-research depending on question, perspective, and design (29).

Rehabilitation Research Should Have an Explicit Biopsychosocial Perspective

Knowledge from different research areas is required and should be collected and analyzed from a holistic perspective (30). The ICF-model has proven to be a suitable framework for applying the holistic perspective to rehabilitation efforts (9), and an ICF matrix has been established to address this perspective in rehabilitation research. Based on the ICF-model, the rationale is that research is needed to inform how to improve physical functioning, activity, and participation of the person in interplay with the personal and environmental factors. The idea is that this contributes to being explicitly aware of the interacting components when long-term multifaceted interventions are investigated. In planning new studies, the ICF matrix can transparently structure the initial literature search and its results to clarify the existing knowledge base and pinpoint where new knowledge is warranted. Furthermore, the matrix can be useful in considering the impact of changes in one aspect of the ICF framework on other aspects of the framework. **Table 2** shows the ICF matrix with the y-axis indicating the focus of research within five components of the ICF model and the x-axis provides space for research results (meaning or effect) in relation to each component. The ICF factor, health condition, is not included in the matrix, as the primary aim of rehabilitation is to address the close interaction between factors within and around the person that impair the person's everyday functioning and quality of life.

Rehabilitation Research Should Reflect the Entire Rehabilitation Process

The research focus should adapt to ongoing changes in service users' needs due to their limited resources, complex and evolving problems (31). Research programs with longitudinal studies may be considered, as it is difficult to cover the entire rehabilitation process in one rehabilitation study. A series of studies focusing on different aspects of the rehabilitation-process and including patient reported outcomes could be a solution and requires a clarification of where in the rehabilitation process each study should be performed and why. Likewise, the necessity of investigating the cross-sectoral processes and efforts of the involved professions should also be acknowledged in rehabilitation research. It is pertinent to consider short- and long-term outcomes, as the latter can reveal developments or problems after termination of the active rehabilitation period.

Relevant Knowledge Gaps Should Be Prioritized in Collaboration With End Users

There are many suggestions concerning how prioritizations in research should be established (32). It is important to acknowledge the mutual interest for evidence among end-users and researchers, but also their differing perspectives and priorities. It is therefore recommended to conduct an iterative process based on an actual problem. In researching e.g., low back pain, a problem could be identified by researchers, a group of service users, stakeholders or professionals. Next, relevant stakeholders should be involved to qualify and delineate the problem, for instance by using the ICF-matrix described above. Finally, existing knowledge is reviewed and incorporated to avoid reproduction of existing evidence, to identify knowledge gaps (using the ICF-matrix) and to prioritize the most relevant problem to investigate.

Rehabilitation Research Should Encompass Considerations About Implementation

The gap between research-based knowledge and daily practice is well-known (33). Despite strategies for efficient transfer of new research-based knowledge into daily practice, it has been experienced that implementation of research into clinical practice may take a decade, and changes can be difficult to maintain (34, 35). A smoother transfer of new knowledge may be accomplished by addressing issues of relevance to the end users (26). This implies that a research protocol must specify the relevance of the project to the current practice in the field. Rehabilitation is a complex intervention involving multiple professionals and other stakeholders, and research is often aimed at informing the development of new tools, interventions or organizational approaches. Therefore, it is important that the protocol explicitly describes the necessary professional competencies and organizational structures required

TABLE 1 | Recommendations for rehabilitation research.

1. **Service users should be involved in the research process.** In both the planning phase and during the research process, involvement of service users should reflect their illness experience, values, and knowledge of the rehabilitation efforts.
2. **Rehabilitation research should have an explicit biopsychosocial perspective.** Functioning should be assessed in interaction with health status, disease, and individual life circumstances.
3. **Rehabilitation research should reflect the entire rehabilitation process.** Rehabilitation research should reflect that rehabilitation is often a cross-sectional process of simultaneous and sequential multi-professional efforts.
4. **Relevant knowledge gaps should be prioritized in collaboration with end users.** It should be clarified if identified knowledge gaps are *relevant* to investigate, and which knowledge gaps are the most *pressing* to investigate according to both end users (service users, professionals, politicians, or administrators) and researchers.
5. **Rehabilitation research should encompass considerations about implementation**. Implications for the individual end user as well as for the competencies and organization of professionals should be considered.
6. **Rehabilitation research should encompass considerations about how to disseminate results.** Dissemination should reach the large number and variety of end-users and include implications for practice, research and education.

TABLE 2 | ICF-matrix to provide an overview of research contributions and gaps.

	Body	**Activity**	**Participation**	**Personal factors**	**Environmental factors**
Body					
Activity					
Participation					
Personal factors					
Environmental factors					

← Meaning or effect

↑ Focus or exposure

for implementation. If these prerequisites are not (yet) met in practice, suggestions for knowledge-translation must be articulated to ease the implementability of the results. Many granting bodies now expect such clearly articulated knowledge translation plans. An important way of ensuring knowledge translation is by prioritizing implementation studies: in line with the Medical Research Council's guidance for developing and evaluating complex interventions (3), we stress that implementation questions should be considered throughout the intervention development, feasibility testing, process, and outcome evaluation.

Rehabilitation Research Should Encompass Considerations About How to Disseminate Results

All rehabilitation research should identify what the results mean for service-users, front line service providers, rehabilitation programs and policy makers so the implications and results are there for everyone to see. To reach the large number and variety of end-users of rehabilitation research, targeted presentations must be prioritized for narrower groups e.g., service user organizations and profession-, practice-, and sector-specific stakeholders. Qualitative findings have the potential to be more accessible to end-users than complex statistics (36), and a narrative format is a powerful tool to communicate scientific messages especially to non-academic audiences (e.g., the general public and policy makers) (37). Rehabilitation research, whether it has developed new insights, new tools, interventions, organizational approaches to rehabilitation etc., should always be followed by considerations and discussions of how the findings may guide future rehabilitation development and practice and facilitate further research and education.

DISCUSSION

In this paper, we have raised the need for targeted recommendations in rehabilitation research and have attempted to establish such recommendations to potentially clarify and increase the quality of the research and to ensure a transparent process from idea to implementation of results.

Rehabilitation is recognized as an important part of health care services. However, there is a need for more high-quality research, that encompasses a broad field of disciplines and methodologies covering the full spectrum from basic to applied science, and involves many different specialists with different research traditions. Ideally, a scientific process uses the most appropriate design to answer or illuminate the research question, and no single research tradition or method can be recommended or stand alone in rehabilitation research. The randomized controlled trial (RCT), often the default choice for intervention studies, has been claimed unfeasible for some clinical questions (e.g., if a particular presentation or condition is heterogeneous or rare) (38). The WHO guideline from 2017 stressed the limitations of randomized controlled trials and suggested that results from case-, observational or longitudinal studies can capture how environmental factors impact interventions at health system-level) (39). Likewise other types of evidence, as qualitative studies, are needed, too. Other methodological questions to address in relation to effect studies have been pointed out in relation to Cochrane studies. They relate to heterogeneous patient populations, complex rehabilitation interventions that are difficult to standardize, and to often vaguely described control conditions (38). The challenge of applying appropriate designs implies a need for future scholarly work on design development for rehabilitation research.

Using our recommendations can be a way to establish common ground for future discussion and development of holistic rehabilitation research, e.g., by using the biopsychosocial perspective of the ICF and the new ICF-matrix and the perspectives of the people receiving rehabilitation services to define the specific area of interest in each research project. It is important to emphasize that these recommendations are intended to guide researchers, decision-makers and funders within rehabilitation and rehabilitation research, all of whom do not necessarily have long experience with the discipline.

Although the recommendations are targeting rehabilitation researchers, there should be no doubt that we find it absolutely crucial that end users, including service users and stake holders, participate in the rehabilitation research process. End users are to be involved at distinct stages of the process: (1) priority setting and formulating research questions (2) study design, data collection and analysis (3) dissemination of findings and knowledge translation. This will improve the relevance and quality of rehabilitation research. Thus, the ultimate aim of the recommendations is to increase the knowledge base for rehabilitation by improving the actuality, relevance and implementability of rehabilitation research. Therefore, an important part of the recommendations stresses the involvement of all end users in the field of rehabilitation, in line with Solvang et al.'s emphasis on identifying and involving all agents in the field of rehabilitation at micro, meso, and macro level (40).

Methodological Considerations

The NGT has been used in several fields including multidisciplinary health care integrating a patient-centered approach (20, 41, 42). Methodological rigor was optimized following the stepwise approach and recommendations for the NGT-technique (19). However, using the NGT raises some critical issues concerning the prioritization of the question in focus, participants' expertise, facilitators' competencies, group dynamics and equal discussions (19, 41, 42). The need for addressing specific recommendations for rehabilitation research was identified by 33 rehabilitation experts, and six experienced researchers from this group were appointed to fulfill the work. The process facilitator, an experienced group leader and expert in rehabilitation, secured balanced discussions (19, 20). The recommendations have been discussed by the 33 rehabilitation experts, including service users, who found them of high relevance and importance. However, the NGT application is a versatile exploratory method (42), and future use of the recommendations will examine their value in relation to further development of the field of rehabilitation research.

Rehabilitation can be defined both as a health strategy and a set of interventions based on the biopsychosocial model of functioning and disability (43). The International Society of Physical and Rehabilitation Medicine acknowledge this complexity and has developed categories linking different levels of healthcare in rehabilitation with areas of the scientific field to illustrate the diversity of research perspectives and related methodologies (44). This complexity is captured in our list of compiled and collectively presented principles that serve to support rehabilitation research.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Developing and Implementing ICF-Based Tools for Occupational Rehabilitation Supporting the Communication and Return to Work Process Between Sickness Absentees, Clinical Team and Jobcentre Contacts

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Background: The ICF model is applied as a conceptual framework in occupational rehabilitation in Norway.

Objective: To systematically apply the ICF model in rehabilitation this study had the following aims: (1) apply an ICF subset by merging an ICF core set and an ICF set to assess functioning in rehabilitation patients related to work; (2) develop a patient-reported ICF questionnaire and a clinician-friendly ICF report complementing the clinician-rated ICF subset and (3) evaluate whether ICF-based tools (subset, questionnaire, report) support the communication between a clinical team, patient and jobcentre contacts during return to work (RTW) follow up.

Methods: Forty-one patients completing four weeks rehabilitation were recruited. The patients were referred from general practitioners and jobcentres. The ICF subset was a combination of the EUMASS core set for disability evaluation and suggested ICF categories by experts in vocational rehabilitation from Iceland. A clinical rehabilitation team interviewed the patients using the ICF subset and problems were quantified on a generic qualifier scale for body functions, activities and participation and environmental factors. The research team and clinical team developed an ICF questionnaire, by cross-culturally adapting the Work Rehabilitation Questionnaire to Norwegian. The same teams also developed an ICF report. The rehabilitation clinic forwarded the report and questionnaire to the patients' jobcentre contact, which was responsible for the RTW follow up. To evaluate the benefits of ICF-based tools, the clinical team, user representative and jobcentre contacts together participated in four workshops. They were asked the degree to which and in what way the tools supported the communication between them.

Results: The ICF subset captured RTW challenges but was found to be time consuming. The jobcentres experienced the ICF report and questionnaire beneficial in the follow up as it strengthened their RTW decision-making basis and communication with the rehabilitation clinic and the patients about follow-up interventions.

Conclusion: The development and implementation of ICF-based tools for clinical practice was a preliminary success in supporting the communication between three stakeholders during RTW follow up. Future applications of ICF-based tools ought to integrate personal factors to capture both facilitators and barriers related to functioning and work, thus, getting closer to a holistic assessment.

Keywords: ICF core set, occupational rehabilitation, work ability, sick leave, return to work (RTW), functioning

INTRODUCTION

The International Classification of Functioning, Disability and Health (ICF) is a classification and coding system based on a theoretical biopsychosocial model. The ICF reflects a holistic view of health, meaning that functioning and disability capture the biological and psychosocial aspects of health. One of the aims of the ICF is to provide a common language of functioning which all health professionals and patients can use (1). The ICF seeks to address health and functioning as a relationship between health condition, body functions and structures, activities, participation, environmental factors and personal factors (2). The latter are not classified in the ICF coding system mainly due to ethical aspects related to such factors as well as challenges reaching common factors based on societal and cultural diversity (3).

The ICF (2) and the Sherbrooke model, an ecological case-management model of work disability prevention (4) are the two models applied as frameworks in occupational rehabilitation in Norway (5). The case-management model is an operational model that emphasizes the importance of all stakeholders around the worker (personal, workplace, healthcare and compensation systems) that influence the return to work (RTW) and disability process. A key component in rehabilitation, highlighted in the Sherbrooke model, is collaboration with local stakeholders such as the workplace, and jobcentres responsible for the RTW follow up of rehabilitation patients (5). Assessing functioning and work ability, based on the ICF, may be fruitful to apply in occupational rehabilitation, thus complementing existing assessment procedures during rehabilitation related to work ability, RTW self-efficacy, RTW expectations, anxiety, depression and pain (6). This is also the case for jobcentres having their own work ability assessment because they are responsible for the follow up of sick-listed individuals, the target group of the present study. Each sickness absentee has their own case management worker supporting them in the RTW process.

The WHO has in collaboration with several research groups worldwide developed ICF core sets for a variety of health conditions and diagnoses (7). The main goal has been to operationalize the comprehensive ICF classification system, consisting of more than 1,400 ICF categories. An ICF core set refers to an extract of categories from the ICF classification that are relevant to assess for a given health condition. The ICF does not provide guidelines on how to apply the classification in clinical practice. However, the development of core sets is one way to promote the implementation of ICF in clinical practice. Systematic research has been invested in developing, testing and validating ICF core sets (8). In Norway, testing and validation of ICF core sets for low back pain (9, 10) and rheumatoid arthritis (11) have been conducted. Moreover, an ICF core set for disability evaluation related to functional assessments in social security benefits has been developed by the European Union of Medicine in Assurance and Social Security (EUMASS) where 11 countries participated (12). The ICF core set used in the present study was a combination of the EUMASS core set (12) and suggested ICF categories by experts in vocational rehabilitation in Iceland (13). Although the EUMASS core set and the vocational rehabilitation set did not adhere to the established ICF core set development process (7) they were developed through a rigorous and standardized consensus procedure (12, 13). Therefore, we use the term ICF subset referring to the fact that an ICF core set was not used in the present study. We wanted to take a broad approach and included categories that would capture functioning related to work in both short and long term sick-listed individuals (14), hence we decided to combine the two sets that together covered the biomedical, social and psychological aspects of a person's lived experience of health. Long term sick leave was in the present study defined as sickness absence of more than six weeks (15, 16).

The ICF is unique in the sense that it is generic and that disability related to both work and non-work settings can be compared. That is why this study attempted to establish a collaboration between three key stakeholders responsible for RTW, namely, rehabilitation patients, clinical team in rehabilitation and jobcentre contacts, all emphasizing personal factors of will and goal, complying with the strong focus on goal setting in rehabilitation. It was guided by a process model in occupational rehabilitation, involving several stakeholders having emphasis on goal setting and the coordination of services (17) as well as recommendations to standardize the use of ICF for clinical practice (18). The aim of the present study was threefold to take into account the process perspective with regards to RTW: (1) apply an ICF subset, by merging one already established ICF core set and another ICF set, to assess the functioning in rehabilitation patients related to work; (2) develop a patient-reported ICF questionnaire and a clinician-friendly ICF report complementing the ICF subset assessment; and (3) evaluate whether ICF-based tools (subset, questionnaire, report) support the communication between a clinical team, patient and jobcentre contacts in RTW follow up.

METHODS

Participants

Occupational Rehabilitation Patients

The patients were recruited from an occupational rehabilitation clinic in the specialist health care service, serving the South-East of Norway. Inclusion criteria were: aged between 18 and 67 and completing a 4-week inpatient rehabilitation programme. The patients were referred for rehabilitation by general practitioners or jobcentres (sickness absence insurance offices). Before referral to the rehabilitation programme, appropriate medical and work-related interventions had been attempted in the primary health care service, and thus, the patients required more comprehensive rehabilitation to be able to RTW. The patients attended individual and group-based interventions aiming to improve work ability, functioning related to work and goal setting for future work participation. Specific interventions included physical activity, making a written RTW plan, cognitive treatment components based on principles from cognitive therapy, acceptance and commitment therapy, psychoeducation, and motivational interviewing, and collaboration with the employer and the jobcentre (19).

User Representative

A former patient having previously completed occupational rehabilitation and who was working closely with a national rehabilitation user organization ensured user involvement. The user representative was systematically involved in developing the ICF questionnaire and ICF report.

Clinical Occupational Rehabilitation Team

The interdisciplinary clinical team comprising a physician, physiotherapist, work consultant, psychiatric nurse, psychologist and sports pedagogue performed the clinician-rated assessments (**Table 1**).

Research Team

Two research institutions participated each having one researcher in the working group (TJ and ÁDK).

Jobcentres

Six jobcentres located in the South-East of Norway participated. The jobcentres apply their own work ability assessment, which is conducted as a semi-structured interview addressing barriers and facilitators for RTW, education, interests, personal goals, social circumstances and health. This assessment is also carried out to determine the degree to which the worker is entitled to health-related benefits, such as sick leave benefits or disability benefits (20).

Materials and Procedure

Clinician-Rated ICF Subset

Prior to using the ICF subset in clinical practice, the clinical team received extended training in administering the subset by the research collaborator (ÁDK). This included a presentation on ICF, how human functioning is conceptualized through the ICF model and its classification system. The hierarchical arrangement of ICF components, chapters and level categories was also studied in detail. The training also included the usage of the generic ICF qualifiers, which quantify the extent of a problem experienced by a person in a specific ICF category (2). For body functions and activities and participation the qualifiers from 0 to 4 were used (0 = no problem, 1 = mild problem, 2 = moderate problem, 3 = severe problem, 4 = complete problem). The performance qualifier was used for activities and participation. For the environmental factors there are nine response categories that can either be facilitator or barrier (+4 = complete facilitator, +3 = substantial facilitator, +2 = moderate facilitator, +1 = mild facilitator, 0 = neither barrier nor facilitator, 1 = mild barrier, 2 = moderate barrier, 3 = severe barrier, 4 = complete barrier). The response options "8 – not specified" and "9 – not applicable" were used when appropriate.

The clinical team used the qualifiers and assessed the patients when commencing rehabilitation (pretest) and at the end of rehabilitation (posttest). The assessment was based on a semi-structured interview. First, in a consensus meeting prior to assessing patients, the six clinical team members were assigned ICF categories according to their domain of expertise. For example, all team members were assigned to assess attention functions (b140), while sensation of pain (b280) was assigned to the physician and physiotherapist, and school education (d820) was assigned to the work consultant. This assignment of qualifiers was adopted because the collaborating partner in Iceland had positive experiences in assigning domain specific qualifiers to ensure a competence-based assessment. Second, during the assessment of patients, each clinician individually assigned qualifiers on their own before discussing the individual ratings with the other team members. Consensus was reached where there were discrepancies.

The ICF subset used in the present study is displayed in **Table 2**, and comprised the EUMASS core set for functional assessments in disability evaluation (20 categories) (12) and the set for vocational rehabilitation developed in Iceland (13 categories) (13). The latter is different from the brief ICF core set for vocational rehabilitation (21). The EUMASS core set was developed through a formal decision-making process, where national EUMASS experts first suggested ICF categories and thereafter members of a working group voted on which ICF categories to be included in the final core set (12). The ICF categories from Iceland were also developed through a formal decision-making process where national experts in vocational rehabilitation first suggested ICF categories to be evaluated in vocational rehabilitation and thereafter a working group of physicians, physical therapists, occupational therapists, psychologists and social workers reached a final consensus on the included categories (13).

Patient-Reported ICF Questionnaire

The Work Rehabilitation Questionnaire (WORQ), an ICF-based instrument for vocational rehabilitation, has been validated to assess functioning in vocational rehabilitation (22). The

TABLE 1 | Overview of stakeholder involvement.

Stakeholder	ICF-based tool	What did the stakeholder do?
Clinical team	ICF subset	Assigned problem (body functions), problem (performance) (activities and participation), barrier (environmental factors) qualifiers
Clinical team	ICF report	Summarized results from subset and questionnaire
Rehabilitation patient	ICF questionnaire	Completed the patient-reported questionnaire
Jobcentre contact	ICF report, ICF questionnaire	Used the results in the report and questionnaire to decide upon appropriate interventions during RTW follow up

TABLE 2 | ICF subset categories for occupational rehabilitation ($n = 33$).

ICF code	Category title	Origin
	Body functions	
b130	Energy and drive functions	Vocational rehabilitation Iceland
b134	Sleep functions	Vocational rehabilitation Iceland
b140	Attention functions	Vocational rehabilitation Iceland
b152	Emotional functions	Vocational rehabilitation Iceland
b164	Higher-level cognitive functions	EUMASS disability evaluation
b280	Sensation of pain	EUMASS disability evaluation
b455	Exercise tolerance functions	EUMASS disability evaluation
b710	Mobility of joint functions	EUMASS disability evaluation
b730	Muscle power functions	EUMASS disability evaluation
	Activities and participation	
d110	Watching	EUMASS disability evaluation
d115	Listening	EUMASS disability evaluation
d155	Acquiring skills	EUMASS disability evaluation
d177	Making decisions	EUMASS disability evaluation
d220	Undertaking multiple tasks	EUMASS disability evaluation
d240	Handling stress and other psychological demands	EUMASS disability evaluation
d399	Communication, unspecified	EUMASS disability evaluation
d410	Changing basic body position	EUMASS disability evaluation
d415	Maintaining a body position	EUMASS disability evaluation
d430	Lifting and carrying objects	EUMASS disability evaluation
d440	Fine hand use	EUMASS disability evaluation
d445	Hand and arm use	EUMASS disability evaluation
d450	Walking	EUMASS disability evaluation
d470	Using transportation	EUMASS disability evaluation
d570	Looking after one's health	Vocational rehabilitation Iceland
d720	Complex interpersonal interactions	EUMASS disability evaluation
d760	Family relationships	Vocational rehabilitation Iceland
d820	School education	Vocational rehabilitation Iceland
d850	Remunerative employment	Vocational rehabilitation Iceland
d870	Economic self-sufficiency	Vocational rehabilitation Iceland
d920	Recreation and leisure	Vocational rehabilitation Iceland
	Environmental factors	
e310	Immediate family	Vocational rehabilitation Iceland
e460	Societal attitudes	Vocational rehabilitation Iceland
e580	Health services, systems and policies	Vocational rehabilitation Iceland

patient-reported WORQ is a derivative of the ICF core set for vocational rehabilitation (21). WORQ comprises two parts: part one sociodemographics and part two ICF-based items. For the present study it was appropriate to cross-culturally adapt part two of the WORQ self-reported English version into Norwegian as 33 of WORQ's 42 items were identical with the categories in the ICF subset (**Table 2**). Existing instruments already applied in rehabilitation covered part one (sociodemographics). The general recommendation for cross-cultural translation was followed in the adaptation process (23) with some modifications to integrate learned lessons from administering the ICF subset. The forward translation was conducted by three translators of which one was bilingual in English. All translators were aware of the purpose of the questionnaire and their backgrounds were psychology, physiotherapy and nursing. The three translated questionnaires were compared and a questionnaire synthesized from the translation of the three translators, resolving discrepancies between the versions, was developed. The synthesis version of the ICF questionnaire was pre-tested on nine patients to investigate its user friendliness, wording and verbal feedback given by each patient. The time taken to complete the pre-test version of the questionnaire and give feedback to the examiner was 15–30 min.

Clinician-Friendly ICF Report

The research team, clinical team and jobcentres developed an ICF report to systematically follow up patients who did not return to full time employment following rehabilitation. In the report, the clinical team summarized the clinical and patient-reported findings of functioning and work ability from the clinician-rated ICF subset assessment, patient-reported ICF questionnaire assessment and other standardized assessments carried out during rehabilitation. This summary of findings was used to provide the jobcentre contacts with individual patient specific information on functioning and work ability, and on that basis, suggest specific RTW interventions to be discussed between the contact and the patient during the RTW follow up period. The collaborating stakeholders structured the report according to the ICF components including personal factors and goal setting. The report is included as **Supplementary Material**. Thus, the content of the report was divided into four sections: (1) summary of functioning and work ability assessments carried out prior to rehabilitation by the employer, general practitioner and jobcentres, (2) patient-related RTW goals during rehabilitation, (3) summary of functioning and work ability according to ICF subset and ICF questionnaire for activities and participation, personal factors, environmental factors including RTW facilitators and barriers based on physical and psychological demands in current work, and (4) suggested work-related interventions in the primary health care service, specialist health care service or by employer and jobcentres following rehabilitation. On the final day of rehabilitation, the patient read through and approved the content of the ICF report prior to sending it to the patient's jobcentre contact.

ICF Workshops

An overview of ICF workshops is given in **Table 3** where the topic of the workshops and the participating stakeholders are presented in chronological order during the 2-year study period. The workshops were designed to facilitated knowledge transfer and exchange between the stakeholders. There were three project phases. Phase 1 (pre-project phase) included supervisory guided ICF training to ensure that all clinicians in the team were at the same level with regards to ICF knowledge and competencies. A session was also devoted to assigning ICF subset qualifiers according to each clinicians' area of expertise to ensure that each qualifier was scored and evaluated based on optimal clinical knowledge. This was followed by a workshop where clinicians discussed the scoring and consensus procedure in the ICF subset assessments. Phase 2 (project phase) included workshops devoted to identify the common language between the ICF subset assessment and the work ability assessment used by the jobcentres, cross-cultural adaptation of the 33 items from the WORQ to Norwegian to produce the ICF questionnaire, development of the ICF report and usage of common language to better communicate ICF results to the jobcentres. Progression was ensured during weekly supervision. Phase 3 (learning evaluation during and after project period) focused on what the stakeholders had learned and achieved and what would be the preferred learning outcome at the end of the project period. The learning evaluation conducted after the project period focused on implications for clinical practice and implementation of results in clinical practice. A workshop was also devoted to reaching consensus on the common ICF language in the report contributing to improved communication between the clinical team, patient and jobcentre. Here the clinical team, patient and jobcentres were specifically asked the degree to which and in what way the tools supported the communication between them. The written content of each workshop was summarized and distributed among the participating stakeholders (research team, clinical team, user representative, jobcentres).

Study Design

In the first phase of the study, the clinical team administered the ICF subset assessment at posttest. In the second phase, the subset was administered at the timepoints pretest and posttest to capture the degree of changes during rehabilitation in functioning and work ability. The application of the patient-reported ICF questionnaire followed the same phases. First administration at posttest followed by pretest and posttest assessments. The ICF report was completed by the clinical team at posttest. Posttest assessments were carried out first because the team needed to get experience in reporting on the patients' functioning and work ability to the jobcentres. To provide the jobcentre contacts with information on the degree of changes in functioning and work ability the assessments were also conducted at pretest and posttest for the ICF subset and ICF questionnaire. The period between the pretest and posttest was 4 weeks.

RESULTS

Sample Characteristics

The total sample included 41 patients of which 60% were on partial sick leave and 40% were on full time sick leave (28 female, 13 male, mean age = 47, standard deviation 6.5). The mean length of sick leave prior to rehabilitation was 23 weeks. Full time sick leave refers to 100% sickness absence whereas partial sick leave is any graded sickness absence below 100%.

Clinician-Rated ICF Subset

The ICF subset assessment of each patient took ∼10–20 min and the duration of the consensus meeting in the clinical team for each patient lasted 30–60 min. The clinical team assessed the patients to have problems in all 33 ICF categories with a frequency from 5 to 95%. The five most frequently

TABLE 3 | Chronological order of ICF workshops and topics including the participating stakeholders [research team (RT), clinical team (CT), Jobcentre (JC), user representative (UR)].

	Chronological order of ICF workshops	Participating stakeholders				Topic of workshop
Phase 1	2-Day preparation workshop prior to project start	RT	CT			- Supervisory guided ICF training of classification, model, qualifiers, components, codes and category definitions of the ICF subset - Team training in administering the ICF subset
	ICF category assignment	RT	CT			- Each clinician assigned ICF categories according to area of expertise
	ICF related project issues	RT	CT			- Supervision of the ICF subset assessment - Two weekly meetings during project period between research team/clinical team/jobcentre
	1-Day ICF core set workshop	RT	CT	JC		- Scoring and consensus procedure in ICF subset assessment
Phase 2	1-Day preparation workshop	RT	CT	JC	UR	- Supervisory guided ICF training in collaboration with jobcentre - Identification of common language between ICF subset and work ability assessment instrument from jobcentre supporting the communication between stakeholders
	ICF questionnaire	RT	CT	JC	UR	- Cross-cultural adaptation (using 33 of 42 Work Rehabilitation Questionnaire items)
	1-Day ICF core set workshop	RT	CT	JC		- Identification of common language supporting the communication of ICF results to jobcentres
	ICF report	RT	CT	JC	UR	- Development of report - Report structured according to ICF model and work ability assessment from jobcentre
Phase 3	1-Day learning evaluation workshop	RT				- What have I/my organization learned/achieved from the collaboration? - My organization is/I am so pleased at the end of the project period because?
	1-Day learning evaluation workshop	RT		JC		Key reflection statements: - ICF questionnaire support the follow up because… - ICF report contains sufficient information during follow up because… - Jobcentres should be involved prior to rehabilitation because… - Jobcentres can merge the ICF report with the work ability assessment because… - ICF report could be improved in the following way… - My main message to the research team is…
	1-Day learning evaluation workshop	RT	CT			- Implications for clinical practice
	2-Day final evaluation workshop	RT	CT	JC	UR	- Reach consensus on common language in report - Implications for clinical practice and implementation of project results in clinical practice

scored problem categories in body functions and activities and participation and the two most frequently scored barrier categories in environmental factors are displayed in **Table 4**. A problem and a barrier were defined if the clinical team assigned a qualifier between 1 and 4. The clinical team found the subset assessment to capture the patients' functioning, work ability and return to work challenges but was experienced as time consuming.

Patient-Reported ICF Questionnaire

The 33 ICF categories shown in **Table 2** were adapted to Norwegian from the WORQ. The research team and clinical team agreed that the ICF subset mainly focused on barriers and addressed this issue during the development of the ICF questionnaire, shifting the focus from barriers to facilitators. This followed from the feedback from the patients and the examination of the translated version of the ICF questionnaire by the user representative, research team, clinical team and each of the six contact persons at the jobcentres. It was therefore decided to frame the ICF items in the questionnaire positively.

Example question from the adapted ICF questionnaire: Item b730, ≪During the past four weeks, to what extent have you… …had enough muscle strength to carry out your daily activities≫ Response options: ≪0 = to a very small extent≫ to ≪10 = to a very large extent≫. The recall period was changed from one to four weeks corresponding to the length of rehabilitation. These modifications to items and recall period were carried out to increase the applicability of the questionnaire in the current

TABLE 4 | The five most frequently scored problem categories by the clinical team (qualifiers 1, 2, 3 and 4) in body functions and activities and participation and the two most frequently scored barrier categories in environmental factors related to functioning and work ability at posttest ($n = 23$).

ICF categories	% of patients with problems
Body functions	
b130 Energy and drive functions	96
b134 Sleep functions	91
b152 Emotional functions	87
b280 Sensation of pain	87
b455 Exercise tolerance functions	74
Activities and participation	
d240 Handling stress and other psychological demands	100
d920 Recreation and leisure	100
d570 Looking after one's health	96
d220 Undertaking multiple tasks	74
d850 Remunerative employment	63
Environmental factors	
e310 Immediate family	70
e460 Societal attitudes	35

rehabilitation context and do not adhere to the design and content of the standardized WORQ.

Clinician-Friendly ICF Report

The time taken to complete the ICF report by the clinical team for each patient took ∼20–30 min. In total, the clinical team and the research team completed a report on 11 rehabilitation patients who all read their individual ICF report and consented to sending the report to their local jobcentre contact responsible for the RTW follow up. The jobcentres found the ICF questionnaire and the ICF report beneficial in the follow up of patients after rehabilitation as it strengthened their RTW decision-making basis and communication with the clinical team and the patient about further work-related interventions.

ICF Workshops

The workshops facilitated knowledge transfer and exchange during the study period and after study completion. The clinical team and the jobcentre contacts emphasized that the main learning outcome at the end of the study period was the adoption of new ways of working and collaborating, based on the ICF, between the clinical team, patients and jobcentre contacts (see also **Table 3** for an overview of topics covered during the workshops).

DISCUSSION

Summary of Findings

The results of this study showed that the collaborating stakeholders, a clinical team, patients and jobcentre contacts, found the ICF subset not suitable to be administered in clinical practice on its own and therefore supplementary tools were needed to carry out a holistic assessment during occupational rehabilitation. This led to the development of a patient-reported ICF questionnaire and clinician-friendly ICF report supporting the clinician-rated ICF subset assessment. These tools were found to be beneficial in the communication between the clinical team, patients and jobcentre contacts during the RTW follow up period after rehabilitation. It was a step in the direction of reaching a common language based on the ICF, supporting the communication between the clinical team and the jobcentres and between the patients and the jobcentres. The jobcentres argued that the report and questionnaire gave them a stronger foundation to make decisions about further work-related interventions for RTW seeing facilitators and barriers together to capture a holistic perspective on the opportunities for RTW.

ICF Training

Supervisory guided training to increase the knowledge about the ICF classification, its coding system and the rationale for developing and administering ICF core sets was conducted prior to using the ICF-based tools. We suggest this to be mandatory for all clinicians intending to use ICF-based tools. Ideally the supervisor should be a clinician with extensive training and experience in using and applying the ICF in clinical practice, such as in the present study. It seems fruitful to dedicate one or two clinicians who receive extended training in using the ICF and are responsible for collaborating with stakeholders during rehabilitation, and in the RTW follow up process (24).

ICF Subset Assessment

The clinical team experienced challenges in using the ICF subset in clinical practice. The assessment was time consuming, taking at least 40 min for each patient. The time consuming administration procedure was a barrier for implementing the ICF subset in a Norwegian occupational rehabilitation setting. These findings corroborate other studies applying ICF core sets in clinical practice (9, 10). Furthermore, using ICF core sets in clinical practice has been identified as challenging (25). Which of the 1,400 ICF categories are suitable for assessment, given a specific health condition? And how do we ensure that clinicians have the expertise and competence required to administer core sets? Personal factors, which is a major component in rehabilitation, tend not to be linked to goal setting in the ICF (26). Having said this, the WHO has emphasized that the ICF is a terminology and a classification system, and not a measurement instrument. The terminology can be used to develop an instrument and existing instruments can be mapped to ICF terminology, such as the WORQ (22). The ICF categories in the subset are assumed to be relevant for occupational rehabilitation because we combined the core set for disability evaluation (12) and the set for vocational rehabilitation (13). Therefore, the ICF subset assessment did capture relevant facilitators and barriers for RTW, but the clinicians argued that the patient perspective was lacking. The clinicians also stated that it was unsuitable as a communication tool between the jobcentre contacts and the patients. This laid the foundation for integrating the three ICF-based tools and will be further discussed and elaborated upon.

Integration of ICF-Based Tools in Rehabilitation

The clinical team found the combination of using the ICF subset, the ICF questionnaire and summarizing the findings in the ICF report beneficial for the patient because the jobcentres experienced the information in the ICF report highly relevant. The workshops contributed to maintain effective communication between the stakeholders and to develop a common understanding of RTW facilitators and barriers based on the ICF. And further, to improve competencies about the application of ICF-based tools in clinical practice and at the jobcentres. It can be argued, based on the discussions in the workshops, that the usage of ICF-based tools was partly successful in operationalising the ICF model and creating a common language that supported the communication between the clinical team, patient and jobcentres. It made the communication in the ICF report more efficient because it was founded on the language and content of the jobcentre's work ability assessment. The work ability assessment from the jobcentres can be viewed as a static assessment because it provides a cross sectional glimpse into work ability, whereas the ICF report is a dynamic report based on a 4-week rehabilitation programme taking into account actions relevant in the RTW follow up process. Therefore, the report was found to strengthen the decision making of the jobcentres, where specific follow up interventions were suggested for each patient. The content of the report was also synchronized with the aims of rehabilitation, namely, the focus on person-centered functioning such as coping, work-related self-efficacy, RTW expectations, experiences and resources (27–29). The development and application of the ICF-based tools seem to have resulted in an extended understanding of functioning and work ability, thus having the focus on salutogenic factors in the personal and activities and participation domains. Specifically, the positive framing of the items in the ICF questionnaire, may have contributed to focus not only on barriers but also on facilitators by all three stakeholders. Complementing the ICF qualifier approach by framing the ICF stem question positively could encourage reflections around empowerment and RTW self-efficacy (27). We believe that the framing modification was important due to the impact ICF have, and will have, on clinical practice (18, 30). The usage of ICF-based tools in the present study contributed to making ICF more applicable for clinical practice as well as during RTW follow up (18) where the focus was on opportunities for RTW, improving work ability, RTW expectations and RTW self-efficacy (6).

Sickness absence and work disability is a focus within the domain of activities and participation according to the ICF model (31). Occupational rehabilitation requires a relational approach between contextual factors both at home and work, with an emphasis on work participation. Successful RTW is more likely to be achieved if stakeholders in all system levels are involved (32). Focusing only on the individual is too narrow because a worker with a disability is dependent on the workplace, legislation and context. Still, the key challenge is knowing how and when to intervene in activities and participation and environmental and personal factors (17, 33). The present study was guided by the pragmatic application of the conceptual ICF model in occupational rehabilitation where the following questions are posed (17): (1) How should we describe functioning based on facilitators and barriers? (2) Which goals should be targeted in the rehabilitation process? (3) Which interventions support the goals? (4) Who is responsible for coordinating the services? These open-ended questions underpins the importance of approaching rehabilitation in terms of a process involving key stakeholders. ICF core sets guide clinicians to look at functional items that are often relevant for a particular group of patients and subsequently apply a process model. Applying a pragmatic approach seems to be an fruitful way forward contributing to holisitic assessments in rehabilitation (24). The usage of the conceptual ICF model, as the starting point of the current study, is consistent with the view that rehabilitation is about establishing an opportunity for participation according to individuals' desires and motivations (25, 26) and to enhance the subjective experience of human functioning despite a challenging health condition or disability (34).

Strengths and Limitations

The strengths of this study were the usage of established ICF-based tools such as the EUMASS core set and WORQ as well as applying the ICF, which is an accepted international reference standard for operationalizing functioning. The description of the content of the ICF workshops was carried out to document the progress and reach consensus on the way forward to increase the standardization of the assessments. The main limitation was the lack of using ICF as a person-centered tool which was not fully captured in the semi-structured interview between the clinician and the patient. We did not use the ICF assessment sheet nor the rehabilitation problem-solving form which could have enhanced the assessments (35). To develop a thorough competency of ICF requires continuous and systematic work by clinicians and researchers, which was not the case for all clinical team members involved. The research team provided training if a new team member was not familiar with the ICF. However, this training was not considered comprehensive and may have negatively affected the quality of assessments. The user representative was only involved in developing the ICF questionnaire and ICF report, and systematic user involvement was not applied throughout. The results of the patient-reported ICF questionnaire and the clinician-rated ICF subset assessment must be considered exploratory, because of the small number of participants recruited. Further, it was decided to frame the questions in the ICF questionnaire positively, which contrasts with the framing in the WORQ. This change in psychometric properties should have warranted calculations of the instrument's internal consistency and inter-rater reliability using the intraclass correlation coefficient. Similarly, we did not carry out reliability or validity analyses on the ICF questionnaire because of the low number of participants recruited. More research is therefore needed to confirm the usefulness of the report and the questionnaire and the present results should be taken as exploratory.

CONCLUSION

There is a need to develop and implement new and current assessments tools of functioning and work ability in occupational rehabilitation and the ICF-based tools developed in the current study is a step in that direction. The integration of the ICF subset, questionnaire and report was a preliminary success in creating a common language supporting the communication between a clinical team and six jobcentres and between the patient and the jobcentre contacts in the RTW follow up period. The result of the ICF subset assessment was deemed insufficient to communicate to the jobcentres during follow up of rehabilitation patients. To better fit with the work ability assessment language used by the jobcentres, ICF-based tools were developed. The jobcentres stated that the results in the report and the questionnaire laid the foundation for improved communication with the clinical team, enhanced the decision-making process where the jobcentre contact in dialogue with the patient could make informed decisions on appropriate interventions in the follow up period to increase the chances of RTW. Using ICF tools and include the person-centered focus in future clinical practice studies, should lay the foundations for a deeper understanding of the clinical and work-related implications of the ICF, underpinning holistic principles as well as making the ICF more applicable for clinical practice.

DATA AVAILABILITY STATEMENT

The data and documentation supporting the conclusions of this article will be made available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The participants were informed about the nature of the study and all gave written informed consent, which formed part of the standard procedure at the clinic prior to commencing rehabilitation. Therefore, it was not required to seek ethical approval for this study. Nevertheless, all procedures followed were in accordance with the ethical standards of the Helsinki Declaration.

AUTHOR CONTRIBUTIONS

TJ and ÁDK planned and designed the study. TJ and AMK were responsible for data collection. TJ carried out the analyses and wrote the first draft of the manuscript. AMK and ÁDK commented on and reviewed later versions of the manuscript. All authors read and approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2022.830067/full#supplementary-material

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Peer Counseling: Method, Metaphor, or Mindset?

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Peer Counseling and Peer-to-Peer-Counseling are two common counseling formats worldwide where people meet each other at eye level. Rooted in the Independent Living and Self-Help Movement, "classic" Peer Counseling can be considered a professional counseling service offered by and for people with disabilities. In this article, the question is explored whether Peer Counseling is far more reaching than just being labeled as a counseling method. In many countries, it has now found a permanent place in the counseling landscape among others. Furthermore, the question arises whether it does not also serve as a metaphor for a self-determined way of life. In addition, in this study it will be determined whether and why the mindset and attitude are also important in professional Peer Counseling. Since 2018, Peer Counseling has been offered at over 500 counseling centers in Germany as part of the "Ergänzende unabhängige Teilhabeberatung—EUTB®" (Additional Independent Participation Consulting). At a low-threshold and accessible level, advice seekers can find competent individual-centered professional counseling here—often from experts by experience: peers. For many people seeking advice, this is the first and last point of contact for all matters relating to rehabilitation, inclusion and social participation. As part of my PhD-project, I am doing research on Peer Counseling and parallel to this, I train EUTB- and Peer Counselors. Peer Counseling actually is (much more than) a counseling approach which represents a true enrichment for everyone.

Keywords: peer support, independent living, Ergänzende unabhängige Teilhabeberatung – EUTB, Peer Counseling, ableism, counseling methods, expert by experience

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WHAT IS PEER COUNSELING?

> *"You want to work? You are blind. You wouldn't even find the office!"*
> *"If you want to advise others, then you must take part in specific trainings and exude confidence and competence—how do you want to do that as a wheelchair user?"*
> *"You want to counsel others despite your depression? That's not possible—you are mentally ill. You cannot pursue gainful employment in this condition!"*

Similar like this, it may sound when people, who are chronical ill or have a handicap or a participation impairment[1], tell other people about their career aspirations or future plans.

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[1] In this article, the terms *participation impairment, handicap, impairment*, and *dis_ability* are used synonymously. This refers to people with one (or more) chronic illnesse(s), existing and/or officially recognized (severe) dis_ability(ies)—regardless of the type and extent of the disability(ies) because for participation in Peer-Counseling-Training-Courses, the *form of participation impairment* is subordninated.

In March 2009, Germany ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD); a paradigm shift, manifested in 50 articles from the medical-deficit perspective on dis_abilities[2] to the establishment of the human rights approach.

Reasons for the development of this convention was the experience of discrimination, disadvantage and exclusion of people with chronic illness and/or dis_abilities worldwide.

Since the 1960's, interest groups and self-advocacy organizations have been campaigning for equal opportunities, the promotion of a self-determined independent lifestyle, non-discrimination, full accessibility and equal participation in social and cultural life. The ratification of the UN CRPD can be identified as a milestone on the way to an inclusive society in which "deviations from the norm" are anticipated as enrichment and diversity.

Peer support services, i.e., forms of mutual support by other persons with disabilities, are cited in Article 26, paragraph 1 of the UN CRPD as a suitable approach to enable persons with dis_abilities to achieve the highest possible degree of self-determination and sovereignty over their own physical, mental-emotional and psychosocial abilities as well as the greatest possible participation in all aspects of life by activating available resources. This can be achieved by the *empowerment approach* used in Peer Counseling [cf. (3), p. 2].

Results of relevant studies point out that Peer Counseling by and for people with dis_abilities can promote the individual's awareness of their abilities, skills, gifts and talents—as required by Article 8 of the UN CRPD [cf. (4, 5)].

The consulting approach of *Peer Counseling* is not new, but has undergone a transformation process since the first utilizations in the 1960's in the USA. Up to a professional counseling offering, which is no longer to be excluded from the counseling landscape of many countries.

Among other formats of structured and formalized Peer Support Offerings, e.g., Peer Education, Peer Mediation, Peer Tutoring, Peer Mentoring or Peer Listening as pictured on the graph (**Figure 1**).

Peer-to-Peer Consulting is used in different fields and contexts. *Specially trained peers*[3] accompany, for example, deployment contingents of the German Army in crisis intervention teams as "*psychological first aiders*" [cf. (6), p. 12–21], can be found in the area of emergency support for civil defense and disaster control forces [cf. (7), p. 42–46], advise students (8), or are involved in education of teachers [cf. (9), p. 74–80].

Whereas, *"classical" Peer Counseling* is a specific counseling service offered *by and for people with dis_abilities*. Here, counseling professionalism and individual biographical experiential knowledge work together [cf. (10), p. 16].

Parallel to other *social movements*[4], the first Peer Counseling Programs were implemented in the USA in the 1950's. Initially, the focus was on participation programs for seniors [cf. (12), p. 49 f.]. Sponsored by the "Disabled-Student-Program," in 1962, four students were enabled to study at the University of Illinois and live self-determined—supported by Personal Assistance. In the same year, Ed Roberts sued successfully to the University of California, Berkeley for admission. Shortly afterward other mobility-impaired students, the "Rolling Quads," followed his example. Those first groups of disabled students initiated to support each other and started empowerment programs for students with participation impairments. Together, they advocated for barrier-free access to university education and self-determined living in the community. As a result, since the 1970's, the "Independent Living Movement" and "Disabled in Action" have been spreading in the USA, advocating for equal participation of people with dis_abilities, offering Peer Counseling, and utilizing the empowerment approach [cf. (13), p. 28–31 and 56–73].

In many countries, anti-discrimination laws have been passed as a result of activities and campaigns by organized self-help and advocacy groups since the 1970's. In Germany, "*Zentren für selbstbestimmtes Leben*" (Centers for Independent Living) have been established since the 1980's. In many places, in addition to barrier-free and accessible contact opportunities and leisure activities, professional qualified advice—Peer Counseling—is also offered by and for people with participation impairments; organized in Germany under the umbrella organization "*Interessenvertretung selbstbestimmtes Leben*—ISL e. V." [Representation of Self-Determined Life; cf. (14), p. 7].

Since 1994, the "*Bildungs- und Forschungsinstitut für die Selbstbestimmung Behinderter*—bifos e. V." (Education and Research Institute for the Self-Determination of Disabled Persons) offers annual training courses for Peer Counselors. The curriculum is based on the curriculum developed by the US Independent Living Movement. Other self-advocacy associations have designed curricula to qualify people with various forms of participation impairments as Peer Consultants as well:

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[2] The spelling of dis_ability with an underscore (*ability gap*) points out that the transitions to "non-disability" are partly fluid, change in different phases of life and are not an obstacle/barrier per se in everyday life and situation. Rather, disability represents a partly medical, partly structural, and partly socially constructed category that favors the exclusion of people with physical or psychological "deviations from the norm" through attributions or the design of architecture [cf. (1), p. 1]. In addition, the ability gap points out that there is no such thing as "*the* disabled person/s," since people who have the same diagnosis, for example, deal with symptoms in different ways. This is depending on the manifestations, individual life situation, the individual living environment, as well as other personal conditions. In *Intersectionality Research* as well as in the emancipatory-participatory oriented *Disability Studies*, disability is understood as a socio-cultural process of categorization and stigmatization. Therefore, the ability gap visually forms a reference to these relations of difference and inequality of a hierarchical-normative social order [cf. (2), p. 38].

[3] *Peer* means "of equal rank, equivalent, similar interests." In this context, the peer-concept aims at the fact that both the counselor and the counselee are, for example, in a similar life environment (professional affiliation, biographical experience or else) or both are in a comparable (life) situation or – as found in "classical" Peer Counseling"—both are people living with a chronic illness and/or dis_ability.

[4] Like "need-based" associations, *social movements* have sociopolitical, economic or cultural origins. The intention is to work toward changes in the public and political sphere in order to assert interests, intentions and goals in politics and society. Examples of those civic emancipation movements are: anti-nuclear movement, labor movement, civil rights movement, peace movement, women's rights movement, student movement, veterans' movement, or the disability movement [cf. (11), p. 13–60].

- *"EXperienced-INvolvement—Genesungsbegleitung"* (EXperienced-INvolvement Recovery Support): Since 2005, people with a psychiatric diagnosis have been trained nationwide as EX-IN-Recovery-Supporters. More than 500 EX-IN-Supporters advise people with psychiatric illnesses on various topics—such as structuring everyday life, resilience, resource orientation, and dealing with medication.

  Some are offerering consultation hours in psychiatric clinics, others are affiliated with self-help associations and initiatives[5].
- *"Blickpunkt Auge-Beratung"* (Eyepoint Eye-Consulting): The "*Deutsche Blinden und Sehbehinderten Verband—DBSV e. V.*" (German Association for the Blind and Visually Impaired) has also been conducting training courses at various locations by and for blind and visually impaired people since 2012. Providing comprehensive and independent advice to other affected people, their relatives and interested parties on topics relating to vision (loss), eye diseases and visual impairments as well as the provision of aids and appliances[6].
- *"Beratung auf Augenhöhe"* (Eyelevel Consulting): In various model projects, people with so-called intellectual disabilities have been enabled by *"Lebenshilfe Service gGmbH"* at different locations since 2013 to advise other people with learning difficulties on the topics of housing, work, and leisure time[7].
- *DeafMentoring*: As the name suggests, in first line this Peer–Consulting-Offer is located in the area of mentoring programs. Deaf and severely hearing impaired people accompany other deaf people as mentors on their way into professional life, aligned at Rheinisch-Westfälische Technische Hochschule Aachen[8].

With the nationwide introduction of the *"Ergänzende unabhängige Teilhabeberatung—EUTB®"* (Additional Independent Participation Consulting) in Germany in 2018, the offering structures of Peer Counseling shall also to be strengthened [cf. (15), p. 12 f.].

In many EUTB-offices, people with chronic illness and/or dis_ability are employed; some as full-time counselors, several on a part-time basis, and about one third of the EUTBs employ Peer Counselors on voluntary basis. Since, according to the mandate, advice is given on all questions of rehabilitation, inclusion and social-cultural participation, it is not least the people seeking advice who benefit from the heterogeneous composition of the advice teams (4).

In Germany, the diverse range of professional peer-consulting-offers rests on several pillars, as pictured in the model (**Figure 2**).

Even if the preparatory qualifications for Peer Counselors and Peer Consultants are neither standardized nor uniform, it is still possible to speak of *professional counseling*. Following the *extended concept of profession*, Peer Counselors are trained *to act professionally*, learn to *apply conversation and communication techniques* appropriate to the situation and addressee, have a broad (experiential) knowledge, organize the counseling sessions in a *formalized setting*, and there is a clear dividing line between counselor and counselee: Here in the form of a knowledge advantage between those seeking advice and those providing it.

PEER COUNSELING: ONLY A COUNSELING METHOD?!

In the relevant literature, Peer Counseling is referred to as "*the* pedagogical method" of the Independent-Living-Movement. As accessible voluntary counseling offered by and for people with participation impairments in all four dimensions[9]—content, spatial, social, and temporal—the *"Berufsverband für Peer Counseling—BVP e. V."* [Professional Association for Peer Counseling; cf. (17)] is oriented toward approaches and methods that are also used in other counseling and consulting offers.

Traditionally, Peer Counseling follows an *integrative approach* to counseling based on a humanistic view. According to the person-oriented empowerment concept, Peer Counseling takes place in a context- and issue-specific on all topics that the counselees bring to the table [cf. (17, 18), p. 43 f., (19), p. 20–31]:

- active listening and questioning,
- client-centered conversation according to Carl Rogers,
- resource and social space orientation,
- systemic interventions,
- solution-focused approaches, such as Personal Future Planning, and
- following the basic attitude of empathy, acceptance, and authenticity.

In principle, Peer Counseling is free of charge counseling service, and independent of economic, business, or budgetary interests [cf. (20)]. Although, Peer Counseling is—even if the counselors are "only" engaged in voluntary or part-time work—a (partially) formalized *professional counseling service*. Information transfer and accompanying support, based on conversations and other (crisis-) intervention techniques, take place in a protected setting in an appealing atmosphere. The roles are clearly defined in advance: There is the qualified Peer Counselor and the person seeking advice (counselee); both encounter each other on an equal footing, unlike is sometimes the case with

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[5] Further information online: https://ex-in.info; last reviewed on: 19.10.2021.

[6] Further information online: https://blickpunkt-auge.de; last reviewed on: 19.10.2021.

[7] Further information: https://www.lhbl.de/peercounseling-116.html?file=files/lebenshilfe/pdf-anlagen/art ikel-360-peercounseling.pdf and online at: https://www.inform-lebenshilfe.de/inform/veranstaltungen/termine/bv/210253-bv-peer-unterstuetzung.php; last reviewed on: 19.10.2021.

[8] Further information online: https://signges.rwth-aachen.de/go/id/ljbg; last reviewed on: 19.10.2021.

[9] These four dimensions of low-threshold accessible (Peer-) Counseling Offers are described in the literature as follows: In terms of *content and concept* (open setting, openness to all topics and concerns), in the area of *spatial accessibility* (accessible without steps or obstacles, easy to find with good local transportation connections, and appropriate equipment), *social low-threshold* (no administrative hurdles, protecting the anonymity of counselees, counseling is free of charge), and the *temporal* dimension [clearly communicated office and consultation hours as well as time-independent options for making contact and prompt allocation of appointments; cf. (16), p. 98–106].

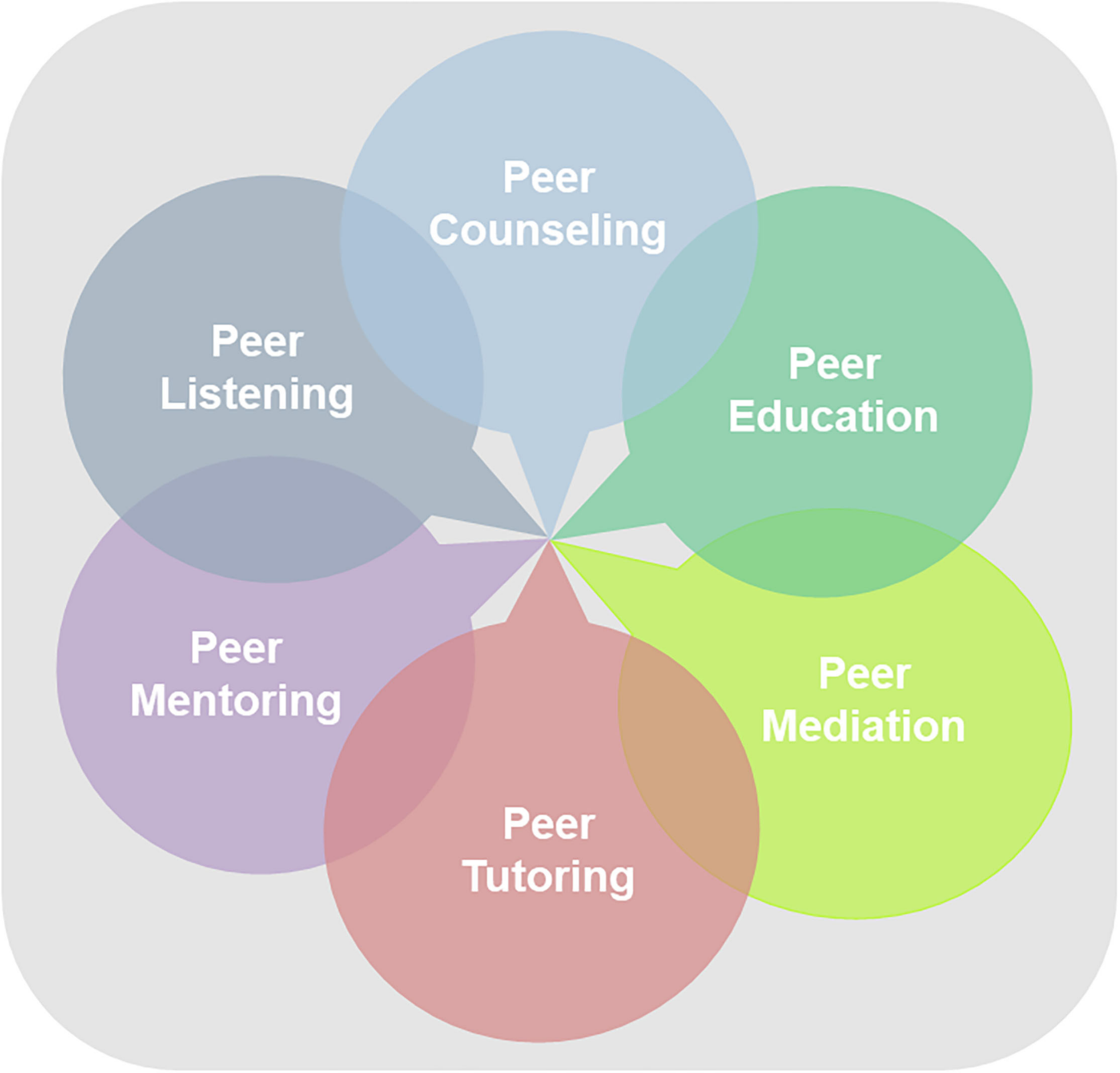

FIGURE 1 | Formats of Peer Support Offerings. In the interest of accessibility, here a complete description of the image: The picture shows a gray square with six circles containing different peer support services. The circles are in semi-transparent colors and overlap partly. With an arrow they all point to the center. On top (on 12 o'clock on a dial) the circle "Peer Counseling", in the right upper quadrant (2 o'clock) "Peer Education", in the bottom right quadrant (4 o'clock) "Peer Mediation", down (on 6 o'clock) "Peer Tutoring", in the bottom left quadrant (7 o'clock) "Peer Mentoring" and on the upper left quadrant (11 o'clock) "Peer Listening."

professional consulting services offered by government agencies and authorities, coaching or psychotherapy.

Peer Counseling—following the idea of a low-threshold and accessible open setting—is mostly oriented toward a "come structure," i.e., the counselees decide the topics and contents to be discussed (*participatory justice*). In addition to leading the conversation and clarifying concerns, Peer Counselors tend to take the role of *experienced process facilitators*. Due to their reflected professional biographical (dis_ability) experiences, they can help to shape the counseling relationship and process with their expertise, but they do not bear the responsibility for successful crisis management, solution development, or implementation of new knowledge [cf. (21, 22), p. 52 ff., (23), p. 74–85].

Rather, it is the concern and mission of Peer Counselors to (re-)discover individual resources together with the counselees, to support them in decision-making and problem-solving processes—always

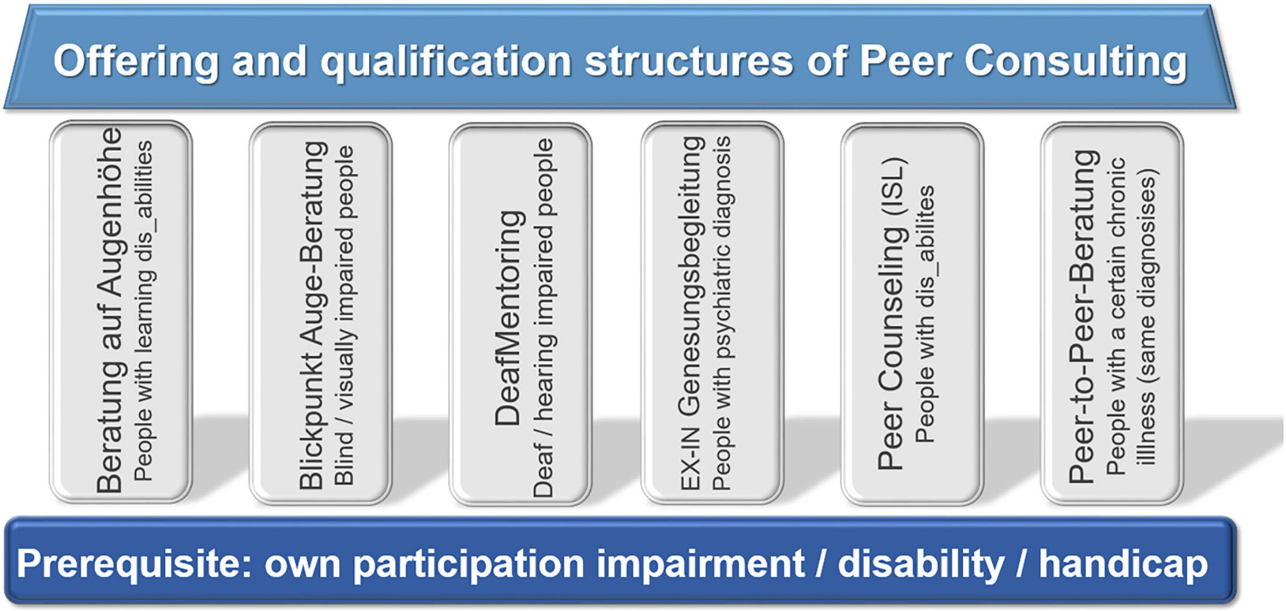

FIGURE 2 | Offering and qualification structures of Peer Consulting in Germany. Pictured is a graphic that resembles a house in its structure. At the bottom of the picture—corresponding to the foundation of a building –is a transverse bar, titled "Prerequisite: own participation impairment / disability / handicap." Based on this, there are six pillars that carry the roof "Offering and qualification structures of Peer Consulting." Each of these six pillars represents an approach to Peer Consulting Training: From left to right there are: "*Beratung auf Augenhöhe*"—Eyelevel Counseling by and for people with learning disabilities, "*Blickpunkt Auge-Beratung*"—Eyepoint Eye-Consulting by and for blind and/or visually impaired people, "*DeafMentoring*"—a mentoring program, by and for deaf and/or hearing impaired people, "*EX-IN-Genesungsbegleitung*"—EX-IN-Recovery-Support by and for people with psychiatric diagnosis, *Peer Counseling* by and for people with disabilities, "*Peer-to-Peer-Beratung*"—Peer-to-Peer-Counseling by and for people with a certain chronic illness (same diagnosis).

with the aim that the counselees (re-)gain self-determination and the ability to act for living in independency.

Current research shows that, in the context of Peer Counseling, a significant role can be attributed to the shared lifeworld, similar life realities, and the shaping of relationships. Aspects of this social, societal, and at the same cultural construction of reality are depicted in the approaches of *interactionist constructivism* according to Reich [(24), p. 121 f.]. In particular, interaction at the peer *and* counseling relationship level makes it possible to initiate reflection and learning processes in a targeted manner and to facilitate changes in perspective at a low-threshold appreciating level.

Personal development limits can be recognized and overcome in direct peer-to-peer contact during counseling. Here lies a great opportunity in the *uniqueness of the peer moment* in the professional setting of Peer Counseling.

In addition to *consulting-specific knowledge* of counseling methods, approaches, and techniques, Peer Counselors have specific professional and *content-related field knowledge* and are located "in the group" of people with chronic illness and/or dis_ability who, despite all the challenges, have achieved certain basic stability and self-determination in their personal way of life. They may not necessarily be older in terms of years of life than the counselees, but they do have a head start in terms of knowledge and competence, more experience in dealing with authorities, and can draw on a supportive network of colleagues.

A differentiated professional and informal knowledge as well as experience and action knowledge form, in addition to a reflective collegial exchange—ideally supplemented by supervision, intervention, or case and team discussions—a secure basis for professional Peer Counseling, in order to develop adequate approaches to solutions together with the counselees [cf. (21), p. 274 f., (25)].

For many concerns, Peer Counseling Services can be the first and central point of contact, in addition to professional competence, psycho-emotional support with a respectful welcoming culture in the sense of the empowerment. An appreciating approach and deep inside-understanding encounter at eye level alone can encourage counselees to become active themselves, to stand up for themselves and their own needs, and to want to take control of their own lives (again). Peer Counselors can be irreplaceable guides and companions in this process.

PEER COUNSELING—ATTITUDE AND MINDSET?!

People with a chronic illness and/or dis_ability still experience paternalism, pitying looks, derogatory remarks, and exclusion in everyday life; they are often not expected to lead a self-determined independent life, their ability to make decisions is denied and their failure to conform to physical and psychological norms is viewed with a deficit-oriented eye—as recited in the

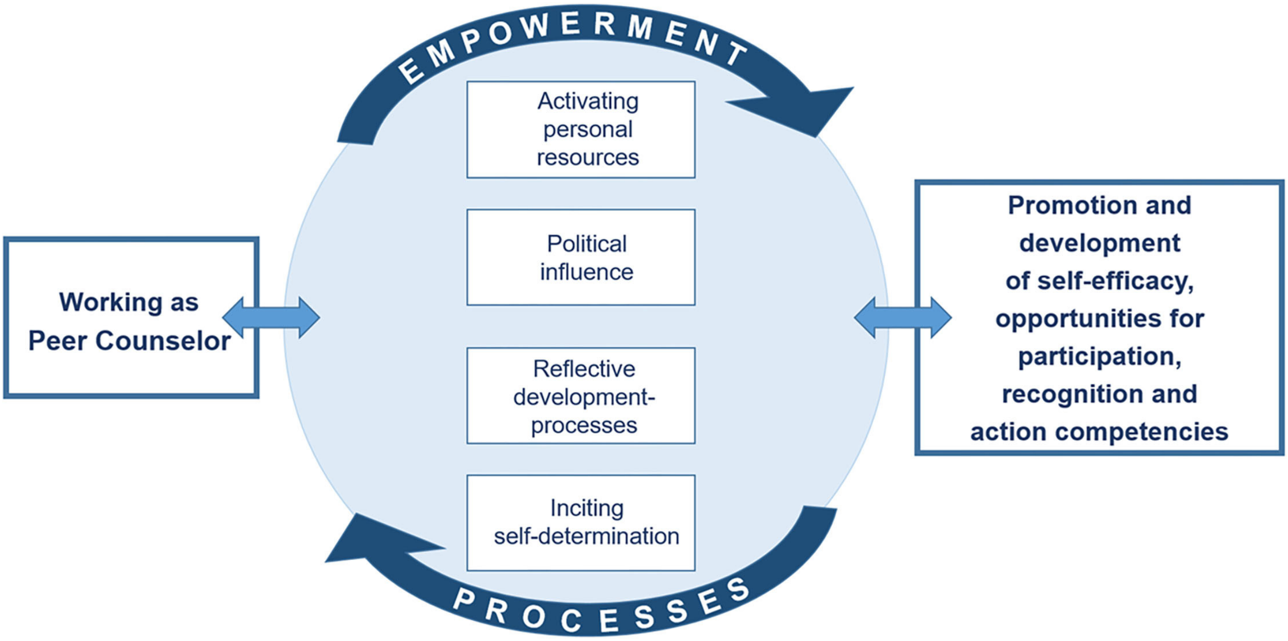

FIGURE 3 | Circle of empowerment in Peer Counseling. Shown here is a circle which contains four terms in rectangles. From top to bottom: "Activating personal resources," "Political influence," "Reflective development-processes," and "Inciting self-determination." Above this circle, is an arrow in which "Empowerment" is written—pointing clockwise, and below, the arrow picks up the direction with the word "Process." To the left (on 9 o'clock), next to the circle, is a rectangle that reads "Working as a Peer Counselor." On the opposite side, at 3 o'clock, it reads "Promotion and development of self-efficacy, opportunities for participation, recognition and action competencies."

introducing sentences at the beginning. Statements like these are familiar to many Peer Counselors as well as to people with dis_abilities and/or chronic illnesses.

It is precisely the *reductionist medical view* of (socially undesirable) deviations from norms that makes it difficult to develop a positive self-image, value one's own body as "beautiful" or realize one's own resources, gifts, and talents.

Of course, there are impairments and dis_abilities which do affect the achievement of performance standards. Of course, not all impairments can be "treated away" and full recovery is not always possible. It cannot be wiped aside that impairments hinder everyday life or in certain situations. But it is important to overcome obstacles and find a good way to deal with existing and emerging barriers.

It is precisely at this point that Peer Counseling can intervene with its empowerment approach: Consistently, the focus here is on the individual and not on the impairments, deficits, or deviations. Rooted in the self-help and self-advocacy movement, Peer Counseling counters experiences of devaluation and demoralization with proven strategies, measures, and concepts in addition to active listening.

On an *intra- and interpersonal level*, Peer Counseling can help people to (re)find a reconciliatory way of dealing with their own body and lovingly accept it despite its deviations from the norm, to (re)discover inherent resources, talents, and gifts, to find a new way of dealing with an illness and to accept the limitations that come with it. As well as realizing that the counselees are not alone in their situation and that life with the existing impairment can still be enriching, worth living, and enjoyable.

As mentioned above, the UN CRPD is based on a human rights understanding of dis_ability and the idea of an inclusive diversity-oriented society. Explicit reference is made to the active participation of people with dis_abilities in political decision-making processes. Societal and socio-political changes arise through the activism of social movements, this is also due to the commitment of self-advocacy and self-help groups. People who come together to form networks of peers—occasionally encouraged by Peer Counselors can give their interests considerably more emphasis, communicate them to third parties and actively represent them externally.

In fact, people—encouraged by empowerment processes in Peer Counseling—become "experts for their own life situations." Self-aware, they can succeed in standing up for their personal needs with an open view and healthy self-confidence, or in asserting interests together as a group in solidarity with peers [cf. (26)].

The outcome of Peer Counseling was demonstrated in a study of people with mental illness in the early 2000's in the USA: The rehabilitation sociologist Salzer (27) describes that those people who go through a peer program learn to deal with their illness in a positive way.

The Peer Counselors are not only perceived as hopeful role models, but this "upward comparison" leads to an increase in self-confidence in one's own abilities, which can lead to empowerment processes (*social comparison theory*). Similar results have also been obtained by researchers who have evaluated different Peer Counseling Programs [cf. (4, 5, 26, 28)].

Peer Counselors can be attributed—partly explicitly, partly implicitly—to have the *function as role model* in different ways. Not least because counselees meet peers in a professional setting who are engaged in a regular (gainful) activity or occupation despite/because of living with a chronic illness and/or dis_ability. Plus, the participation impairment itself is anticipated as (only) a part of identity.

Central methods of professional Peer Counseling approaches are actually exemplified and related to one's own person/personality development. Therefore, empowerment processes have a circular effect in the context of Peer Counseling.

Working as a Peer Counselor might include activating personal resources of counselees and counselors, has a political influence, enables reflective development processes and is inciting self-determination. Empowerment-effects of Peer Counseling can be: promoting and developing self-efficacy, providing opportunities for participation, recognition and enhancing action competencies; illustrated in the following model (**Figure 3**).

CONCLUSION

Peer Counseling, as a professional counseling service offered by and for people with chronic illness and/or dis_ability, can contribute at the socio-political level to ensure that people with participation impairments also receive attention and consideration in the political arena. Representatives of umbrella organizations are, for example, heard as experts in legislative procedures, are active in advisory committees, and within the framework of the nationwide offer of "*Ergänzende unabhängige Teilhabe-beratung—EUTB*" (Additional Independent Participation Consulting) both, the Peer Counseling format and Peer-to-Peer-Consulting approaches find an equal place in the professional counseling landscape in Germany.

The qualifying training for Peer Counselors are conducted by experienced Peer Counselors who often also have a relevant academic degree and are employed in counseling professions, e.g., as a psychotherapist, social worker, educational consultant, teacher, coach, lawyer, or similar.

Many Peer Counselors are also involved in self-advocacy and self-interest associations and advocate for an inclusive society with equal education and opportunities through their work, but also actively demand equal participation in all aspects of social and cultural life [cf. (26)].

On an *individual level*, Peer Counseling can enable people to cope with crisis situations in life in a self-determined way, to mobilize their own abilities and resources to overcome challenges, find a reconciliatory way of dealing with their own illness/dis_ability and be valued as a person.

Although Hermes [(25), p. 8 f.], Wienstroer [(29), p. 179 ff.], and van Kan [(20), p. 17 ff.] refer to *Peer Counseling as an independent method* in contrast to psychotherapy and other counseling and consulting formats, different principles of action are intertwined in "classic" Peer Counseling:

- **Personal life-world (dis_ability) experiences:** The common backexperience of living with a chronic illness and/or dis_ability—regardless of the type and extent of the form of participation impairment—forms a trust-building basis for the encounter in Peer Counseling. Qualified Peer Counselors can encourage counselees to come to terms with their dis_ability-related effects, inform them about practical support options for a self-determined lifestyle, to point out choices and various options for taking responsibility in dealing with crises.

  Through their commitment (and their way of life), Peer Counselors might also be seen as role models: They succeed in motivating counselees extrinsically and intrinsically to lead a life on their own, formulate goals, and work toward achieving them.
- **Partiality:** In Peer Counseling, the counselors use their competencies and expertise in the interest of the counselees. Since both actors are people with participation impairments, counseling concerns can be perceived, analyzed, and comprehended from a professional meta-level as well as from an internal perspective.

  In contrast to other counseling formats, Peer Counselors can identify with many issues and concerns in different qualities, because they themselves may have already dealt with similar situations or have been confronted with comparable challenges.
- **Holism:** Counselees can inquire about Peer Counseling with all concerns about all questions of lifestyle, dealing with their dis_ability, rehabilitation-possibilities, and participation issues. Different approaches and methods are used in counseling processes in order to understand and accompany the counselees in the best possible way.

  In accordance with the bio-psychosocial model of the International Classification of Disabilities and Health (ICF), the individual life situation, personal views, and interests, environmental and personal resources, goals, and needs of the counselee are always included in the decision-making and solution-finding processes in professional Peer Counseling.
- **Emancipation:** Influenced by the historically conditioned medical-deficient perspective on dis_ability and the associated equation of illness and dis_ability with the need of care and welfare, it was and is a concern of Peer Counseling—in close connection with interest and self-advocacy associations—to appeal to the autonomy, judgment, decision-making, and agency of people with participation impairments.

  Based on the assumptions of the empowerment principles, every person has abilities, talents, gifts, and resources. Peer Counseling can support other people in knowing these and using them in a meaningful way to realize the own dreams and future perspectives, in order to stand up for own interests and needs with healthy self-confidence.

These described resource-oriented approaches of Peer Counseling can support individuals as well as them as a "group of people with chronic illness and/or dis_ability" to overcome patronizing, excluding, and stigmatizing structures.

This specific counseling service represents also an opportunity to offer marginalized people, at a low-threshold level, an accessible space where their concerns are heard. People in crisis situations, for example in the midst of sudden and profound changes in entire life situation due to an illness or (newly acquired) dis_ability, find competent and understanding contact persons in a timely manner. Aware of their function as guides and their competencies, Peer Counselors can also refer to other institutions or services, if needed or wanted.

Despite possible proximity due to a similar illness or dis_ability, qualified Peer Counselors must find a balance in the counseling relationship. In addition, professional field competencies complement their own reflected biographical experiences, so that only specific and in individual cases do Peer Counselors incorporate personal coping strategies into counseling processes. For the most part, "classic" elements of communication-, interviewing- and intervention techniques are used to exploit the possibilities of the empowerment approach.

Peer Counseling, with the factual and technical competencies taught in training courses, counseling-specific methodology, and the underlying approaches of empowerment, is much more than just a target group-specific professional counseling format. Performance-oriented use of methodology, professional biographical competencies, and the personal prerequisites, as well as the fact that Peer Counselors are themselves people with a participation impairment, distinguish this unique counseling format.

In a mutually complementary way, Peer Counseling can be understood not only as an indispensable additional counseling method but also as a tool for self-help and self-advocacy. The theory-based approaches described above are also reflected in the values and action convictions by Peer Counselors themselves.

With the implementation of more than 500 counseling centers of "*Ergänzende unabhängige Teilhabeberatung—EUTB*" (Additional Independent Participation Consulting) throughout Germany, there is an opportunity to create nationwide structures of professional Peer Counseling and Peer-to-Peer-Consulting Services. The draft "one for all" can be implemented in a truly low-threshold and accessible manner in the sense of lived participation in a diversity-oriented society.

Who can advise more professionally and comprehensively on questions in the field of participation opportunities, rehabilitation, or social inclusion than qualified peers? Who—in addition to relevant qualifications—is having suitable experiences themselves? Not always academic degrees from the profession (orientation), but also biographical knowledge and preparatory courses can lead to special skills and expertise.

At this point, answers to the questions formulated at the beginning of this article can be found: In Peer Counseling, counselees can be given competent and comprehensive advice on planning and organizing everyday life issues, individual career perspectives, the application of remedies and aids, educational and occupational opportunities and dealing with illness and dis_ability; on the other hand, there is the possibility—assuming interest and suitability—of taking training courses to become a Peer Counselor oneself, in order to support other people in similar situations in the future. Peer Counseling can be clearly understood as a highly specialized counseling method, as a metaphor for emancipation and self-determination, and as an underlying attitude and mindset.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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Moving goals. Goal-work in Parkinson's disease rehabilitation

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Chronic diseases often demand considerable work by patients: they must adhere to medical regimes and engage with social and embodied discontinuities. In Denmark, rehabilitees in Parkinson's disease rehabilitation talk about Parkinson's as their new job. In this article, we introduce *goal-work* as an optical lens to enlarge and explore the micro-social practices that concern a core practice in rehabilitation where professionals and rehabilitees set goals for the future and work toward the goals. To work with goals adds a new task to living with Parkinson's. Rehabilitation research tends to focus on the actual goal-setting meeting. Drawing on data from long-term ethnographic fieldwork on goals and their setting in Parkinson's disease rehabilitation, we show how participants in rehabilitation imagine, set, enact, review or share their rehabilitation goals, and how goals are worked with before and after the goal-setting meeting, across settings. We conceptualize these micro-social practices as goal-work, which we argue is a spatio-temporal process. The concept of goal-work emphasizes the fact that goal-setting is one event in a string of goal-related activities, and it turns our attention to the intersubjective dimensions inherent in goal-work, such as the role of relatives and how acts of imagination and acts of sharing form part of goal-work.

KEYWORDS

goal-work, Parkinson's disease, rehabilitation, chronic disease, goal-setting

Introduction

In a rehabilitation context, a goal can be defined as a future state to be achieved through rehabilitation activities (1, 2). As the future is not yet, imagination becomes a vessel to access the future; participants in goal-setting tour the future in order to determine which goals they should aim for (3). Goal-setting may be viewed as a temporal practice with an imaginative component to it.

A time-gap exists between the present, when goals are set, and the future, when they may be achieved. This means that when goals are set in the present, it opens a space of potentiality that can be worked with. However, as we will show, this space of potentiality can also evaporate; goals may not always actualize. The effort to achieve rehabilitation

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goals has many moments of uncertainty attached to it. Yet this is the work task for participants in rehabilitation.

In rehabilitation, goal-setting serves multiple purposes, e.g., establishing a direction of the rehabilitation trajectory, making transparent the link between components in the process, enhancing patient autonomy, enabling change to be monitored, and demonstrating adherence to e.g., professional requirements (1, 4). As has been described in the literature, phases in the goal process include preparation, negotiation, goal-setting, goal pursuit, and review (5, 6). Goal-related activities thus "span the whole continuum of service delivery from admission, to implementation of treatment, to evaluation of progress and outcome" [(7), p. 12]. However, researchers have pointed to a gap in the literature. A scoping review on goal-setting among chronically ill individuals found that 39 of 58 included articles did not pay attention to the phases prior to and after the actual goal-setting (8). Yet in order to fully comprehend the phenomenon of working with rehabilitation goals there is a need to describe and analyze the continuum of goal related activities, thus adding contemporary observational data to studies by e.g., Struhkamp (9) or Mattingly (3).

Another gap in the goal literature concerns Parkinson's disease (PD), though studies have been published on the actual goals set in PD rehabilitation (10–12). Considering that neurological disorders are "the leading source of disability in the world, and PD is the fastest growing of these disorders" (13), it appears relevant to add ethnographic studies to literature on goal-setting in PD rehabilitation.

PD is a progressive, neuro-degenerative disease which has no cure. PD symptoms include a range of motor and non-motor symptoms, rigidity, tremor, problems with cognition, speech, depression, sleeping disorder, and apathy (14, 15). The symptoms progress. PD can be called a designer-disease, tailored each individual (16). An experience of embodied uncertainty enshrouds life with PD (17); fluctuations happen over time and even within the day, which makes it difficult to trust one's body (18).

Chronic illness entails chronic work. Living with PD entails work such as exercise, adjusting medicine, getting out of bed when low on medicine and dealing with a body that one cannot rely on (16). As the disease progresses and the body changes, social relationships also change with spouses taking over tasks and caring; managing PD can be "a collective undertaking" [(18), p. 59], as also found in Warren and Sakellarious' writing about motor neurone disease and PD and the intersubjectivities of care (19). Intersubjective means that individuals are never isolated, but related to others, to structures and contexts (20).

The progressive character of PD makes it difficult to match the etymological meaning of the *re* in rehabilitation, i.e., "to come back to." Though functioning may improve, PD rehabilitation often concerns maintaining functioning for as long as possible. PD demands continuous work, adapting to the progression of the disease. Goal-work adds to this on-going work. The term goal-work is inspired by informants expressing how, "Parkinson's disease is my new job," "training is a job," and anthropological studies linking chronic illness and work, e.g., the "chronic home-work" that takes place in people's lives when illness becomes part of life (21) and the "work of care" that relatives do in caring for and caring about (22). Extending this line of thinking about care, Andersen et al. (23) note how informal caring is not a one-way stream, but requires sharing.

The aim of this article is two-fold. The primary aim is to introduce the concept of goal-work as a way to conceptualize the different and manifold micro-social practices that goes into the goal process in a Danish rehabilitation center and beyond, including the phases before and after the formal and institutionalized goal-setting meeting. Another aim is to add knowledge about goals and their setting in PD rehabilitation, i.e., a situation with declining functioning. To our knowledge, this article is the first to describe and analyze how goals are worked with in PD rehabilitation.

Goal-work refers to the multiple micro-social practices that rehabilitees, their relatives, and professionals engage in as they set, pursue, review, and share goals, using different skills and methods. In this article, we conceive of work as an intentional activity that requires effort and attention, be it social, sensory or cognitive. *Work* stimulates an attention to the who (workers), the where (workplaces), and the how (tasks involved, skills required). We emphasize that goal-work is a spatio-temporal process, meaning that goals are worked with in different settings and over time, and relating to the fact that goals are often imagined and set in the present for the future, yet drawing on experiences from the past. Our conceptualization of goal-work focuses on micro-social activities and also point to the intersubjective dimensions of goal-work, in the sense that goal-work requires acts of sharing intimate and private insights (23).

Methodology

This ethnographic study was designed as a multi-sited fieldwork, as coined by Marcus (24). Fieldwork took place from January 2019-December 2020, and the first author worked with a total of 20 key-informants and their social networks. This included being "hospitalized" with them and follow them and their goals from a rehabilitation unit to their homes, local physiotherapist clinics and neurologists at hospitals and private clinics.

Sampling methods and setting and informants

The first author entered the field through a Danish unit for specialized rehabilitation (Sano), being "hospitalized" with two different groups of persons with Parkinson's Disease, 20 persons in all, throughout their rehabilitation stay. Rehabilitees' ranged in age from their 50s to 70s. Besides PD, some rehabilitees had heart disease, osteoporosis, two were cancer survivors, and several had rheumatic diseases. The 20 persons lived in different regions of Denmark; all but three lived with spouses. They had diverse occupational backgrounds; four were still working, three of them part-time.

Approximately 12.000 persons live with Parkinson's disease in Denmark, with an average age of diagnosis of 60–62 years. Denmark has free health and social services, financed by general taxes. PD rehabilitation at Sano is thus free, eligible for persons (with no dementia) in phase two "the maintenance phase," where symptoms increase, typically gait problems and phase three, "the complex phase" with e.g., fluctuations and hyperkinesia, depression, problems regarding self-care, dysphagia, decreased mobility, and hallucinations [(25), pp. 43, 44]. PD rehabilitation at Sano takes place over several months, starting with an assessment day, followed a few weeks later by a two-week in-patient stay with a goal-setting meeting on the first day; after a couple of months, there is a 2-day follow up stay (Figure 1). The rehabilitation course combines group sessions (training/educational) with individual sessions with a physiotherapist (PT), an occupational therapist (OT), and a nurse. The following tests are repeated three times: timed up and go, 5 times sit to stand, and a 6-min walk test. The inter-professional staff members are required to work with rehabilitation goals, as Sano adhere to the Danish White Paper on rehabilitation (4), and to the professional guidelines that emphasize goal-setting as part of the rehabilitation process, e.g., European Physiotherapy Guideline for Parkinson's disease (26). They use no particular goal-setting tool [as e.g., Goal Attainment Scale as described by Kiresuk and Sherman (27)].

In a multi-sited fieldwork, field-sites often materialize during fieldwork. In order to follow the flow of goals over settings, rehabilitees were asked to map their present PD landscape, i.e., the situations and places of importance when living with PD. All 20 rehabilitees participated in this. The mapping pointed to home as an essential setting, together with neurological clinics and physiotherapy clinics. Neurologists are the medical specialists central to PD trajectories (general practitioners refer PD related matters to the neurologist) with consultations once or twice a year (a few less, a few more), about 30 min per consultation. The majority of rehabilitees attend group-based physiotherapy once a week. These were thus settings where goals might be worked with. *Via* the rehabilitees, a purposeful sampling of neurologists and physiotherapists that rehabilitees in this study consulted was made. The plan was to explore if they worked with goals or showed interest in rehabilitees' goals. Contacting them to ask for interviews coincided with the Covid-19 pandemic, which impacted their work. Some did not return calls, some declined due to lack of time, or lock-down restrictions.

Methods

Participant-observation

A study of goals in rehabilitation requires an attention to spoken, enacted, and written goals. At the Sano rehabilitation center entailed participating in training sessions (morning gym, gym, Nordic walking, boxing, voice training), attending educational sessions (on PD, on training, etc.), and observing individual sessions between a rehabilitee and professional staff member(s). To live, to do and to be together, provided an insight to living with Parkinson's, and helped us crystallize our concept of goal-work. To reverse the view from rehabilitees to professionals, three inter-professional teams (each with nurse, physiotherapist, occupational therapist) were followed on goal-setting days, and several staff meetings were attended. Participant observation outside Sano involved attending local training sessions with physiotherapists, Parkinson's dances and observation during consultations with neurologists. Participant observation in 2019–2021 includes approximately 2 months at Sano, following two full courses. Observations include 90 individual consultations, 85 at Sano and 5 at neurologist consultations and physiotherapy group sessions.

Interviews

In total, 64 semi-structured interviews and a substantial number of unstructured interviews were conducted with 20 rehabilitees, 6 relatives and 29 professionals attached to the Sano course and beyond. All these interviews were structured by an interview guide and audio-taped. Two semi-structured interviews were conducted with each of the 20 rehabilitees, first during their hospitalization at Sano, and again approximately 2 months later in their home, before the follow-up stay; here the spouses sometimes participated in part of the interview. Rehabilitees were asked about their illness narratives to provide an understanding of their rehabilitation stay from a wider perspective, with reflections on their lives before and after diagnosis, and about their experience of setting and working with goals. They were asked to map their PD landscape, sometimes *via* drawings on a piece of paper. Spouses were asked about living with PD as a relative, and about their thoughts on PD rehabilitation goals. Eighteen Sano professionals were interviewed *via* focus group interviews and six professionals (two had also participated in focus-group interviews) participated in in-depth interviews. An additional seven external neurologists and physiotherapists have participated in in-depth interviews.

Several unstructured interviews were conducted with most rehabilitees, either contacting them with follow-up questions, or to hear how they were doing, or they phoned to have a chat. Over time, multimodal data such as text messages, e-mails, paintings,

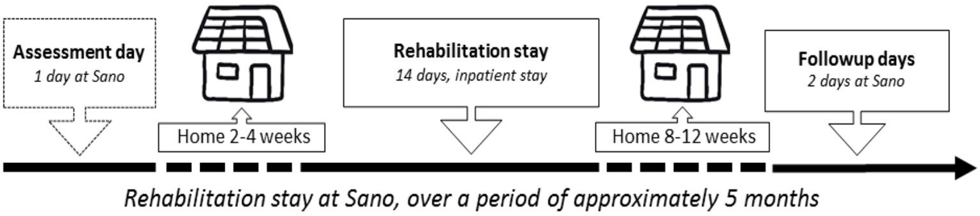


FIGURE 1
A rehabilitation process including periods at the rehabilitation center and at home.

photos and poems entered the study from rehabilitees or from their relatives. Notes were taken in all unstructured interviews.

Document analysis

An analysis of rehabilitees' records was conducted to describe demographic and health data of rehabilitees, to compare the written documentation with observational data on goal-work, and finally to make an analysis of documented goals using ICF as a way to classify goals. In this article, we primarily draw on data from observations and interviews.

Analysis

Data were analyzed through an iterative process that involved reading the research literature, revisiting research questions, and analyzing data from observations and interviews (28). Notes from informal conversations, observation, and unstructured interviews and text messages and e-mails have been coded together with transcribed interviews. A thematic analysis was made, both to find some common denominators in the data, for instance "work" and "sharing" that appeared as themes across informant groups and settings but also being attentive to specific themes that may shed light on nuances of goal-work, though not necessarily mentioned by the majority of informants. Data were also analyzed chronologically, i.e., notes and transcriptions from each rehabilitee from assessment day to months after the end of the course were analyzed and compared with data from other rehabilitees' trajectories. Patient journals were also consulted in the analysis. The chronological analysis was made to track how goals were formulated and altered over time, to distinguish goal phases in a trajectory and to analyze across rehabilitee trajectories the modus operandi during each activity, e.g., assessment days, scheduled goal-setting meeting, in talks with e.g., a nurse regarding goals, or consultations with neurologists. Coupling chronological and thematic analysis enabled an understanding of the flow of goals over time and space and paved way to pick the scenes that best illustrate the findings.

Ethics

The American Anthropological Association' principles of ethical obligations for anthropological work guided the project. A verbal introduction to this study was supplemented with a written description, including ethical matters, such as access to own transcripts and procedure to exit the study if so wished. Participants provided written consent to use data from interviews, observations, and patient records in an anonymized form. Fieldwork included access to intimate details of persons' lives, shared in confidentiality. In order to ensure anonymity, all names described in the examples below are pseudonyms and specific goals or identifiable traits of a person have been slightly changed.

Findings

Goal-work

In the following, we illustrate goal-work through particular scenes from fieldwork. We attend closely to how the goal process unfolds in an ordinary everyday rehabilitation context in order to elucidate the outreach of rehabilitation goals and the multiplicity of doings surrounding rehabilitation goals. The scenes are chosen among 90 individual consultations observed because they represent noteworthy aspects of what goal-work can entail. They will be recognizable across different rehabilitation settings, yet rarely analyzed in detail in contemporary goal-literature. Furthermore, the scenes illustrate how differently PD shows and affects everyday life. Some find PD devastating to their everyday life within a few years after diagnosis, while others experience a slower progression. The continuous progression of the disease makes it difficult to distinguish whether symptoms relate to PD, aging, or to the side-effects of medication. A great deal of work goes into training the body, the voice, and skills, trying to postpone a future that will entail a degeneration of functioning. Incentives for this kind of work emanate from a fear of becoming a vegetable, as many informants said, someone who cannot move nor participate in social life. To obtain a sense of the flow of goals in a rehabilitation trajectory, we present the scenes in the same chronological order that informants would normally experience, (see Figure 2 below).

Analysis across goal-setting meetings exposes a common modus operando. As hosts, professionals set the scene and open up the meeting, the person who writes down the goals on the PC often facilitates the meeting, inviting the rehabilitee to present goals. Some come prepared with goals, others do not, in which case the team mentions the goals discussed at assessment day. Professionals emphasize that they try to use a person's own words in the documented goals.

The 20 rehabilitees, our informants, had lived with PD for some years before attending the rehabilitation program. When asked why they applied for the program, they responded 1) to get a boost, mentally and especially physically, 2) to meet other people with PD, and 3) to gain knowledge about the disease.

David: Scenes from assessment day

During the assessment day, the person with PD, often accompanied by a relative, meet an inter-professional team. Preliminary goals are discussed.

David, a man in his 70s, has brought his wife Anette to the assessment day. He was diagnosed with Parkinson's 3 years ago, but believes his symptoms appeared 10 years prior to that. In the consultations during the day, he meticulously responds to professionals' questions and explains how his changing body affects everyday life. He finds his cognition impaired, has problems with his diaphragm, he experiences pain, has a bent-over posture, he easily falls, has difficulty turning around in bed at night, and his walking and dancing abilities have weakened. Asked about freezing episodes, a sudden inability to move, he says, "I see others worse off than me." Anette adds to the picture: "Remember to mention your hip problems [...] since the diagnosis you find it hard to go for walks. [...] You also have problems with your vision—double-vision."

After consultations with an OT, a PT, a nurse, and a neuropsychologist, the final meeting of the day is an inter-professional consultation where a neurologist also participate. Upon leaving the room, the OT asks David to wait:

> OT: I have made a print-out of some of the goals we have talked about. I will go and fetch it for you.
> David: Are they your goals or my goals?
> OT [smiling]: Those are just preliminary goals based on our talk. Then we have a point of departure for the first day of your rehabilitation stay. They are changeable—take a look at them at home.

During assessment days, each talk or examination add new layers of information as professionals try to obtain a picture of who the rehabilitee is and how he or she manages everyday life. Sometimes spouses contribute with information, like Anette, exposing a "shared doctoring" (29), as participants work together to add parts to the bigger picture in order to find the appropriate interventions, and thus exposing the intersubjective dimension to goal-work.

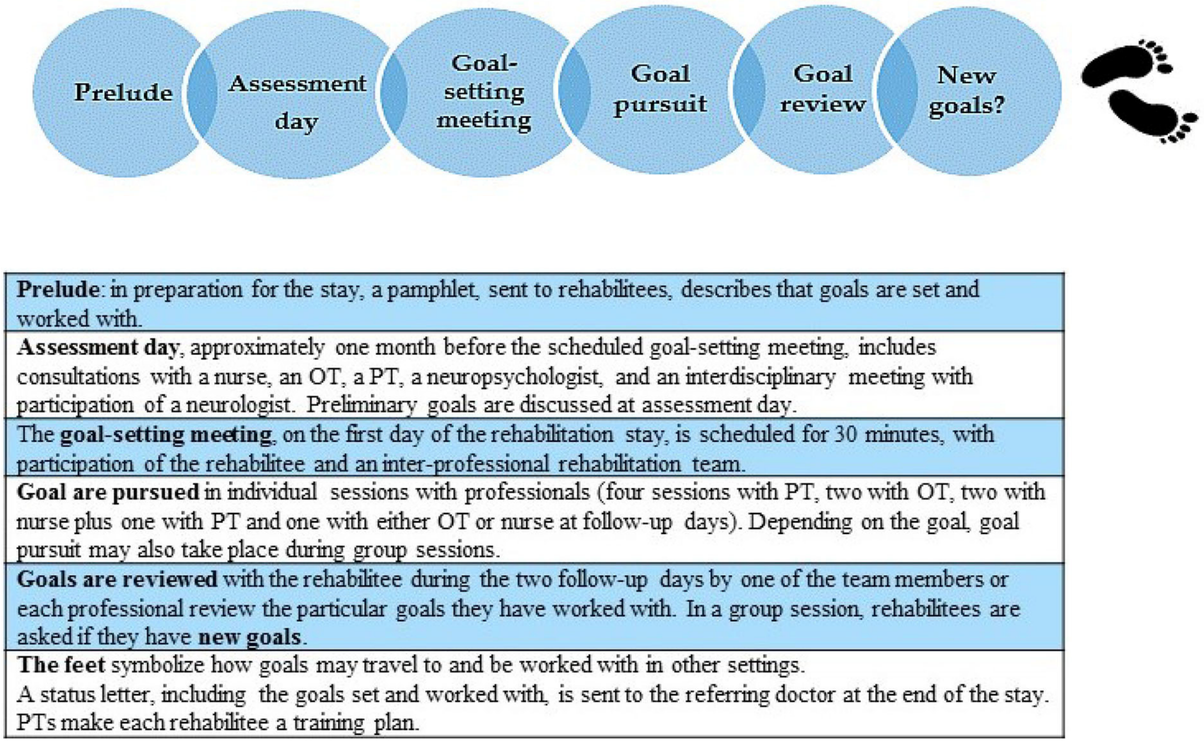
In the rehabilitation process, the assessment is followed by goal-setting (30). In this scene, goals materialize as topics of conversation during the assessment. In the words of the OT, the goals are "preliminary" and "changeable." David's long-term goal is to keep dancing, short-term goals concerns maintaining ability to go for walks and improve balance to enable participation in dance lessons. Although David nodded in assent during the summary discussion, when the preliminary goals were mentioned he was still skeptical: whose goals are they? This could suggest an insecurity as to the purpose of goals and for whose sake they are set; or it could exemplify what David plainly states as "I don't always get what is going on." Generally, preliminary goals are mentioned, maybe printed and handed over to the person with PD, with a word of encouragement to do "homework" and think about goals. In reflections about assessment day, a number of rehabilitees found that their goals were actually set that day, while others did not remember talking about goals (though fieldnotes showed that goals were mentioned).

Peter: The goal-setting meeting

Goals are imagined, discussed, set (or consolidated), negotiated, and documented at goal-setting meetings. In patient journals, under the heading "treatment plan," goals are listed together with a list of mainly group sessions which can be ticked off. Most of the 20 rehabilitees set three short-term goals, about half set a long-term goal.

Peter, in his 60s, has lived with Parkinson's for more than a decade. He lives with his wife. In his part-time job, he is used to set and work with organizational goals. He comes well prepared for the goal-setting meeting with his team. "I have my goals here", he says, pointing to his head.

> Nurse: Do you remember we spoke about you writing some sentences that contain the goals you'd like to work with? [Peter nods in agreement]. We wrote some things down at the assessment day, but maybe you've had some new ideas?
> Peter: Yes, but let's take what you wrote as a starting point.
> They discuss the goals. Regarding the first goal, "walk more smoothly to be able to carry a plate 15 meters," Peter explains that he trips (almost stumbles) a lot, "and if only you can help me with the tripping—that would solve the rest." The PT asks what less tripping would enable him to do, which opens



Prelude: in preparation for the stay, a pamphlet, sent to rehabilitees, describes that goals are set and worked with.

Assessment day, approximately one month before the scheduled goal-setting meeting, includes consultations with a nurse, an OT, a PT, a neuropsychologist, and an interdisciplinary meeting with participation of a neurologist. Preliminary goals are discussed at assessment day.

The **goal-setting meeting**, on the first day of the rehabilitation stay, is scheduled for 30 minutes, with participation of the rehabilitee and an inter-professional rehabilitation team.

Goal are pursued in individual sessions with professionals (four sessions with PT, two with OT, two with nurse plus one with PT and one with either OT or nurse at follow-up days). Depending on the goal, goal pursuit may also take place during group sessions.

Goals are reviewed with the rehabilitee during the two follow-up days by one of the team members or each professional review the particular goals they have worked with. In a group session, rehabilitees are asked if they have **new goals**.

The feet symbolize how goals may travel to and be worked with in other settings.
A status letter, including the goals set and worked with, is sent to the referring doctor at the end of the stay.
PTs make each rehabilitee a training plan.

FIGURE 2
Goal process at Sano rehabilitation center.

> for a glimpse of Peter's imagining: going shopping and going for walks with his wife in a forest nearby their home. The second goal, "minimize sleep interruptions', is agreed upon immediately and without any discussion. Regarding the third goal, "to get up and down a chair without help", Peter stands up in order to illustrate his problems rising from a chair or the toilet. They discuss his balance and after a while, the OT says: "Did you bring some goals?" "Yes Incontinence." They discuss what the problem is and the nurse explains that there are several means to handle incontinence. The fourth goal becomes "making it to the toilet in time."
>
> Finally, the nurse points to the computer and says that she has written everything down. Peter replies: "Okay, as long as you don't show it to anyone." Pointing at her colleagues and me, the nurse says affirmatively, "we have all signed a confidentiality agreement". "As long as my employer does not know this" "No, this is your paper". The goals are printed and handed to Peter.

Peter's case illustrates several aspects common to goal-setting meetings observed. Firstly, how imagination is part of goal-work. Goal-setting requires acts of imagination, i.e., participants have to imagine scenarios for the future. To direct activities to match Peter's goals, the PT had to gain access to what Peter imagined being able to do if his tripping lessened (going for walks with his wife). Secondly, how sharing of information (e.g., imaginings of the future, everyday losses encountered and intimate bodily changes) is inherent to goal-setting. Bladder dysfunction, a common problem in PD (15), is an embarrassing issue for Peter, which he only shared with the team because they might be able to help. Information may be shared beyond the persons participating in the meeting. The PC symbolizes a connective capacity to other settings and to other people. It is not unusual that rehabilitees question the further flow of written words, i.e., with whom the electronic correspondence connects. In some instances, the computer is transformed into a dangerous vessel that can distribute information about a person's most intimate issues. This touches on ethical aspects of goal-work. Thirdly, setting goals seems to be a fluid process: goals are discussed at assessment day and documented as preliminary goals in patient journals. Some rehabilitees do homework, making a list of goals at home, new goals may appear during the goal-setting meeting, and goals discussed on the assessment day are reiterated and refined. There is thus a build-up phase to goals. Finally, goals are manifested in writing, handed over manually as a print out to rehabilitees, which can both be interpreted as empowering, as handing over ownership of goals, or as a pragmatic reminder of the goals agreed on, or it can signify a contract between the team members (including the rehabilitee). Several rehabilitees referred to goals as a contract made with themselves and with their team. It should be noted, that while Peter came prepared and readily set goals, others found goal-setting less straightforward for different reasons; unacquaintance with goal-setting and its purpose, problems with imagining goals for a future that seems uncertain regarding how fast will PD progress, or lack of knowledge about viable goals, e.g., which goals could be worked with at Sano.

Morten: Goal-pursuit. Nurse consultation during the two-week rehabilitation stay, scheduled as a "talk about coping"

In individual consultations, rehabilitees and professionals pursue goals. At times, other matters of importance materialize.

Morten in his late 60s, was diagnosed with PD 4 years previously. In their first session, the nurse asks, "Have you thought of something you'd like to talk about? Otherwise I have, but I'd like to hear from you first." Morten would like to work with physical activity—"that's the problem, I lost motivation." His training has almost come to a halt. One of his goals is to get a physical boost, with a long-term goal stated as "To get motivated to keep up my training and regain belief that what I do matters." Morten and the nurse gradually unravel what made him lose motivation: an operation and how "for the past 5 years, things have gone downhill, I have to fight to not let things go further downhill." His words indicate how, with neuro-degenerative diseases, goals may be set to *maintain* rather than *improve* functioning.

> Morten: I get depressive spells at times. On some days, my body simply won't cooperate. Some days I put on my clothes [to do training], but I find my body to be too stiff, and I get angry.
> [It takes effort to keep a body with PD agile, the nurse agrees, probing into Morten's anger and discussing strategies for the "rainy days," when Morten gets depressed]. Morten: I just have to get out of the house, with the mood I have, and keep on going. I know *you* have an understanding, but people who don't have PD, they don't know what it feels like. Yesterday at a session, we heard about all the things that are wrong with us—when relatives notice this, they want us to change it. My wife gets irritated with me—you know when I leave things, and she feels she has to clean up my stuff.
> Nurse: Can you talk about this?
> Morten: Some days, yes. I understand why she gets annoyed.
> Nurse: That's tough on both of you, but each in your own ways. You live with it, and your wife observes it, that can be tough.
> Morten: I used to be the patriarch of the family, but no more [His voice trembles, tears roll down his cheeks]. And she would like me to be. I haven't stopped playing this role. I try, but things are not the way they used to be.

Asked about his family's reactions to his diagnosis, Morten cries, "It's not easy to talk about … there is a lot of going downhill. My problem is I'm so sad that I cannot be me." The nurse gets up from her chair, places a hand on Morten's shoulder, and says some soothing words. They have gone beyond their scheduled time. The nurse suggests that Morten shares his thoughts with his family.

This case illuminates several aspects of goal-work. One concerns how affect and managing one's emotions form part of micro-social activities of goal-work. Morten shows emotions as he laments his identity loss, sharing how he feels forced to recast his identity. The nurse embraces the emotions, having a catalog of strategies at her disposal (listening, calm voice, smile, eye contact etcetera), exposing how goal-work is embodied. Another concerns the navigational skills involved in finding what matters to the individual and how an intimate space created between a rehabilitee and a professional can bring to light issues of importance that may not have materialized during the goal-setting meeting. Relatedly, goals may follow a linear line, such as one of Morten's short term goals "to get a physical boost and be able to do 1,5 km walks in the nearby park again, on a regular basis." This goal was set, worked toward with the PT, evaluated, and achieved, even if 1,5 km became 1 km. Other goals are less linear and a goal-talk can take new directions. In this case, Morten's goal about motivation and what to do when the motivation fails open the talk, but then other issues of importance come to the forefront and the conversation narrows down to what really matters to Morten, i.e., his loss of identity, a common theme in interviews with informants, and also described elsewhere (17, 31, 32). Finally, this case exemplifies how the past (being a family patriarch), present ("cannot be me") and future (going downhill) entangle.

David: Goal-pursuit and review at home, between rehabilitation stay and follow-up days

Goals travel over time and may be set, pursued or reviewed at settings beyond the rehabilitation setting, e.g., at home.

On David's goal-sheet, his long-term goal is to "keep participating in the PD dance," whereas short-term goals are to "be able to walk with less pain, and continue to walk without any aids, except for Nordic walking sticks for longer walks" and "improve balance to enable participation in dance lessons," resembling the goals discussed during the assessment day. During his stay at Sano, he told me: "I can't imagine a nice life with a rollator, I just can't. Of course that's where it ends, but somehow I hope I die before that […] the things

I've written down bother me on a daily basis. And if these could be eliminated, I might experience a better quality of life." However, he also expressed some concerns, he had expected his team to take his hand and lead him toward achieving his goals, but feels unsure whether "the tools they provide me with here are that helpful—but time will tell." Two months later, in an interview at David's home, I ask him to tell if his goals matter to him.

> David: Probably yes, but… it might matter more to Sano than to me. That sounds harsh. And I'm not quite sure about it… I've never been good at setting goals. So setting goals like that was new to me. I wrote it all down before going to Sano.
>
> Anette (his wife who left work early to join the interview): We discussed [your goals] when we came from assessment day, and then you added onto the goals before leaving for the 14-day course.
>
> *And during those 14 days—how did you all work toward your goals?*
>
> David: I think what the nurse gave me [suggestions for pain control] was most useful. And someone suggested that I change physiotherapist if I was not happy with my local group-based training.
>
> Anette: If I can add to your thoughts, the goals were to continue going for walks and dancing. And I think both of us find that there was not enough focus on those goals.
>
> At the end of the interview, David reflects on his rehabilitation stay: "I had expected more, I think… but as time passes, I notice that I did get something out of it after all." He mentions pain management (and shows a medication schedule), exercises (and points to the floor in the living-room: "I've bought a yoga mat and that big ball. Those exercises relieve my pain"). He now does his Parkinson's training at a new physiotherapist (who is "much better"), and uses breathing exercises given by the physiotherapist at Sano (that "really helps").

The scene exemplifies the spatio-temporal aspect of goal-work, i.e., how goals travel from rehabilitation setting to home as some rehabilitees take their goals home with them and continue working on them. In this scene, the goals took on physical manifestations: a yoga mat and a medication schedule, both technologies used to work toward achieving the goals. It also shows how spouses may be co-workers, doing joint home-work by discussing possible goals before the stay, reviewing goals and assessing the goal-work performed by professionals at Sano. This illustrates the intersubjective dimension to goal-work. In this case, the couple had expected more focus on specific goals, which may indicate a more general observation during fieldwork that steps taken in the goal-pursuit may seem obvious to professionals, yet appear less visible to rehabilitees. In another case, a husband incited to go on strike, as he believed his wife's exercises to achieve her goals were too tiring.

Bodil. Goal-pursuit and review with OT at follow-up days

Goals are pursued and reviewed in individual consultations.

The last scenes are with Bodil, a woman in her mid-70s. She lives on her own, and was diagnosed with PD 4 years ago. Her long-term goal is to be able to balance between daily tasks at home and training so she has energy to pursue her hobbies. Her short-term goals are to improve walking and "organize and plan everyday tasks *via* a weekly schedule." We meet at an apartment at Sano, where Bodil changes bedlinen, an increasingly demanding task, in pursuit of this particular goal. The OT explains they will repeat the test from last time, asking how Bodil has been doing since her stay.

> Bodil: It's been a bit messy, but I've really tried [working with goals].
>
> The OT asks detailed questions: where does she keep the bedding—in a drawer, right, so put it in a drawer here, etcetera, trying to imitate a home situation. Bodil fights her way against the linen, while the OT records her observation on a piece of paper. 'I don't get this, what's wrong', Bodil whispers to herself, while struggling with the linen. Finally, finishing with the top sheet, she says, 'I could have joined the military!' We smile. 'Oh, I did it in the wrong order.' She had forgotten to put the duvet cover on. She seems more and more stressed.
>
> OT: I see that at times you become doubtful—does that happen at home?
>
> Bodil: This is a new situation.
>
> OT: How do you think it went?
>
> Bodil: Fine, considering it's a new place, sometimes I get a bit confused if many things happen at the same time.

We could say that the scene exemplifies the cognitive impairment that is common in PD, but it would perhaps be more accurate to call it a loss of embodied knowledge; the loss of being able to perform those taken-for-granted activities that we carry out without thinking about them. Making the bed is an embodied life task that Bodil has done for years without thinking about it. Now, this and other seemingly easy tasks have become difficult. The scene generates both an understanding of what we could call "detective work": "Does that happen at home?," the OT asks, in order to establish the extent of the problem, and also why professionals at Sano underscore the importance of observation. They often experience a difference between what people say and do.

The scene also shows how goal-review can occur in a very subtle way. The OT assesses the goal achievement *via* the test and by asking Bodil how she worked with the goal at home. However, Bodil's PT reviewed her goal-list, evaluating with Bodil whether goals were achieved and discussing a plan for the future, which was a contact with her local municipality to continue rehabilitation. This shows the spatial aspect to goal-work, linking to new professionals in other settings to "take over" and linking the bed linen situation at Sano to the one at home. Based on observation, goal-review seemed in some cases almost invisible. Exploring this finding in interviews with professionals, they pondered on their practice. They agreed that goal-review during follow-up days may not always appear visible to rehabilitees, as it was done in consultations with a professional, not with the team, nor was it scheduled as part of the program.

Bodil's first consultation at the neurologist after rehabilitation stay

Goals may travel to other settings and be shared—or they may not.

We wait with in the hospital corridor. A sign says 'Neurological Unit.' A colorful painting contrasts the white walls. It is called 'Hunting for Dopamine.' Persons with PD lack dopamine. Bodil evaluates her stay at Sano—she was happy to go, but she found it difficult to implement the advice given. Once seated in the neurologist's office on each side of a desk, Bodil tells the neurologist she has been to Sano. The neurologist asks a few questions about her stay, but none about her goals. The two then review the list of questions that Bodil has prepared.

Rehabilitation goals travel from Sano with the rehabilitee as a medium, or through a discharge letter sent from Sano *via* electronic communication to the doctor who made the referral to Sano. Discharge letters encompass goals set, a resume of interventions pursued with each professional and strategies suggested. Judging from this and other observations and interviews with rehabilitees and neurologists, neurologists took no particular interest in rehabilitation goals. One neurologist said: "I do read the discharge letter from Sano, but I think the goals tend to be similar, like walking?" This was correct: the majority of goals among informants in this study were activity and participation related, with a large majority concerning the ability to walk or move around. Goals related to bodily functions mostly concerned sleep and cognitive challenges. A temporal aspect may also influence an interest in goals—in Bodil's case, her appointment with the neurologist took place 4 months after her stay at Sano, her PD symptoms had deteriorated, and she had a long list of questions.

This scene exemplifies how and where goals travel or move forward and the engagement (or lack of engagement) in rehabilitation goals among various specialists. Following goals beyond the inpatient rehabilitation center showed how goals that stretched beyond the stay were mainly "hand-carried" by the rehabilitee to other settings. Many, like Bodil, presented their training plan from Sano to their local physiotherapist, who then incorporated Sano suggestions into their training program.

Concluding discussion

Through the representation of scenes from the Danish Parkinson's Disease Rehabilitation context, we have shown that the goal process entails different temporal, social and spatial dimensions, which may be conceptualized as goal-work. The scenes expose how PD can shake taken-for-granted assumptions about life—what used to be ordinary embodied knowledge and routines have become exhausting, difficult tasks. Several issues of living with PD impact rehabilitation and thus goal-work, e.g., good days and bad days, apathy, cognitive impairment, depressive spells, and also a need to keep active.

By attending closely to practice, to the phases prior to, during and after the formalized goal-setting meeting, we exposed some of the micro-social activities involved and the inter-subjective and spatio-temporal dimensions of these activities. Levack et al. (33) call goal-setting a complex intervention, and the scenes described display how all the micro-activities of goal-work require a diverse variety of skills and tools, not just for professionals, but for all involved, including communicational and observational skills. We have shown that goals move across settings and that goal-work changes character during the rehabilitation process. Workplaces included the rehabilitation center, the home environment and the local physiotherapist clinic. Some rehabilitees did home-work to prepare for or work with goals, thus adding to the chronic home-work involved in living with PD (21). Goals moved, aided by an infrastructure such as the electronic documentation system. We showed how rehabilitees, professionals and spouses enacted goal-work in speech acts, in writing, and in mundane everyday tasks such as making a bed or during more profound emotional processes involving the family.

Goal-work entailed shared work, as participants worked together trying to find a way, setting and working toward the goals in a rehabilitation trajectory with many possible roads to pursue. Finding the right way was not always a straightforward task. While professionals at Sano are steadfast that the goals should be the rehabilitee's, rehabilitees at times found it difficult to figure out what professionals wanted when they asked about goals, which interventions were offered at Sano, indeed, whose goals were formulated and discussed—the professionals or the rehabilitees. Shared work entails shared responsibilities, professionals and some rehabilitees underscored, comparing their goals with having a contract. The invocation of *contract* may indicate a moral imperative to work toward the goals, with the expectations not only from professionals, but also from a personal expectation toward one's own work.

We have shown that although the goal process has a certain linearity to it, the process of setting goals is fluid, as goals are not necessarily set at the scheduled goal-setting meeting, but maybe at assessment day, at home with the spouse, or after the goal-setting meeting, suggesting a quasi-linear goal-process. In one of the scenes, an intimate space was created by a nurse and a rehabilitee which paved way for talking about sensitive issues, not revealed during the goal-setting meeting. This shows how goals may only appear in intimate rooms but also how a goal-talk can form an entry into other issues of importance. We have shown how goals are materialized or enacted, and how they travel, i.e., move forward, and also how they may come to a dead end.

Furthermore, part of the goal process, review of goals, happened in a subtle way. Professionals reviewed goals, but while goal-setting was scheduled and interdisciplinary, reviews were un-scheduled and uni-disciplinary, and in some cases hardly noticeable. In several interviews, rehabilitees expressed doubt that their goals had been reviewed. Nevertheless, they all believed that once their goals had been set, that they should be subject to evaluation. This underscores the importance of a certain calibration of expectation and more transparency in the steps being taken, as these steps may be unclear or invisible to rehabilitees (and spouses). So which insights does this study offer the rehabilitation field concerned with goals? We will stress particular insights that concern micro-social activities such as acts of imagination and sharing, and the embodied and intersubjective dimensions to goal-work.

We could call goal-setting a technology of imagination, because to set goals requires a view to an imagined future. As proposed by Mattingly (3), the practical actions necessitate an orientation from imagined endings. Professionals rely on rehabilitees to share their imagination in order to support the steps toward the goals. Thinking about goals as imagined lends way to understand that while goals represent a space of potentiality, goals do not necessarily follow a linear line, from set to pursued to achieved. Things happen, the imagined may not materialize and goals may be discarded or forgotten.

Acts of sharing among participants also form part of goal-work; sharing concerns tasks, responsibilities and information about the everyday losses encountered, worries, or intimate issues. Goal-work is thus embedded in sociality as Andersen et al. (23) note, from studies of cancer patients, how information sharing is enmeshed in "social risks and notions of selfhood," and those who receive care must commit to involving "oneself in difficult and sometimes emotional situations" [(23), pp. 2,13]. Rehabilitees may share tasks, information and uncertainty (34) with spouses and professionals—or they may not. As depicted in the scenes, sharing involved a delicate and ethical balancing. For staff, this balancing concerned which information to share across sectors, how to ask questions in a respectful way, refraining from overstepping an invisible discretion line, or how to handle rehabilitee goals that seem out of sync with reality. For rehabilitees, balancing implied deciding which information to share. Acts of sharing can involve a risk once documented, because where does information flow and who might gain access to the information? While goal-work seems to require acts of sharing, it should therefore be remembered that to decide what to share is hardly straightforward or self-evident.

Goal-work is embodied, intersubjective, and reflected individual life circumstances. It involves senses, emotions, cognition, and is enacted through the body in the practical activities. It takes emotional skills for professionals to do goal-work.

Families can be part of goal-work. This insight is not new, but it is an under-researched theme in the goal literature (35). In our study, some spouses were co-workers in goal-work. They added information to the assessment, helped in the homework process by discussing goals, collaborated in setting and reviewing goals, or they reminded their spouses to do goal-work. Home-visits revealed that the participation spousal co-working was common, making goal-work "a collective undertaking" with the family involved (18). While the role of family in goal-work differs from one PD rehabilitee to another, it nevertheless remains a factor which rehabilitation professionals must acknowledge.

Strengths and limitations

A strength of our study is that it is based on a long-term ethnographic fieldwork which allowed an exploration of goal-work over time and settings, using a range of different methods. Following 20 persons over two years provided rich data concerning goal-work and living with PD. We also find it a strength that we represent an ordinary practice of working with goals, rather than testing a "polished" model. Working with goals is complex, with no recipe of *the* right way of doing it. However, paying attention to the ordinary may expose obvious flaws in a practice, for instance as described a need to make goal-review explicit to all involved. Describing this may inspire others to reflect on their practice.

There are some limitations. Covid-19 did, to a certain extent, affect the exploration of how goals were worked with after Sano. Though we used information from rehabilitees to support the data obtained from neurologists and physiotherapists, it would have enriched data if the original plans for fieldwork could be followed. Furthermore, even though a rehabilitation stay is free of charge, it has to be applied for, which may result in socially skewed access. We do not claim that our sample of 20 informants is representative of people in rehabilitation, but the richness of fieldwork data, in terms of the number of goal-setting meetings, social interactions and situations observed during 2 years of intense data generation, ensures study validity. We have chosen to depict a few carefully selected scenes from the many situations and interactions observed. In order to represent the temporal and spatial aspects of goal work, we introduce a few informants of the 20 key-informants; each case is illustrative of general issues which arose from our analysis. We aimed to introduce goal-work as a way to conceptualize the manifold micro-social practices in a goal process, and to add knowledge about goals and their setting in PD rehabilitation. While we believe that the concept of goal-work may be applicable in a wide range of rehabilitation settings, as a useful framework to open up and discuss components of the goal-process, the particular findings concerning PD may not be directly applicable to other settings, even if the findings will probably find resonance among professionals working with persons with degenerative diseases. While the scenes illustrate aspects of goal-work, the activities of goal-work are not exhausted in our cases, nor do we pay much attention to organizational structures, discourses, regulations, logics, or obstructions that might influence goal-work, all of which are matters of importance in the PD rehabilitation process.

In conclusion, we found the concept of goal-work a valuable framework for analyzing the work of goals as a process, with goal-setting as an event in that process. Goal-work allows for an attention to the different workplaces, the broad variety of micro-social activities involved and the persons involved, exposing the spatio-temporal and intersubjective aspects of goal-work. The title of our article is “Moving Goals.” Moving indicates how goals are dynamic, on the move, aided by infrastructure, and moved by participants over time and settings. Moving also refers to the emotions so clearly moved by goal-work, as persons with PD imagine and orientate to an uncertain future.

Clinical implications

There are some clinical implications of our findings: Goal-work may take place in settings beyond the actual rehabilitation setting and be a collective undertaking with spouses or other professionals taking active part. To coordinate and support goal-work, clinicians could uncover who is involved, and if considered appropriate and approved by the rehabilitee, involve co-workers more openly. As the rehabilitation and goal-work processes may be unclear to some rehabilitees (and spouses), clinicians must share their expectations of responsibility in the process and make explicit and visible the how and why of actions, including the connection between goal and intervention. Inter-professional teams must review goals with the rehabilitee (what have we done, why and how did it go), clearly dividing tasks between them (who does the review and how). Clinicians make use of emotional and ethical skills in their work. Rehabilitation management should acknowledge and support this type of work, incorporating these themes in staff-meetings or staff-education.

Further research is needed into the dynamics of how goals move between settings, how clinicians across settings share goals, and how participants in rehabilitation divide goal tasks between them.

Data availability statement

The datasets presented in this article are not readily available because informants are guaranteed full anonymity.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

Author contributions

MT is the primary author, the article is based on her fieldwork. CVN is the second author and RSA is the last author. Data analysis was done by MT, development of the argument and the analytical concept, and goal-work was done in collaboration between all three authors. MT and RSA did most of the editing of the article. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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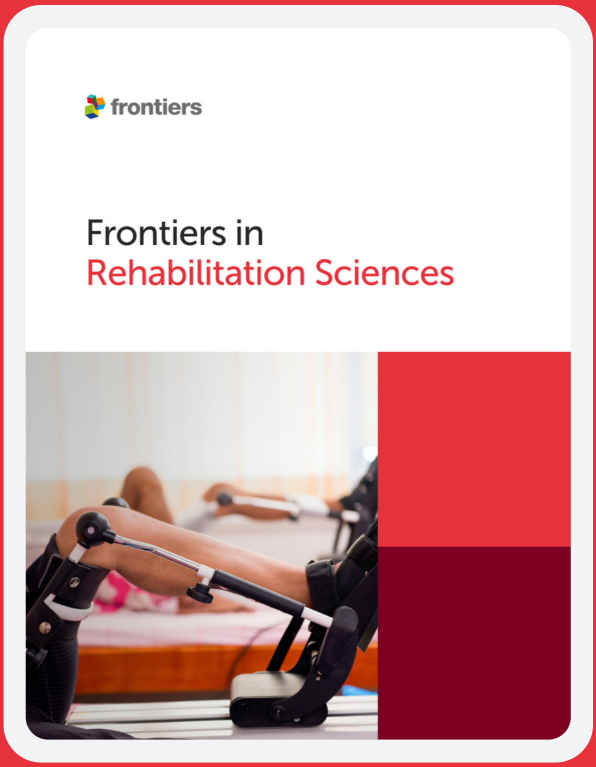

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