

Determining the true impact of Dupuytren's Disease: A qualitative study

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Objective

Dupuytren's Disease (DD) is a connective tissue disorder mainly affecting the hands and fingers. It is characterised by the formation of a simple thin scar-like nodule in the palm of the hand. The first written description in 1614 describes the tendons contracting "and in doing so were loosed from the bonds by which they are held and became raised up, as two cords forming a ridge under the skin" [1]. This soft tissue restriction can lead to a progressive flexion contracture of the affected fingers [2].

Although there is no cure, DD can be improved significantly with corrective hand surgery [3,4]. However, there is a subsequent high rate of recurrence [5].

DD is a debilitating condition that can result in loss of function of the fingers leading to significant impact on quality of life (QoL). A literature search failed to identify a PRO measure specific to DD. In clinical practice health professionals focus mainly on range of hand movement. Scales such as the Disabilities of Arm, Shoulder and Hand [6], the QuickDASH [7], the Michigan Hand Questionnaire [8] and the Short-Form 36 [9] have been used.

These outcome measures cover some of the activity limitations associated with DD but fail to assess QoL. A carefully developed disease-specific PRO measure should cover all important issues in DD and avoid questions of limited relevance to the condition. As a consequence they are more likely to detect benefits associated with effective treatment.

This poster reports findings from qualitative interviews in which patients describe the impact of DD on their lives.

Aim

To explore the impact of Dupuytren's disease (DD) from the patients' perspective. The study was designed to be the first stage in the development of DD-specific QoL measure.

Figure 1: Stages of Dupuytren's disease



Methods

Participants

Patients attending an out-patients clinic were invited by their clinician to be interviewed by a trained and experienced interviewer.

Interviews

The interviews were conducted by experienced qualitative researchers in a private room at the clinical centre. Open questions and a non-directive approach were used to encourage participants to talk openly on any aspect of their illness they considered relevant. Thus the content of the interview was primarily guided by the interviewee.

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Interview quotations

"I had to start getting changed before everybody else just to get everything on"

"I was aware of my hand all of the time, you had to really think about what you were doing you know"

"You'd change the conversation away from the subject of introduction, as a way of avoidance because I was embarrassed about shaking hands with people"

QoL was defined according to the widely applied needs-based model [10]. This concerns the extent to which the disease prevents fulfilment of needs considered important by the interviewees. QoL is high when these needs are fulfilled and low when few needs are satisfied.

Analysis

All interviews were audio-recorded with the permission of the interviewee and transcribed verbatim.

Thematic analysis was conducted on the interview transcripts to identify key areas of impact. Thematic analysis was guided by the WHO definitions of symptoms (impairments) and activity limitations (disability) and the needs-based QoL model. Lists of themes covering the three different areas of impact were prepared.

The transcripts were then re-analysed to identify potential items for inclusion in a PRO measure.

Results

Thirty four patients were interviewed. Interviews lasted up to 45 minutes and all participants gave consent for their interview to be audio-recorded. Demographic information for the sample is shown in Table 1.

Table 1: Demographic Information

Age (years)	Mean (SD)	64.2 (12.5)
	Range	41 – 80
Gender	Male	25 (73.5%)
	Female	9 (26.5%)
Marital Status	Married/Living as married	21 (77.8%)
	Living alone	6 (22.2%)
Employment Status	Full-time	13 (38.2%)
	Part-time	5 (14.7%)
	Retired	16 (47.1%)

There was a wide range of disease duration that was related to the age. Most participants reported their DD to be mild.

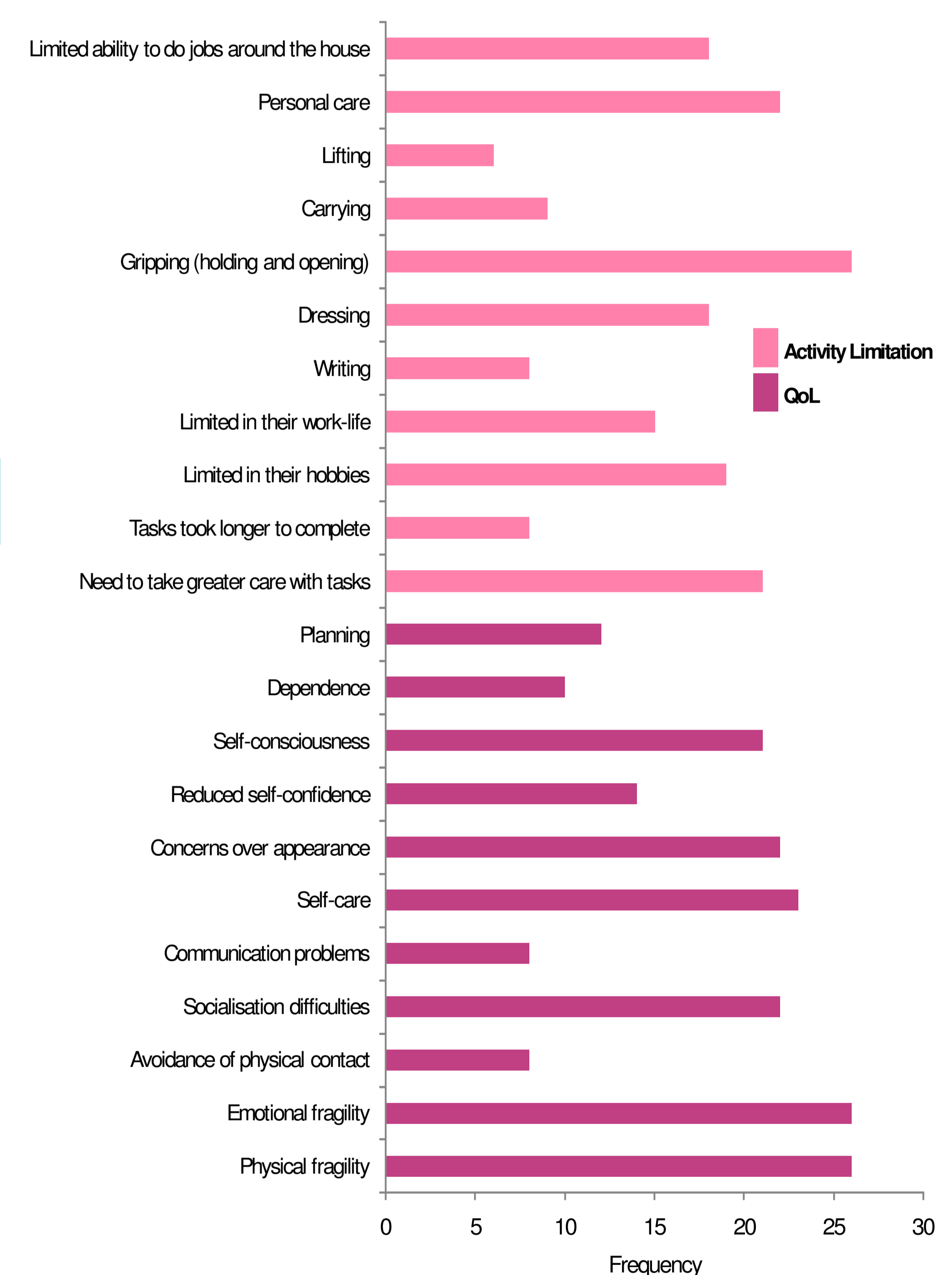
953 statements relating to the impact of DD were identified from the transcripts. These statements fell into two major categories of impact; Activity limitation (11 themes) and QoL (11 themes).

Figure 2 shows the frequency with which each of the themes was raised by interviewees.

Table 2: Disease Information

Self-reported severity of DD	Mild	20 (62.5%)
	Moderate	5 (15.6%)
	Quite severe	4 (12.5%)
	Very severe	3 (9.4%)
Areas affected	Hand	31 (91.2%)
	Hand & foot	1 (2.9%)
	Hand & penis	2 (5.9%)
Currently receiving treatment	Yes	9 (27.3%)
	No	24 (72.7%)

Figure 2: Frequency of themes



Conclusions

The interviews indicated that DD has a profound effect on two major aspects of patients' lives; activity limitations and QoL.

Any study designed to determine the benefits of new interventions for DD should ensure that the themes identified are adequately assessed.

Based on these findings the authors are developing DD-specific scales of activity limitation and QoL suitable for use in clinical practice and studies.

References

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