

# The Impact of Dupuytren Disease on Patient Activity and Quality of Life

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**Purpose** To explore the impact of Dupuytren disease (DD) from the patients' perspective.

**Methods** Audio-recorded interviews were conducted for patients with Dupuytren disease (DD) attending outpatient clinics. The interviews were transcribed and subjected to content analysis. This analysis highlighted key impact areas and common themes in individuals' personal experiences. These were then allocated to categories specified by the World Health Organization International Classification of Functioning, Disability, and Health (impairments and activity limitations) and the needs-based model of quality of life (QoL).

**Results** Qualitative unstructured interviews were conducted with 34 patients (74% men; age, 41–80 y; mean [SD], 64 [13] y). The sample had a wide range of severity and duration of DD (range, 0.5–40; mean [SD], 13 [10] y). Nine hundred fifty-three statements relating to the impact of DD were identified from the interview transcripts. These statements fell into 2 major categories of impact: activity limitations (10 themes including problems with dressing, gripping, and personal care) and QoL (6 need categories: physiological, safety and security, social, affection, esteem, and cognitive needs).

**Conclusions** Findings from the interviews suggest that DD affects both performance of activities and QoL. To determine accurately the effectiveness of DD interventions from the patients' perspective, it is important to determine their impacts on both activity limitations and QoL. We intend to develop valid, reproducible, and responsive DD-specific scales for this purpose.

**Clinical relevance** The study identifies key issues specific to DD that influence patients' functioning and QoL. The information reported will form the basis of DD-specific patient-reported outcomes measures for use in clinical practice and evaluations of interventions. (*J Hand Surg* 2013;38A:1209–1214. Copyright © 2013 by the American Society for Surgery of the Hand. All rights reserved.)

**Key words** Dupuytren, PROM, qualitative, questionnaire, QoL.

**D**UPUYTREN DISEASE (DD) is a condition that can result in reduced function of the digits and may cause decreased functionality of the affected hand. This in turn can affect a patient's quality of life (QoL). A patient-reported outcome measure (PROM) specific to DD would be useful. During the course of

this study, 2 studies came to light reporting new scales for use in DD. Beaudreuil et al<sup>1</sup> reported on the development of the Unité Rhumatologique des Affections de la Main scale, a measure of disability. Whereas the measure appears promising, it requires further testing to establish its dimensionality and construct validity. Furthermore, it does

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not attempt to assess QoL. Trybus et al<sup>2</sup> reported the Dupuytren Disease Scale of Subjective Wellbeing of Patients, a 12-item questionnaire covering 4 subscales. The authors did not report how the scale was constructed or the conceptual model underlying its content. The rather complicated items suggest that they were not derived from patients but cover what the developers considered to be important. No assessment of reproducibility was made, and the evidence of construct validity was poor.

To date, health professionals focus mainly on range of movement in DD. They also employ generic assessment scales such as the Disabilities of Arm, Shoulder and Hand (DASH),<sup>3</sup> the QuickDASH,<sup>4</sup> the Michigan Hand Questionnaire,<sup>5</sup> and the Short-Form 36.<sup>6</sup> These PROMs cover some of the activity limitations associated with DD, but again do not assess QoL. Carefully developed scales specific to DD should cover all important issues and avoid questions of limited relevance to the condition.

The present paper reports findings from qualitative interviews in which patients described the impact of DD on their lives, which is the first stage in the development of a PROM specific to DD.

## MATERIALS AND METHODS

Ethical approval was granted by South Manchester Research Ethics Committee and the University Hospital of South Manchester NHS Foundation Trust, England, UK, and patients gave full informed written and verbal consent.

### Participants

Patients with DD (both before and after surgery) were invited for interview. Subjects were excluded from the study if, in the opinion of the investigator, they had a major comorbidity likely to influence their QoL. Care was taken to ensure that patients with DD ranging in severity from mild to severe were included in the sample.

### Interviews

Each interview was conducted by 1 of 3 experienced qualitative researchers not involved in the patient's treatment in a private room at a clinical center close to where they lived. Interviewees were asked to complete a demographic information sheet before the interview. Participants were assured of the confidentiality of the interviews and understood that they could withdraw from the study at any time.

Qualitative research interviews aim to describe the meanings of key themes that are important to the participant. The interviews took the form of informal, focused conversations. Open questions and a nondirective approach were used to encour-

**TABLE 1. Participant Demographic and Disease Information (n = 34)**

Sex (%)	
Male	25 (74)
Female	9 (27)
Age (y)	
Mean (SD)	64.2 (13)
Range	39.0 (41–80)
Marital status (%)	
Married/living as married	21 (62)
Living alone	6 (18)
Missing	7 (21)
Employment status (%)	
Full time	13 (38)
Part time	5 (15)
Retired	16 (47)
Duration of DD (y)	
Mean (SD)	12.5 (10)
Range	0.5–40.0
Self-reported severity of DD (%)	
Mild	20 (59)
Moderate	5 (15)
Quite severe	4 (12)
Very severe	3 (9)
Missing	2 (6)
Other health problems (%)	
Yes	25 (74)
No	8 (24)
Missing	1 (3)
Area(s) affected (%)	
Hand only	31 (91)
Hand and foot	1 (3)
Hand and penis	2 (6)
Currently receiving treatment (%)	
Yes	9 (27)
No	24 (71)
Missing	1 (3)

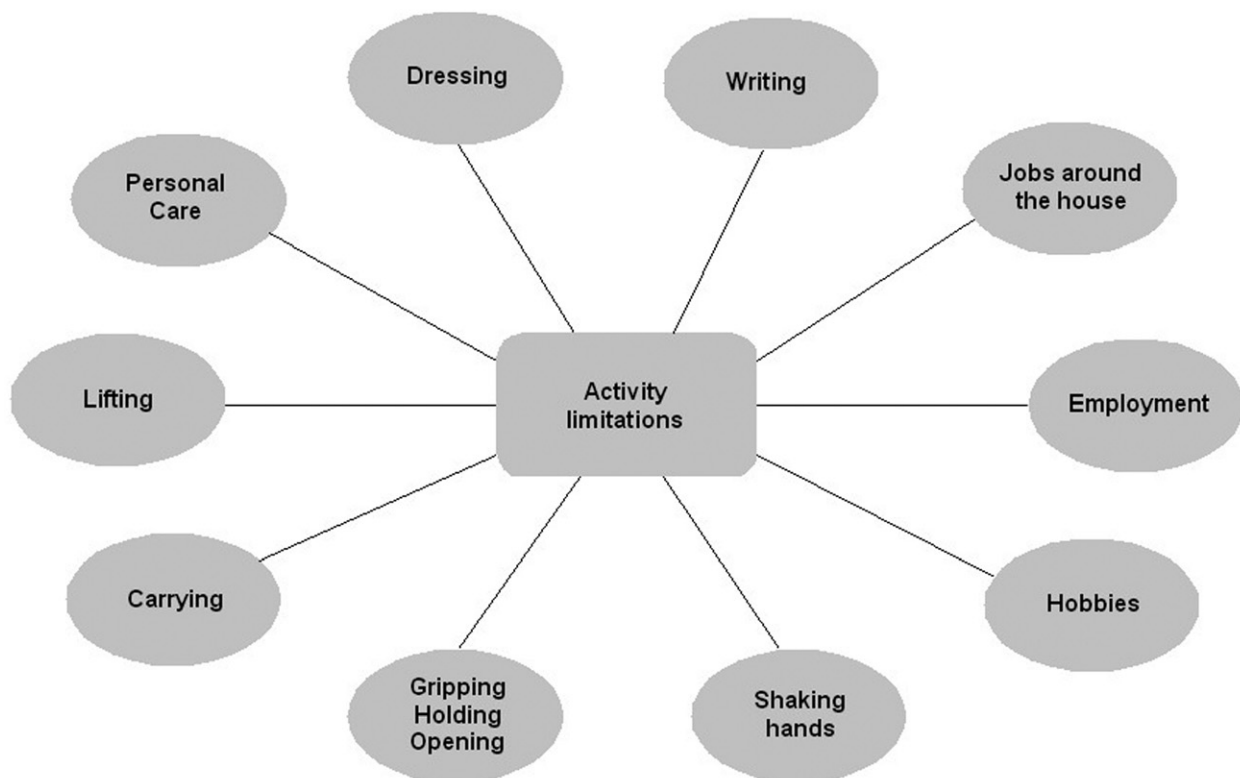
DD, Dupuytren disease.

age participants to talk freely on any aspect of their illness they considered relevant. Thus, the content of the interview was primarily guided by the interviewee. However, the interviewer was able to introduce relevant topics to stimulate further discussion. At the end of the interview, participants were asked to complete the DASH and the General Well-Being Index (GWBI),<sup>7</sup> a generic measure of

**TABLE 2.** Interviewees’ General Well-Being Index and Disabilities of the Arm, Shoulder, and Hand Scores (n = 34)

	Mean (SD)	Median (IQR)	Range	% Scoring Minimum	% Scoring Maximum	% (n) Not Applicable	% (n) Missing
GWBI	42.5 (14.8)	38.0 (33.0–47.5)	65 (25–90)	0.0	0.0	—	2.9 (1)
DASH							
DASH 1–30	13.7 (17.2)	7 (2–21)	77 (0–77)	8.8	0.0	—	8.8 (3)
DASH 31—Work Module	8.4 (13.4)	0 (0–13)	44 (0–44)	26.5	0.0	32.4 (11)	23.5 (8)
DASH 32—Sport/Musical Module	17.4 (17.4)	13 (0–34.5)	44 (0–44)	8.8	0.0	41.2 (14)	29.4 (10)

DASH, Disabilities of the Arm, Shoulder, and Hand; GWBI, General Well-Being Index; IQR, interquartile range.



**FIGURE 1:** Activity limitation impact themes.

well-being. All interviews were audiorecorded with the permission of the interviewee and transcribed verbatim. Any traces of the interviewee’s identity were omitted from the transcripts to maintain confidentiality.

**Analysis**

Content analysis was conducted on the interview transcripts to identify the key areas of the impact of DD on interviewees. This analysis was guided by the World

Health Organization’s International Classification of Impairments, Disability and Handicap<sup>8</sup> and Classification of Functioning, Disability and Health<sup>9</sup> for activity limitations. The classification does not cover QoL, which includes the patient’s response to the impairments and activity limitations they experience. QoL was defined by the needs-based model<sup>10</sup>—the one most widely operationalized in health research.<sup>11–14</sup> This model concerns the extent to which a disease and its treatment prevent fulfillment of needs.

Physiological needs	Safety/security needs	Social needs	Affection needs	Esteem needs	Cognitive needs
Rest	Physical strength	Greeting (shaking hands)	Intimacy	Self-confidence	Concentration
	Hygiene	Participation with family / friends	Relationships	Emotional stability	Interests / hobbies
	Physical confidence (lifting)	Social interaction		Appearance	Reading
	Dexterity	Communication		Independence	
	Limited/slow activities	Planning			
		Handling money			

**FIGURE 2:** Impact of Dupuytren disease on quality of life.

Two researchers conducted analysis on each transcript independently in order not to miss any relevant themes. They focused on indications of activity limitations resulting from DD and evidence of the disease preventing need fulfillment. The results of the analyses were then combined and the research team created a list of themes identified relating to both activity limitations and QoL. These sets of themes covered the impact of DD from the patient's perspective.

## RESULTS

Thirty-four patients were interviewed, and their demographic and disease information are shown in Table 1. Interviews lasted between 30 and 45 minutes. Table 2 records the patients' DASH and GWBI scores.

Nine hundred fifty-three statements relating to the impact of DD were identified from the interview transcripts. The content analyses identified 10 major themes related to activity limitations and 21 linked to QoL. The relative importance of these themes will be determined during later stages of instrument development.

The activity limitation themes identified from the interviews are shown in Figure 1. Commonly expressed prob-

lems included **gripping**, "... getting hold of a jar and getting the cap off, it does create a problem that . . ." (male, age 76); **shaking hands**, "I had to be careful of handshaking. . . . I just tend to shake the tips of people's hands . . ." (male, age 71); and **personal care**, "I poke myself in the eye occasionally, I mean, you've got this finger that either goes up your nose or in your eye and it's just in the wrong place, it's just inconvenient" (male, age 56).

### Quality of life

The QoL themes that emerged from the qualitative interviews are shown in Figure 2. These fell into the following major needs categories: physiological, safety and security, social, affection, esteem, and cognitive needs.

Some examples of the statements made by interviewees follow:

"It was just there all the time, you're always conscious of it" (male, age 70).

"It knocked my confidence . . ." (male, age 42).

"... it makes my hands feel dirty" (female, age 52).

“It’s mainly the grip you know and fear of dropping things . . .” (male, age 59).

All the QoL themes identified could be related back to the needs-based model of QoL. A coherent model of the QoL impact of DD emerged from the interviews.

## DISCUSSION

The aim of this study was to conduct qualitative interviews with DD patients regarding the impact of the condition on their lives either before or after surgery. The interviews were aimed at identifying issues considered important to the lives of patients by the patients themselves. Outcome measures are often derived from what clinicians, rather than patients, deem to be important. Clinicians are more likely to be concerned with disability<sup>15</sup> and appear not to be clear about what patients themselves feel is important.<sup>16</sup>

Qualitative studies provide rich and scientifically rigorous research findings.<sup>17</sup> Most of the questions are formulated during the interviews, making the experience less intrusive and allowing the interviewer to be more flexible. Qualitative research has been used widely to investigate the impact of chronic illness from the patient’s perspective.<sup>18–20</sup>

Findings from the interviews suggest that DD affects both performance of activities and QoL. Figure 1 shows that a wide range of activities were limited by DD, many of which are essential to daily life. This reflects the importance of healthy hands for everyday life. The needs-based model argues that QoL is high when most needs are fulfilled and poor when few needs are satisfied. Conceptualizing QoL in this way clearly sets the construct apart from that of activity limitations. The latter influence QoL but only insofar as they prevent need fulfillment.

The outcome measures most commonly used with DD patients do not measure QoL but, rather, movement and functioning. The most commonly used PROM with DD patients is the DASH. A review of the DASH argued that its validation studies were inadequate owing to poor study design, limited sample sizes, and the absence of evidence of its dimensionality.<sup>21</sup> Content for the measure was selected from existing questionnaires by clinical experts, which indicates that it was not patient-based.

We intend to use the findings from this study to generate items for inclusion in DD-specific PROMs suitable for use in clinical practice and studies. Clinicians and policy makers are becoming more aware of the importance of health users’ concerns and the impact of interventions on QoL. PROMs are now widely used, especially in clinical trials. In addition to establishing

the safety and efficacy of interventions, payers (responsible for either making decisions or influencing the decisions of their organization or country to reimburse and pay for tests and treatment) both in the United States and Europe require evidence of patient-perceived benefit mainly through the use of questionnaires.<sup>22</sup> Any study designed to determine the benefits of new interventions for DD should ensure that the activity limitations and QoL themes identified previously are assessed. In order to do this in an efficient manner, it is necessary for high-quality PROMs to be developed. Such measures should be based on coherent models of outcome and have high psychometric properties including reproducibility, construct validity, and responsiveness to changes in health status.<sup>21</sup>

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