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Major Life Changing Decision Profile (MLCDP): creation of the Polish language version

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Conflict of interest. AYF is joint copyright owner of the MLCDP.

ABSTRACT

Chronic diseases have long-term consequences and can affect individuals' life course. The aim of this study was to create the Polish language version of a questionnaire estimating the impact of the disease on important life decisions-the major life changing decision profile (MLCDP). The translation of the MLCDP followed international guidelines. The created Polish language version of the questionnaire was administered to 32 nephrology and dermatology ward inpatients. To assess its properties, statistical analysis of the results obtained was conducted. The Polish language version of the MLCDP demonstrated very good internal consistency with a Cronbach α coefficient of 0.84. The questionnaire presented excellent test-retest reliability, established with a coefficient ICC of 0.97. The Polish language version of MLCDP has shown high internal consistency and reproducibility, and can be used effectively to assess the cumulative impact of the disease by indicating the number of major life decisions affected by chronic disease.

INTRODUCTION

Research on health-related quality of life (HRQoL) is mostly concentrated on the current impact of chronic disease on patients' physical, mental and social status. Meanwhile, chronic diseases have long-term consequences and, depending on the age of the onset, the nature and severity of symptoms or the treatment methods used, they may influence the patients' life in different ways. (1,2) The psychological burden, serious impairment or disability caused by a chronic disease can induce a profound long-term change in individuals' behavior, perceptions and priorities which may be reflected in their life course. (3) Therefore, the knowledge about patients' goals and ambitions affected by a chronic health condition is relevant in order to better recognize their needs and may facilitate more adequate treatment selection and clinical management. The longitudinal influence of disease is one of the three dimensions of disease burden, along with "Impact now" and "Family impact." (4) Adding a measure of the impact of disease on major life changing decisions therefore provides a more comprehensive understanding of the totality of burden of disease on a patient.

Various instruments have been developed to evaluate HRQoL. However, these are not designed to assess the long-term consequences of the disease. (5) The major life changing decision profile (MLCDP), created by Bhatti et al (6) from Cardiff University, is an exceptional measure, that provides an insight into the impact of the disease on life course of individuals by establishing its influences on important life decisions. The questionnaire contains 32 items, divided into five domains concerning different life aspects: education, job/career, family/relationships, physical and social activities.

Until now, there has been no instrument for estimation of any long-term disease impact on patients' life available in Polish. As the original MLCDP questionnaire was created in English, this study aimed to develop the Polish language version of the tool, possibly contributing to better understanding of the subject in these individuals.

MATERIALS AND METHODS

The process of translation and adaptation of the MLCDP into Polish was conducted in a structured multistage procedure in accordance with international standards. (7) Permission to prepare the Polish language version of the questionnaire was obtained from the copyright holders of the instrument.

Translation and validation process

Initially, the forward translations of the original English version of MLCDP questionnaire into Polish were created by two independent translators. The discrepancies between the resulting versions were analyzed by a third consultant, a bilingual expert in the field, and a consensual Polish version was defined. Afterwards, a back translation from Polish to English was carried out by another independent translator who was blinded for the original version of the MLCDP. To verify the accuracy and semantic equivalence of the back translation it was presented to a member of the team who created the original version. Minor alterations

in conformity with his suggestions were made to elaborate the final Polish version of the MLCDP questionnaire.

In the next stage, cognitive debriefing interviews concerning the ultimate Polish version were conducted with seven patients hospitalized in a tertiary dermatology ward. The participants were two women and five men suffering from psoriasis, aged 23 to 68 years (average age: 44.6 ± 15.9 years). Each respondent was asked to complete the questionnaire and to rate the items of the instrument for comprehensibility and wording. Participants were also encouraged to give suggestions for improvements. Furthermore, the time required to complete the questionnaire was measured. A review of cognitive debriefing results was prepared based on participants' feedback. The report was approved by the authors of the original version of the questionnaire, who expressed their official consent to use the Polish language version of MLCDP.

Subsequently, the Polish language version of the questionnaire was distributed to a group of 32 nephrology and dermatology ward inpatients. The age of the participants ranged from 31 to 72 years (average age: 61 ± 10.1 years). Among them, there were 20 patients with chronic kidney disease undergoing chronic dialysis, nine patients with psoriasis vulgaris, and three patients with atopic dermatitis, vasculitis and dermatomyositis respectively. Every participant was asked to complete the MLCDP for a second time, 5 days following the initial completion, in order to assess the tool's reproducibility. The interval was considered sufficiently long to prevent patients from remembering their previous answers, and to guarantee stability of the disease symptoms and life situation as much as possible.

Statistical analysis

Statistical analysis of the results obtained was carried out to assess the questionnaire reliability. All data analyses were performed using the Statistica 13 (Dell, Inc., Tulsa, USA) software. The level of statistical significance was assumed at $\alpha < 0.05$. The evaluation of the overall internal consistency of the instrument was conducted through Cronbach's alpha, based on the data obtained from the first administration of the questionnaire. Cronbach's alpha values of 0.90 to 1.00, 0.80 to 0.89, 0.70 to 0.79 were considered to indicate excellent, good, and acceptable internal consistency, respectively. (8) The structural validity of the Polish language version of MLCDP was assessed using Spearman's correlation coefficients. The correlations between individual items and total score and between the items within the domain and summary domain score were tested. The intraclass correlation coefficient (ICC), calculated from the parallel scores of two administrations of the questionnaire by the same person was used to estimate the reproducibility of the instrument. ICC values ≥ 0.7 were considered acceptable. (9)

RESULTS

The forward and back translation procedure revealed no major linguistic or stylistic objections. In congenital debriefing, the time measured to complete the questionnaire varied between 3 and 10 minutes (mean 7.0 ± 1.5 minutes). At this phase, none of the respondents

reported any difficulties over understanding the questionnaire items. Furthermore, no suggestions for changing the wording of questions or answers was suggested by the participants. Therefore, the Polish translation was accepted as being semantically equivalent to the English version, accessible and intelligible. The official Polish language version of MLCDP is available from Cardiff University website (<https://www.cardiff.ac.uk/medicine/resources/quality-of-life-questionnaires/major-life-changing-decision-profile>).

The analysis of the data collected during the first administration of the Polish language version of the MLCDP demonstrated very good internal consistency with a Cronbach's α coefficient of 0.84 for the whole instrument (95% confidence interval [95% CI] 0.83-0.86). The effect of exclusion of individual items on overall internal consistency was calculated. The lowest value was generated by question number 19. After its deletion, a minor improvement of Cronbach's α coefficient to 0.86 was seen, indicating that this question had the weakest correlation with the overall questionnaire.

Apart from individual items, significant correlation was found between the results obtained for each item within its respective domain and the complete domain score. The most highly significant results of the Spearman's rank correlation was obtained by the questions in the education section. A moderate to high level of significance of Spearman's rank correlation was obtained for predominant items within the other domains, except for question number 12 belonging to the job/career category and question number 19 belonging to the social category, which did not correlate with the summary domain result. In addition, the particular items within each section had stronger correlation with the summary domain score than with the total score (Table 1).

After the second administration, the reproducibility of the Polish language version of the MLCDP was determined using the ICC, which was 0.97 for the whole questionnaire. All domains demonstrated excellent test-re-test reliability with ICC outcomes of 0.99, 0.94, 0.99, 0.97 and 0.92 for education, job/career, family/relationships, social and physical section, respectively. Moreover, the total scores established after completing the MLCDP twice with an interval of 5 days, did not differ significantly. The comparison of the results of individual questions obtained after the first and second questionnaire application revealed statistically significant differences only for question number 18 (Table 2).

DISCUSSION

Life is about making decisions. Minor everyday decisions are of little importance, but they are required to allow life to run smoothly. Lifechanging decisions are complicated and have long-term consequences, which entail inevitable and irrevocable life alterations. When making life decisions, people are guided by their values, beliefs and experiences. (1,2) Developing a chronic disease is a striking change in circumstances which leads to reevaluation of individuals' priorities and life goals. (3) Unfortunately, it may also cause a significant reduction of possible life choices.

Until recently, the assessment of the longitudinal influence of a chronic disease was based on the comparison of its current impact on a patient's life at certain time intervals. This method did not provide information about patient's experiences throughout the duration of the illness, therefore the long-term impact of chronic disease often remained undetermined and underestimated. (5) Meanwhile, it has been found that the awareness of the implications of the chronic condition over time is one of the factors influencing treatment decisions. (10) The longitudinal influence of disease is one of the three dimensions of disease burden, along with "Now" and "Family impact." (4)

The first attempt to enhance the knowledge about lifelong physical, social and psychological effects of chronic skin disease was made by Kimball et al. (11) They proposed the use of term "Cumulative Life Course Impairment" to describe overall burden of psoriasis interfering with the patient's complete potential development and general wellbeing. Based on the available evidence they established four key components determining the mechanisms of life course impairment in patient's suffering from psoriasis, which were: stigmatization, comorbidities, external factors and coping strategies.

The concept of the assessment of the critical life decisions affected by the disease as the measure of the cumulative impact of the chronic illness was proposed by Bhatti et al. (12) In the research survey conducted in a group of 308 patients suffering from 30 chronic diseases from seven medical specialities they managed to identify crucial disease-related factors influencing critical decisions and specify 41 most frequent major life-changing decisions.

The data collected in their study indicated notable differences between various chronic diseases. The dermatology patients reported the highest number of major life decisions affected, whereas the nephrology patients reported the lowest. Remarkably, important decisions regarding lifestyle were only noted by dermatology patients. (12,13) The most common consequence of cardiovascular disease was early retirement. (14) Among patients suffering from chronic respiratory disease, the most affected decisions involved job and career and having children. (15) The outcomes of this investigation were used for the creation of the MLCDP. (6)

The MLCDP was specifically designed to measure the cumulative life course deterioration by indicating the number of major life decisions affected by chronic disease. The questionnaire can be used across all medical specialities, it is easy to administer, self-explanatory and not time-consuming. In contrast to the majority of available instruments used in health-related quality of life research designed to evaluate present influence of disease, the MLCDP provides information about a patient's experiences over time. Because the MLCDP is designed to be completed by any adult person with any health condition or disease, it potentially enables comparison between the impacts of different medical conditions. Since no equivalent instrument was available in Polish, translation of the MLCDP appeared necessary.

The lack of any critical suggestions from the respondents concerning the content of the questionnaire provides reassurance that the concepts described in the MLCDP have a degree of universality that may transcend cultural differences. In the original qualitative study

from which the MLCDP questions were derived, (12) after the first cohort of subjects provided information about what they considered were major life changing decisions, no additional suggestions were made by subsequent subjects. This “redundancy” provided assurance that all aspects of major life changing decisions had been captured. This point will of course need to be further tested in the future in other cultures.

International guidelines were adopted to achieve a high quality and conceptually equal Polish translation of the original MLCDP. The process followed the same method that our team had previously used in similar projects. (16,17) The statistical analysis of the data collected exhibited very good internal consistency according to the Cronbach’s α coefficient (0.84) and excellent reproducibility according to the ICC (0.97). Due to the unique quality of the MLCDP, no adequate questionnaire was found for use in convergent validity analysis. For the same reason, the authors of the MLCDP did not test its correlation to other instruments during its creation. Based on the results obtained in this study, the Polish language version of MLCDP can be considered as a reliable instrument, useful, alongside available health related quality of life questionnaires, for a more complete evaluation of the burden of chronic disease.

The MLCDP has a potential to be used by healthcare professionals, epidemiologists and members of support services. The information provided by the questionnaire would enable a discerning insight into long-term consequences of chronic conditions. Awareness of the aspects of life most affected by the disease could not only make it easier for physicians to identify and understand their patients' susceptibility to life course impairment, but would also help to determine the best management at an earlier stage of the disease. It would also help to provide prompt psychological support and education on developing coping strategies for patients.

CONCLUSION

The newly created Polish language version of MLCDP has demonstrated very good internal consistency and excellent test-retest reliability. Therefore, it can be used effectively to extend the knowledge about the chronic diseases' implications on the patients' life course in this population. Its widespread utilization may help to better manage the impact of chronic disease by identifying mostly affected aspects of life and providing required support when making important decisions.

REFERENCES:

1. Bhatti ZU, Salek MS, Finlay AY. Chronic diseases influence major life changing decisions: a new domain in quality of life research. *J R Soc Med* 2011; 104:241–250.
2. Heatherton TF, Nichols PA: Personal accounts of successful versus failed attempts at life change. *Pers Soc Psychol Bull* 1994; 20:664–675
3. Ben-Shlomo Y, Kuh D. A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *Int J Epidemiol* 2002; 31:285-293.
4. Finlay AY. The three dimensions of skin disease burden: 'now', 'long-term' and 'family'. *Br J Dermatol* 2013; 169: 963-964.
5. Bhatti ZU, Salek SS, Bolton CE, George L, Halcox JP, Jones SM, Ketchell IR, Moore RH, Sabit R, Piguet V, Finlay AY. The development and validation of the Major Life Changing Decision Profile (MLCDP). *Health Qual Life Outcomes* 2013; 11:78
6. Acquadro C, Conway K, Hareendran A, Aaronson N. Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. *Value Health* 2008; 11: 509–521.
7. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007;60: 34–42
8. Shrout PE, Fleiss JL. Intraclass correlations: uses in assessing rater reliability. *Psychol Bull* 1979; 86: 420–428.
9. Kimball AB, Gieler U, Linder D, Sampogna F, Warren RB, Augustin M. Psoriasis: is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010; 24: 989–1004.
10. Popejoy E, Pollock K, Almack K, Manning JC, Johnston B. Decision-making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child Care Health Dev* 2017;43: 627–644
11. Bhatti ZU, Salek S, Finlay AY. The influence of chronic skin diseases on major life-changing decisions as a parameter for the assessment of long-term impact. *Br J Dermatol* 2010; 163: 39–40.
12. Bhatti ZU, Finlay AY, Bolton CE, George L, Halcox JP, Jones SM, Ketchell RI, Moore RH, Salek MS. Chronic disease influences over 40 major life changing decisions (MLCDs): a qualitative study in dermatology and general medicine. *J Eur Acad Dermatol Venereol* 2014; 28: 1344-1355.
13. Bhatti ZU, Finlay AY, Salek MS, Halcox JJ. The full impact of chronic cardiovascular disease cannot be measured without an assessment of life decisions. *J Heart Dis* 2010;7: 71.
14. Bhatti ZU, Finlay AY, Salek MS, Ketchell IR, Bolton CE. Chronic respiratory diseases strongly influence major life changing decisions. *Thorax* 2009;64: A75–A174.
15. Dimitrov D, Matusiak Ł, Evers A, Jafferany M, Szepietowski J. Arabic language skin-related stigmatization instruments: Translation and validation process. *Adv Clin and Exp Med* 2019; 28: 825–832

16. Marciniak J, Reich A, Szepietowski J. The Family Dermatology Life Quality Index — formulation and validation of the Polish version. *Forum Dermatol* 2016; 2: 24–28 [article in Polish]
17. Wójcik E, Reszke R, Otlewska A, Matusiak Ł, Ali FM, Finlay AY, Szepietowski JC. Family Reported Outcome Measure - 16 (FROM-16): Creation, Reliability and Reproducibility of the Polish Language Version. *Acta Derm Venereol* 2020 Jul 28;100: adv00219

Table 1. Correlation of each item (Q) score with summary domain (A, B, C, D, E) score and total score of MLCDP

Questions	N	R Spearman (Correlation of Q score total score)	R Spearman (Correlation of Q score with total A)	R Spearman (Correlation of Q score with total B)	R Spearman (Correlation of Q score with total C)	R Spearman (Correlation of Q score with total D)	R Spearman (Correlation of Q score with total E)
Q1	32	0.43 **	0.77 †				
Q2	32	0.47 *	0.64 †				
Q3	32	0.42 **	0.80 †				
Q4	32	0.66 †		0.68 †			
Q5	32	0.40 **		0.64 †			
Q6	32	0.14 ***		0.43 **			
Q7	32	0.27 ***		0.51 *			
Q8	32	0.58 †		0.63 †			
Q9	32	0.46 *		0.59 †			
Q10	32	0.11 ***		0.39 **			
Q11	32	0.42 **		0.41 **			
Q12	32	0.45 **		0.30 ***			
Q13	32	0.58 †			0.78 †		
Q14	32	0.40 **			0.66 †		
Q15	32	0.41 **			0.55 *		
Q16	32	0.42 **			0.51 *		
Q17	32	0.40 **			0.45 **		
Q18	32	0.36 **				0.43 **	
Q19	32	-0.04 ***				0.1 ***	
Q20	32	0.74 †				0.87 †	
Q21	32	0.34 ***				0.46 *	
Q22	32	0.32 ***				0.48 †	
Q23	32	0.32 ***				0.58 †	
Q24	32	0.45 †				0.43 **	
Q25	32	0.67 †				0.72 †	
Q26	32	0.70 †				0.76 †	
Q27	32	0.63 †				0.65 †	
Q28	32	0.36 †					0.55 †
Q29	32	0.64 †					0.77 †
Q30	32	0.35 †					0.64 †
Q31	32	0.18 ***					0.55 *
Q32	32	0.45 †					0.44 **

Note: A, education domain; B, job/career domain; C, family/relationships domain; D, social domain; E, physical domain.

P values: † < .0001; ‡ < .001; * < .01; ** < .05; *** > .05.

Table II. Reproducibility of results

Questions	First assessment Mean±SD (median), points	Second assessment Mean±SD (median), points	p-value
Q1	0.47±1.11 (0)	0.41±0.98 (0)	0.18
Q2	0.28±0.92 (0)	0.28±0.92 (0)	1
Q3	0.53±1.22 (0)	0.44±1.05 (0)	0.11
Q4	0.94±1.13 (0)	1.06±1.24 (0.5)	0.14
Q5	0.66±1.15 (0)	0.81±1.40 (0)	0.20
Q6	0.97±1.47 (0)	0.81±1.31 (0)	0.24
Q7	0.88±1.39 (0)	0.91±1.25 (0)	0.75
Q8	0.97±1.18 (0.5)	1.06±1.19 (1)	0.22
Q9	0.75±1.39 (0)	0.69±1.33 (0)	0.18
Q10	0.31±0.65 (0)	0.28±0.63 (0)	0.75
Q11	0.16±0.72 (0)	0.16±0.72 (0)	1
Q12	0.44±1.22 (0)	0.38±1.04 (0)	0.42
Q13	0.81±1.38 (0)	0.78±1.31 (0)	1
Q14	0.50±1.22 (0)	0.50±1.22 (0)	1
Q15	0.63±1.10 (0)	0.72±1.25 (0)	0.72
Q16	0.41±1.19 (0)	0.34±1.04 (0)	1
Q17	0.44±1.13 (0)	0.34±1.00 (0)	0.65
Q18	2.13±1.21 (2)	2.69±1.26 (3)	<0.01
Q19	1.31±1.47 (1)	1.41±1.46 (1)	0.4
Q20	1.69±1.38 (1.5)	1.69±1.36 (2)	1
Q21	0.47±1.11 (0)	0.38±0.94 (0)	0.65
Q22	0.66±1.26 (0)	0.63±1.21 (0)	0.59
Q23	0.84±1.51 (0)	0.66±1.29 (0)	0.11
Q24	1.34±1.58 (1)	1.19±1.42 (1)	0.25
Q25	1.44±1.41 (1)	1.50±1.34 (1)	0.66
Q26	1.59±1.48 (1.5)	1.53±1.44 (1)	0.62
Q27	0.63±0.98 (0)	0.66±1.07 (0)	0.59
Q28	1.97±1.69 (2)	1.94±1.44 (2)	1
Q29	1.75±1.50 (1)	1.66±1.36 (1.5)	0.31
Q30	1.19±1.38 (1)	1.03±1.26 (1)	0.29
Q31	1.06±1.32 (1)	0.84±1.05 (0.5)	0.11
Q32	0.84±1.32 (0)	0.88±1.21 (0)	0.94
TOTAL	29.03±16.88 (26.5)	28.63±15.29 (25.2)	0.93

SD: standard deviation