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Research paper

A person-centered approach in initial rehabilitation needs assessment: Experiences of persons with disabilities[☆]

Une approche centrée sur la personne dans l'évaluation initiale des besoins en réadaptation. Expériences des personnes handicapées

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ABSTRACT

Person-centeredness refers to an individually-tailored, holistic approach to meeting a person's needs and recognizing the client as an expert and active participant in the rehabilitation process. This article focuses on a study conducted in Estonia to analyze the perceptions of persons with disabilities about person-centeredness by exploring their experiences about received disability services and participation in an initial rehabilitation needs assessment process. Twelve in-depth interviews were conducted in different regions of Estonia with persons with disability. Data were analyzed using qualitative thematic analysis. The aim of the research project (2010–2015) was to design a person-centered initial rehabilitation

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needs assessment instrument. Results revealed that in describing their experiences, study participants identified important components of person-centeredness: (1) understanding service users and meeting their individual needs, (2) connecting and partnering with service users, (3) providing appropriate information, and (4) addressing issues of power and empowerment. If these components are included, service users are more likely to become motivated to consider their situation and take more control of their lives. These findings may be of relevance for countries considering needs-based referrals to rehabilitation services and refocusing disability services using a person-centered approach.

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L'approche centrée sur la personne est une approche holistique et individuelle adaptée pour répondre aux besoins de la personne, en reconnaissant le client en qualité d'expert et de participant actif dans le processus de réadaptation. Cet article met l'accent sur une étude qui a été menée en Estonie pour explorer les perceptions des personnes handicapées au sujet de l'approche centrée sur la personne, en étudiant leur expérience des services dont ils ont été bénéficiaires et la participation au processus d'appréciation initiale des besoins de réadaptation. Douze entretiens approfondis ont été effectués auprès de personnes handicapées dans les différentes régions d'Estonie. Les résultats ont été analysés en utilisant l'analyse thématique qualitative. L'objectif du projet de recherche (2010–2015) a consisté en élaboration d'un outil pour apprécier des besoins réadaptation, centré sur la personne. Les résultats ont révélé qu'en décrivant leurs expériences, les participants à l'étude ont identifié des composantes importantes de l'approche centrée sur la personne. En particulier, l'étude montre qu'ils ont décrit que dans la procédure d'évaluation, les facteurs suivants sont importants : (1) compréhension des utilisateurs du service et réponse à leurs besoins individuels, (2) connexion et partenariat avec les utilisateurs du service, (3) fourniture d'informations appropriées, (4) abordant les questions de pouvoir et d'autonomisation. Les résultats suggèrent que si ces composants sont inclus, les usagers des services sont susceptibles de se montrer plus motivés pour prendre en considération leur situation et exercer plus de contrôle sur leur vie. Ces résultats peuvent être pertinents pour les pays qui se réfèrent au besoin des usagers pour transformer les services aux personnes handicapées et qui utilisent une approche centrée sur la personne.

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1. Introduction

Concepts of disability, rehabilitation, and service delivery to persons with disabilities have undergone major paradigm shifts over the past 30 years (Barnes & Mercer, 2010; Shakespeare & Watson, 2002). Medical, followed by social, models of disability and rehabilitation have evolved into civil rights and person-centered perspectives that incorporate biological, psychological, social,

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environmental, and personal aspects of functioning with goals of promoting personal autonomy and societal participation on an equal basis with others (World Health Organization, 2013).

New models of the welfare state have emerged that include individual choice, partnership, empowerment, and community engagement (Das, O'Neill, & Pinkerton, 2015; Sapey, 2009; Stainton, 2009; Taylor & Taylor, 2013). Social service quality standards, agreed to at the international level, echo these perspectives (Social Protection Committee, 2010; World Health Organization, 2010). Together with implementing the United Nations Convention on the Rights of Persons with Disabilities, many countries have made progress in viewing persons who experience disability not as “objects” of welfare but as “holders” of rights (United Nations, 2006; Siegert, Ward, & Playford, 2010).

At the same time, many countries are facing challenges due to population ageing, rising numbers of persons with special needs, work incapacity, or chronic health conditions, and growing social expenditures as they attempt to address citizens' complex needs. According to Organization for Economic Co-operation and Development (2009, 2010, 2014) analyses, governments are facing economic pressures and have reformed their social support systems by tightening eligibility for social security benefits. As a result, the need to find ways to provide high quality social services to more people with special needs and to restore them to optimum functioning with both cost efficiency and cost effectiveness in mind is urgent.

1.1. Rehabilitation services in Estonia

Estonia, a country of 1.3 million people in Northern Europe, faces these challenges. Following re-independence in 1991, Estonia's rehabilitation service was designated through legislation in 1995 as one of the state-financed social services. In 1999, the rehabilitation service was introduced in the format of compiling individual rehabilitation plans and provide rehabilitation services to those who were disabled (Social Benefits for Disabled Persons Act, 1999).

In 2005 the target group, list of services, and financial limits for obtaining services each calendar year were regulated. As one of the core social services for persons with disabilities in Estonia, rehabilitation is intended to improve independent functioning, inclusion, and societal participation (Social Welfare Act, 2015). Under the Social Welfare Act of 2005–2016, the social rehabilitation service is considered an umbrella covering a set of services, including rehabilitation needs assessment, planning, and the services of specialists (primarily social workers, occupational therapists, physiotherapists, psychologists, speech therapists, and special pedagogues) who assist clients individually and in groups or as family units.

According to the Social Welfare Act, all children and adults with a registered disability have a statutory right to rehabilitation services. This right begins with referral to a rehabilitation team, comprised of at least three specialists, that designs a rehabilitation plan as a prerequisite for obtaining social rehabilitation services. Developing such plans is costly and exhausts considerable resources allocated for social rehabilitation, whereas the applicant's needs may be more appropriately met by interventions other than social rehabilitation, e.g., medical rehabilitation, labor market services, or other social services (e.g., home care, a personal assistant, or special transportation). Furthermore, in 2008, Estonia's National Audit Office assessed state-financed social rehabilitation services and criticized the system as overly bureaucratic and for not providing services in a timely manner and according to individual needs. Only about 10% of all persons with a disability received social rehabilitation services each year (National Audit Office of Estonia, 2008).

In 2010, the National Audit Office explored activities for better supporting persons with disabilities and work incapacity pensioners and also identified poor or unequal access to disability services and inefficiencies in the system (National Audit Office of Estonia, 2010). Other studies also concluded that Estonia's rehabilitation services are fragmented across social, health, and labor market sectors and lack coordination (Organization for Economic Co-operation and Development, 2012; Radziwill & Singh, 2012; Praxis, 2011). Persons with disabilities also identified difficulties in understanding differences between the types of rehabilitation services, resulting in mismatches between needs and services (Estonian Chamber of Disabled People, 2011). These organizational- and system-level shortcomings directly impact service accessibility and continuity and do not support a person-centered approach.

To be successful, studies show that rehabilitation services must re-establish a “person’s sense of control over his or her life” (Pryor & Dean, 2012) by allowing each person to maintain connection to the past (e.g., sense of self, connections with family and friends), while constructing his or her own future (e.g., identifying new goals). In Estonia, as in other countries, this requires major changes in rehabilitation approaches. Since 2012, the Estonian government has made efforts to modernize the work capacity assessment system and disability services. Reforms include restructuring social rehabilitation services by introducing an initial rehabilitation needs assessment process to facilitate needs-based referrals to services that better reflect principles of person-centeredness. Reforms are being implemented step-by-step in 2016 and 2017 (Ministry of Social Affairs, 2014).

In the process of restructuring social rehabilitation services, researchers and developers of Estonia’s new approach examined statistical data about clients’ demographic and disability characteristics and their rehabilitation service utilization. They realized that little information was available about clients’ values, attitudes, and beliefs, or about how the latter inform their worldviews and influence their rehabilitation. These insights were necessary for understanding individual and collective experiences of disability services and reforming the rehabilitation service process. Thus, as part of the restructuring, the authors of this article aimed to obtain information from persons with disabilities in Estonia about their experiences with disability services and whether they reflect person-centered principles.

2. Person-centered approach in disability and rehabilitation services

Over the last decade, person-centered approaches have gained momentum in disability and rehabilitation services in North America, the United Kingdom, and elsewhere (Kirkman, 2010). Much has been written about person- (also called patient-, client-, individual-) centered (or oriented, focused, directed) care (Leplege et al., 2007). Although lacking definitional consensus (Leplege et al., 2007; Pryor & Dean, 2012), the central tenets of person-centeredness are respect for and integration of individual differences when delivering care (Lauver et al., 2002; McPherson & Siegert, 2007). The critical characteristics of person-centered care are:

- understanding the patient or client as a unique person with individual characteristics, needs, values, beliefs, and preferences (Pryor & Dean, 2012);
- and responding with flexibility by delivering interventions that are responsive to clients’ initial and changing needs and preferences (Social Protection Committee, 2010).

The current notion of person-centeredness also derives from the approach developed by the American psychologist Carl Rogers and adopted first in the fields of clinical psychotherapy and counseling and later in social work, education, employment, and family therapy (Leplege et al., 2007). According to Rogers, (1951), each individual possesses considerable qualities (e.g., resources and strengths) on which to draw to remedy life’s difficulties. Clarc (2009) also argued that the fundamental philosophical principle of the person-centered approach is social justice, incorporating concepts of citizenship, autonomy, agency, community participation, and choice. Greenfield et al. (2014) added that person-centeredness includes the values of human rights, interdependence, and social inclusion in order to enable people to direct their own services and supports in a personalized way. Other important characteristics of a person-centered approach are taking a biopsychosocial perspective, sharing power and responsibility, and creating a therapeutic alliance with the client (Mead & Bower, 2000; McPherson & Siegert, 2007; Wilken, 2010). Pryor and Dean (2012), and Gzil et al. (2007) argue that rehabilitation always involves co-production; i.e., each group of stakeholders—patients/clients, rehabilitation specialists, rehabilitation service organizations, and policy and funding agencies (and the frameworks they utilize to support service provision)—influence rehabilitation processes and outcomes and the extent to which person-centeredness is embraced.

In this article, the authors apply the theoretical framework that underpins person-centeredness as reflected in the literature to investigate the occurrence of four key features of this approach in disability services clients previously received and compare that to their experiences with a new initial rehabilitation needs assessment process. The four components are:

- the person is treated as the expert in his/her life and as the center of services;
- the person's individual characteristics, values, beliefs, preferences, and changing needs are central in delivering services;
- the professional is empathic and shares equal partnership (power and responsibilities) with the person;
- clients are empowered in making choices, planning, and implementing the rehabilitation process.

3. Background of the study

The study described in this article was a part of a larger research project (2010–2015) used in developing a new model for initial rehabilitation needs assessment in Estonia that would:

- identify an individual's current situation, needs, and difficulties;
- determine if he/she qualifies for rehabilitation services;
- assist in setting initial rehabilitation goals for those who qualify;
- and aid in identifying the services (e.g., social rehabilitation, medical, labor market, other) most appropriate for meeting needs.

The project's overall aim was to reform the referral process to the rehabilitation service to make it more useful for clients, to connect persons with disabilities with services that meet their actual needs, and to improve the quality and use of social rehabilitation services.

The larger project consisted of a preliminary study and, as Fig. 1 depicts, three subsequent research cycles (2010–2015). The preliminary study took place in 2010. A team of researchers, analysts, service providers, and representatives of persons with disabilities analyzed Estonia's rehabilitation service process and suggested an initial assessment procedure as one possibility for employing needs-based referrals in rehabilitation services. In the first research cycle, conducted in 2010–2011, an assessment instrument was developed and pilot tested. Forty-six rehabilitation specialists assessed the needs of 256 individuals applying for rehabilitation services using a semi-structured face-to-face interview procedure in different regions of Estonia. Based on the rehabilitation specialists' feedback and suggestions, the assessment instrument was refined, and from September 2012 to March 2013 (research cycle 2), four rehabilitation specialists (case managers) used it to assess the rehabilitation needs of 101 persons applying for rehabilitation services. Approximately 3–5 months later, the first author of this article conducted face-to-face interviews with four case managers and 12 persons who participated in the assessment process to gain an understanding of their perceptions of the process. Results from the assessment and interviews were used to inform the third research cycle in 2015 when six case managers assessed the rehabilitation needs of another 120 clients and the instrument was finalized. Throughout the process, the assessment instrument was tested and validated to ensure that it correctly identified those who had moderate or severe difficulties in several domains and produced valid, reliable, sufficient, and authentic evidence about rehabilitation needs of individuals in Estonia.

The Ministry of Social Affairs of Estonia approved the study, including describing study procedures to potential participants, allowing them to consider whether or not they wished to participate, and obtaining written consent from those who wished to participate. The larger project and research culminated in 2016 when the use of the initial rehabilitation needs assessment procedure was imposed by law in all regions of Estonia.

3.1. Content of the initial rehabilitation needs assessment questionnaire and assessment process

The new, four-part rehabilitation needs assessment instrument contains:

- a section for the participant's demographic and background information;
- information about previous disability-related services received and how they influenced functioning;
- the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), based on the International Classification of Functioning–ICF (World Health Organization, 2010b), with additional

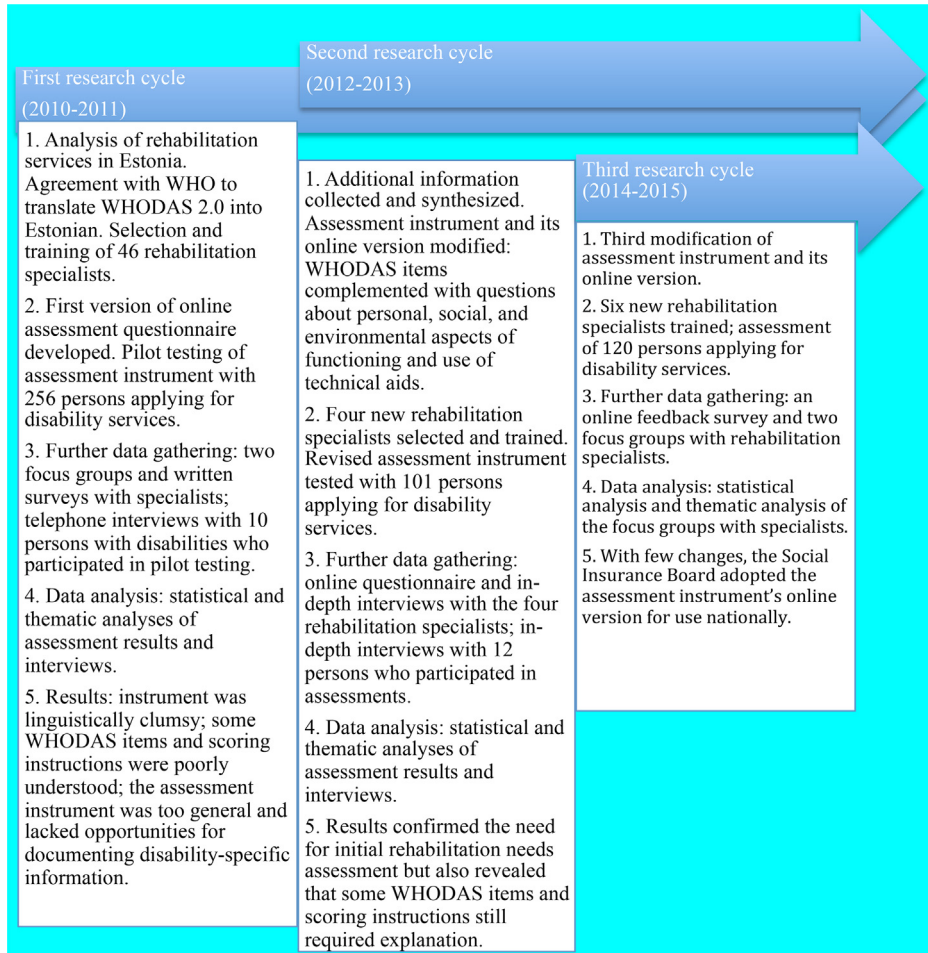


Fig. 1. Development of the initial assessment instrument and process: Research cycles in 2010–2015.

opportunities to specify causes of disability-related problems regarding personal, social, and environmental aspects of functioning (added after the pilot testing in 2011) to make it more person-centered. WHODAS 2.0 covers six major life domains: cognition; mobility; self-care; getting along with others; participation in daily life activities; and participation in social and community activities (World Health Organization, 2010a, 2010b). WHODAS 2.0 was selected because studies support its validity and reliability in a variety of different cultural settings (Federici & Meloni, 2010; Garin et al., 2010);

- a summary that includes the participant's expectations for the future, his/her rehabilitation goals, and determinations about social rehabilitation and/or other necessary services. The assessment instrument is standardized but also allows the case manager to ask open-ended questions to specify the person's situation, difficulties, and desires, also with the aim of increasing client-centeredness.

The initial rehabilitation needs assessment process consists of three steps in which case managers:

- gather formal information (records, documentation);

- conduct a face-to-face assessment, and when necessary, include family members and/or support persons;
- and follow-up with the person to finalize assessment results, connect the person with necessary services, or take other needed steps.

As a rule, the assessment interview lasts an hour and a half to two hours. A second meeting is possible when the person is tired or needs more time to think about his/her rehabilitation goals. Assessments usually take place at the Social Insurance Board's office, but when necessary, at a place the person prefers (e.g., home, day center, hospital). Decisions about qualification for services are made during the face-to-face meeting, but the assessment results are sent to the person by mail or e-mail. In the case of referral to the social rehabilitation service, the case manager helps the person find a suitable rehabilitation team. Those not deemed in need of social rehabilitation services are referred to other professionals or forms of help (e.g., a municipal social worker for counseling, a family or specialist doctor for medical rehabilitation or care, the association of persons with disabilities for peer support) ([Astangu Vocational Rehabilitation Center, 2013](#)).

4. Research methodology

4.1. Research questions

The study's aims were to understand how persons with disabilities in Estonia view the ways in which they are treated in the processes of disability assessment and rehabilitation service delivery and to determine if their descriptions are consistent with principles of person-centeredness. In particular, the researchers were interested in examining whether the following were addressed: individuals' needs and preferences, partnership and equality with rehabilitation professionals, empowerment, and choice in rehabilitation processes. Study participants' perceptions and perspectives were considered vital for designing the initial rehabilitation needs assessment instrument, service processes, and procedures.

The research questions were:

- how do persons who applied for and received disability services in the past two years describe these experiences, and how do these perceptions and experiences correspond with a person-centered approach?
- how do persons with disabilities describe their experiences with the new initial rehabilitation needs assessment procedure, and how do their perceptions and experiences reflect aspects of a person-centered approach as intended?

Although experiences with previously received services may be influenced by issues related to service availability (e.g., long waiting lists, lack of resources), the authors' focus was on how individuals felt they were treated in the assessment and service process, rather than on the number and types of services they received. Thus, the researchers analyzed study data using person-centered principles in order to make recommendations for designing new social rehabilitation service procedures.

4.2. Epistemological perspective

Using qualitative interview methods, the study was conducted through a phenomenological lens. Rooted in personal perspectives and interpretation ([Cohen & Crabtree, 2006](#); [Moustakas, 1994](#)), phenomenology facilitates an understanding of people's experiences and lends insight into their motivations and actions ([Lester, 1996](#); [Trochim, 2006](#)). Qualitative research methods, which involve interpretive and naturalistic approaches to data collection ([Denzin & Lincoln, 2011](#)) are consistent with this phenomenological stance. Qualitative research allows for examination of factors such as the context in which the action takes place and the culture and language through which people create and convey meaning in their lives ([Ritchie & Lewis, 2003](#); [Benton & Craib, 2011](#)). In attempting to make meaning of phenomena through research participants' eyes, researchers must take stock of their own

background, worldview, and use of language, including the ways in which they pose questions and choose the lens for filtering information gathered from participants (Berger, 2015). All these factors will shape the study's findings and conclusions. Researchers should also make their own experiences and positions known to those who read and evaluate their work (Ritchie & Lewis, 2003; Benton & Craib, 2011). The researchers who conducted this study are from Estonia, the Netherlands, and the United States and work in the fields of social work, rehabilitation, human rights, and academia. To guard against research biases, each considered her/his own views and life, including work, experiences, and served as a check to guard against biases in interpretation. By utilizing examples of findings in participants' own words, the authors further demonstrate efforts to ensure that interpretations flow from the data.

4.3. Sample

Of the 101 participants assessed for rehabilitation services during the second research cycle, 12 were purposively selected to aid in obtaining an in-depth understanding of their experiences with the initial rehabilitation assessment process and their previous experiences of disability services. Case managers in Estonia's three main regions/cities (Tallinn, Tartu, and Pärnu) were asked to name four clients who participated in the initial needs assessment process in order to obtain a sample that could provide the perceptions of a broad range of individuals in terms of age, gender, type of disability, employment status, and region of residence. To limit social desirability bias, the sample included both participants who were referred and were not referred to the rehabilitation service after the initial rehabilitation needs assessment. Although these 12 individuals may not represent the experiences of all those assessed for services, the intention was to gather feedback from a diverse group of participants.

Case managers contacted each client and obtained an initial, verbal agreement to participate. Then, the first author of this article contacted each person to find a convenient time and place for the interview. She explained the aim of the research and that each individual's experiences with the assessment were very important in developing the assessment instrument and process to be used nationally. Participants were informed that the information they shared would be used only for analytical purposes and that the data would be presented in a way that would prevent others from identifying them. Participants were encouraged to ask questions about the study and were also informed that they could ask questions at the time of the interview or afterward. All participants gave their written informed consent to participate and were given the name and the contact information of the primary researcher in case they had questions later. Participants were not compensated.

As Table 1 shows, the six women and six men who participated ranged in age from 25 to 77. They had a variety of disabilities, including physical, mental, and cognitive, and many had more than one disability.

Table 1
Characteristics of the sample (n = 12).

Sex	Age	Type of disability	Region of Estonia	Social status	Rehabilitation service decision
Male	25	Mobility and hearing disability	Tallinn	Student	Not necessary
Male	28	Psychiatric disorder	Tartu	Not working	Not necessary
Female	34	Psychiatric disorder, epilepsy	Pärnu	Not working	Necessary
Male	36	Psychiatric disorder, epilepsy	Tartu	Not working	Necessary
Female	50	Cancer	Pärnu	Working	Not necessary
Female	58	Muscle disease, obesity, depression	Pärnu	Not working	Necessary
Male	58	Parkinson's disease	Tallinn	Not working	Not necessary
Female	59	Diabetes, visual and mobility disability	Tallinn	Self employed	Necessary
Female	60	Low back pain, depression	Tartu	Employed	Necessary
Male	62	Psychiatric disorder, schizophrenia	Tartu	Employed	Not necessary
Female	63	Rheumatoid arthritis	Pärnu	Not working	Necessary
Male	77	Speech disability after stroke	Tallinn	Retired	Not necessary

4.4. Data gathering method

Data were gathered using in-depth, semi-structured, face-to-face interviews. Interviews were conducted from March to July 2013, approximately 3 to 5 months after each individual participated in the pilot testing of the initial needs assessment procedure.

Participants were asked to describe their experiences in applying for and using different types of disability services, their contacts with rehabilitation or other specialists (e.g., doctors), and their perceptions of the needs assessment process in which they had recently participated. They were also encouraged to discuss their difficulties/challenges, needs, and wishes about disability services. To avoid leading questions and obtain candid responses, the interviewer did not use the term “person-centered,” nor did she offer any description of person-centered services. Rather than seeking to determine whether participants believe person-centeredness is a good idea, the researchers wanted to know whether, in the natural flow of conversation, participants’ descriptions of their rehabilitation experiences reflected or did not reflect person-centered principles.

4.5. Data analysis

Interviews were recorded and transcribed and the full text was read several times. The first analytic principle applied was an emergent strategy to allow the analysis to follow the data. Therefore, the first author used an open coding process. Then meaningful units (themes) were developed from the text. The data were then organized into increasingly more general units of information to build themes from the bottom up (Rubin & Babbie, 2011). Similar themes that emerged were grouped into categories. The analysis moved back and forth between themes and categories until a comprehensive set of categories for answering the research questions was reached. Then the first author used mind-mapping techniques to visually arrange and conceptualize the themes and categories that emerged and to determine their congruence with concepts of person-centeredness. This stage of the analysis focused on identifying participants’ rehabilitation service experiences that exemplified, described, or referred to key features of person-centeredness (e.g., being treated as a whole person, with respect, as knowledgeable about their life, as equal with the professional; believing their needs and preferences were addressed; feeling empowered to make decisions about their life and hopeful about the future). The researchers also looked for experiences that were antithetical to a person-centered approach and how participants interpreted those experiences.

5. Results

5.1. General observations

Participants talked freely about their contacts with specialists and experiences with the disability services they had received in the past two years. Much information emerged about how participants felt about themselves in the process of receiving services and during the new initial needs assessment and how both had influenced their functioning. Interviews were rife with perceptions about being a “patient,” “sick,” or “disabled.” Participants often mentioned being disabled due to non-supportive relationships with others or living in an environment that lacked supports.

I think that I am not the master of my own life. Why? Because I am disabled. . . my special needs make my choices. . . I cannot go everywhere I want or do everything I would like. Male, age 25, mobility and hearing impairment.

There are lots of hindrances in the environment—stairs, ramps etc. All places [I need or want to go] are far away from my home; my health condition has worsened. I am disabled. Male, age 36, psoriasis, psychiatric disorder, epilepsy.

5.2. Research question 1: past experiences

Participants were asked to describe their experiences with disability services (health care, rehabilitation, social services provided by their local municipality, and labor market services) in the past two years and whether or how those services had influenced their functioning. Four categories of problems emerged that were common to most participants' experiences and the services they had received:

- lack of information about their diagnosis and possibilities for obtaining relevant services;
- poor relationships with specialists;
- unequal distribution of power;
- unmet needs.

Many participants expressed a desire for more involvement in planning or directing their care or rehabilitation, i.e., they wanted a central role in their rehabilitation, but for reasons described below, this did not happen.

The specialist in the Labor Market Office just gave me some papers and some instructions about where to go, and that was it. I felt I needed more time and information [and] more possibilities from which to choose. If I do not have information, I cannot choose. I just did as the specialist said, but it did not work for me. Male, age 25, mobility and hearing impairment.

5.2.1. Lack of Information

Among the most common problems illustrating a lack of person-centeredness was the lack of understandable information, i.e., participants did not get the information and counseling they needed or desired after receiving a diagnosis; nor did they get this information during their treatment. They lacked knowledge about how to cope with their disability or illness and how to get services necessary to improve their health or daily functioning.

If I think about the system, how the services or help are provided, it is not easy to understand. People do not know where to go or what to ask. Male, age 58, Parkinson's disease.

5.2.2. Poor relationships

The second major category included problems with relationships or connections with specialists. Many participants indicated that they did not feel as though the specialists understood them, and they perceived a lack of attention from specialists. Participants wanted the specialists to be more supportive. They thought the specialists should take more time to get to know persons with disabilities in their region and should take the initiative to make contact with them.

It should be their duty to contact people like me and ask how we are doing. Female, age 63, rheumatoid arthritis.

Poor relationships and connections were also reflected in participants' previous rehabilitation experiences due to professionals' poor communication skills or attitudes described as superficial. Most participants had previous contacts with labor market services that also reflect the theme of poor relationships with service providers. Some experienced a friendly attitude from them, but no one received help in finding employment. According to participants, specialists did not give them sufficient attention, and assistance was not provided in a timely manner.

I received no help there [labor market office]. They told me to look on the wall where job advertisements are posted, but there was nothing. Male, age 36, psoriasis, psychiatric disorder, epilepsy.

The doctor seemed ignorant of my situation. I have been to so many doctors. Each time I had to prove that I am sick, that I have pain, that my situation is uncertain. . . I have not experienced understanding from doctors. Female, age 63, rheumatoid arthritis.

5.2.3. Unequal distribution of power

The third category related to situations in which participants felt stigmatized or were afraid to ask questions, especially to doctors whom they see as professionals in positions of great authority. Clients' comments illustrated the unequal distribution of power between specialists and client. A core principle of person-centeredness is partnership, but in those cases, participants did not describe a sense of cooperation. Sometimes the help was not delivered in a respectful way.

The doctor once told me that I'm too poor to afford the treatment I need. She did not even explain what help she had in mind. Female, age 58, muscle disease, obesity, depression.

I do not dare to ask for information, I am afraid of what the doctor is going to say to me again and that she will try to get rid of me if I ask too many questions. Female age 59, diabetes, visual and mobility impairment.

5.2.4. Unmet needs

Many problems participants described were connected to service unavailability and inaccessibility. Criticisms of the system were about how the various disability services are provided—long queues, lack of resources, and service limits. Most participants discussed their unmet medical and social rehabilitation service needs. For example, many had rehabilitation plans that included several services, but due to long waits and lack of funding, they did not get those services, and they lacked recourse to obtain them. Examples of services not received were personal assistance (i.e., a support person), financial support, transportation, dwelling modifications, and housing paid for by the municipality. Thus, the person-centered principle of meeting clients' individual needs was not realized.

Our municipality has reduced different support measures. Some time ago they took away my personal assistant; they are not reimbursing my transportation costs anymore. My home needs adaptations (toilet and bathroom), but I simply cannot afford it. The municipality knows I need help, but it does nothing due to no finances, and that's it. Female, age 58, muscle disease, obesity, depression.

Participants did note positive experiences with some previously received services. Although the current article focuses on person-centeredness in the process of working with clients and not on the content of services, per se, some said the physiotherapy services they received helped with their mobility limitations or that they had received rehabilitation services in pleasant environmental settings conducive to recovery. Positive comments were, however, few and far between.

In summary, most study participants described previous experiences that were not consistent with person-centered principles such as seeing the patient/client as a person, sharing power and responsibility, creating a therapeutic alliance, and empowering patients/clients (Mead & Bower, 2000; Macleod & McPherson, 2007; Pryor & Dean, 2012).

5.3. Research question 2: experiences with initial rehabilitation needs assessment

The newly designed initial rehabilitation needs assessment received more positive feedback. Participants indicated that the initial needs assessment process and 1.5–2 hour face-to-face meeting with a case manager offered them opportunities to talk about their situation and to be heard. They indicated that they received referrals to needed services and other benefits such as useful information, practical and emotional support, and equal partnership and cooperation. For example,

I felt great relief after we [the case manager and I] met. Both practically and emotionally, somebody listened to me, discussed with me, gave hope, and directed me to the help I needed most. At the end, I felt that everything had been said. We made plans and I got psychological counseling and physiotherapy. I feel that I can trust her and turn to her when I have problems again. Female, age 58, muscle disease, obesity, depression.

The benefits participants experienced can be grouped into five categories, reflecting a more person-centered approach, as described below.

5.3.1. *Useful information about opportunities and choices*

Participants indicated that the specialists who conducted the interviews were competent and gave them a great deal of useful information. They also become aware of opportunities available to them because the information was accurate and delivered in a manner they could understand.

I got lots of information. The doctors only prescribe medications; they do not tell you what to do next. After our conversation, I understood that even I have some choices. Male, age 58, Parkinson's disease.

5.3.2. *Opportunity to talk and to be heard*

Almost all participants said they had not had an opportunity before to discuss their situation so thoroughly and that the assessment interview was one of the few times any specialist had dedicated that much time to meeting with them. Such statements indicated that case managers fostered a positive and open relationship in the assessment process and encouraged participants to talk about their situation, needs, and wishes.

I am thankful for that conversation, for the opportunity to discuss my situation with a person who is a specialist in that field. There were so many things I did not connect with my disease. Female, age 50, cancer.

5.3.3. *Empowerment and hope*

The way the assessment was conducted seemed to raise participants' self-confidence, encouraged them to act, empowered them, and helped restore their emotional balance. Though they often used other words, several participants expressed the idea that the process left them with hope, a central concept in psychosocial rehabilitation and the recovery process.

This conversation gave me new hope; I started to make new plans. Female, age 60, low back pain, depression.

5.3.4. *Partnership; practical and emotional support*

Participants indicated that they felt a partnership with the specialist. Comments reflected that they shared equally in setting goals and making decisions about necessary services and that encouraged them to take responsibility for carrying out their action plan made after assessment. Participants felt the specialist was standing with them, offering practical and emotional support in the process. They became more aware of their needs and possibilities for the future and found a sense of peace after the assessment.

I felt great relief. Finally, somebody asked me the right questions—how I think about these things. So far I had to do what the doctor said. Female, age 59, diabetes, visual and mobility impairment.

5.3.5. *Understanding their situation, self-acceptance, and finding solutions*

The initial needs assessment helped participants better understand their situation. As they began seeing connections between the difficulties they were experiencing and their health conditions, they were better able to envision possible solutions. Participants also noted that the needs assessment gave them an opportunity to learn something new about themselves and to accept themselves as they are.

I started to accept myself like I am. All those things I said in the assessment, this gave me freedom, like forgiving myself about these things I was keeping inside of me so long. Female, age 60, low back pain, depression.

6. Discussion and conclusions

Our study revealed that even when not prompted with definitions of person-centeredness, people with disabilities describe important elements of this approach, or the lack thereof, when asked to discuss their experiences with disability services. There are, of course, limitations to the study. First, findings may be exclusive to the particular study context, and participants' comments may not

Table 2

Core elements of designing and delivering services in a person-centered way validated by persons with disabilities.

Understanding clients and meeting their individual needs
Getting to know the person (providing opportunity to talk and to be heard)
Assessing needs holistically
Personalization, flexibility, and availability of needs-based services
Helping, when necessary, in coordinating services
Connecting and partnering with clients
Professional training and competencies (e.g., how to build trusting relationships, create connection, improve communication skills)
Compliance with ethical principles and values, respecting differences and demonstrating this to clients
Adequate facilities (private and comfortable service environment)
Policies supportive of the service process (sufficient time to attend to clients and resources to meet clients' needs, manageable caseload size)
Providing appropriate and adequate information (in an understandable manner, oral and written) about the following
Diagnosis, treatment, medications, and prognosis
Available services (social, employment, disability unions, etc.)
Clients' rights and responsibilities
Self-help and support groups
Addressing issues of power and empowerment
Fostering equality with clients
Recognizing the client as an expert
Empowering clients, helping them increase their self-efficacy and take more control of their lives
Involving clients in planning and decision-making processes, sharing responsibilities with them

represent the views of all participants in the testing of the new initial needs assessment process or the population of Estonia's rehabilitation clients. Second, though participants clearly described differences between prior services and the new assessment process, their views of prior services, in particular, may be colored by factors such as lack of services and unmet needs rather than by the way rehabilitation personnel treated them, per se. Nevertheless, clients who experienced the new assessment process but did not qualify for rehabilitation services also spoke positively of the way they were treated. This lends further support to the idea that the new assessment process is a step towards more person-centered assessment services.

As participants' comments indicated, the new assessment process allowed them to experience a person-centered approach in several ways. They had an opportunity to talk about their situation and felt their story was heard. Specialists had more time to spend with each person to build a trusting alliance. They were able to ask the questions needed to better understand the person's life situation as the literature on best practices in the rehabilitation field urges. The assessment focused on meeting clients' needs in ways that addressed the difficulties each individual experienced. It also focused on giving clients accurate information about their options and choices in an understandable manner. This seemed to empower participants to make informed decisions about the services they needed and wanted. Power and responsibilities were shared. Participants felt equality and partnership in setting rehabilitation goals and in planning and making service decisions.

Four important aspects of person-centeredness lacking in previously received services, as identified by study participants, provided insight into how disability services should be designed and delivered to better meet clients' needs (Table 2). These four aspects can be summarized as:

- understanding clients and meeting their individual needs;
- connecting and partnering with clients;
- providing appropriate and adequate information;
- and addressing issues of power and empowerment.

Each of the four adds knowledge to the theory of person-centeredness and to the practice of designing and delivering services for persons with disabilities in Estonia. The study suggests that if these components are included, clients are more likely to become motivated to analyze their situation, accept themselves, and take more control of their lives. The study is consistent with the findings of McPherson and Siegert (2007), Kirkman (2010), Greenfield et al. (2014), and Den Hollander and Wilken

(2015), who present the characteristics of person-centeredness and find that when patients/clients' expectations are met, care or rehabilitation services are at their best, giving patients/clients strength and raising their motivation.

Initial rehabilitation needs assessment is, however, just the first step in the rehabilitation process. Alone, it will not provide significant change for service users over the long run. Agreement on person-centered principles and how they are to be achieved will require improvements throughout the rehabilitation process. This means restructuring other parts of the service system (a system-level approach) so that a person-centered approach permeates all aspects of service delivery; for example, increasing service availability and quality are also needed to complete the picture.

As a follow-up to this project, several actions have been taken in Estonia. Besides implementing the new assessment instrument and procedures, materials have been prepared to inform clients about what to expect from the initial rehabilitation needs assessment and the subsequent rehabilitation process. New legislation in Estonia will ensure that service procedures include more time for face-to-face meetings with clients and for matching services to clients' needs. Training and program monitoring have also been implemented to ensure that specialists not only understand what a holistic, person-centered approach is, but that they carry it out with clients.

7. Recommendations

The information gleaned from this study provides encouragement for transforming rehabilitation services in Estonia and in other countries. Based on several international studies and the current study in Estonia, the authors make several recommendations for improving services to persons with disabilities. First, person-centeredness should be consciously implemented as a quality component of the initial rehabilitation needs assessment and in providing all types of disability services. Second, person-centeredness should be fixed in legal frameworks (legislation), social services quality standards, and detailed work regulations (initial rehabilitation needs assessment service description, specialists' job descriptions, and personnel evaluations). Third, person-centeredness should be an essential component of rehabilitation specialists' training to increase their knowledge and skills in order to promote the centrality of people with the lived experience of disability in their rehabilitation process. This includes an imperative for rehabilitation specialists to develop extensive knowledge of rehabilitation services and technologies, and most importantly, mastering skills such as active listening, motivational interviewing, and client empowerment to assist clients in meeting their rehabilitation goals. Implementing a person-centered approach in rehabilitation requires the allocation of adequate time and other resources to specialists, as well as supervision of and co-vision among specialists to support their casework, especially for the most complex cases. Without these components, clients are unlikely to reach an optimum level of functioning despite specialists' good work and intentions during the initial assessment.

Disclosure of interest

The authors declare that they have no competing interest.

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