Patients' perspective on surgical intervention for Dupuytren's disease: experiences, expectations and appraisal of results

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Linköping University Post Print

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

This is an electronic version of an article published in:

Christina Engstrand, Joanna Kvist and Barbro Krevers, Patients' perspective on surgical intervention for Dupuytren's disease: experiences, expectations and appraisal of results, 2016, Disability and Rehabilitation, 1-12.

Disability and Rehabilitation is available online at informaworldTM:

<http://dx.doi.org/10.3109/09638288.2015.1137981>

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

Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-125964>

Abstract

Purpose

To explore patients' perspectives on surgical intervention for Dupuytren's disease, focusing on patients' appraisal of results, involving previous experiences, expectations, and patient characters.

Method

The participants were twenty-one men, mean age 66 years, scheduled for Dupuytren's disease surgery. Qualitative interviews were conducted two-four weeks before, and six-eight months after surgery. The model of the Patient Evaluation Process was used as theoretical framework. Data was analysed using problem-driven content analysis.

Results

Five categories are described: previous experiences, expectations before surgery, appraisal of results, expectations of the future and patient character. Previous experiences influenced participants' expectations, and these were used along with other aspects as references for appraisal of results. Participants' appraisal of results concerned perceived changes in hand function, care process, competency and organisation, and could vary in relation to patient character. The appraisal of results influenced participants' expectations of future hand function, health and care.

Conclusions

Patients' appraisal of results involved multidimensional reasoning reflecting on hand function, interaction with staff and organizational matters. Thus, it is not enough to evaluate

results after Dupuytren's disease surgery only by health outcomes as this provides only a limited perspective. Rather, evaluation of results should also cover process and structure aspects of care.

Introduction

Dupuytren's disease (DD) is a common soft tissue disorder affecting one or both hands. DD usually starts in the palm causing an extension deficit in one or several fingers [1]. This leads to impairments in hand function and problems with performance of daily activities as well as quality of life [2-5]. The prevalence of DD increases with age and varies depending on sex [6, 7] and ethnic group [7]. In Western populations, a mean prevalence of 21% has been reported among men and 5% among women aged 65 [6]. Appreciable risk factors are heredity and diabetes mellitus [8]. The disease is also more common among men from northern Europe [8, 9]. Although both surgical and non-surgical treatment options exist, treatment does not cure DD and recurrence of the finger joint contractures is common within 17-33 months [10], leading to the need for repeated treatment.

To facilitate positive clinical outcomes health care providers must consider different types of knowledge in order to meet the philosophy of a client-centred approach. This knowledge should not be isolated to diagnosis or physical findings but should also include the patients' experiences, preferences and needs [11-13]. Assessment of health care can be divided into three parts: structure, process and outcome. Structure aspects of care refers to human, material or organizational resources; process aspects refers to patient-health care provider communication and interaction, and patients' involvement in decision-making; and outcome refers to care effects on health [14]. DD has been extensively researched with a focus on determining functional outcomes after treatment [15-19]. The functional outcomes have usually been documented through physical measurements and through patient-reported outcome questionnaires [17]. Patient satisfaction with the outcome or with the treatment

for DD, evaluated with different methods has also been reported in several studies [17, 20-25]. However, previous research has concluded that patient satisfaction is a multidimensional concept that can be difficult to capture [26-30], and that it is associated with structure and process aspects of care [28]. Thus, structure and process aspects of care are important factors that can influence patients' overall evaluation of care positively [28, 31-33]. Furthermore, many other components, as described in the model of Patient Evaluation Process, can also influence the patients' evaluation of their care and health outcome, e.g. previous experiences, expectations, needs, and patient character [34]. Therefore, to fully understand the patients' experiences and how they evaluate the care and the outcome, it is crucial to include the patients' perspective. The aim of the present study was to explore patients' perspectives on surgical intervention for Dupuytren's disease, focusing on patients' appraisal of results, involving previous experiences expectations, and patient characters.

Method

Study design

This is a qualitative study with interviews conducted at two different time points: two to four weeks before, and six to eight months after surgery. The model of Patient Evaluation Process [34] was used as a theoretical framework for the study. Data were analysed using problem-driven content analysis [35]. Problem-driven content analysis uses predefined coding categories based on specific research questions by making inferences from a body of text, in relation to a specific context [35].

Theoretical framework of the study

The model of the Patient Evaluation Process (figure 1) [34] was used as a framework for data collection and analysis of the present study. The model consists of five phases that constitute the patients' care process and it describes the patients' evaluation of results as a flexible process and not simply as a linear course. The patients' evaluation of results involves multiple factors such as needs, previous experiences, and present and future expectations. Patients can have previous experiences of illness and care that influence their expectations of the care they are about to receive. Their needs can vary during the care process, and the ways in which these needs are met can influence patients' evaluation of results. However, patients' evaluation of results can also be influenced by the patient's life history, life situation and the patient character. Four patient characters are described in the model: active, passive, tolerant and frustrated. Briefly, the active patient character is actively seeking to influence the situation, while the passive patient character takes few initiatives to participate in communication and decision making. The tolerant patient character waits to see what is going to happen and participates as directed by the staff. The frustrated patient character wish to participate and influence their situation but feel they lack the competence and knowledge required to be involved in decision making. A patient character is not static and should not be seen as a personality type. Rather, in the model of the Patient Evaluation Process, a patient character is a product of the patients' own descriptions of themselves and their involvement in communication and activities of care and rehabilitation [34].

Figure 1. Model of patients' evaluation process in Krevers B, Närvänen A-L, Öberg B. Patient evaluation of the care and rehabilitation process - within geriatric hospital care. In *Disability and Rehabilitation* 2002;24(9);482-491.

Setting and researchers' position

The participants in the present study were recruited from a specialist clinic for hand surgery in Sweden that treats patients with different levels of severity of DD. The participants went through an outpatient surgical intervention process, with follow-ups at the clinic for wound care and rehabilitation. Most of them were receiving postoperative hand therapy, except those with less severe DD (e.g. joint contracture $\leq 45^\circ$) who were given instructions about exercise directly by their surgeon. As researchers of this study, we had no association with the clinic providing the care. The first author (CE), who performed the interviews, was a doctoral student and hand therapist with long experience of clinical practice with patients with DD. The interviewer introduced herself as a doctoral student performing a research project at Linköping University, Sweden, and the participants were not informed about her clinical expertise.

Participants

The intention was to include 15-20 participants, as this was considered appropriate to capture both unique variations and common patterns within a group of patients with DD. Participants were selected via a relevance sampling strategy [35] based on age, working or retired, extent of the disease (recurrence, uni- or bilateral DD), and we included both patients with and without previous experience of surgery for DD. Only men were included in the study as DD is more common among them. An exclusion criterion was not being able to communicate in Swedish. Patients selected for the study and scheduled for DD surgery were invited by mail to participate in the study. A written invitation letter about the study was sent to 7-10 patients at a time, adapted to the flow of patients due for surgery. The first author (CE) telephoned the patients after one week as a follow-up to the invitation and made appointments for the first interview. Inclusion of participants was performed parallel to the pre-surgery interviews and was stopped after inclusion of 21 participants when interviews were deemed providing no new information. The twenty-one men who gave informed consent to participate and were included in the study had a mean age of 66 years (± 7 , range 46-83 years). They had experience of private and public health care providers, from the primary health care level to specialist clinics. Their previous experience of treatment for DD varied from never having surgery before to having surgery more than 15 times. The majority, 16 participants, were married and five were living alone. Background data on the study sample is presented in table 1. Their 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).

Table 1. Background information on the study participants (n=21) regarding age range, working status, severity of DD, previous experience of treatment for DD and heredity of DD.

No	Age range	Working status	Severity of DD	Experience of treatment for DD	Heredity for DD
1	45-59	Working	Bilateral DD	Previous treatment of other hand or finger	Yes
2	45-59	Working	Bilateral DD	No previous experience	Yes
3	45-59	Working	Bilateral DD	No previous experience	
4	45-59	Working	Unilateral DD	No previous experience	
5	60-64	Sickleave due to other health reasons	Bilateral DD	No previous experience	
6	60-64	Working	Bilateral DD	No previous experience	Yes
7	60-64	Retired	Bilateral DD	No previous experience	
8	60-64	Working	Bilateral DD	Previous treatment of other hand or finger	Yes
9	65-69	Retired	Bilateral DD	Previous treatment of other hand or finger	
10	65-69	Retired	Bilateral DD	Previous treatment of other hand or finger	Yes
11	65-69	Working	Bilateral DD	Previous treatment of other hand or finger	Yes
12	65-69	Working	Bilateral DD	No previous experience	Yes
13	65-69	Retired	Unilateral DD	No previous experience	
14	65-69	Retired	Bilateral DD	Previous treatment of same hand and finger	Yes
15	65-69	Retired	Unilateral DD	No previous experience	Yes
16	65-69	Retired	Unilateral DD	No previous experience	
17	65-69	Retired	Unilateral DD	No previous experience	Yes
18	70-84	Retired	Bilateral DD	Previous treatment of other hand or finger	Yes
19	70-84	Retired	Bilateral DD	Previous treatment of same hand and finger	Yes
20	70-84	Retired	Unilateral DD	No previous experience	
21	70-84	Retired	Bilateral DD	Previous treatment of other hand or finger	

Data collection

The interviews were carried out during 2012-2013. Each participant was interviewed twice by the first author (CE): two to four weeks before surgery and six to eight months after surgery. The time points were chosen based on having the first interview as close as possible to the coming intervention, and the second interview when hand function would be recovered and the participants would still have their treatment experience in mind. Two participants were only interviewed before surgery as one of them was not available for the post-surgery interview and the other had his surgery postponed due to other health reasons. All interviews were performed by phone, except one interview (the pre-surgery interview with the first participant) which was performed at the clinic providing the care. An interview guide in two parts, pre- and post-surgery, was created inspired by the model of the Patient Evaluation Process [34]. The interview guide followed the phases of the care process, i.e. the past, present and future. The first interview covered *previous experience* of care regarding DD and other health issues, *present life situation*, *needs* and *expectations of results*. The second interview covered *results*, *changes in hand function*, and *expectations of future hand function and health* (table 2). The interview guide was tested at the pre-surgery interview with the first participant, which resulted in no changes.

Table 2. Content of the interview guide for each time point, with areas covered and starting questions in the interviews.

Time point	Area of interview guide	Starting questions
Pre-surgery interview (2-4 weeks before surgery)	Previous experience	<i>What did you know from before about your hand condition?</i>
	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 (6-8 months after surgery)	Results	<i>What do you think about the treatment you have received?</i>
	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>

The interviews were conducted in an open style with adapted probing in order to create a dialogue that would be as respondent-oriented as possible. Follow-up questions were asked with respect to the aim of the study and what the participant was willing to talk about. The pre- and post-treatment interviews with each participant lasted between 20-45 (median 23) minutes each. They were recorded digitally, and field notes about the interview were written down immediately after it was finished. The interviews were transcribed verbatim by the first author (CE). All interviews were performed before starting the analysis.

Data analysis

The pre- and post-surgery interviews with each participant were analysed as a whole as they represented the patients' care process. The coding process was performed using the QSR NVivo 10 software. The analysis in the present study consisted of two steps to capture the components in the model of the Patient Evaluation Process: a) analysis of data based on predetermined coding categories, and b) analysis of typologies.

The first step of the analysis based on the predetermined coding categories included data from all 21 participants. The coding categories represented components in the model of the Patient Evaluation Process: *previous experiences, expectations before surgery, needs, results, life history, life situation and expectations of the future*. To allow for openness to data that did not fit into the predetermined categories, one category was labelled “other”. The analysis was performed in a deductive - inductive manner, which meant that the analysis started with deductive coding of text based on the predetermined coding categories, and the inductive element consisted of creation of subcategories based on their content. The analysis proceeded by continuously moving back and forth between categories, subcategories and text.

As patient character is one component of the model of Patient Evaluation Process, the second step of the analysis consisted of analysis of typologies. This is a method for classifications of some aspect to describe alternative ideal types along a continuum [36]. This step of the analysis was performed on the 19 complete pre- and post-interviews and on the interviewer’s field notes. Each interview was categorised based on participants’ *descriptions of themselves as persons, their initiatives during the care process, interaction with the staff, involvement in decisions during the care process, and appraisal of results*. This was summarized into a description of each participant. The field notes were used to complete the description of the participants and the situation. The description of each participant was given a label inspired by the patient characters as identified in the model of the Patient Evaluation Process.

The first author (CE), who had completed doctoral courses in qualitative research methods, performed the initial coding of data and analysis of typologies independently. However, in a

collaborative work process, this coding was continuously discussed with the third author (BK), who was familiar with the theoretical framework and experienced in qualitative analysis and research. The preliminary analysis was presented to the second author (JK), an experienced researcher, and discussed by all three authors (CE, JK, and BK). If there were disagreements during the analysis, the authors revisited the data in order to reach consensus. Based on the aim of the present study, data from five categories are presented in this paper: previous experiences, expectations before surgery and of the future, appraisal of the results, and patient characters. These categories represent selected components of the model of Patient Evaluation Process, with some minor adjustments of labels' adapted to the context of the present study.

Results

The results are presented as five main categories: previous experiences, expectations before surgery, appraisal of results, expectations of the future, and patient characters. Figure 2 shows an overview of the categories and their content. Quotations from participants are included to illustrate findings; text within brackets is the authors' clarifications.

Figure 2. The interconnected main categories and their content in the study, based on selected components of the model of Patient Evaluation Process. Previous experiences influenced patients' expectations before surgery. Patients' appraisal of results involved previous experiences, expectations, patient character, and concerned changes in hand function, care process and organisational matters. Expectations of the future were influenced by appraisal of results. The three pointers placed before the category 'Previous experiences' and after the category 'Expectations of the future' indicate the entry and exit of the care process the patient went through. The dotted line illustrates how experience from one care process can form the basis for evaluation of future care processes.

Previous experiences

Participants carried *previous experiences of DD* with them and expressed how these caused a range of activity limitations and problems with hand function. Difficulties with gripping, holding or carrying objects interfered with self-care, work or leisure activities. Participants also had *previous experiences of health care*, e.g. previous treatment for DD or other illness, or experiences gained by other means. The latter could be through friends or relatives' treatment experiences, but also through newspapers or the internet. There were both positive and negative previous experiences of changes in hand function and of treatment. Positive experiences of changes in hand function could be expressed as being able to extend the fingers fully or having improved range of motion. Positive experiences of treatment could be described as not having pain during or after surgery, being involved in decisions, the staff being competent, or that the care process was rational and smooth. Negative experiences in relation to hand function could be recurrence of the contractures, scar issues or impaired sensation. Negative experiences of treatment could be related to having a lot of pain after surgery, having many different doctors, being sent back and forth between health care providers, surgery being postponed at short notice, or not getting enough information or follow-up.

Expectations before surgery

Expectations before treatment consisted of four subcategories: expectations of the trajectory of illness; expectations of the results based on the surgeon's competence; expectations of the care process; and readiness for treatment.

Expectations of the trajectory of illness

Previous experience of surgery coloured participants' expectations of the treatment effect.

There were comments about hope for a better or an equally good result compared to previous treatment experiences.

"Since I have been through surgery once before I know what this is all about now so it's no problem at all" (9)

Regardless of having previous experience of surgery or not, there was an emphasis on expecting *improvement* of hand function. Participants could talk about this with different degrees of certainty based on how they perceived the information they had. There were statements of the expected improvement as proportions of what was considered a normal hand function, and there were hopes for activities that would be possible to perform after treatment.

"I'm counting on a hundred percent recovery during the time it lasts, then it might come back, I have no guaranties for that but I assume it will be a hundred percent recovered" (7)

Although aware of the risk of recurrence, participants expressed hope for long-term *stability* regarding hand function and that the surgical treatment was a one-time event.

"I really hope so [that surgery is a one-time event] but I haven't really thought about that. I have rather thought you do this once, then it is ok in this hand of course, then it might come in the other hand but that is a different thing. But I

thought with this surgical procedure you solved the problem once and for all”

(16)

Despite expecting and hoping for an improvement in hand function, participants could also feel *uncertain* about the treatment effect. They were aware of the risk of recurrence, and that there were no guarantees. There was fear of hand function getting worse after treatment, and some said they were prepared to have the finger removed instead.

“If only it doesn’t get worse, so I have any problems afterwards. That is what I am thinking about, that I will not have any trouble afterwards” (2)

Based on previous experiences, there was also *resignation* about hand function, where doubts that anything could be achieved at all overshadowed the hope for improvement of hand function.

“Since I’ve done this once before and it didn’t work out then, why should they succeed this time” (19)

Expectations of results based on surgeon’s competence

Participants’ views of the surgeon’s competence and skills could influence their expectations of the outcome. This was not an expression of the surgeons’ formal qualifications but rather the participants’ non-professional view of competence. This could be connected to previous experiences of treatment, or to trust and confidence in the hand surgeon being a specialist. There were also comments about the importance of how the surgeon managed and handled tissue during surgery to limit the traumatisation.

“I have high confidence in the surgeons and that they know what they are doing”

(11)

Expectations of the care process

Participants with previous experience of surgery could expect the coming care process to be similar. However, regardless of having previous experience or not participants could also be uncertain about the content of the coming care process. They had thoughts about whether they would have pain, if they would receive a cast or a splint after surgery, and if there would be time delays on the day of surgery. There were concerns about how it would be to have local anaesthetic, what was to be done during surgery, or whether they would be able to watch the surgical process.

“I don’t know about this being awake. I’m not really sure how they do this but I assume you are behind a screen in some way, and you will of course be drugged so you think everything is nice and so on. I assume that is how it is” (4)

Participants expected having to perform exercises after surgery, but were uncertain whether they would get help with rehabilitation or not. They acknowledged the importance of exercise or using the hand in activities as a way for them to influence the outcome positively. However, there were also doubts about their own ability to influence the outcome, with some saying that their own efforts would not influence the outcome to any particular degree. Instead, they spoke of having to rely on following the staffs’ advice.

Expectations about the extent of surgery differed and were connected to previous experiences or to the participants’ interpretation of the information they had received from

the surgeon or others. There were some participants who described surgery as a minor thing as it could be performed under local anaesthetic and there were no risks. Others described it as a complicated procedure with risks connected to the anaesthetic procedure or to infections.

“No I don’t think we talked about risks. I think it is such a trivial thing, the fingers you know, it is so (laughing) simple in a way I imagine, even if it is a very complicated operation. But I don’t really believe there are any [risks]. I don’t really know what the risks would be” (1)

Thoughts about time needed for recovery after surgery varied among the participants, from recovery taking some weeks up to several months. These thoughts were connected to participants’ previous experiences or assumptions.

Readiness for treatment

Readiness for treatment was expressed in different ways. Reluctance towards treatment could occur, with some describing it as choosing between two bad things - having the contractures or going through surgery. Participants expressed fear of pain, worry, or unpleasant thoughts about surgery and anaesthetic. Reading negative things in the media or looking at pictures on the internet made their concerns even worse.

“And now I have been looking at the internet at these operations, and you should not do that because it’s terrible. Pictures with skin transplants and stuff so you get a bit scared, so right now it feels a bit unpleasant”(17)

However, there was also happiness and confidence about treatment, with participants looking forward to surgery, and the coming surgery meaning a lot. Participants spoke of feeling safe and informed about what was going to happen.

Appraisal of results

The participants' appraisal of results involved three subcategories: changes in hand function; care process; and competency and organisation.

Changes in hand function

Participants valued several aspects of the changes in hand function after treatment. They used previous experiences of surgery for comparison and described differences or similarities, leading to being more or less pleased with their present hand function. Participants could also reflect on whether their expectations of changes in hand function had been met, expressing being positively surprised or disappointed of not being better.

“I must say that I thought before surgery that it was a much simpler, a relatively simple operation, and that in a month or so you would be a hundred percent recovered, but it wasn't like that at all”(10)

Changes in hand function were also valued in relation to improvement of previous activity limitations or problems, and if there was better use of the hand after treatment. Progression of the healing process and present issues with hand function also influenced how the outcome was viewed. Participants described feeling shocked when first seeing the hand during the healing process, and they spoke of present issues with hand function such as

stiffness, sensitivity to cold, or not having regained sensibility. If hand function was viewed as much improved the remaining issues with hand function were described as less bothersome, while if only minor improvements in hand function were seen there were more concerns with the remaining issues. Changes in hand function could also be seen in relation to the participants' view of a normal hand, i.e. how a hand is supposed to look and function.

“It looked really great! It was truly amazing. I almost cried when I saw the hand was normal again” (4)

Participants could also express how a positive change in hand function had given a higher quality of life. In contrast, they also viewed the changes in hand function in relation to general health and could describe DD as just a small part of their life.

Care process

The participants' appraisal of results also involved the care process as a whole. Previous information/knowledge and expectations from before surgery was used for comparison with the care process they had went through. Based on this comparison, there were wishes for further information about the care process but also comments about information being exaggerated. Participants reflected on how previous information and knowledge, from the media or other sources, had influenced their expectations in a negative way. They could state that their experience of the care process was better than expected or surprisingly simple.

“I continued to live with this perception that this had to be repeated and that it was doubtful if it could be fixed and so on. Afterwards, when I had gone through

this I had a feeling that this kind of surgery could be done and that it was nothing strange so to speak. I think there is a lot of information out there that is available and that you can get, and that perhaps is misleading” (6)

The progression of the care process and the response from the staff were also important for how participants looked upon the care process. There were descriptions of feeling pleased when everything was going as planned and on time. Participants could express being pleased with the care process in contrast to the negative picture of health care in general that they felt was spread in the media. Participants also spoke of being pleased with the care based on their perception of the staff being professional. Examples of this were that the staff had given enough support, letting the participants share their knowledge and expertise, or that the hand surgeon had made them believe treatment would be successful. Participants with experience of health care from further back in time could speak of positive changes in health care in general when it came to the staff response and the staff's view of them as patients.

Competence and organisation

Participants' appraisal of results also concerned competence and organisation. When talking about the outcome of surgery, the participants said there had been a good result because they felt that the surgeon was skilled and competent. This positive view could be connected to that surgery in their opinion was well done. There were also descriptions of outcome in relation to organisation and logistics, and that it felt safe to be treated at an institution with long and wide experience.

“The logistics are effective, so you know it [surgery] will be done. If surgery is planned for a certain day, you know it will be that day, you are depending on it for your own planning. So if you just get information you can plan, but if they said ‘no not this week’, that wouldn’t be good. So I appreciate the professionalism, and that it is a professional institution” (14)

Expectations of the future

Expectations of future hand function and health were coloured by the appraisal of the results. There was confidence among the participants regarding the trajectory of illness, and that the condition would remain stable for many years. Despite this, there were comments also indicating uncertainty about the future hand function. There were comments about fear of recurrence, which could be described as an awareness that changes in hand function after surgery were not permanent. Participants expressed thoughts about how to avoid recurrence by being more careful with their hands and heavy activities, but remaining active. Participants also had thoughts about the strong heredity factor and the risk of their children having DD in the future. *Expectations of future care* were also influenced by evaluation of the results, and there was hope for new treatment methods in the future, as alternatives to surgery. Based on their view of the results, participants expressed being more or less prepared for a new care process. They spoke of being positive towards and ready for a new care process, but also of preferably not going through another treatment. Having further treatment could also be considered unlikely, depending on their age.

“With knowledge about other people I’ve seen that have done this, I don’t believe this is a static state. So, I’m ready to do this again” (21)

Patient characters

Two different patient characters, *the eager* and *the tolerant patient character*, were identified in the present study based on the participants' descriptions of themselves, their own initiatives, involvement and participation in decisions and treatment. These can be seen as different approaches towards participating in care. Depending on the situation and the opportunities given to participate in care, the two patient characters could also vary in an active-passive behaviour continuum.

The eager patient characters described taking initiatives, asking questions, seeking information and making active choices about their treatment. They could express the importance of being fully informed and highly involved in the decisions about treatment. They wanted to influence their care, and if not given this opportunity to be actively involved, they could become frustrated.

The tolerant patient characters described themselves as waiting and watching to see what was going to happen. They described themselves as being partly involved in decisions, but commonly, they put their trust in the surgeon's expertise or transferred control to the surgeon/staff to a large degree. Initiatives were in general few, although there were tolerant patient characters that in some situations described taking action/initiatives. Some obstacles to participating in decisions that were mentioned were lack of knowledge and not understanding the "language" used in health care.

Appraisal of results in relation to patient character

The participants' view of the results varied depending on the patient character. Those with the *eager* patient character generally described the results as positive. Although there could

be experiences of negative events during the care process, this did not influence their view of the outcome. Those with the *tolerant* patient character had diverse views of the results and could be positive, hesitant or negative about them. Among those who were hesitant about the results, some had remaining issues with hand function or expressed that their expectations were not met. Still, they could regard the care process as positive in general. It could also be the other way around, i.e. that they had concerns about the care process but had a positive view of changes in hand function. Those with a negative view of the results could express it as not having their expectations met. Regardless of the view of the results, those with the *tolerant* patient character spoke of wanting more information before treatment about time for recovery, the care process as a whole, and the anaesthetic procedure. They also expressed the importance of seeing the surgeon after surgery, and of wanting further follow-up on exercise.

Discussion

The present study demonstrates factors that influence the participants' evaluation of surgical intervention to treat DD. This is new knowledge about patients with DD undergoing surgical intervention that is important to understand to promote improvement in care quality and outcome assessments. Our study shows that previous experiences influenced the participants' expectations before surgery. Both previous experiences and expectations, along with other aspects, were used as references for appraisal of the results of surgery. Participants' appraisal of results concerned changes in hand function as well as the care process, staffs' competency and the care organisation. Further, it was also influenced by the patient character, which can be seen as a product of the patient health care provider

interaction. The participants' evaluation of the results influenced their expectations of future hand function, health and care, thereby forming experiences that the participants would use when evaluating future care processes.

There has been an increasing interest in considering patients' expectations of orthopaedic procedures, with a focus on pain, physical, social and psychological function [37]. However, evidence concerning the importance of fulfilment of preoperative expectations is inconclusive [38]. The present study shows that unfulfilled expectations can be one reason for a negative view of the intervention outcome, and this is in line with previous research findings arguing for the importance of fulfilment of expectations [30, 39]. Expectations can form a frame of reference that patients use for making comparative judgements [39]. However, the present study found that having expectations met was not the only aspect involved in participants' evaluation of changes in hand function. Rather, patients employed multidimensional reasoning reflecting on whether the treatment had solved their previous activity limitations or problems, how the healing process had progressed, if there were present issues with hand function, how a normal hand should function, and how quality of life or general health had been affected. This supports previous research suggesting that a positive view of changes in hand function is based on whether the hand can be lived with and used in most contexts [27].

Expectations are multifaceted [40] and may evolve and change [34], and can therefore be difficult to measure [38]. In the present study, expectations of the trajectory of illness changed over time. Before surgery, expectations for four different trajectories of illness

were identified (improvement, stability, uncertainty, resignation) with emphasis on improvement of hand function. After treatment, based on the participants' new experience, expectations of future hand function were dominated by the wish for long-term stability, uncertainty and fear of recurrence. The change in expectations of trajectory of illness reveals the close connection between experience and expectations, which has been shown previously [40]. Expectations can represent needs patients want to be met, and these needs may differ during the phases of the care process [34]. Issues brought up by participants in the present study as reasons for a negative view of the outcome included unmet expectations, lack of information and wish for further follow-up. These could be expressions of unmet needs during the care process, and in order to understand patients' experiences further, it is important to explore and describe patients' underlying needs during a care process in future research.

The quality of care should not be assessed only in terms of health outcome, i.e. the effect of care on health, but also in terms of structure and process aspects of care [14]. However, previous research about DD has focused on functional outcomes after treatment while little or no attention has been given to other aspects of care. In the present study, both structure and process factors could be identified as influencing the participants' appraisal of results either positively or negatively. Factors related to structure[14] were for example the participants' non-professional opinion of the surgeon's competence or of the organisation in general. Examples of factors related to process[14], were the participants' views of response from the staff in terms of support and shared knowledge, and issues of lack of information and a wish for further follow-up. These findings supports previous research from other areas

of health care concluding that structure and process aspects of care are of importance for patients' overall evaluation of care [28], and that patients evaluate their caregivers intervention, their knowledge and skills, and the interaction between them [41].

Participants' appraisal of results in the present study could also be related to patient character. To identify patient characters we used analysis of typologies, based on an inductive analysis of patterns that appear in the data [36]. In the present study, as well as in the original model of the Patient Evaluation Process, patient characters are a product of the participants' own descriptions of themselves as persons and the situation interaction. One of the two patient characters identified in the present study (the eager patient character) is new compared to those identified in the model of the Patient Evaluation Process [34]. In the original model, four patient characters, including an active and a passive patient character were identified. In the present study, the patient characters could vary in an active-passive behaviour continuum which was most evident among the tolerant patient characters. Based on the result of the present study it seems as if the 'eager' patient characters were more positive towards outcome, and perhaps this was due to their active participation and information gathering before surgery. This is supported by previous research showing that patients who are more engaged in their health care have better outcomes [42]. While there were 'tolerant' patient characters that certainly could take initiatives in some situations, it was still among the 'tolerant' that a wish for further information, or expectations not being met were expressed. Perhaps they did not inform themselves about what was going to happen or what they could expect as much as the 'eager' patient characters did. These

findings of the present study is consistent with previous research highlighting the importance of patient caregiver communication during the care process [2].

In the present study, content analysis was performed in a deductive-inductive manner which gave the opportunity to use a theoretical framework as a starting point but also to move outside it [35]. The model of the Patient Evaluation Process has not been used previously for evaluation of the patients' perspective on hand surgery or hand therapy intervention.

Though the model was developed in a different context (geriatric hospital care), the present study shows that model of the Patient Evaluation Process is applicable in other settings. The present study contributes with some new findings that complement the original model. As mentioned above, a new patient character was identified that could vary on a passive-active behaviour continuum. New trajectories of illness (resignation and recurrence) were identified in the present study in the categories expectations before surgery and expectations of the future. Expectations of the future also involved expectations of future care, which is new information compared to the original model. These findings contribute to development of the model and show that the components of the model of Patient Evaluation Process are useful for elucidating patients' evaluation of care and rehabilitation in different contexts.

The strengths of the present study with regard to trustworthiness are that several researchers in a collaborative work process performed the analysis and triangulation of results. The use of a conceptual model in the study provides a theory triangulation and contributes to systematising data collection and analysis which can increase credibility. The sample in the present study shows variation in several aspects (e.g. age, previous experience

of surgery, working/retired) that contributes to finding both the unique and the common patterns of the patients' perspective on surgical intervention for DD. A limitation is that the sample consisted only of men due to DD being more common among them, thus, the result does not reflect differences that might be present based on sex. To ensure authenticity participants were informed that the interviewer had no association with the clinic providing the care. Furthermore, to eliminate the interviewer effect, participants were not informed that the interviewer had long experience of clinical practice with patients with DD. Several steps were taken to minimize the potential influence this experience might have on the analysis and synthesis of findings, i.e. the interview guide design, a conscious interviewer approach, the close analysis collaboration with other researchers not experienced in hand therapy and the use of the theoretical framework. The findings of the present study are linked to its context but still it provides insights about patients' perspectives on hand surgery and hand therapy interventions. This might be transferable and relevant for other health care providers involved in surgical interventions, rehabilitation, or working with patients with recurrent disease patterns or diseases with strong heredity. This information may contribute to improving health care services and better evaluation of outcomes.

Clinical implications

It is important to be aware of the role that previous experiences, expectations, structure and process aspects of care play in patients' appraisal of treatment results. Improving health care services means not only providing the best treatment method available, but also providing accurate information, allowing patient participation, and dealing with staff or organisational aspects of the care provided. Patient participation can be promoted by maintaining focus on the individual and taking their experience into account in decision making. Health care

providers should allow time for a dialogue with the patient when treatment is planned, taking the patient's previous experiences and expectations into consideration. For assessment of results after surgery and rehabilitation, different questions should be used to capture the diverse dimensions of care, i.e. structure, process and outcome. This can be done by using questions regarding the communication/interaction between patient and health care provider, e.g. if the patient felt listened to, received clear information and explanations in certain situations related to the care process, or was included in decision making. Further, questions can also target for example waiting time or continuity of care. This would provide knowledge about why patients' have a positive or negative view of hand function and the care process, which can be used for future improvement of care. Health care providers should also be aware of different patient characters, and take appropriate steps to make sure that all patients fully understand what is to be done and what can be expected. This would facilitate patient participation and "calibration" of the patients' expectations regarding the outcome, which could improve the patients' evaluation of care.

Conclusions

Patients' appraisal of results involved multidimensional reasoning reflecting on hand function, interaction with staff and organizational matters. Thus, it is not enough to evaluate results after Dupuytren's disease surgery only by health outcomes as this provides only a limited perspective. Rather, evaluation of results should also cover process and structure aspects of care.

Acknowledgments

The authors thank the department of hand surgery in Malmö, Sweden for practical support.

Declaration of Interest section

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

Implications for rehabilitation

- To improve health care services, it is important to be aware of the role played by patient's previous experiences, expectations, as well as staff and organizational aspects of care.
- Knowledge about patients' experience and view of the results from surgery and rehabilitation should be established by assessment of care effects on health as well as structure and process aspects of care.
- Evaluation of structure and process aspects of care can be done by using questions about if the patient felt listened to, received clear information and explanations, was included in decision making, and their view of waiting time or continuity of care.
- Improving health care services means not only providing the best treatment method available, but also developing individualised care by ensuring good interaction with the patient, providing accurate information, and working to improve the structure of the care process.
- Before treatment, health care providers should have a dialogue with the patient and consider previous experiences and expectations in order to ensure the patient has balanced expectations of the outcome.

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