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Client-centred practice from the perspective of Danish patients with hand-related disorders

Short title: Perceptions of client-centredness in hand therapy

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Abstract

Purpose: The objectives of this study were to investigate perceptions of client-centred practice among Danish patients with hand-related disorders engaged in rehabilitation at outpatient clinics, and to decide on domains to serve as a conceptual foundation for item generation in the development of a new, standardised questionnaire to evaluate the experience of client-centredness among patients with hand-related disorders.

Method: Focus group interviews were held with 25 patients with hand-related disorders from six outpatient hand clinics in Denmark. Deductive content analysis was used to decide on domains for item generation.

Results: Patients found that information was paramount in understanding their situation and to feel empowered and motivated. They attached importance to participation in decision making so that rehabilitation was considered meaningful. Most of all, they thought rehabilitation should be individualized by taking their life situations and personalities into account. Six domains were found to be central to client-centred practice: patient participation in decision making, client-centred education, evaluation of outcomes from patient’s perspective, emotional support, cooperation and coordination and enabling occupation.

Conclusions: The domains can be used in the further development of a Danish questionnaire to evaluate the experiences of client-centredness among patients engaged in rehabilitation at outpatient clinics for hand-related disorders.

Keywords: client-centred enabling, client-centred rehabilitation, hand injuries, occupational therapy
Introduction

Hand-related disorders are quite common. Because we use our hands in almost all everyday life activities, a hand disorder can have a significant impact on a patient’s domestic, paid work and leisure activities [1-3]. Existing research provides evidence that supports client-centredness as an underlying approach in occupational therapy, and the approach is widely adopted [1,4]. However, patients’ perceptions of client-centredness have hardly been investigated and are poorly understood for outpatients. Hand therapy is conducted in close collaboration with hand surgeons. There are detailed protocols or regimes for many diagnoses, which describe rehabilitation for injuries relating to body structure and body function, thereby reducing deficits in physical function [5-7]. The needs and resources of the individual patient are less incorporated in hand therapy [7]. Most patients with hand-related disorders are engaged in rehabilitation at outpatient clinics. They are cognitively unaffected, live at home, are in employment and perform their everyday life activities throughout rehabilitation. These circumstances highlight how important it is that the hand therapist is client-centred and involves patients’ resources, personalities and life situations in rehabilitation.

The client-centred approach was first described in 1939 by psychologist Carl Rogers (1902-1987) [8]. Since then the client-centred approach has been adopted by many professionals. In Denmark, almost all hand therapists are occupational therapists (OTs). Therefore, it is natural to use definitions and core elements from occupational therapy literature and here at least four definitions have been published [1-3,9]. However, there is no Danish definition. The first definition was given in 1995 by the Canadian Association of Occupational Therapists (CAOT) [1]. Danish occupational therapy literature [10] has assumed and cites the reviewed
Canadian definition published in 1997 [2] and stated values in the national ethical guidelines, published by the Danish Association of Occupational Therapists, are congruent with the core values and elements in the Canadian concept of client-centredness. They are: activity and participation as a human right, respect, equality, sufficient and relevant information, partnership with clients, and partnership with relatives [11]. Several studies have described the core elements of client-centred practice and its definitions [1,12,13]. Although there is a high degree of congruence between the descriptions of client-centred practice, there remains a lack of consistency in the definitions in occupational therapy literature. In 2007, CAOT amended the term ‘client-centred practice’ to ‘client-centred enablement’ and presented a new definition without an explicit discussion of how it differed from earlier versions [9]. Although the idea of ‘enablement’ was included in the earlier definition, it now became essential in client-centredness. The core values and elements of client-centred enablement became: choice, risk and responsibility, client participation, knowledge about options, changes, justice and power [9]. Most of the above were consistent with the values and elements in previous descriptions of client-centred practice, but some notions, such as ‘respect’ and ‘recognition of client’s experience and knowledge’, were no longer stated explicitly [14]. The client-centred approach is still being developed. The fact that no single, clear definition of client-centred practise exists makes it challenging to investigate.

Despite inconsistencies in defining client-centred practice, studies have shown that outcomes of adopting the client-centred approach include an increase in the level of client service satisfaction [1,15-17] and an improvement in functional outcomes in everyday life activities [1,15,16,18]. Most studies that show improvement, however, explore the outcomes of only some elements of client-centred practice, for example, partnership or participation in goal setting [1,19-21]. Furthermore, the majority of studies define client-centred practice from a
theoretical or occupational therapy perspective [17,20,22-25]. Only a few studies investigate patients’ perceptions and experiences of the approach [19,21,26-32], although it seems to be an important perspective when investigating client-centred practice. Maitra et al. [21] found that clients did not experience client-centred treatment to be as client-centred as did their therapists. It would seem important, therefore, that, in striving to improve satisfaction and functional outcomes by being client-centred in agreement with professional ethical values, the core elements considered significant by the patients should be investigated. It is essential, therefore, to conceptualise domains, founded on both theoretical and empirical perspectives, before developing a questionnaire, that incorporate patients’ perception on client-centredness in local cultural context.

To evaluate the extent to which outpatient rehabilitation is client-centred from the patients’ point of view and has an effect on rehabilitation outcomes, assessment tools are needed [4]. A literature search resulted in several questionnaires for inpatients [13,26,27,33], but none targeted to outpatients [4].

The objectives of this study were a) to explore the perceptions of client-centred practice among Danish outpatients with hand-related disorders in relation to occupational therapy literature about client-centredness, and b) to select important domains serving as a conceptual framework for the development of a client-centred evaluative questionnaire.

**Material and methods**

Prior to the current study, we investigated whether an existing questionnaire to evaluate patients’ experiences of client-centredness was suitable for translation and use among Danish
outpatients with hand-related disorders. This process will be presented at the beginning of this section, because the findings are used in the present study.

**The Client-Centred Rehabilitation Questionnaire in Danish**

In the literature search, the questionnaires found were either solely theoretically based, or focused on care or single elements of the client-centred approach [21,34,35]. However, the Canadian Client-Centred Rehabilitation Questionnaire (CCRQ) seemed transferable, because it embraced the entire definition of the concept, most of its items seemed relevant for Danish outpatients and it was both theoretically and empirically based. Furthermore, psychometric properties were published [13,26]. The CCRQ was developed from interviews with clients with a range of diagnoses and client-centred rehabilitation theories. The CCRQ has seven domains: 1) *client participation in decision making and goal setting*, 2) *client-centred education*, 3) *evaluation of outcomes from client’s perspective*, 4) *family involvement*, 5) *emotional support*, 6) *coordination/continuity* and 7) *physical comfort*. We carried out a feasibility study of the CCRQ before implementing it in outpatient hand rehabilitation. The feasibility study consisted of a systematic comparison of the domains and items in CCRQ and the core values found in occupational therapy literature and the Danish ethical guidelines [11]. Furthermore, focus groups were set up to investigate if the domains and items were in agreement with the understanding of client-centred practice among Danish OTs and patients with hand-related disorders in an outpatient context (unpublished data). The interviews were analyzed by deductive content analysis by the first and second authors [36]. Apart from the domain *physical comfort*, acceptable agreement was found when data were systematically mapped against the domains in CCRQ [36]. None of the outpatients addressed the *physical comfort* domain and, when prompted, they did not find it relevant to client-centred practice for outpatients. Instead, the mapping required a new domain, *enabling occupation*, with items
that would reflect the need for activities of everyday living to be taken into account in rehabilitation. The CCRQ was translated by a dual translation panel [37,38]. However, during the cognitive test and test of psychometric properties, it became clear that the generic CCRQ was not sufficiently sensitive to Danish outpatients with hand-related disorders due to the high level of ceiling effect and significant use of the ‘does not apply’ response [39,40]. Thus, there was a need for the development of a standardised questionnaire comprising all aspects of the client-centred approach, from the patient’s perspective. However, to develop a relevant and sensitive questionnaire for outpatients with hand-related disorders, we needed more knowledge on outpatients’ perceptions and experiences of client-centredness.

The current study
Focus group interviews were chosen as a method to guide participants to present and discuss their perceptions and experiences of client-centred practice. It is a relatively non-hierarchical research method [41-46] that urges participants to react to and build upon other participants’ responses. Thereby, it often results in more elaborated explanations than those generated in individual interviews [47]. Throughout this article, the word ‘client’ is used when we refer, in general, to the recipients of client-centred practice, whereas, ‘patient’ is used to denote a person in the target group. However, patients are not regarded in the traditional way – as passive recipients of healthcare. The designation is the most typical choice in the area of hand therapy. We also differentiate between client and patient in domains and headlines. Referring to domains in CCRQ we use the term client and in domains in our results we use the term patient. The patient participants are called participants in the Results and Discussion sections.

Setting: In Denmark, patients with hand-related disorders engage in rehabilitation in different settings, according to the severity of their injury. Patients with the most common and less
severe injuries are generally treated at outpatient clinics in the community. Patients with more severe and complex injuries are treated at either specialized or highly specialized outpatient clinics at hospitals. The health professionals in all settings are mostly occupational therapists; however, surgeons, physiotherapists and nurses are also sometimes members of the team. In Denmark, all patients are covered by public health insurance; therefore, everyone who needs treatment will be treated. Six clinics participated in the study. We chose two clinics from each setting and stratified our choice to achieve variability in clinic size and geographical setting. The focus group interviews were conducted in February and March 2016, at which time thematic saturation was reached. Thematic saturation was reached when no new themes were identified during the search for patterns [48].

Participants: Hand therapy generally focuses on body function, regimes and structural recovery. Most patients with hand-related disorders in outpatient clinics experience rehabilitation, since many are engaged for at least a month, and therefore they constituted a relevant group to engage in the study. Access to the participants was obtained through OTs who worked at the outpatient clinics. They selected a convenience sample of 5-7 adult patients with hand-related disorders [49,50]. The number of participants was chosen to ensure time and possibility for each participant to contribute with experiences, opinions and examples from their rehabilitation process [49,50]. To ensure variation in the focus groups and experience of rehabilitation, we asked for participants who had undergone at least three weeks of rehabilitation for a hand-related disorder and differed in age, sex and kind of injury in each focus group. The first author had been in contact with all the OTs to ensure representativeness.
Interview guide: An interview guide was developed based on the domains in the CCRQ, central core values and elements from occupational therapy literature and the Danish national ethical guidelines. The interviews began with broad, open-ended questions. The open-ended questions were: “In your own opinion, what facilitates or inhibits the effect of a rehabilitation process?” and “What characterizes participation in rehabilitation?” The formulation of the questions aimed to encourage participants to think broadly about a range of aspects involved in rehabilitation. Additional questions in the interview guide were designed to enhance reflection about the approach, if required [51]. The questions were based on the structured examination of how the core values and elements from client-centred practice literature fit the domains found in the feasibility study. Additional questions regarding participation and decision making were: “What do you think about patients participating in decision making in rehabilitation?”, “Have you been participating in decision making during your rehabilitation? What are your reflections on it?”, “In your opinion, what would be the optimal approach to participation?” [1,2,3]. To encourage reflection on the domain “emotional support”, the additional questions were: “What is your understanding of emotional support in rehabilitation?”, “Is it relevant?” and “If it has to be given, how can it be offered in the most optimal way?”, “Can you describe your experiences about being listened to or not being listened to?” [1,2,3].

Interviews: All interviews were hosted at the outpatient clinics where the participants were engaged in rehabilitation. There were two moderators at each focus group interview. One moderator, the interviewer, was the same for all interviews (first author). She facilitated and guided the discussion while the other moderator took notes throughout the interviews. Each interview started with a brief introduction to the project and a summary of the aim of the focus group interview. We pointed out that all opinions were important and that it was not
the aim to seek consensus in the discussions. Demographic information was obtained from participants before each interview. At the end of the interviews, the moderators summed up their understanding of the key issues to allow the participants to validate the moderators’ understanding of the most important topics. The interviews lasted one and a half to two hours. They were all audio-recorded. The interviewer and one of the two other moderators (second author), who participated on one occasion, were OTs with a theoretical understanding of client-centred practice. The other moderator (fourth author), who participated in most of the interviews, had no prior knowledge of the client-centred approach or hand therapy, but was experienced in conducting focus group interviews and developing questionnaires.

Analysis: A deductive, directed content analysis was employed [36,51], because the aim was to explore an already theoretically defined approach among patients with hand-related disorders. A matrix for the categorization of the analysis was created, based on the domains found in previous interviews, where the CCRQ domains were tested in a Danish context and compared to occupational therapy literature about client-centredness [36]. The seven domains found were used as headlines: 1) patient participation in decision making and goal setting, 2) client-centred education, 3) evaluation of outcomes from patient’s perspective, 4) family involvement, 5) emotional support, 6) coordination and continuity and 7) enabling occupation (Table 1).

To get an overall sense of the data, the first author transcribed the focus group interviews verbatim. The entire text from each interview was read several times and first impressions of text that appeared to represent statements about client-centred practice were highlighted by the first author. Interactions between group members were not analysed further, due to small group sizes and because the focus was on perceptions regarding core values and elements
rather than on interactions, feelings or relations. Statements were then mapped by the first author in relation to the domains in the matrix. Elements that could not be mapped in the matrix were assigned a new theme (called “other” in the matrix (Table 1)). New themes were further inductively analysed to decide whether the data represented a potential new domain related to client-centredness [36,50]. To validate how the data were mapped, the second and fourth authors examined the mapping and then the mapping was discussed among the authors [36]. This researcher triangulation was performed with the intention of increasing credibility [52,53].

Ethical considerations: All participants were provided with oral and written information about the study and it was stressed that participation was voluntary. They were told that information given in the group was confidential and would not be communicated to their therapists. Written consent was obtained from all participants prior to the focus group interviews. The study was approved by the Danish Data Protection Agency and was registered as j. no. 2008-58-0035. Due to the nature of the study, approval by the Research Ethics Committee was not required, in accordance with Danish legislation on research ethics.

Results

The results are presented in the same order as the domains in the analysis matrix (Table 1). A total of 25 patients were included in the study. All participants participated in the discussions and provided meaningful contributions. Among the participants, there was a range of ages, educational levels, and number of treatments; and both sexes were represented.
Characteristics of participants are shown in Table 2. Severity of the injury varied according to setting; participants from specialized and highly specialized settings had more severe injuries compared to those from a municipal setting.

Insert Table 2 around here

When discussing the open-ended question at the beginning of the interviews, all groups gave comments on all domains except family involvement, on which they had to be encouraged to debate. The overall findings indicate that most opinions, needs or wishes did not differ in relation to injury severity or demographics, but seemed to be more related to personality and different levels of coping ability. As expressed by a participant:

“the most important thing, in reality, has to be one’s own attitude to how it’s going to go. Am I going to just sit here being disabled and unable to do anything, am I going to need help with everything, or do I want to do it myself?” (Male, 58 years old, with CMC arthrosis, from community setting)

**Patient participation in decision making and goal setting**

All focus groups stressed the importance of patient participation in decision making and priority setting. They expressed that their engagement was central because it ensured that the rehabilitation became purposeful and meaningful to their everyday lives and made them feel responsible for their own situation. However, the participants in the focus groups requested an individualised level of partnership. They concluded that, to be client-centred, treatment should be individually tailored to meet each patient’s everyday life situation, resources, interests, roles, family and job situation.
“It’s absolutely crucial. One of the most important things is that it is adapted for the patient, because otherwise it just goes wrong. It’s one of the most important things – that the training programme, that it can be adapted throughout together with your therapist, it’s vitally important” (Male, 32 years old, with a trigger finger, from specialized setting)

"The fact that we get to decide together, and that I’m also jointly responsible, I think that’s really good. It really motivates me, and the motivation is a big part of me getting even better. It gives me the motivation to do these things at home as well. Being included means that I do these things at home and that I get to try them out. And it’s done in such a way that it’s ordinary, everyday things that I’m working with” (Female, 58 years old, with complex wrist fracture, from highly specialized setting)

When they talked about experiences of not being involved, they mentioned routine training, regimes that were not individually adapted and situations in which said that they were treated like a number or a diagnosis instead of a person.

”And, of course, it’s great to be seen as a whole person and be treated as a whole person instead of a zero or a one” (Male, 58 years old, with CMC arthrosis, from community setting)

The participants also requested participation in planning and organising their rehabilitation course. One participant said: “Being a part of the planning makes it possible to have a life alongside the rehabilitation”. Most participants would like the decision to end the course of rehabilitation to be a shared decision between them and the health professionals. This would
help them to feel ready to continue on their own. When asked what they thought would be a good way to end the rehabilitation course, a typical answer was:

“I’d really like to think that it would be, like, a consultation. That it doesn’t just end without me being involved in the decision. That the clinicians don’t just say: well, we can’t do any more for you now, you have to train the rest yourself. I completely understand that you have to, but it would also be good to have the opportunity, for example, to have a check-up three months later” (Female, 58 years old, with complex wrist fracture, from highly specialized setting)

Theory about client-centred practice considers goal setting to be essential so that therapists and patients strive for the same goals. The participants in the focus groups felt they were aiming for the same goals as the OTs, even though this was not always stated explicitly. The participants’ main goal was to get back to their everyday lives as well and as quickly as possible, which they felt OTs implicitly knew and understood. Some participants were very satisfied with their goal setting process, and had both short and long-term goals; others did not have any experience of explicit goal setting and did not miss it. Most participants did not mention subsidiary goals in the interviews. However, when talking about their situation, they continuously talked about activities they could or could not manage, for example, how irritating it would be not to be able to peel potatoes, use a saw, go fishing, drive a car or bake a cake.

“I’ve been really well included in working towards getting back to my job, and I was also asked about the problems I have in everyday life, and what I want to achieve with my hand. Being included has been really good for setting small goals, and to say, ok, let’s see if, next time, you can do such and such. And I think
that’s been fantastic” (Female, 58 years old, with complex wrist fracture, from highly specialized setting)

“It’s nice to have some objective goals. It can be as ridiculous as eating with a fork, it’s a good goal to set up together, but they should be realistic goals” (Female, 67 years old, with complex wrist fracture and ligament injuries, from highly specialized setting)

Participants’ desire to participate varied in degree, but they all stated that it was important that patients participated in decision making on some level, because it facilitated them to feel responsible for their own rehabilitation.

**Client-centred education**

Information was essential for the participants; it made them feel confident, gave motivation and meaning to rehabilitation and allowed them to understand their situation better. The participants in the focus group interviews talked extensively about the importance of information; information about the rehabilitation, the injury, restrictions, the processes, and what to expect in the future. It helped them to understand how the rehabilitation processes worked, gave hope and allowed them to become familiar with the prognosis and expected outcomes. Information about the reasons for type of intervention was another important issue, and meant that it made sense as to why time should be spent on rehabilitation. It helped them to understand the importance of extending the rehabilitation to their everyday lives at home. When the participants were informed about the prognosis and outcomes, it felt easier to evaluate their progress and subsequently make choices about exercises or orthosis. The participants requested information, not only concerning restrictions and outcomes, but also about how to overcome these restrictions and what to do instead, so that
they could adapt and manage their everyday lives during and after rehabilitation. During the focus group interviews, it became clear that participants were in need of different kinds of information and that it should be individually tailored:

“Information gives you a sense that what you’re doing makes sense” (Female, 37 years old, with nerve and tendon injuries, from specialized setting)

“I have to admit that, sometimes, the information given at the check-ups with the doctor was really bad. I mean, you should just do this or that. They told me all about the fracture, and it looks fine, it has healed well and so on. Yes, but, I would have much preferred to know, I mean, you can have these and these side effects, and it’s these we need to work more on” (Female, 58 years old, with complex wrist fracture, from highly specialized setting)

“Maybe it’s not quite so much about the amount of information as it is about getting the kind of information you need” (Male, 34 years old, with tendon injury, from highly specialized setting)

The participants in the focus groups also mentioned additional information that dealt with issues regarding insurance reporting, domestic help and aids and devices:

“Perhaps you could say that what one might want is even more focus on areas quite apart from the function of the body. Like, what leisure activities you can do, what consequences there would be in terms of insurance, what it means for my work situation. It’s not that the occupational therapists should be experts in all areas, but rehabilitation should be seen as being about a lot more than just being able to move your fingers. It can also mean that one can’t work. It can also
mean that one can’t do sports.” (Male, 34 years old, with tendon injury, from highly specialized setting)

Some participants had to ask for the information they needed while others found that information was provided without request and individually adapted. Most participants found it acceptable to ask, while some were unsure if they had been given all the relevant information.

**Evaluation of outcomes from the patient’s perspective**

All groups valued the evaluation of function of the body, and ability to engage in everyday life activities and participate in, for example, their local society. The participants expressed different opinions as to how often they would like to evaluate changes. They stated that patients should be involved in the planning of evaluations and that evaluations often motivated them.

**Family involvement**

Only a few of the participants’ families or friends had been involved in their rehabilitation. Some husbands had participated with their wives at consultations with the surgeon and few had participated in a therapy session. Discussions of this domain did not crop up in the interviews without prompting. When urged to discuss it, all groups stated that it was important for patients to have the opportunity for family involvement, if they needed it.

“I think that one should be encouraged to have relatives with you, if you feel you want that. They hear the professional saying, no, you can’t do that, and take care with this and remember that. It helps to understand the situation you are in” (Male, 34 years old, with tendon injury, from highly specialized setting).

**Emotional support**
Participants felt it was important that mental and emotional needs were addressed, if necessary. They had a range of perceptions about needs in this regard. Some groups pointed out that it was important that OTs referred patients to psychologists, etc., if required. The participants considered it to be vital that they were listened to, when they talked about their frustrations and problems and that all health professionals at the outpatient clinic acknowledged their problems or symptoms. They also considered it was essential that the OTs treated them with respect, acknowledged their frustrations and helped them manage them.

"You feel really welcome and you feel listened to when you come in here. And I think that means a hell of a lot" (Male, 41 years old, with a crush injury, from specialized setting)

"I think it’s important to be heard, it’s important to feel that you are heard, if you’re in the middle of something difficult. That’s probably the most important thing” (Female, 67 years old, with wrist fracture and ligament injury, from highly specialized setting)

Another important issue was not to have their hopes dampened; they expected the health professionals to be realistic but still work together with the patients in their striving to fulfil their goals.

"So the doctor said, well, I’m sending you for rehabilitation, and it will go as it goes, but you’ll never have your hand back. For me it would have been better if he’d said that they’re good over there, and it’s going to be fine. It might be a lie, but it gives you a sense of hope, where the other just doesn’t for me. Everything
went so fast and suddenly you were a patient” (Female, 75 years old, with wrist fracture, from community setting)

**Coordination and continuity**

The participants emphasized the importance of fast and efficient communication between the referring ward and the outpatient clinic. Most of the participants stressed the importance of having easy access to consultations with the surgeon, especially at the specialized and highly specialized outpatient clinics. However, their needs differed in terms of the severity of the injury and their personality.

“It’s a bit like, you know, a bit like you start on a process. So you expect continuity, and it’s not there. So, throughout the process, you feel that you have to beg and plead to be looked at by the doctor. It’s difficult ... in any case, it’s not a nice situation to be a patient in, you could say. You get frustrated, and don’t really know where to turn” (Female, 67 years old, with wrist fracture and ligament injuries, from highly specialized setting)

“I thought that there was a lot of flexibility from the doctors when I was here. If the occupational therapist wants to ask them something, they just go up and ask them if they’ll pop in. They are really good at that. I thought it was very efficient that there was a system that was so flexible. It impressed me.” (Male, 45 years old, infection from cat bite, from highly specialized setting)

At the highly specialized and specialized clinics, most participants stated that they preferred to see the same OT each time, because it made them feel comfortable and in good hands. They discussed the OT’s role as advocate, acting for patients, for example, in consultations with surgeons or social workers. In cases where the participants were not treated by the same
health professionals each time, they stated that it was important that they all worked towards the same goals.

“When it’s the same therapist the whole time, that person can see your progress, or if the situation is status quo. It’s much clearer than if it’s different therapists every time” (Female, 69 years old, with finger and metacarp fractures, from highly specialized setting)

**Enabling occupation**

The participants specified the fact that the overarching aim in rehabilitation was to enable them to perform activities of everyday lives. Most participants pointed out that it was crucial that their everyday life activities were included in the rehabilitation or at least addressed verbally. However, some had not experienced that this aim was met.

“I actually think it’s very important, I mean, it’s not all the same, if you want to sit at the computer and that’s the most important thing for you, or, as a carpenter, you want to go out and cut wood or hammer in nails. It’s absolutely not that it doesn’t matter whether one’s involved in what’s important to you personally. Because probably none of us will have 100% of the movement and feasibility that we had before, but it’s important for a person to work towards it. I think that’s really crucial” (Female, 44 years old, ligament injury, from specialized setting)

Most participants found it important to get advice and guidance on how to handle their everyday life activities. However, some participants found they did not need advice because they figured things out on their own. During the interviews, however, some participants
discovered that there were tips they would have liked to have been offered during their rehabilitation.

“But it might have been a good idea to get little tips and tricks about everyday life activities. How do you tie your shoelaces, use a shoehorn and this is what you can do doing this or that. The occupational therapist collects experiences and shows such tips and tricks, maybe in a written rehabilitation programme. That might be good. You anyway discover for yourself your own small methods.”
(Male, 34 years old, with tendon injuries, from highly specialized setting)

Other aspects

The participants also mentioned that they felt reassured if there was a pleasant atmosphere at the clinic. They mentioned that the skills and experiences of the OTs were important factors. These were evaluated as environmental issues and therapist skills that were not included in any of the client-centred practice domains. All groups talked about pain management, specifically exercises and orthosis. However, this was related to treatment as well as oedema reduction and strength exercises. These factors are important in facilitating the outcomes of the rehabilitation, but they were not directly related to the domains of client-centred practice.

Discussion

The 25 participants from six different focus groups had a common understanding of the core values and elements of client-centred practice and their perceptions were well covered by the seven domains in the analysis matrix obtained from the literature and earlier interviews [unpublished]. The majority of the CCRQ domains for inpatients are also relevant for outpatients, but items have to be adapted. Items for outpatients should be more specific with
regard to living at home while undertaking rehabilitation, while items regarding care are not relevant. In outpatient clinics in Denmark, patients are treated by the same OT at each session, for 30 to 60 minutes. The circumstances are different to the inpatient setting. For example, the patient and OT have time to become familiar with each other, and the patient’s injury is not in the very acute state. Items should reflect these differences. The most important results showed that participants wanted rehabilitation to be individually tailored and their everyday life activities to be taken into consideration in their rehabilitation. They want their priorities to be taken into account in rehabilitation planning as a whole, and goals have to be relevant to their life situations. These detailed aspects should be reflected in a new questionnaire, so that the tool can be made sensitive enough to differentiate patients’ needs and experiences.

**Enabling occupation**

Enabling occupation is not an independent domain in the CCRQ, although mentioned by patients in the interviews behind the development of the questionnaire [26]. Investigating the approach in occupational therapy literature, enabling occupation was found to be essential and it was added as a domain [1,2]. The six focus group interviews supported the development of this new domain. The participants talked about being able or unable to manage activities of everyday life and how it affected their life, physically, mentally and socially. As performing everyday life activities was their main rehabilitation goal they agreed on the importance of including this in rehabilitation. They pointed out the importance of being able to handle everyday life activities despite restrictions. This is in line with findings in a study investigating how patients with severe or major hand injuries handle everyday life activities. These patients also pointed out the importance of getting knowledge about coping
strategies or compensatory strategies to handle everyday life activities [54]. It is also supported by findings from a qualitative study with 23 patients after flexor tendon repair, in which all participants addressed the difficulties involved in doing everyday life activities and how this affected their life situation. They had all received information on orthosis wear and restrictions; but the therapist addressed the performance of everyday life activities with less than one third of the patients. When the subject was addressed, however, the patients rated it very useful [55]. In a qualitative study with 20 patients with different somatic disorders, Palmadottir [56] found that they all identified enabling everyday life activities as the most important outcome of occupational therapy – for example, learning new performance methods to manage everyday life or learning how to alter their environment. As stated before, all participants in our study would like everyday life activities to be a part of their rehabilitation. However, they wanted it in different ways; for some, it was important that the intervention was occupation-based where occupations are used as both means and endpoints, while others considered having occupations in focus as endpoints would be sufficient [57].

The participants in our study also discussed feeling frustrated and angry if they were not able to cope in their everyday lives. They were in need of support and strategies to be able to manage both their life situations and emotions. The need for emotional strategies to handle their everyday life activities was also considered important in the study with patients who had a severe or major hand injury [54]. The importance of being active and maintaining activities and roles is probably related to the fact that engagement in occupation is, in many ways, positively linked with mental health, self-efficacy and quality of life [58,59]. We believe these issues should be included when developing a relevant questionnaire for outpatients with hand-related disorders.
Client-centred education

Information and education were considered essential. The participating patients were highly focused on getting relevant and timely information, which is in accordance with studies based on interviews and surveys with other patient groups, for example, patients with spinal cord injuries, stroke, orthopaedic injuries and geriatric disorders [18,27,28,32,60]. The acquisition of information enables patients to engage in and negotiate decisions and take more responsibility for their rehabilitation, which reduces functional limitations [27,28]. According to the participants in our study, information should be individually tailored. Gill et al. [30] supports this, but they also found that patients required different information at different stages of their rehabilitation process. This is in line with theories on the importance of flexible, timely and relevant information [1,12]. Participants in our study pointed out they want individual tailored information and education and that they wanted information, not only concerning the injury and restrictions, but also about what alternatives they had and how to handle everyday life. As a result, we suggest that a questionnaire evaluating client-centredness should provide items, both about whether the required information had been given, but also whether it was timely and relevant in relation to the patient’s life situation at the time.

Patient participation in decision making and goal setting

According to the literature on rehabilitation and client-centred practice, participation in goal setting is essential [20,61,62]. Not all participants in our focus group interviews were aware of their rehabilitation goals. Although they expressed that it was essential to be able to resume everyday life activities, they did not express this in terms of subsidiary goals. Most of the participants described that they had not participated in a formal goal setting session,
whereas a few had set up goals with the OT or they felt that goals were implicit. However, they found it important that the rehabilitation focus was on getting back to everyday life activities as quickly and as independently as possible and that their priorities was respected. Similar disparities were found in other interviews with patients with hip replacement, hand injuries, stroke and in older patients [21,56]. Here, only a few recalled their goal setting and the goal-directed processes [21,56], even though they considered the enablement of everyday life to be crucial [56]. Participants in our study emphasized the importance of patient participation as a basis for successful rehabilitation, but they wanted it to varying extents. Hence, the level of desired participation can vary from patient to patient, as well as for the same patient within the course of rehabilitation. This finding is consistent with other qualitative studies with patients and OTs [14,24,27,31]. They found that variation in desired engagement could be due to differences in personality, culture, preferences and different stages in the patients’ rehabilitation processes. Our findings suggest that it is crucial that a questionnaire evaluating client-centredness with outpatients allow patients to express whether they participated in the rehabilitation to the extent that they wished, and not merely whether they participated or not. This would add clarity to the analysis and avoid any ambiguity caused by the fact that patients did not want to participate to the same degree.

**Evaluation of outcomes from the patient’s perspective**

In line with the International Classification of Functioning, Disability and Health (ICF) [63] and the holistic focus within occupational therapy [64], the participants in this study pointed out that they valued evaluations of both function, activity and participation level. This is in line with the finding that enabling occupations is important and results showing that evaluation on body function, activity and participation levels provided a comprehensive understanding
of limitations in everyday life activities [65]. Keeping in mind that the participants’ main focus was on being able to perform everyday life activities again, it seems natural that they wanted a holistic evaluation. Other studies with patients with hand-related disorders also find the importance of linking the objective measurements of body function to everyday life activities [66].

**Emotional support**

Findings in our study indicate that OTs must show respect for patients, interact with them as individuals and motivate them. The participants wanted their therapist to make them feel comfortable and listen to their frustrations when their progress was slow, and to their hopes for the future and joy when they regained the ability to do a specific activity. Apart from being listened to, they also wanted their feelings to be taken seriously by all health professionals at the outpatient clinic. Other studies exploring patients’ experiences and perspectives of client-centredness are remarkably consistent in their findings [1,14,29,33]. They describe collaboration, listening and respect shown by therapists as important issues and add that the therapist should accept, and respect, patients’ experience and knowledge [14,17,29,30]. These aspects should be reflected in a new questionnaire in items about being listened to by all health professionals, if their hope for the future were included in the rehabilitation and if their emotional feelings were addressed and taken serious.

**Coordination and continuity**

The participants in this study were mostly treated by the same OT during the course of their rehabilitation, and they valued this. This was not an issue in interviews with inpatients concerning the same topic, probably due to the multi-disciplinary setting [26,27]. Participants in this study pointed out that it was essential not only to know who to ask, but also to be
comfortable in asking questions. It is important that patients are treated using best evidence, but the organisation of systems around the patient is also of great importance [67,68]. The participants valued access to consultations with the surgeon, when needed. This was mentioned in all three types of setting; however, in the Danish system, not all clinics offer the same level of daily access to surgeons since some clinics are at a specialized hospital and some are not. The participants pointed out that despite of setting, collaboration between health professionals was essential if they or the OT found that a consultation with the surgeon was required. The participants’ experiences of coordination between wards varied, but they all agreed about the importance of fast and efficient communication between the referring ward and the outpatient clinic. The effects of fast and efficient communication and coordination between wards are supported in other studies [68,69]. Furthermore, it makes the patients feel safe and confident in the health care system [68,69].

Family involvement

The possibility of having family members or important others involved in rehabilitation as a support was important for most participants, although only a few made use of it. The domain of family support is covered in the Patient Participation in Rehabilitation Questionnaire (PPRQ) [27,33] for patients with spinal cord injuries, as well as in the CCRQ [13] and it is an issue for patients with severe or major hand injuries [54]. However, according to our results, it does not seem that the topic is significant enough to patients with all kinds of hand-related disorders to warrant a domain; however, the issue should be addressed in the new questionnaire, since some patients need their family to be involved due to severe injuries or because they need help to cope with their situation [54]. The domain of family involvement might be more relevant for inpatients with other diagnoses, for example, stroke or spinal cord
injury than for cognitively unaffected patients with hand-related disorders living at home and engaged in rehabilitation at outpatient clinics.

The lack of concurrent core values and elements along with the lack of explicit argumentation for the differences in definitions of client-centred practice and client-centred enablement make client-centredness difficult to evaluate. However, despite cultural disparity between Canadians and Danes, it seems that the participants in the six focus group interviews to a large extent supported all the core values and elements in occupational therapy literature about the client-centred approach. Many aspects seem to be identical to those mentioned by patients in the interviews that led to the development of the CCRQ [26], which validate the findings in our feasibility study, where good face and content validity of the CCRQ was found. However, our findings support the need for a questionnaire in which items would be modified for outpatients. Because it would not be a multi-disciplinary questionnaire in the same way as the CCRQ, items can be more detailed and related to the specific situations for outpatients. Hopefully, if these changes are taken into account, it would be possible to make a useful questionnaire to evaluate outpatients’ experiences of client-centredness.

**Methodological considerations**

The number of participants in the focus group interviews is a limitation of this study. We aimed to have five to seven participants in each group, but in most groups some participants cancelled just before the interview. This causes a limitation in the dynamic of the group and interaction between the participants [70]. However, despite the lower number of participants in the groups, different age groups, levels of severity of injury and both sexes were represented. All were living at home. The participants represented a great variance in patients with hand-related disorders and, even though the interviews were held in different settings
across the country, the perceptions and opinions were quite similar. Hence, no new information appeared in the final interviews. Furthermore, findings correspond with findings from other qualitative studies concerning client-centredness, which adds credibility [27-32,56,58].

The deductive content analysis might seem to be a limitation in exploring the perceptions of client-centred practice among Danish patients with hand-related disorders. However, the analysis method seems to be justifiable because the modified domains from the CCRQ reflected all core values and elements within client-centred practice. No new concepts emerged from the open question posed at the beginning of each interview, and supported the domains – apart from family involvement, which was not supported as a domain in the future questionnaire. In the interview analysis, issues not covered by the domains in the analysis matrix were analyzed inductively [50]; however, nothing new appeared.

The categorization of the core values and elements within the domains, used to develop the interview guide and the analysis matrix, could be called into question. Because there is, as yet, no consensus, the categorizations are based on literature studies and the interviews. However, statistical analysis with factor analysis will be undertaken to further qualify the position of the items in the new questionnaire for outpatients within the domains.

The fact that most hand therapists in Denmark are OTs differs from other countries, where physiotherapists, for example, are also involved in rehabilitation of patients with hand-related disorders. However, even though the rehabilitation might differ, perceptions about client-centredness should be independent of the type of health professional involved.

**Conclusion**
Patients with hand-related disorders from different settings in Denmark want individually tailored rehabilitation. They want information about alternative solutions, despite restrictions, and they want to participate in decision making, which would render the rehabilitation more relevant to their life situations and personalities. Six domains were found to comprise the client-centred approach for outpatients with hand-related disorders: patient participation in decision making, client-centred education, evaluation of outcomes from patient’s perspective, emotional support, coordination and continuity, and enabling occupation. The domains inform the development of a new questionnaire which would measure outpatients’ experiences of client-centredness.

Acknowledgments

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Declaration of Interest

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70) Halkier B. Focus groups as social enactments: integrating interaction and content in analysis of focus group data. Qualitative Research 2010; 71-89.
Table 1. Analysis matrix with core values and elements in client-centred practice

Table 2: Demographics of participating patients with hand-related disorders
<table>
<thead>
<tr>
<th>Domains</th>
<th>The CCRQ sub-categories (6)</th>
<th>Core values/elements found in client-centred practice literature</th>
</tr>
</thead>
</table>
| Patient participation in decision-making and goal setting | Partnership  
Participating in goal setting  
Participation in prioritizing  
Treatment choices explained  
Individual needs taken into consideration in care planning | Partnership  
Individual autonomy  
Facilitating choices and informed decisions  
Therapist and client responsibility  
Reciprocal relationship  
Active role in goal setting and decision making  
Recognize client’s experience and knowledge  
Clients’ roles, interests, environments and culture are central |
| Client-centred education               | Timely and relevant education/information  
Clients define educational needs | Information  
Flexibility                                                                                                                          |
| Evaluation of outcomes from patient’s perspective | Evaluation of goals and expectations from client’s perspective | Clients active in choosing outcomes of intervention  
Assessment and intervention reflect the client’s vision and values |
| Family involvement                    | Involvement of family in rehabilitation as much as client wants  
Emotional support of family/friends  
Information about client’s condition and treatment | Involvement of family                                                                                                                |
| Emotional support                     | Treated with respect  
Clients feel listened to  
Emotional needs and concerns addressed  
Treated with dignity | Respect for the client  
Listen                                                                                                                                    |
| Coordination and continuity            | Know how to access information in the community  
Know role and responsibilities of team members  
Team members work well together | Coordinate  
Advocate for client                                                                                                             |
| Enabling occupation                   |                                                                                             | Facilitating clients to participate in their daily lives  
Engagement  
Coaching clients to develop and sustain daily activities  
Teaching new ways  
Adapt activities and environment |
| Other                                  |                                                                                             |                                                                                                                               |
Table 2: Demographics of participating patients with hand-related disorders

<table>
<thead>
<tr>
<th>Demographics - characteristics</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Group 5</th>
<th>Group 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>5</td>
<td>7</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Setting:</td>
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<tr>
<td>General</td>
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<tr>
<td>Specialized</td>
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<tr>
<td>Highly specialized</td>
<td>5</td>
<td>7</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sex: Female/Male</td>
<td>2/3</td>
<td>4/3</td>
<td>3/2</td>
<td>3/0</td>
<td>1/1</td>
<td>2/1</td>
</tr>
<tr>
<td>Age: mean (range)</td>
<td>46.8(26-67)</td>
<td>46.9(37-67)</td>
<td>61.6(58-67)</td>
<td>65.3(58-69)</td>
<td>74.5(74-75)</td>
<td>47.7(32-59)</td>
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<tr>
<td>Education:</td>
<td></td>
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<tr>
<td>Vocational education</td>
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<tr>
<td>Short-term third-level education (&lt;3 years)</td>
<td>2</td>
<td>2</td>
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</tr>
<tr>
<td>Medium-term third-level education (3-5 years)</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Long-term third-level education (&gt;5 years)</td>
<td>2</td>
<td></td>
<td></td>
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<tr>
<td>Diagnosis:</td>
<td></td>
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<tr>
<td>Fracture in wrist or carpus</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Ligament injuries</td>
<td></td>
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<tr>
<td>Arthrosis/arthritis</td>
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<tr>
<td>Fractured finger(s)</td>
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<tr>
<td>Tendon injuries</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Tendon and nerve injuries</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
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<tr>
<td>Catbit</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Number of treatments: mean (range)</td>
<td>24.2(2-65)</td>
<td>28.6(9-50)</td>
<td>5.8(3-10)</td>
<td>13.7(8-18)</td>
<td>22.5(5-40)</td>
<td>25.3(8-50)</td>
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<tr>
<td>Earlier experience of rehabilitation yes/no</td>
<td>1/4</td>
<td>1/6</td>
<td>1/4</td>
<td>0/3</td>
<td>0/2</td>
<td>1/2</td>
</tr>
</tbody>
</table>