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Title:

Experiences of living with Dupuytren's disease – consequences of the disease for hand function and daily activities.

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Abstract

Study Design: Qualitative descriptive.

Introduction

Dupuytren's disease (DD) is a chronic hand condition causing impairment in hand function. Research describing persons' experiences of living with DD is limited. Understanding the subjective experience of illness is valuable for planning and implementing health care services.

Purpose of the Study

To explore experiences among men living with an impaired hand function due to DD and the consequences of the disease for daily activities.

Methods

Interviews were conducted with 21 men before surgery. The model of the Patient Evaluation Process guided data collection. Data was analyzed using problem-driven content analysis.

Results

Participants described DD as a chronic disease caused by heredity, previous injury, hard work or aging. DD was, according to the participants, an uncomfortable and sometimes painful condition, causing a feeling of constant stiffness in the affected hand. DD could cause participants to have fear of hurting the hand, feelings of shame or embarrassment, and a sense of being old. Participants handled the deteriorating hand function by avoiding or refraining from activities, adapting their performance, or performing activities with less quality. The ideal hand function was seen as being able to use the hands without effort.

Discussion

The diverse experiences of DD and if the hand is experienced as something causing distress can be understood further using body-self dialectic and Gadamer's states of embodiment, as well as the process of adapting and learning to live with the functional limitations.

Conclusions

A clinical implication for hand therapy is to acknowledge patients' individual experiences and support self-modifications and development of new skills.

Level of Evidence: N/A

Introduction

Dupuytren's disease (DD) is a soft tissue disorder of unknown etiology that causes extension deficits in the finger joints, in one or several fingers of one or both hands (1). The prevalence of DD in the general population of Western countries varies from 0.6 to 31.6 percent and a higher prevalence is related to higher age. The prevalence is higher in men (21%) than in women (5% in Western populations aged 65) (2), and the prevalence of doctor-diagnosed DD in a Swedish population has been found to be 1.35 percent for men and 0.5 for women (3). Several treatment strategies for improving the digital extension exist for DD but none of them cure the disease. Rather, recurrence or disease extension to previously unaffected fingers is common (4). Hand therapy is usually provided to the client after the corrective procedure (5). Thus, DD is a health condition that impacts hand function and performance of daily activities during the patient's life (6).

There is extensive research on outcomes after surgery for DD focusing on physical aspects of body function, and on disability or quality of life using patient-reported outcome questionnaires (7-15). However, in order to meet the values of a person-centered approach, health care providers must not only study bodily functions connected with diagnosis but should also include the patients' experiences, preferences and needs (16-18). These matters are essential to consider as patients' experiences may influence their expectations of and satisfaction with health, care and outcome (19-23). Ueda and Okawa (2003) means that understanding the patient's inner world and experience of illness is valuable in clinical practice when planning and implementing health care services (24). Subjective experiences of functioning and disability can be related to the dimensions body function, activity and participation, but also to self-confidence, self-esteem, relationship with others, social acceptance and attitudes to life (24).

Previous research has not fully investigated the patients' subjective experience of having a hand deformity caused by DD. From other patient groups with hand deformities, e.g. patients with rheumatic disease, it has been shown that participation in activities or social situations can be restricted due to the deformities (25). Further, it has been shown that adjustment to major chronic disease such as neurological or heart disease, is a process involving several aspects including development of competence, finding motivation and becoming confident (26). However, it is unclear if these findings from other types of health conditions are applicable on patients with a chronic hand condition such as DD, as the meaning of impairment must be understood in relation to a specific context (24, 27). Previous research regarding the patients' subjective experiences of DD has shown that patients lack information about DD and available treatment options (28). Wilburn et al. (29) concluded that DD caused activity limitations and affected quality of life, and identified key issues to be used for development of a patient reported outcome measure specific for DD. Although a range of activity limitations were identified in the study, these were only described superficially and information is still lacking about what these limitations meant for the individuals in their everyday lives. Thus, knowledge about what it means to live with an impaired hand function caused by DD is limited.

Purpose of the study

The aim of the study was to explore experiences among men living with an impaired hand function due to DD and the consequences of the disease for daily activities.

Research questions:

- What do the participants know about DD?
- How does DD impact the participants' hand function and activities of daily living (self-care, work and leisure)?

Methods

Study design

This qualitative descriptive interview study is part of a larger project on clients with DD in which the model of the Patient Evaluation Process (23) constitutes the theoretical framework. Data was collected via interviews and was analyzed using problem-driven content analysis (30). The model of Patient Evaluation Process describes the patients' care-process through five phases, from pre-admission to post discharge (figure 1) (23). The model describes patients' evaluation of care and results as a dynamic process involving patients' previous experiences and significance of care and illness, expectations, needs and results. The patients' life situation, life history and patient character also influence patients' evaluation of care and results (23). Two articles have been published previously with the objectives of describing clients' experiences of care, needs, expectations, and appraisal of results during a surgical intervention process for DD (19, 31). This article focuses on the phase pre-admission and patients' experience and significance of illness.

Setting and researchers position

Participants in the present study were scheduled for treatment for DD at a specialist hand surgery unit in south Sweden. As researchers of this study, we had no connection with the clinic providing the care.

Participants

Recruitment of participants was performed via a relevance sampling strategy (30) to include participants of different ages, who were working or were retired, or with varying extent of the disease (recurrence, uni- or bilateral DD). Both participants with and without previous experience of surgical treatment for DD were included in the study. Participants also had to be able to communicate in Swedish. Participants scheduled for treatment were invited by mail to participate in the study, and the first author followed up the invitation one week later by

phone where the participants gave informed consent to participate. In this study we interviewed only men as it was not enough women planned for treatment during the period of inclusion to get sufficient data for a qualitative analysis that could provide a result applicable for both men and women. Inclusion of participants continued in parallel to the performance of the interviews and was stopped when 21 men had been included in the study and the interviews were deemed to render no new information. The participants had a mean age of 66 years (range 46-83 years) (table 1). The mean time since the debut of DD was 14 years (range 3-40 years). Twelve participants had no previous experience of treatment for DD, while the remaining participants had previous experience of one to 15 surgical treatment sessions. The majority of the participants had bilateral DD, and most of them (12) had retired from work. The participants' confidentiality and right to withdraw from the study was assured.

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

Data collection

All participants were interviewed two to four weeks before treatment. One interview was performed at the clinic providing the care while the remaining interviews were performed over the phone due to geographical distances. An interview guide was used during the interviews, and the interview guide was developed with inspiration from the model of the Patient Evaluation Process to capture experiences and significance of illness. The interview guide consisted of open question regarding experiences of DD in relation to the participants' life situation i.e. activities of daily living (self-care, work and leisure), and the participants' physical and social environment. Starting questions were as follows: What did you know from before about your hand condition? And: Can you tell me about an ordinary day? Follow-up questions were asked with respect to what the participants were willing to talk about. Adapted

probing was used during the interviews to create a dialogue that was responder oriented. The interview guide was tested at the first interview and rendered no changes. The interviews were recorded digitally and field notes about the interview were written immediately after each interview. The interviews lasted on average 23 minutes (range 20-45 minutes). The first author (CT) performed the interviews and transcribed the interviews verbatim. Her experience of working as a hand therapist and of meeting clients with DD in clinical practice was not revealed to the participants of the study.

Data analysis

Analysis of data was performed using problem-driven content analysis (30), and the QSR NVivo 10 software was used for the coding process. The analysis of data started when all interviews were completed. The analysis was performed in an inductive manner focusing on experiences and significance of living with DD. The analysis started with reading the text several times and identification of meaning units in the text. The meaning units were given a code and preliminary subcategories and categories were developed. The analysis continued by moving back and forth between the text, subcategories and categories. The ongoing collaborative work between the three authors during the analysis guided correction and checking of the interpreters' subjective view of data (32). All three authors contributed with their unique perspective although the first author (CT), who had completed doctoral courses in qualitative research methods, performed the initial coding of data independently. The analysis was continuously discussed with the third author (BK), who was an experienced researcher in qualitative methods. The analysis was presented to the second author (JK), who was an experienced researcher, and all three authors (CT, JK and BK) discussed the analysis and results. If there was disagreement regarding the analysis the authors revisited the text to reach consensus.

Results

The results are presented as six categories: understanding the condition; a changed hand function with stiffness, pain and limited range of motion; difficulties with gripping and fine motor skills; thoughts and feelings about the influence of DD; strategies for managing difficulties in daily activities; and the ideal hand function (table 2). Quotations from participants are included to illustrate the findings; text within brackets is the authors' clarification.

Understanding the condition

The participants' understanding of DD varied and touched on what type of disease DD is, the cause of the disease, disease mechanisms and sources of information. Participants spoke of DD as a disease that had originated with the Vikings, and a chronic condition that could be hard to master. Participants had different thoughts about the cause of DD, and could mention the strong heredity of the disease, none all could relate it to their own family history.

I have never seen it on my father or so but perhaps I'm the only Viking in the family (laughing). (Participant 21)

Having a previous hand injury or working hard lifting heavy things for many years were also mentioned as causes of the disease, but it could also be described as starting after being diagnosed with diabetes. DD was also described as related to aging, or as mainly affecting craftsmen.

It started with one finger, I noticed it when I was lifting things, I have been incredibly strong, so I lifted heavy and then I felt that something happened in the finger...that's how it started. (Participant 5)

The disease mechanism was described in different ways: as related to the flexor tendons, as related to other tissue in the palm, or as formations of cartilage. Sources of information about DD could be relatives, friends, or the internet but some participants also said that they had never heard of DD before and knew very little about it.

It is the joints, or the tendons that contract, and I'm not sure if it is related to age or...but I don't think so because they call it the disease of the Vikings so it has always been there. (Participant 19)

A changed hand function with stiffness, pain and limited range of motion

The change in hand function was related to stiffness, pain and limited range of motion. The impact this had on hand function could vary depending on the severity of the disease, i.e. how many fingers were involved, if one or both hands were affected, if participants had it in their dominant hand or if they had fingers amputated due to the contractures.

Three finger on one hand and two on the other are affected [by DD] so it's the thumb and index finger that I can use. (Participant 5)

There were descriptions of feeling a constant stiffness in the hand and that DD was an uncomfortable and sometimes painful condition. Some participants described having a lot of pain in the evenings and at night, or having pain only when the finger got caught on things or when bumping things with their hand.

It's mainly the last year that it has been very painful, sort of inside the hand. You wake up in the morning and it's hurting. (Participant 4)

The limited range of motion could be described as problematic, leading to inability to open the hand when some fingers were lying flat in the palm. However, participants said that a larger degree of contracture, i.e. having the finger flat in the palm, in some way could be better than having the finger in a straight angle toward the palm. Despite the impairment in

range of motion some participants thought the limited range of motion they had was still better than having a completely stiff joint.

It's almost more troublesome with the finger in a straight angle than when it [the finger] is almost all the way in the palm. (Participant 10)

Difficulties with gripping and fine motor skills

DD leads to difficulties with the performance of self-care, work or leisure activities due to impaired gripping and fine motor skills. The difficulty with gripping, e.g. holding or carrying objects, interfered with manual or heavy work. Participants described problems when handling all kind of tools, heavy material or when climbing on ladders. Some participants described how the fingers got caught in different situations, especially when working with machines.

If you reach out with your hand you don't have all your fingers in the same direction, and then you're in trouble, you get the fingers caught in things everywhere. (Participant 8)

Activities involving fine motor skills, such as playing instruments (guitar, piano) were also difficult due to the contractures, and participants also felt limited when it came to doing things suddenly, like catching something. Some participants mentioned only minor consequences for daily activities as most of them were not performed with the fingers at full extension.

I have been able to do all I want, since the things you do are often done with the fingers slightly bent. (Participant 1)

Still, a range of troublesome activities were identified that involved a more or less flat hand: washing the face or body, collecting water or soap in the hand, putting on gloves, putting the

hand in a pocket, working at a computer, clapping the hands, stroking a surface with the hand , physical activities like doing push-ups on the floor, or swimming.

It's like you don't have a palm, you can't feel a surface. You can't have the same tactile function then. (Participant 14)

Thoughts and feeling about the influence of DD

The psychosocial impacts of DD were diverse, ranging from no impact on the participants' lives to affecting thoughts and feelings about themselves as well as interactions and relationships with others. Some participants said that DD was a minor detail in their life, that they got used to it, or that it was uncomfortable but not impossible to live with. Others expressed fear of hurting their hand or concerns about the appearance of the hand, e.g. that it looked strange or that they did not want to see it. Some said that they could not hide their hand or felt ashamed of it, and there were also experiences of people making comments about their hand.

My children know about it [DD] and they think it's disgusting....so they wish they will never get it. (Participant 7)

Some participants also expressed feelings of having half a body and of something being wrong with their body.

I mean...I can use two fingers on one and three on the other [hand] ...well, that is just half a body... (Participant 5)

Others said that it was depressing to have DD, and that it was a handicap, or gave them a sense of being old and of going downhill. Participants mentioned others not understanding their problem and that they had trouble with things others took for granted.

It [DD] makes me feel old, old and ugly, my dad was very shamed about his hands and he had it worse than me. I don't think it's anything but at the same time it's at my age that many things starts to remind you about aging, and we live in a society that in my opinion is very fixated about age, and then it's easy to get the idea that you're getting old and behind and this [condition] contributes to it a bit. (Participant 6)

DD also interfered with interactions and relationships with friends, and intimacy within the family. Shaking hands was a main cause of embarrassment for those with contractures in their right hand and this could lead to the need to explain and excuse themselves.

It's impractical when the fingers are at different angles and you are going to shake hands with people, and I do that a lot at work. And when you do, it feels strange and I have to really separate my fingers because otherwise they disappear into the palm of the person you say hello to, and it's such a strange situation. I think that is the worst part, to shake hands with people. (Participant 1)

Strategies for managing difficulties in daily activities

Strategies the participants used for managing difficulties with hand function could be to avoid or refrain from activities like playing instruments. Others avoided activities such as carrying plates due to fear of dropping and breaking things.

I cannot play guitar at all anymore...because I can't hold it, and it's the left hand that is the worst. (Participant 8)

Some also said they tried to perform activities anyway, though they could not do so very well, and although it was a little more complicated they could still manage everything they needed to do.

Participants also spoke of how they, consciously or not, adapted their performance of activities. They used the other hand, a different grip or had learned to use only the three radial fingers when gripping.

It's my left hand I have problems with, and of course you have to use the left [hand] too but in some situations you avoid using it, but that's something you do unnoticed... without really thinking about why (Participant 18)

There were also descriptions of overloading the other hand or having to ask for help in some situations. Some participants also described how they always held their hand with all the fingers flexed, which made it impossible for others to notice the contractures.

No one notices it because I keep it [the fingers] in a flexed position all the time, so no one sees them [the contracture] or knows that it is there. (Participant 1)

The “ideal” hand function

Participants also spoke of what their hand function meant to them, and they related their own problems with hand function to an idea of the “ideal” hand function. These thoughts about the ideal hand function came from DD making them aware of the importance of individual fingers and that both hands are needed in many situations. Participants expressed having a good hand function meant being able to use the hands practically and without effort. It was also described as having coordination, precision, and finger function.

I think it is about being able to move them, the fingers, and the precision in the fingers are very important to me as I play instruments like the violin.

(Participant 6)

Participants expressed regret at not having normal fingers, something they thought they did not have themselves with the contractures caused by DD.

I want to have normal fingers, not this strange type. (Participant 3)

Discussion

The present study explores experiences and significance of DD and consequences of the disease on hand function and daily activities. DD had an impact on the performance of many daily activities due to its associated stiffness, pain and limited range of motion, and it affected the participants' views of the hand causing distress. There were diverse descriptions of experiences of DD and the novel contributions of the present study are that it elaborates on thoughts and feelings the participants had about DD. The study finds that the disease can influence self-confidence and the persons' body image.

The diverse descriptions of the impact of DD given in the present study can be understood based on the body-self dialectic and Gadow's states of embodiment (33). When patients experience illness the unity between the body and self is disrupted and the hand is experienced as something causing distress. This is labeled as the *object body*, where there is a heightened consciousness of the hand (33). Social contexts can especially provoke the state of the object body (27) and in the present study, the object body can be seen when participants in the present study spoke of how their hand functioned and looked, and in the fact that they tried to hide it or were ashamed of it. They also described a feeling of something being wrong with their body, feelings of depression, and a sense of being old. However, there were also

descriptions of participants becoming used to the altered hand function and that DD, despite severe contractures, only caused minor problems. This can be regarded as *cultivated immediacy*, where there is still a distinction between body and self but the person is adapting and learning to live with the functional limitations (33). The transition from the object body to cultivated immediacy can involve treatment interventions such as surgery but can also include self-modifications or development of new skills (33). In the present study, the transfer between these two states of embodiment might have been possible due to the strategies used by the participants to manage difficulties with hand function. The participants spoke of, consciously or not, adapting their performance of activities as their hand function deteriorated over time. Thus, diverse descriptions of the impact of the disease among clients with DD can depend on their state of embodiment. The clinical implication for patients with DD is that hand therapy also needs to strengthen patients' strategies to reach a state of cultivated immediacy through acknowledging problems and support self-modifications and development of new skills.

The present study also shows that pain is a problem among clients with DD. The participants spoke of nightly pain or pain when the contracted finger got caught on things. DD has usually been described as a non-painful condition but there is research that has shown pain to be a common problem in DD that is not always addressed (34, 35). It has been shown that nerve fibers are embedded in the inelastic diseased tissue of DD and pain may be a consequence of local nerve compression (35). Pain is a factor that is strongly related to satisfaction (21), and thus is an essential area to target in the assessment and evaluation of treatment for DD.

Trustworthiness

In the present study, transferability (30) was addressed by recruitment of participants based on a relevance sampling strategy which enhanced a sufficiently varied sample. The sample varied with regard to the participants' experience of the disease and experience of treatment for DD,

and regarding whether they were retired or still working. However, the study sample only consisted of men as DD is more common among them which influenced the possibility to include enough women in the present study to provide a result that was valid for both men and women. Thus, there may be differences in experiences due to sex. It has been shown that the disease presentation is similar in men and women although women tend to have more severe contractures to the proximal interphalangeal joint (36) which may lead to different experiences of the disease than those reported in the present study. Data collection was performed in a systematic way by using an interview guide and a conscious interview approach was used to enhance rich descriptions, i.e. creating an atmosphere where the participant could develop his views (37). To assure authenticity (37), the participants were not informed prior to the interview about the interviewer's clinical experience of meeting clients with DD. This was a conscious step to minimize the potential influence this preunderstanding of DD could have on the interview. The analysis was performed based on verbatim transcriptions to ensure that findings were grounded in patient data. The analysis was performed based on verbatim transcriptions to ensure that findings were grounded in patient data. To strengthen the credibility of the study, we applied a collaborative work process between the three researchers (32). The collaboration between the researchers with and without clinical experience of hand therapy reinforced the awareness of preunderstanding so that it would not influence the analysis.

The findings from the present study are limited to its context. However, it can contribute knowledge about the experiences of having a chronic hand condition and the impact on daily life. A better understanding of the persons' experience and significance of DD may be useful for health-care providers when planning and implementing health-care services.

Conclusions

This study can raise the awareness among hand therapists about the diverse experiences of DD and if the hand is experienced as something causing distress or not. These experiences can be understood further by using body-self dialectic and Gadow's states of embodiment and the process of adapting and learning to live with the functional limitations. The consequences of DD was related to physical aspects such as stiffness, pain and limited range of motion, and to the participants' views of their hand function. DD could cause participants to have fear of hurting the hand, and feelings of shame or embarrassment as well as a sense of being old. A clinical implication for hand therapy is to acknowledge patients' individual experiences of limitations in hand function and support self-modifications and development of new skills.

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Figure caption:

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. *Disability and Rehabilitation*. 2002;24(9):482-491. Taylor & Francis Ltd, <http://www.tandfonline.com>. Reprinted by permission of the publisher.

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 Engstrand C, Kvist J & Krevers B. Patients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. 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. Overview of the categories and brief description of their content based on the coded meaning units.

Category	Content	Brief description of the content based on the coded meaning units.
Understanding the condition	Type of disease.	A chronic disease. A disease from the Vikings
	Cause of the disease.	Heredity. Previous injuries. Hard manual work. Diabetes. Aging.
	Disease mechanisms.	Disease related to flexor tendons or other tissue in the palm. Cartilage formations.
	Sources of information.	Information from the internet, friends and relatives.
A changed hand function with stiffness, pain and limited range of motion	Stiffness, pain and limited range of motion.	An uncomfortable condition. Sometimes a painful condition. Feeling a constant stiffness. Inability to open the hand.
	Depending on the severity of DD.	Impact on hand function depends on number of affected fingers, unilateral or bilateral disease, or contractures in the dominant hand.
Difficulties with gripping and fine motor skills	Problems with gripping, holding and carrying objects.	Problems when handling tools, heavy material or climbing ladders. Get caught with the fingers.
	Problems with fine motor skills interfere with leisure activities.	Difficulty when playing instruments, working on a computer or doing things suddenly.
	Problem with self-care or leisure activities demanding a flat hand.	Problems with washing face or body, putting hand in pocket, doing push-ups, or clapping hands.
Thoughts and feelings of the influence of DD	DD described as a minor detail but uncomfortable or as depressing and a handicap.	Diverse experiences. You get used to it. It is not impossible to live with. Feels like having half a body. Something is wrong with the body. A sense of being old and going downhill.

	Concerns about hand appearance.	The hand looks strange. Other people make comments about the hand. Try to hide it.
	Interfere with interaction and relationships.	Problems with shaking hands or intimacy within family.
Strategies for managing difficulties in daily activities	Avoid or refrain from activities.	Stopped playing instruments, fear of dropping and breaking things.
	Perform activities anyway.	Performance is more complicated. Cannot perform so well.
	Adapt performance of activities.	Use the other hand or a different grip. Use the three radial fingers.
The “ideal” hand function	Being able to use the hands practically without effort.	Awareness of the importance of individual fingers or both hands. Having coordination, precision and finger function. Having normal fingers.

DD = Dupuytren’s disease