Patients' needs during a surgical intervention process for Dupuytren's disease.

Christina Turesson, Joanna Kvist and Barbro Krevers

The self-archived postprint version of this journal article is available at Linköping University Institutional Repository (DiVA):

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-145622>

N.B.: When citing this work, cite the original publication.

This is an electronic version of an article published in:

Turesson, C., Kvist, J., Krevers, B., (2017), Patients' needs during a surgical intervention process for Dupuytren's disease., *Disability and Rehabilitation*, , 1-8.

<https://doi.org/10.1080/09638288.2017.1402095>

Original publication available at:

<https://doi.org/10.1080/09638288.2017.1402095>

Copyright: Taylor & Francis (STM, Behavioural Science and Public Health Titles)

<http://www.tandf.co.uk/journals/default.asp>

Abstract

Purpose

To explore and describe clients' needs during a surgical intervention process for Dupuytren's disease.

Materials and methods

Design: Interview study with 21 men undergoing surgical intervention for Dupuytren's disease. Qualitative content analysis was performed with the model of Patient Evaluation Process as a theoretical framework.

Results

The primary reason for seeking medical care was to receive an intervention to improve hand function. The need for knowledge was evident during the care process, and was connected to involvement in decision-making. During surgery and rehabilitation, participants needed support with pain relief, a sense of security, support for self-care or sick leave. There was also a need for participation in the evaluation and improvement of care. Clients' life situations contributed to the occurrence of needs or were a resource for handling them. Depending on patient character, clients handled their perceived needs differently.

Conclusions

Clients' needs during a surgical intervention process include needs for improvement of hand function, knowledge, and support during treatment, and participation in evaluation. Clients' needs change during the care process and can be influenced by their life situation or their character. The identified needs ought to be included in quality assessments from the carers' perspective, to ensure that important needs of the clients are met by the surgical intervention

process. Communication and interaction between client and health care provider is a key aspect of fulfilling clients' needs.

Keywords:

Hand surgery, occupational therapy, hand function, qualitative interviews, care process, information.

Introduction

Clients with Dupuytren's disease (DD) experience limitations in hand function and quality of life due to extension deficits in the finger joints caused by the disease (1, 2). DD is a chronic soft tissue disorder of unknown aetiology (3), and the disease is more common among men than women (4, 5). DD can be treated with surgery or non-invasive methods intended to correct the finger joint contractures and thereby improve hand function. However, the treatment does not cure the disease and recurrence of contractures is common (3, 6). Previous research has shown that 20-44% of clients experience recurrence between 17-48 months after treatment (6, 7).

Evaluation of treatment for DD has mainly focused on health outcomes in terms of physical changes in finger joint range of motion and patient-reported questionnaires regarding disability, quality of life and satisfaction (8). However, research has shown that process and structure aspects of care are also of great importance as regards how clients evaluate the results of care (9-11). Process aspects refer to what is done in giving and receiving care and the interpersonal relationship between patient and health care provider, such as information, communication and involvement in decision-making. Structure aspects are material, human and organisational resources of health care (12). Furthermore, the clients' view of the outcome has been shown to be connected to how different needs are met (13, 14). Therefore, the challenge is to detect patients' needs and target them in order to identify areas for improvement in health care services and improve patients' evaluation of care (13). Previous research on the clients' perspective on treatment for DD has proposed that unmet expectations, lack of information and wish for further follow up were possible reasons for a negative view of the outcome (11). It was suggested that these could be clients' expressions of unmet needs during the care process (11), but little is known about what clients' needs during

a surgical intervention process for DD consist of. In order to understand clients' experiences further, the aim of the present study was to explore and describe clients' needs during a surgical intervention process for DD. The surgical intervention process comprises a chain of actions including medical care seeking, surgery and rehabilitation interventions.

Materials and methods

Study design

This is a qualitative interview study, where data were collected via interviews performed on two different occasions: pre-treatment i.e. two to four weeks before surgery, and post-treatment i.e. six to eight months after surgery for DD. This study is a part of a larger project on clients with DD and their views on their care process, and a paper with the objective to describe clients' experiences, expectations and appraisal of results has been published previously (11). In the present study, we focused on identifying the needs expressed by the participants during the surgical intervention process. The model of Patient Evaluation Process (14) constitutes the theoretical frame work of the study and guided data collection and analysis. The analysis was performed using problem-driven content analysis (15) with a deductive-inductive approach, i.e. initial classification of codes into predefined categories from the framework, and then creation of subcategories in an inductive manner.

Theoretical framework of the study

The theoretical framework used in the present study consisted of the model of Patient Evaluation Process (figure 1) (14). This is a model describing five phases that constitute the patients' care process, from pre-admission to post discharge. The model also describes what factors influence patients' evaluation of care and health results, i.e. previous experience, present and future expectations, needs and results. According to the model, how patients'

needs are met during the care process is a central issue as this can influence their view of the results. Needs have a broad spectrum and in a health care context can be described as general human and specific medical needs. General human needs are fundamental physical and psychosocial needs that exist in any context, while patients' perceived specific medical needs are linked to patients' expectations regarding health or illness and to their interpretation of the trajectory of illness. Patients' evaluation of the results is also influenced by the patients' life history, life situation and patient character. Patient character describes the patients' possibility, willingness and ability to be involved in their care and in decision-making. The patient characters were categorised based on the patient's description of themselves and their involvement in communication and interaction with staff during care and rehabilitation. Thus, patient character is a product of the patient-health care provider interaction and is not a personality type. In the original model, four different patient characters were formulated: active, passive, frustrated and tolerant (14). In our previous study on DD we were able to identify two patient characters: the tolerant and the eager, thus we have used these two in the present study as a part of the framework for the analysis. The tolerant patient character was described as waiting and watching to see what was going to happen and putting their trust in the surgeon/staff, while the eager patient character was described as being eager to be involved in their care in some way. The analyses of patient characters also showed that they could vary in an active-passive continuum depending on the situation and the opportunities given to patients to participate in care (11).

Insert figure 1 here

Setting

The study participants were treated for DD at a specialist clinic for hand surgery in the south of Sweden. The surgical intervention was performed via an outpatient care process where the participants returned to the clinic for wound care and rehabilitation. Postoperative hand therapy was provided to most participants, except those with joint contractures $\leq 45^\circ$, who were given instructions about exercise directly by their surgeon. The researchers of this study had no connection to the clinic providing the care. The first author (CT), who is an experienced hand therapist, performed the interviews during her doctoral training and introduced herself as a doctoral student. The participants were not informed of her experience of clinical practice with clients with DD.

Participants

Participants were recruited via a relevance sampling strategy (15) based on age, working/retired, extent of the disease (recurrence, uni- or bilateral DD), and both clients with and without experience of previous surgical treatment for DD were included. Participants had to be able to communicate in Swedish. Clients planned for DD surgery were invited to the study by mail, and the first author (CT) followed up the invitation letter one week later by phone. Inclusion of participants and pre-surgery interviews continued until 21 participants were included and it was decided the interviews were rendering no new information. Finally, 21 participants with a mean age of 66 years (range 46-83 years) were included in the study. Twelve participants were retired, eight participants were still working and one participant did not work due to other health reasons. They had experience of treatment at a primary health care level and at specialist clinics, and from both private and public health care providers. There were varying previous experiences of treatment for DD among the participants, from not having surgery before to having surgery more than 15 times (median 1). Information

regarding the study sample is presented in table 1. The participants' confidentiality and right to withdraw from the study were assured.

The study was approved by the Regional Ethical Review Board in Linköping, Sweden (Dnr 2011/472–32).

Insert table 1 here

Data collection

The first author (CT) interviewed each participant twice: pre- and post-treatment. Two of the participants were only interviewed pre-treatment: one of them was unreachable for the second interview; the other participant had surgery postponed for other health reasons. The first interview with the first participant was performed at the clinic providing the care, while the rest of the interviews were performed by phone. An interview guide was created based on the model of Patient Evaluation Process, following the phases of the care process (past, present and future). The pre-treatment interview covered *previous experience* of care regarding DD and other health issues, *present life situation*, *needs* and *expectations* of results. The post-treatment interview covered *results*, *changes in hand function*, and *expectations* of future hand function and health. The questions in the interview guide (table 2) have been published previously (11), and consisted of open questions such as “why did you seek medical care for your hand condition?”. The interviews were performed in an open style to create a dialogue. The interview guide was tested at the first pre-treatment interview with the first participant and no changes were made. The two interviews with each participant lasted on average 23 minutes each (range 20-45 minutes). All interviews were recorded digitally, and field notes about the interviews were written down immediately after each interview. The first author

(CT) transcribed the interviews verbatim. Analysis was performed after all the interviews were completed.

Insert table 2 here

Data analysis

Analysis of data in the present study was performed using a problem-driven approach of content analysis (15) based on concepts from the model of Patient Evaluation Process. The two interviews with each participant were analysed as a whole as they represented the participant's care process. The QSR NVivo 10 software was used for the coding process. The analysis was performed in two steps: a) analysis of data based on a coding scheme and b) analysis of needs in relation to patient characters, identified in the previous study on the same sample (11), and life situation.

Step a). Analysis of data based on a coding scheme: This part of the analysis was performed in a deductive-inductive manner on data from all 21 participants. A coding scheme was created based on components of the model of Patient Evaluation Process and consisted of the categories *previous experiences*, *expectations regarding care/health*, *needs*, *results*, *life history*, *life situation* and *expectations regarding the future*. One category was labelled *other* to allow for openness to issues participants talked about that were relevant to the aim of the study but did not fit into the predetermined categories. The analysis started with deductive coding of text based on the coding scheme and as the analysis proceeded, subcategories were created inductively based on the content. The analysis consisted of continuously going back and forth between categories, subcategories and text. During the analysis, the category needs were divided into four phases representing the care process: *seeking medical care*, *planning/deciding about treatment*, *surgery*, and *rehabilitation*.

Step b). The needs that were described in step a were analysed in relation to the two patient characters, tolerant and eager, and to their life situation. This part of the analysis was performed on data from 19 participants with complete pre- and post-treatment interviews.

The first author (CT), who had completed research courses in qualitative research methods, independently performed the initial coding of data and analysis of typologies. However, the analysis was continuously discussed in a collaborative work process with the senior author (BK) who was familiar with the theoretical framework and experienced in qualitative analysis and research. The analysis was also presented to the second author (JK) who was an experienced researcher, and all three authors (CT, JK and BK) discussed the analysis.

Disagreement regarding the analysis was handled by revisiting the data in order to reach consensus. Based on the aim of the present study, data from the category needs are presented in the results, as well as the categories of life situation and patient characters, as these two influence clients' needs. The needs identified in the present study are based on the participants' positive experiences of fulfilled needs and negative experiences of needs not met.

Results

Four categories of needs were identified: need for an improved hand function; need for knowledge; need for support during treatment; and need for participation in evaluation and improving care. Clients' life situation could contribute to the occurrence of needs, but could also be a resource for handling them. Patient characters describe how clients may handle their perceived needs. An overview of the categories is presented in figure 2.

Insert figure 2 here

Quotations are included in the text to illustrate findings and text within brackets is the authors' clarifications.

Need for an improved hand function

The clients' primary need for *seeking medical care* and *planning/deciding* to undergo treatment was to get an intervention that could improve their hand function. This was an overarching need they wanted to be met, to enable their activities of daily life. Participants described being tired of the problematic hand and fingers, that it was a handicap, or that the current situation had become unmanageable. A crucial point was when limitations in hand function interfered with activities considered as important to them.

“It [to get an intervention] is necessary now because I have difficulties gripping the bike handlebars, paddles or an axe and things I find necessary to grip” (participant 14)

Need for knowledge

Clients' need for knowledge was evident during the different phases of the care process.

During the phase *seeking medical care* participants needed knowledge about the disease and risk factors for DD. Participants described the information about DD they had been provided with as diverse; it could be written information about DD, or only receiving the medical name of the disease. Participants also spoke of not getting accurate information until they came to the specialist unit for hand surgery. There were participants who had sought medical care previously, when contractures were minor, and had received information that it was too early

to treat the condition. However, they described being uncertain about how long to wait until seeking medical care again.

During the phase *planning/deciding about treatment* participants needed knowledge about available treatment options, practical and medical information, and the care process as a whole. The need for knowledge in terms of practical and medical information was closely connected to experiences of being involved in making decisions. Participants expressed different opinions about available treatment options based on the information they had. They could express the opinion of being fully informed about treatment options and why they were going to have surgery. However, they could also be unaware of other treatment options than surgery, or they could express the view that they had just been advised to have surgery. Surgery could also be described as their only option, yet the reason for this was not always clear. Participants also described a range of practical or medical information they had received, such as the advice not to drive after surgery, details regarding the anaesthetic procedure, and how to handle other medical issues. They sometimes described happiness about the opportunity to choose the type of anaesthetic procedure, but there were also descriptions of not fully understanding what their choice meant and feeling limited by the lack of information

“I think it’s strange that they leave so much to you to decide about the anaesthesia, and whether you want full anaesthesia or not. I think they should give you better information about that or at least suggest something...” (participant 12)

Positive experiences of being involved in decision-making could be about which hand to prioritize or choosing the time of year to have surgery. During the phase *planning/deciding about treatment* participants also reflected on the care process as a whole, e.g. the course of

events, the time needed for recovery, whether they would feel pain, or the time needed for sick leave.

“What I’m thinking about is whether it will hurt and how much it will hurt afterwards and how long it takes before, I mean, what I should do with my hand when it is recovering, to help with rehabilitation and stuff”
(participant 6)

Furthermore, the risk of surgery being postponed in the case of acutely injured clients was mentioned by participants as a cause for worry, as this information could not be received until close to surgery.

In connection to *surgery*, participants needed knowledge about what had been done. Participants who had received a local anaesthetic could speak of how this enabled them to get information by talking to the surgeon during the surgical procedure. Those with full anaesthesia could emphasize the importance of seeing the surgeon afterwards to get information about what had been done during surgery.

“He was very good during surgery because I had many questions but he just said ‘Ask your questions now’; he was sitting there and suturing the wound. So I took all my questions: Does it look worse than others do? How does it look? How do you clear it up? Can you prevent ...and so on. But he just answered all those questions and said do you have any more? No, I said, I’m completely satisfied” (participant 4)

During *rehabilitation*, participants needed knowledge about recovery of hand function. Participants mentioned the importance of follow-up as an opportunity to receive further information about the surgical procedure, or to ask about aspects of recovery of hand function

that might bother them, for example diminished sensibility.

Need for support during treatment

During *surgery* and *rehabilitation*, participants' need for support to address both general human or specific medical requirements was apparent. It could be support to cope with worry, for pain relief or regarding sense of security, support for self-care, rehabilitation issues or sick leave. Participants spoke of how they appreciated receiving a warm blanket, something to eat after surgery, or proper pain relief. However, they also described failure of the local anaesthetic or having discomfort from the arm.

“I think the local anaesthetic was the worst part. That it did not take and then I was given a full anaesthesia and you can't call it a complication, but you know what happens after you have had a full anaesthesia, with a sore throat and mouth and so on. That is the only thing I felt was uncomfortable”
(participant 8)

Some participants described a sense of being vulnerable or nervous during surgery and expressed gratitude for how the staff handled it. Participants who had a local anaesthetic described how the staff talked to them during surgery, which had a calming effect and distracted their focus from what was going on behind the curtain.

“You were in a way entertained during surgery, they talked about different things, about ordinary everyday things and what have you done in your life previously and then you told them what you had done, and stuff like that. It was like a part of the treatment, or of surgery” (participant 17)

In general, participants spoke of the staff as being friendly and courteous at all times. Nevertheless, some participants also mentioned noticing differences in care when staff shifted and the participant's contact person finished for the day, and described not knowing who was

responsible for them. They could also feel uncertain and worry about whether they would be able to go home by themselves, as it was difficult to have relatives come and get them since they did not know when they would be ready.

During the *rehabilitation*, there was a need for support with recovery of hand function. The participants spoke of coming back for wound care, removal of the stitches, and visiting the occupational or physical therapist (OT or PT) for hand therapy. They spoke of rehabilitation of hand function through follow-ups and hand therapy. Regarding rehabilitation, they could express that there were many things to handle, such as splints, silicone sheets etc. Some participants said either that they felt comfortable managing exercises and rehabilitation at home, or that they had wished for further support, from the surgeon or the OT/PT. The latter was an expression of wanting someone to check on them, confirming that things were going in the right direction, or that they were doing things in the right way.

“Maybe it could have been visits [to the OT/PT] once a month or something so you’d have a check of everything” (participant 10)

There was also a wish for support with the administration connected to sick leave from work, and some participants also expressed disappointment when there was a lack of continuity in the care process and they could not see “their” hand surgeon who had performed the operation.

Need for participation in evaluation and improving care

During *rehabilitation*, there was a need for participation in evaluating and improving care, i.e. communicating the participants’ view of the care process through follow-ups or systematic evaluations. Participants spoke of filling in questionnaires or being asked about how they experienced the care, and said that they appreciated being asked about their opinion.

“I got a questionnaire to fill in, from someone at the office, about my experience of the operation and treatment and everything. I think it is good that someone independent is checking up on things” (participant 17)

Life situation

The participants' various life situations could *contribute to the occurrence of needs*, but also could also be a *resource for handling* them. Participants living further away from the city expressed concerns about not knowing the exact time for surgery until the day before surgery, which made it impossible to plan their travelling in advance. This, combined with not being familiar with the city, was a cause for worry among those going by public transportation. Some participants also wished to have the follow-up performed at a health care provider closer to home. Family members could be described as a resource for handling needs by providing practical support with transportation, daily activities or work during the care process. Some participants also spoke of how relatives working in health care provided guidance and help in interpreting information or actively taking part in the treatment.

“It [the surgical treatment] is just for the day, and what time of day is not decided yet, I have to call the day before to find out what time. That’s stressful, I have a distance to travel from here”(participant 12)

Patient character

The tolerant and the eager clients' engagement in relation to different needs could vary in a passive-active continuum, depending on the situation. When it came to *the need for knowledge*, the eager clients prepared and asked questions, or contacted health care if they felt forgotten or that they had need for further information. The tolerant clients thought they should ask questions or contact health care, but described how they instead waited for the health care provider to contact them. Similarities between the two types of patient character

were that both described seeking information on the internet about the disease, treatment options, and rehabilitation. This also influenced descriptions of involvement in making decisions about treatment. The eager clients described being highly involved in the decision about treatment, and could describe the decision about surgery as their own or as a mutual understanding. The tolerant clients described varying involvement in decision-making. They could say that they had enough information and were aware of what was going to happen, although they did not actively take part in the decision about treatment. They could also have an unclear view of what was going to happen and described not being involved in the decision-making about treatment at all. Instead, they described surrendering to care givers, expecting them to do their job.

Similarities between the eager and the tolerant clients regarding *making decisions* were that both spoke of how they would only follow the instructions they were given to a certain degree. They spoke of making their own decisions about medication, instructions not to drive after surgery, wound care or rehabilitation, based on whether they felt the information given to them made sense or was in line with how they perceived their own health condition.

“I’m going to do everything as they say and then I’m going to change what I think is wrong” (participant 5)

Discussion

The present study shows that clients have a variety of needs they want to be met during the chain of action that comprises a surgical intervention process for DD (medical care seeking, surgery and rehabilitation interventions). These needs differ and can be more or less evident during the phases of the care process. The need for improved hand function led participants to seek medical care. The need for knowledge was crucial through all phases of the care process and was connected to involvement in decision-making. The need for support with both

general human and medical needs during surgery and rehabilitation was explicit, and during rehabilitation, participants also spoke of the need to participate in evaluation and improvement of care. Clients' life situations can contribute to the occurrence of needs, or be a resource for handling them. The two different patient characters, i.e. eager and tolerant, can determine how clients may perceive and manage their needs.

Previous qualitative research on DD has concluded that DD clients could lack information about their condition and possible treatment options (16). It has also been suggested that lack of information and a wish for further follow-up can be possible reasons for a negative view of the outcome after surgery and hand therapy (11). Findings of the present study provide more detailed information about clients' needs. It emphasise the importance of clients' needs of knowledge about several things i.e. risk factors, when to seek medical care, practical and medical information about surgery and the care process, and information about recovery of hand function. It has been shown from other areas than hand surgery and rehabilitation that clients' needs for knowledge may differ due to their prior experiences, and the knowledge provided should therefore be individually adapted (17). The participants in the present study had various previous experiences of undergoing treatment (11), and thus may have had different needs for knowledge they wanted to be met.

In the present study, clients' need for knowledge was closely connected to being involved in making decisions regarding treatment; these could be decisions about treatment options or the anaesthetic procedure. It has been shown in a recent study that there is substantial heterogeneity in clients' preferences for different treatment options, which can be addressed by shared decision-making (18). However, the present study shows that not all clients may be comfortable with being involved in making decisions, especially concerning specific medical

decisions such as the anaesthetic procedure. Previous research has shown that some clients may view participation as a burden and prefer to rely on health care providers' advice (19). Thus, the goal in health care of enhancing patient participation may not suit all clients. Perhaps clients would benefit most from personalised care, where health care providers identify clients' needs and aim to influence their knowledge to increase patient activation and empowerment (20, 21).

The clients' needs identified in the present study were all more or less related to process aspects of care, i.e. communication/interaction between patient and health care provider (12). From the health care providers' perspective, communication between team members has been regarded as the most important factor for positive team performance and patient outcome (22). However, based on the findings of the present study, it can be concluded that communication between patient and health care provider is equally important for fulfilling clients' needs. In the present study, both general human and specific medical needs were evident during surgery. Participants described how they could feel vulnerable or nervous and participants spoke with appreciation of how their needs were noticed and handled by the staff. This was a contrast to the other phases of the care process, where participants described different ways to handle their needs by themselves, partly influenced by patient character or their life situation. This implies that during surgery, clients may feel more left out and under the staffs' control, and that communication/interaction with the staff is important in order to handle the situation. During follow-up, clients needed support with rehabilitation of hand function. According to previous research, staff can tend to see practice in a "follow through/carry out" way, and as designed to facilitate a certain (successful) outcome (10); thus, from a health care provider's perspective, the care process may be considered as completed once surgery is over and postoperative rehabilitation is initiated. However, the findings of the

present study imply that the value of support and follow-up by a health care professional (surgeon or OT/PT) familiar with rehabilitation of hand function and outcome after surgery for DD should not be underestimated. This finding highlights the clients' view of care, and supports previous research concluding that for the clients, the whole experience of care is what matters (10). As fulfilment of clients' needs can influence their view of the outcome (13, 14), offering support with rehabilitation and discussion of recovery of hand function can be one way to improve clients' satisfaction with the outcome and their care.

The context in which the model of Patient Evaluation Process was developed (geriatric hospital care) differs from the present study context. However, the findings of the present study both confirm the original findings of the model of Patient Evaluation Process and contribute deepened knowledge related to the specific context of the present study. One of the main findings of the present study, confirming the original model, is that clients' needs change during the care process. Furthermore, a critical event identified in the original model, requiring adequate interaction with the staff, was when responsibility for the patient changed (14). This is equivalent to the findings in the present study of needs during surgery where some participants felt uncertain about who was responsible for them. Furthermore, as described in the original model, general human and specific medical needs were closely connected in the present study. The two patient characters highlight how clients may respond differently to their perceived needs for information and involvement in decision-making. However, it is important to notice that the patient characters are not personality types; rather, they are created by the interaction between patient and health care provider.

The analysis in the present study was performed in a deductive-inductive manner, and started with predetermined categories based on the model of Patient Evaluation Process. The use of

this model contributed to systematising data collection and analysis. This approach of using previous research findings, a model or a theory for further studies of a phenomenon, may give a better chance of contributing to existing knowledge, compared to starting the analysis from scratch (15). The study sample was heterogeneous in aspects such as age, previous experience of surgery, or whether participants were working or retired, which contributed to finding both unique and common patterns in the analysis. A limitation was the absence of women in the study sample due to DD being more common among men, and therefore the results do not capture differences that may exist between men and women with regard to needs during a surgical intervention process. With regard to trustworthiness, the participants were informed that the interviewer had no connection to the clinic providing the care, which enhanced authenticity. Certain steps were taken to minimize the potential influence of the interviewer's long experience of clinical practice with DD clients, as follows: clients were not informed about this experience, a conscious interview approach and an interview guide were used, during the analysis there was collaboration with other researchers not experienced in hand therapy, and a theoretical framework was used. A conscious interview approach refers to being aware of the importance of creating a good atmosphere; giving the participant room to open up and opportunity to develop his/her view, attempting to discover the participant's life-world (23). The collaboration among the authors during the analysis for interpretations of collected data constituted an investigator triangulation (24).

The findings of the present study are limited to its context, but may be transferable and of interest to other health care providers involved in surgical intervention or rehabilitation. The findings of the present study can contribute to future improvement of health care services.

Conclusion

Clients' needs during a surgical intervention process consist of need for improvement of hand function, need for knowledge and support during treatment, and participation in evaluation.

Clients' needs change during the care process and can be influenced by their life situation or their character. Our study suggests that the identified needs ought to be included in quality assessments from the carers' perspective, to ensure that important needs of the clients are met by the surgical intervention process. Communication and interaction between patient and health care provider is a key aspect for fulfilling clients' needs.

Acknowledgements

The authors thank the Department of Hand Surgery in Malmö, Sweden for practical support.

Declaration of interest statement

The authors report no conflicts of interest. The study was supported by grants from the County council of Östergötland, Sweden.

References

1. Wilburn, J, McKenna, S, Perry-Hinsley, D, et al. The impact of Dupuytren disease on patient activity and quality of life. *J Hand Surg Am.* 2013;6:1209-1214.
2. Engstrand, C, Krevers, B, Nylander, G, et al. Hand function and quality of life before and after fasciectomy for Dupuytren disease. *J Hand Surg Am.* 2014;7:1333-1343.
3. Shih, B and Bayat. A Scientific understanding and clinical management of Dupuytren disease. *Nat Rev Rheumatol.* 2010;6:715-726.
4. Dahlin, L, Bainbridge, C, Leclercq, C, et al. Dupuytren's disease presentation, referral pathways and resource utilisation in Europe: regional analysis of a surgeon survey and patient chart review. *Int J clin pract.* 2013;3:261-70.
5. Gudmundsson, K, Arngrimsson, R, Sigfusson, N, et al. Epidemiology of Dupuytren's disease. Clinical, serological and social assessment. The Reykjavik Study. *Journal of Clinical Epidemiology.* 2000;291-296.
6. Dahlin, L, Bainbridge, C, Szczypa, P, et al. Current trends in the surgical management of Dupuytren's disease in Europe: the surgeon's perspective. *Eur orthop and traumatol.* 2012;1:25-30.
7. Crean, S, Gerber, R, Hellio Le Graverand, M, et al. The efficacy and safety of fasciectomy and fasciotomy for Dupuytren's contracture in European clients: a structured review of published studies. *J Hand Surg Eur.* 2011;5:396-407.
8. Ball, C, Pratt, A, Nanchahal, J. Optimal functional outcome measures for assessing treatment for Dupuytren's disease: a systematic review and recommendations for future practice. *BMC musculoskeletal disorders.* 2013;14:131.
9. Rademakers, J, Delnoij, D, de Boer, D. Structure, process or outcome: which contributes most to clients' overall assessment of healthcare quality? *BMJ Qual Saf Health Care.* 2011;20:326-331.
10. Small, N, Green, J, Spink, J, et al. The patient experience of community hospital-the process of care as a determinant of satisfaction. *J Eval Clin Pract.* 2007;1:95-101.
11. Engstrand, C, Kvist, J, Krevers, B. Patients' perspective on surgical intervention for Dupuytren's disease - experiences, expectations and appraisal of results. *Disabil Rehabil.* 2016;1-12.
12. Donabedian, A. The quality of care. How can it be assessed? *JAMA.* 1988;12:1743-8.
13. Asadi-Lari, M, Tamburini, M, Gray, D. Patients' needs, satisfaction, and health related quality of life: towards a comprehensive model. *Health and quality of life outcomes.* 2004;32.
14. Krevers, B, Närvänen, A L, Öberg, B. Patient evaluation of the care and rehabilitation process in geriatric hospital care. *Disabil Rehabil.* 2002;9:482-491.
15. Krippendorff, K. Content Analysis. An Introduction to its methodology. 3 ed. 2013, Thousand Oaks: Sage Publications.
16. Pratt, A, Byrne, G. The lived experience of Dupuytren's disease of the hand. *J Clin Nurs.* 2009;12:1793-1802.
17. Sjostedt, L, Hellstrom, R, Stomberg, MW. Patients' need for information prior to colonic surgery. *Gastroenterol Nurs.* 2011;5:390-7.
18. Kan, H J, de Bekker-Grob, E W, van Marion, E S, et al. Patients' preferences for treatment for Dupuytren's disease: A discrete choice experiment. *Plast Reconstr Surg.* 2016;1:165-73.
19. Andersson, V, Otterstrom-Rydberg, E, Karlsson, AK. The Importance of written and verbal information on pain treatment for patients undergoing surgical interventions. *Pain Manag Nurs.* 2015;5:634-41.

20. Chen, J, Mullins, C D, Novak, P, et al. Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Educ Behav.* 2016;1:25-34.
21. Coulter, A, Entwistle, V A, Eccles, A, et al. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database Syst Rev.* 2015;3:CD010523.
22. Main, D S, Henderson, W G, Pratte, K, et al. Relationship of processes and structures of care in general surgery to postoperative outcomes: a descriptive analysis. *J Am Coll Surg.* 2007;6:1157-65.
23. Hermanns, H. Interviewing as an Activity, in U. Flick, E.v. Kardorff, and I. Steinke (eds.), *A Companion to Qualitative Research.* 2004, London: SAGE. pp. 209-213.
24. Flick, U. Triangulation in qualitative research, in U. Flick, E.v. Kardorff, and I. Steinke (eds.), *A Companion to Qualitative Research.* 2004, London: SAGE. pp. 178-183.

Table 1. Background information on the study participants (n=21) regarding age range, severity of DD, previous experience of treatment for DD and family history of DD. Reprinted from Clients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. Engstrand C, Kvist J & Krevers B. Disability and Rehabilitation. 2016; 38(26), 2538-2549. Reprinted by permission of the publisher Taylor & Francis Ltd, <http://www.tandfonline.com>.

No	Age range	Severity of DD	Experience of treatment for DD	Positive family history of DD
1	45-59	Bilateral DD	Previous treatment of other hand or finger	Yes
2	45-59	Bilateral DD	No previous experience	Yes
3	45-59	Bilateral DD	No previous experience	No/unknown
4	45-59	Unilateral DD	No previous experience	No/unknown
5	60-64	Bilateral DD	No previous experience	No/unknown
6	60-64	Bilateral DD	No previous experience	Yes
7	60-64	Bilateral DD	No previous experience	No/unknown
8	60-64	Bilateral DD	Previous treatment of other hand or finger	Yes
9	65-69	Bilateral DD	Previous treatment of other hand or finger	No/unknown
10	65-69	Bilateral DD	Previous treatment of other hand or finger	Yes
11	65-69	Bilateral DD	Previous treatment of other hand or finger	Yes
12	65-69	Bilateral DD	No previous experience	Yes
13	65-69	Unilateral DD	No previous experience	No/unknown
14	65-69	Bilateral DD	Previous treatment of same hand and finger	Yes
15	65-69	Unilateral DD	No previous experience	Yes
16	65-69	Unilateral DD	No previous experience	No/unknown
17	65-69	Unilateral DD	No previous experience	Yes
18	70-84	Bilateral DD	Previous treatment of other hand or finger	Yes
19	70-84	Bilateral DD	Previous treatment of same hand and finger	Yes
20	70-84	Unilateral DD	No previous experience	No/unknown
21	70-84	Bilateral DD	Previous treatment of other hand or finger	No/unknown

Table 2. Content of the interview guide for each time point, with areas covered and starting questions in the interviews. Reprinted from Patients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. Engstrand C, Kvist J & Krevers B. Disability and Rehabilitation. 2016; 38(26), 2538-2549. Reprinted by permission of the publisher Taylor & Francis Ltd, <http://www.tandfonline.com>.

Time point	Area of interview guide	Starting questions
Pre-surgery interview	Previous experience	<i>What did you know from before about your hand condition?</i>
(2-4 weeks before surgery)	Present life situation	<i>Can you tell me about an ordinary day?</i>
	Needs	<i>Why did you seek medical care for your hand condition?</i>
	Expectations on results	<i>What do you think about the treatment you are going to receive?</i>
Post-surgery interview	Results	<i>What do you think about the treatment you have received?</i>
(6-8 months after surgery)	Changes in hand function	<i>In what way did this treatment influence your ability to use your hand in daily activities?</i>
	Expectations on future hand function and health	<i>What do you think about the future and your hand condition?</i>

Figure captions

Figure 1. Model of patient evaluation process in Krevers B, Närvänen A-L, Öberg B. Patient evaluation of the care and rehabilitation process - within geriatric hospital care. Disability and Rehabilitation. 2002;24(9):482-491. Taylor & Francis Ltd, <http://www.tandfonline.com>.
Reprinted by permission of the publisher.

Figure 2. Overview of the main categories of needs, life situation and patient character.
Clients identified four needs that were more or less evident during the different phases of the surgical intervention process. Clients' life situations could contribute to the occurrence of needs, but also be a resource for handling them. Patient characters can determine how clients may handle their perceived needs.

Manuscript title:

Patients' needs during a surgical intervention process for Dupuytren's disease.

Running head:

Patients' needs during an intervention process

Article category:

Research paper

Authors:

Christina Turesson^{1,2}, Joanna Kvist³, Barbro Krevers⁴

¹Department of Hand Surgery, Plastic Surgery and Burns, and Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden.

² Department of Social and Welfare Studies, Linköping University, Norrköping, Sweden.

³Division of Physiotherapy, Department of Medical and Health Sciences
Linköping University, 581 83 Linköping, Sweden.

⁴Division of Health Care Analysis, Department of Medical and Health Sciences
Linköping University, 581 83 Linköping, Sweden.

Corresponding author:

Christina Turesson

Department of Hand Surgery, Plastic Surgery and Burns, County Council of Östergötland,
Rehabilitation Unit, floor 09, 581 85 Linköping, Sweden.

Phone: +46010-1031887

E-mail: christina.turesson@regionostergotland.se

Declaration of interest:

The authors report no declarations of interest.

Table 1. Background information on the study participants (n=21) regarding age range, severity of DD, previous experience of treatment for DD and family history of DD. Reprinted from Patients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. Engstrand C, Kvist J & Krevers B. Disability and Rehabilitation. 2016; 38(26), 2538-2549. Reprinted by permission of the publisher Taylor & Francis Ltd, <http://www.tandfonline.com>.

No	Age range	Severity of DD	Experience of treatment for DD	Positive family history of DD
1	45-59	Bilateral DD	Previous treatment of other hand or finger	Yes
2	45-59	Bilateral DD	No previous experience	Yes
3	45-59	Bilateral DD	No previous experience	No/unknown
4	45-59	Unilateral DD	No previous experience	No/unknown
5	60-64	Bilateral DD	No previous experience	No/unknown
6	60-64	Bilateral DD	No previous experience	Yes
7	60-64	Bilateral DD	No previous experience	No/unknown
8	60-64	Bilateral DD	Previous treatment of other hand or finger	Yes
9	65-69	Bilateral DD	Previous treatment of other hand or finger	No/unknown
10	65-69	Bilateral DD	Previous treatment of other hand or finger	Yes
11	65-69	Bilateral DD	Previous treatment of other hand or finger	Yes
12	65-69	Bilateral DD	No previous experience	Yes
13	65-69	Unilateral DD	No previous experience	No/unknown
14	65-69	Bilateral DD	Previous treatment of same hand and finger	Yes
15	65-69	Unilateral DD	No previous experience	Yes
16	65-69	Unilateral DD	No previous experience	No/unknown
17	65-69	Unilateral DD	No previous experience	Yes
18	70-84	Bilateral DD	Previous treatment of other hand or finger	Yes
19	70-84	Bilateral DD	Previous treatment of same hand and finger	Yes
20	70-84	Unilateral DD	No previous experience	No/unknown
21	70-84	Bilateral DD	Previous treatment of other hand or finger	No/unknown

Table 2. Content of the interview guide for each time point, with areas covered and starting questions in the interviews. Reprinted from Patients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. Engstrand C, Kvist J & Krevers B. Disability and Rehabilitation. 2016; 38(26), 2538-2549. Reprinted by permission of the publisher Taylor & Francis Ltd, <http://www.tandfonline.com>.

Time point	Area of interview guide	Starting questions
Pre-surgery interview	Previous experience	<i>What did you know from before about your hand condition?</i>
(2-4 weeks before surgery)	Present life situation	<i>Can you tell me about an ordinary day?</i>
	Needs	<i>Why did you seek medical care for your hand condition?</i>
	Expectations on results	<i>What do you think about the treatment you are going to receive?</i>
Post-surgery interview	Results	<i>What do you think about the treatment you have received?</i>
(6-8 months after surgery)	Changes in hand function	<i>In what way did this treatment influence your ability to use your hand in daily activities?</i>
	Expectations on future hand function and health	<i>What do you think about the future and your hand condition?</i>

PHASES IN THE SURGICAL INTERVENTION PROCESS

Seeking
medical
care

Planning/
deciding
about

Surgery

Rehabilitation

N
E
E
D
S

Need for an improved hand
function

Need for support during treatment

Need for participation in
evaluation and improvement
of care

Need for knowledge

LIFESITUATION

PATIENT CHARACTER