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## PSYCHOLOGIC ASPECTS OF DUPUYTREN'S DISEASE: A NEW SCALE OF SUBJECTIVE WELL-BEING OF PATIENTS

## PSYCHOLOGICZNE ASPEKTY CHOROBY DUPUYTRENA: NOWA SKALA OCENY SUBIEKTYWNEGO SAMOPOCZUCIA PACJENTÓW

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### Streszczenie

*Wstęp:* Choroba Dupuytrena to schorzenie, które pojawia się zwykle w średnim wieku, występuje 2–10-krotnie rzadziej u kobiet niż u mężczyzn. Choroba może być związana z cukrzycą, paleniem, alkoholizmem, HIV, a także występować u osób z padaczką. Nie ma lekarstwa na tę chorobę. Powoduje ona nadzwyczajne pogarszanie się jakości życia, głównie w dwóch aspektach: niższej wydajności i niesprawności fizycznej oraz oszpecaenia fizycznego.

*Material i metody:* Zbadano 38 pacjentów cierpiących na chorobę Dupuytrena w latach 2007–2008, na 2. Oddziale Chirurgii Uniwersytetu Jagiellońskiego. Użyto kwestionariusza skali oceny subiektywnego samopoczucia pacjentów z chorobą Dupuytrena (DDSP), który zawierał pytania oceniające 4 obszary jakości życia pacjentów.

*Wyniki:* Z przeprowadzonych badań wynika, że pracownicy fizyczni doświadczyli więcej problemów w ich zawodowym życiu niż pracownicy umysłowi.

*Wniosek:* Nie stwierdzono różnic pomiędzy prawo- i leworęcznym rozmieszczeniem choroby.

**H a s ł a:** choroba Dupuytrena – ręka – DDSP.

### Summary

*Introduction:* Dupuytren's disease usually appears in middle-age patients and is more prevalent in men than

women (2–10 times less often than in men). Dupuytren's disease may accompany diabetes, smoking, alcoholism, HIV, and epilepsy. There is no cure for this disease. The disease causes a remarkable worsening of the quality of life resulting mainly from two factors: reduced physical performance or disability, and disfigurement.

*Material and methods:* We studied 38 patients suffering from Dupuytren's disease. The study was done in 2007–2008 at the Second Department of Surgery of the Jagiellonian University. We used the Dupuytren's disease scale of subjective well being of patients (DDSP) questionnaire covering four areas of the quality of life.

*Results:* Blue-collar workers experienced more severe problems at work than white-collar workers.

*Conclusion:* There were no differences between location of the disease in left- and right-handed patients.

**K e y w o r d s:** Dupuytren's disease – hand – DDSP.

### Introduction

Dupuytren's disease is a condition in which excessive growth of fibres of the palmar fascia followed by their contraction causes progressive palmar contracture of the fingers in the metacarpophalangeal and interphalangeal joints of one or both hands [1, 2, 3]. The disease belongs to the fibromatosis group [1, 2]. Pathologic changes mostly affect the ulnar surface of the palm, i.e. fingers IV and V;

finger III is rarely involved and the thumb and index are nearly always spared [2, 3, 4, 5]. Usually, the disease develops over years and when untreated can lead to significant contracture of the finger/fingers limiting the function of the hand [2, 3, 5, 6].

The first records of finger contracture probably caused by excessive growth and contraction of fibres of the palmar fascia come from the 12<sup>th</sup> and 13<sup>th</sup> century from Iceland and the Orkney Islands and were passed down from generation to generation in old Scandinavian sagas [7]. In Scotland during the 16<sup>th</sup> century this disease was called "The Curse of the MacCrimmons". MacCrimmons were pipers who played for amusement of the chieftains of Clan MacLeod of Skye. Because of this contracture, it became impossible for them to play the bagpipes and this affected their position due to the fact that in those times musicians were ranked high in the social hierarchy, practically after the local chieftain [3, 7, 8].

The first written description of the disease comes from Felix Platter of Basel in the year 1614. However, he thought that the cause of the disease was a contracture of the flexor muscles of the fingers of unknown origin [7] and this error is still perpetuated in surgical referrals from general practitioners. Although this condition was later described by English surgeons (Henry Cline in 1777 and Astley Cooper in 1822), it was not until 1831 that a detailed description and suggestions for treatment were presented by baron Guillaume Dupuytren, personal surgeon of the French King Louis XVIII. Hence, the disease was named after the baron and this name is still in use today [3, 7, 8].

The aetiology of Dupuytren's disease is still unknown. The disease is most common in Scandinavia and in the north-eastern parts of Europe [2, 3, 7, 9], afflicting up to 5% of the population [7, 8]. Dupuytren's disease often has a strong hereditary association [3, 5, 7, 8, 9, 10]. Women develop Dupuytren's disease 2–10 times less often [7, 9] than men and it is considered that an autosomal dominant gene of various penetration plays a role in the aetiology [1, 3, 5, 7, 9]. Symptoms of the disease usually appear in the 5<sup>th</sup> or 6<sup>th</sup> decade of life [3, 5]. The relationship between Dupuytren's disease and diabetes [5, 7, 8], chronic alcoholism [1, 3, 5, 8, 10], and tobacco smoking [1, 3, 6, 7, 9, 10] has also been proven.

The radial part of the hand (fingers I, II, and III) is generally used for precise, manipulative functions, and the ulnar part (fingers IV and V) serves for a strong grip [11]. In Dupuytren's disease, contracture usually affects the fingers of the ulnar part of the hand (fingers IV and V). Manual workers, using their hands in a forcible way, are more likely to suffer from disability resulting from contracture and function limitation than office workers who use the fingers of the radius part of the hand (I–III) considerably more often than other fingers so contracture of fingers IV and V does not affect them that much. There are also surgeons suffering from Dupuytren's disease whose performance is not affected because of the fact that in most cases their

fingers I, II, and III are fully efficient. This particular issue looks totally different in the case of musicians because all their fingers must be fully functional. Because of the long course of the disease, patients usually adapt themselves to the gradually decreasing efficiency of their hands. However, growing contracture of the fingers may cause functional and aesthetic problems [3]. Except for difficulties in some types of work or simple everyday activities such as washing, patients usually complain that they are unable to straighten their fingers during greetings and hand shaking and experience difficulties when placing their hands in pockets or putting on gloves.

The one and only effective method of treatment of Dupuytren's contracture is surgical intervention in which the thickened fibres of palmar fascia are excised allowing the fingers to straighten [3, 5, 6]. Surgery is recommended if the contracture appears in metacarpophalangeal joint or joints making it impossible to place the hand on the table in a flat position (the so-called tabletop test). This relates particularly to the dominant hand (usually the right one) [12].

The literature concerning medical and pathophysiologic aspects of Dupuytren's disease is relatively large, but there is no research on the psychologic and social functioning of the patients. However, it is obvious that this disease produces a strong psychic stress and impairs normal everyday functioning. Dupuytren's disease causes a remarkable worsening of the quality of life resulting mainly from two factors: lower physical efficiency and the inability to hide the unpleasant view of the hand. Therefore, research into the psychologic and social aspects of Dupuytren's disease would seem to be necessary but until now such research is lacking. One reason for this situation may be the absence of appropriate tools addressing the psychologic and social areas of life of the patients. There are quite a lot of general questionnaires measuring the subjective quality of life, for example the 'Nottingham Health Profile' (NHP) [13] which is widely used in research on the quality of life and has demonstrated satisfactory internal reliability. However, it is a general purpose tool and is not designed for any specific kind of disease. What is lacking is a tool tailored specifically to Dupuytren's disease. From the clinical point of view, NHP has one important problem: it is quite extensive and consists of 38 items. This makes it difficult to apply NHP in a clinical context as it takes too much time for patients to answer all the questions. What is needed is a relevant, convenient, short tool.

Taking all this into account, we decided to design a new tool which we called the Dupuytren's disease scale of subjective well being of patients (DDSP), addressed specifically to patients with Dupuytren's disease. It should allow for both scientific research and practical applications such as quick assessment of the psycho-social functioning of the patient to determine, for example, whether psychologic support is needed. Considering the second area, we decided that the new tool has to be concise. Obviously, the shorter the scale, the lower the reliability and accuracy of measurements.

On the other hand, a concise tool can be widely used. The final version of DDSP includes 12 items.

### Aim of the research

We decided to verify the psychometric properties of the questionnaire and to look at the relationship between the severity of the disease and age of respondents. In addition, we wanted to verify several hypotheses concerning possible correlations among the results of DDSP. First, we hypothesised about a negative correlation between the severity of the disease and psycho-social functioning measured by DDSP. Second, we compared the results of DDSP for blue- and white-collar workers. This seemed important since Dupuytren's disease which mainly affects physical labourers. Our last hypothesis was that psycho-social functioning would be different in the case of right- or left-handedness as the right hand, because of its dominance, is usually more important in everyday life than the left one. For exploratory reasons we also checked the correlation between DDSP and age.

### Method

#### Participants and procedure

DDSP was administered to thirty-eight patients suffering from Dupuytren's disease. They were surgically treated in 2007 and 2008 at the 2<sup>nd</sup> Department of Surgery of the Jagiellonian University. The study group was not large because Dupuytren's disease is rather rare in the population and it is difficult to form larger groups.

#### Description of DDSP

The final version of the questionnaire included 12 items covering four areas (subscales) of the quality of life: self-esteem, family life, occupational life, and social life. Each subscale comprised three items. A seven-point Likert-like response format from "Definitely not" to "Definitely yes" was used. Therefore, higher scores indicated greater problems. All items are listed in Table 1.

#### Data analysis

For all subscales and for the general score, the following statistics were done:

1. Cronbach's alpha to verify the internal consistency of DDSP;
2. The discriminant power of each item measured as the corrected item-total correlation;
3. Cronbach's alpha for subscales and for the general scale after removal of each item;
4. Mean, standard deviation, minimum, and maximum for all items and scales.

Pearson's  $r$ s were computed to verify the relationships between the results of DDSP and the severity of the disease or age. Differences between white- and blue-collar workers, as well as between right-handed and left-handed persons with the disease located in the right or left hand were compared with Student's  $t$ -test. The level of statistical significance was taken as  $p < 0.05$ .

### Results

#### Reliability of DDSP and descriptive analyses

Table 1 presents the descriptive statistics and the results of reliability analyses for DDSP. The internal consistency of the subscale 'Self-esteem' was very high. All items in this subscale had a good discriminant power reflected by the corrected item-total correlation. None of the items lowered the general Cronbach's alpha.

The reliability of the subscale 'Family life' was rather low but Cronbach's alpha of this magnitude is not surprising for a scale consisting of only three items. The item 'I become irritated at the fact that contracture of the fingers makes some everyday activities difficult', had a poor discriminant power and lowered the general internal consistency of this subscale.

The internal consistency of the subscale 'Occupational life' was very high and all items had a good discriminant power as indicated by the corrected item-total correlation. Finally, the subscale 'Social life' had a satisfactory internal consistency and discriminant power except for the item 'Due to the disability of my hand (hands) I have to restrict or change the way I spend my leisure time' which was not as good as the remaining ones. Given the small number of items in the subscales, their reliability can be considered satisfactory.

Table 2 presents the reliability coefficients for the total score of DDSP. Cronbach's alpha for the total score was 0.90 which obviously indicates very high internal reliability of DDSP, especially when the small number of items is considered. All items had a high discriminant power and none of them lowered the general alpha remarkably. Therefore, the reliability of the total score was very high.

#### Correlations and differences between groups

The next aim of our study was to determine correlations between the scores of DDSP and the severity of the disease and age, as well as differences between blue- and white-collar workers and left- or right-hand location of the disease. Table 3 presents correlations between severity and scores. It can be seen that the severity of the disease correlated positively with the severity of problems relating to self-esteem. Age correlated negatively with the general score and with the 'Social life' subscale (the older the subject, the less problems he/she had, especially as regards social life). The duration of the disease correlated negatively with the total score and the 'Family life' subscale. Given the

Table 1. Reliability statistics, means, and standard deviations for items of DDSP  
 Tabela 1. Statystyka wiarygodności, średnie i odchylenia standardowe dla elementów DDSP

Subscale Podskala	Item Element	Mean Średnia	SD	Corrected item-total correlation Poprawiona korelacja element- suma	Alpha without the item Alfa bez elementu
Self-esteem Samooocena $\alpha = 0.85$	my disease makes me less valuable przez moją chorobę jestem gorszy	3.27	1.61	0.73	0.77
	due to my disease I feel less physically attractive, disfigured / przez moją chorobę czuję się mniej atrakcyjny fizycznie, oszpecony	3.56	1.61	0.76	0.75
	the look of my hand (hands) makes me feel ashamed and I try to hide it (them) from people's sight wygląd mojej (moich) dłoni zawstydzają mnie i usiłuję ją (je) ukryć przed wzrokiem innych	4.00	1.92	0.67	0.84
Family life Życie rodzinne $\alpha = 0.50$	due to my progressive disease, daily contact with family has worsened moje codzienne kontakty z rodziną uległy pogorszeniu z powodu mojej postępującej choroby	2.22	0.96	0.44	0.33
	my disability (deformation of the hand) negatively influences my intimate life moje inwalidztwo (zniekształcenie ręki) ma negatywny wpływ na moje życie intymne	2.61	1.39	0.45	0.18
	I become irritated at the fact that contracture of the fingers makes some everyday activities difficult denerwuję się, ponieważ przykurcz palców utrudnia wykonywanie niektórych czynności codziennych	4.61	1.97	0.19	0.76
Occupational life Życie zawodowe $\alpha = 0.85$	my disease makes my occupational performance worse moja choroba pogarsza moją sprawność zawodową	4.97	1.55	0.63	0.88
	due to my disease I am a less valuable worker to my managers / jestem mniej ceniony przez przełożonych z powodu mojej choroby	3.79	1.66	0.79	0.73
	because of my disability I am treated leniently by my colleagues at work and sometimes even helped with more precise operations z powodu mojej choroby moi koledzy w pracy traktują mnie z pobłażaniem i czasami pomagają mi przy bardziej precyzyjnych zadaniach	3.05	1.56	0.76	0.76
Social life Życie społeczne $\alpha = 0.79$	people from my environment react in a negative way when seeing my hand (for example ridicule, distrust, are unwilling to shake hands) osoby z mojego otoczenia reagują negatywnie na widok mojej ręki (na przykład naśmiewają się, wykazują brak zaufania, niechęć do podania ręki)	2.73	1.38	0.78	0.55
	due to the disability (deformation) of my hand (hands) I avoid social occasions and feel worse in the presence of friends and colleagues z powodu niesprawności (zniekształcenia) mojej ręki (rąk) unikam spotkań towarzyskich i czuję się gorzej w obecności przyjaciół i kolegów	2.73	1.45	0.69	0.65
	due to the disability of my hand (hands), I have to restrict or change the way I spend my leisure time z powodu niesprawności (zniekształcenia) mojej ręki (rąk) muszę ograniczyć lub zmienić sposób spędzania wolnego czasu	2.95	1.38	0.45	0.89

Table 2. Reliability statistics for the total score of DDSP  
 Tabela 2. Statystyka wiarygodności dla wyniku ogólnego DDSP

Item Element	Corrected item-total correlation Poprawiona korelacja element-suma	Alpha without the item Alfa bez elementu
My disease makes me less valuable / Przez moją chorobę jestem gorszy	0.79	0.89
Due to my disease I feel less physically attractive, disfigured Przez moją chorobę czuję się mniej atrakcyjny fizycznie, oszpecony	0.71	0.89
The look of my hand (hands) makes me feel ashamed and I try to hide it (them) from people's sight Wygląd mojej (moich) dłoni zawstydza mnie i usiłuję ją (je) ukryć przed wzrokiem innych	0.62	0.90
Due to my progressive disease, daily contact with family has worsened Moje codzienne kontakty z rodziną uległy pogorszeniu z powodu mojej postępującej choroby	0.73	0.89
My disability (deformation of the hand) negatively influences my intimate life Moje inwalidztwo (zniekształcenie ręki) ma negatywny wpływ na moje życie intymne	0.76	0.89
I become irritated at the fact that contracture of the fingers makes some everyday activities difficult Denerwuję się, ponieważ przykurcz palców utrudnia wykonywanie niektórych czynności codziennych	0.37	0.91
My disease makes my occupational performance worse Moja choroba pogarsza moją sprawność zawodową	0.59	0.90
Due to my disease I am a less valuable worker to my managers Jestem mniej ceniony przez przełożonych z powodu mojej choroby	0.66	0.89
Because of my disability I am treated leniently by my colleagues at work and sometimes even helped with more precise operations / Z powodu mojej choroby moi koledzy w pracy traktują mnie z pobłażaniem i czasami pomagają mi przy bardziej precyzyjnych zadaniach	0.61	0.90
People from my environment react in a negative way when seeing my hand (for example ridicule, distrust, are unwilling to shake hands) / Osoby z mojego otoczenia reagują negatywnie na widok mojej ręki (na przykład nasmiewają się, wykazują brak zaufania, niechęć do podania ręki)	0.70	0.89
Due to the disability (deformation) of my hand (hands) I avoid social occasions, and feel worse in the presence of friends and colleagues / Z powodu niesprawności (zniekształcenia) mojej ręki (rąk) unikam spotkań towarzyskich i czuję się gorzej w obecności przyjaciół i kolegów	0.80	0.89
Due to the disability of my hand (hands), I have to restrict or change the way I spend my leisure time / Z powodu niesprawności (zniekształcenia) mojej ręki (rąk) muszę ograniczyć lub zmienić sposób spędzania wolnego czasu	0.40	0.90

Table 3. Pearson's correlations between the severity of the disease and DDSP score  
 Tabela 3. Korelacje Pearsona pomiędzy nasileniem choroby a wynikiem DDSP

Item Element	General score Wynik ogólny	Self-esteem Samooceana	Family life Życie rodzinne	Occupational life Życie zawodowe	Social life Życie społeczne
Severity of disease / Nasilenie choroby	0.18	0.34	0.16	-0.11	0.23
Duration of disease / Czas trwania choroby	-0.32	-0.22	-0.32	-0.27	-0.28
Since when it has been a disturbance Od kiedy choroba stała się odczuwalna	-0.13	-0.04	-0.12	-0.13	-0.14
Age / Wiek	-0.34	-0.26	-0.24	-0.28	-0.35

Table 4. Differences between blue- and white-collar workers (Student's t-test)  
 Tabela 4. Różnice między pracownikami fizycznymi a umysłowymi (test t Studenta)

Dependent variable Zmienna zależna	Mean / Średnia		SD		N		t(38)	p
	blue fiz.	white umysł.	blue fiz.	white umysł.	blue fiz.	white umysł.		
General score / Wynik ogólny	41.76	34.45	12.94	13.43	29	11	1.58	0.123
Degree of psychology / Stopień psychologiczny	2.34	2.27	0.67	0.79	29	11	0.29	0.773
Self-esteem / Samooceana	10.66	10.73	4.29	5.24	29	11	-0.04	0.965
Family life / Życie rodzinne	9.83	8.27	3.32	2.72	29	11	1.38	0.174
Occupational life / Życie zawodowe	12.21	8.45	4.50	4.82	29	11	2.31	0.026
Social life / Życie społeczne	9.07	7.00	3.64	2.76	29	11	1.70	0.097

Table 5. Differences between left- and right-hand location of the disease (Student's t-test)  
Tabela 5. Różnice między prawo- a leworęcznym umiejscowieniem choroby (test t Studenta)

Dependent variable Zmienna zależna	Mean / Średnia		SD		N		t(39)	p
	left lewa	right prawa	left lewa	right prawa	left lewa	right prawa		
general score / Wynik ogólny	40.26	39.33	15.01	10.76	23	18	0.22	0.826
Degree of psychology / Stopień psychologiczny	2.35	2.33	0.78	0.59	23	18	0.07	0.948
Self-esteem / Samoocena	10.70	10.94	4.86	4.18	23	18	-0.17	0.864
Family life / Życie rodzinne	9.65	9.11	3.50	2.76	23	18	0.54	0.594
Occupational life / Życie zawodowe	10.70	11.83	4.79	4.82	23	18	-0.75	0.456
Social life / Życie społeczne	9.22	7.44	4.09	2.28	23	18	1.65	0.108

small number of participants (N = 38), correlations seem interesting. However, for the time being, the hypothesis concerning the relationship between the severity of the disease, its duration, and DDSP score can be considered only partially confirmed.

Differences between groups are presented in Tables 4 and 5. It can be seen in the Tables that only one result was statistically significant: blue-collar workers experienced significantly more severe problems in their occupational life than white-collar workers. This is consistent with the hypothesis that Dupuytren's disease has a greater impact on occupational life of blue-collar labourers.

## Discussion

Our analyses of the internal consistency of DDSP confirmed its good reliability. The lowest Cronbach's alpha was 0.50 for the 'Family life' subscale, which is not satisfactory. The reliability of all remaining subscales exceeded 0.79 and the Cronbach's alpha of the total score was 0.90. This result reflects the very high reliability of DDSP considering the small number of items (twelve). In conclusion, it can be stated that the effort to construct a short, yet reliable, scale concerning the psycho-social functioning of patients suffering from Dupuytren's disease was successful. However, the results for the 'Family life' subscale should be interpreted with caution.

The hypothesis postulating a negative relationship between DDSP score and the severity of the disease was confirmed only for the 'Self-esteem' scale. This may indicate that Dupuytren's disease indeed affects psychologic aspects. Even if the disease does not worsen actual life performance, the patient may still suffer, for example, from lower self-esteem. The difference between blue-collar and white-collar workers was significant only in the case of the 'Occupational life' subscale. This seems logical, as right-handed location of the disease affects mainly physical workers (assuming that all subjects were right-handed). It should be borne in mind that contractures occur mainly in fingers IV and V (eventually, finger III) which are responsible for a forced grip, such as used when holding axes, shovels, etc. Considerably less often and to a lesser degree do contractures

affect the thumb and index which are responsible for precise, manipulative movements.

On the other hand, no differences between left- and right-handed location of the disease were revealed. This may indicate that patients are able to adapt to the disease even if it occurs in their dominant hand.

Somewhat surprisingly, age correlated negatively with the results of DDSP. This means that the older the patient, the less pronounced were his/her psychologic and social problems. To be precise, the correlation was significant in the case of the general score and the 'Social life' subscale. This may indicate that the older the patient, the better he or she is able to adapt to the illness, at least as far as social life is concerned.

In summary, the new tool seems promising as regards its psychometric properties. It also seems promising as regards its usefulness in exploring the psychologic and social areas of Dupuytren's disease. Even with the relatively small number of patients, we found some interesting correlations.

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### Komentarz

Dobrze, w sposób wyczerpujący i ciekawy opisana historia odkrycia i etiologia choroby. Autorzy artykułu opisują badanie jakości życia pacjentów z chorobą Dupuytrena przy użyciu kwestionariusza własnej konstrukcji, który postanowili stworzyć, gdyż nie znaleźli nigdzie w piśmiennictwie narzędzia do badania tego wymiaru życia pacjentów. Kwestionariusz nazwany przez nich DDSP składa się z 12 stwierdzeń odnoszących się kolejno

(po trzy) do różnych obszarów życia pacjentów z chorobą Dupuytrena: samoocena, życie rodzinne, praca, życie społeczne (znajomi).

Na plus należy zapisać również podejmowanie tematyki jakości życia u pacjentów. Ważne, aby dostrzegać, szczególnie jeśli robią to lekarze, że oprócz ciała i dokuczliwych objawów choroby, pacjent posiada inne obszary funkcjonowania, takie jak rodzina, przyjaciele, praca, samoocena.

Zagadnienie jakości życia jest obecnie tematem bardzo popularnym, nie ma jednak jasności co do dokładnej definicji tego zjawiska. W naukach medycznych, które dążą do uproszczenia i usprawnienia diagnostyki, występuje tendencja do tworzenia krótkich, „szybkich” testów, aby prawie natychmiast otrzymać oczekiwany wynik. Jedyny zarzut, jaki można wysunąć pod adresem autorów artykułu, dotyczy właśnie tego. Jest to jednak pytanie szersze i dotyczy w ogóle zasadności badań ilościowych, które usiłują zmierzyć niemierzalne, w tym przypadku jakościowe, subiektywne doświadczenie człowieka.

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