

Short Communication

Happiness: A Novel Outcome in Parkinson Studies?

Caro I. Cools^a, Nienke M. de Vries^b and Bastiaan R. Bloem^{b,*}

^a*Faculty of Psychology and Neuroscience, Maastricht University, Maastricht, The Netherlands*

^b*Donders Institute for Brain, Cognition and Behaviour and Department of Neurology, Centre of Expertise for Parkinson and Movement Disorders, Radboud University Medical Centre, Nijmegen, Netherlands*

Accepted 18 May 2020

Abstract. In this viewpoint, we draw attention to using happiness in clinical studies as an interesting outcome that is highly relevant to patients with Parkinson's disease. Quality of life (QoL) is thus far commonly used as main outcome in clinical trials. Happiness is a part of QoL, but also represents a construct on its own. While QoL mainly consists of quality perceptions of different extrinsic aspects of life, such as the environment or performance, happiness entails the intrinsic quality of the subjective enjoyment of life. Around 70% of people rate happiness as the most important thing in life. Happiness can be a difficult construct to measure, but we argue that self-compassion and well-being could serve as reliable indicators for happiness. We expect that happiness as outcome could probe the true value of an intervention for a patient, well beyond what is captured by more traditional outcomes such as motor scores or the general concept of QoL, which better reflect external factors. Because of the apparent importance of happiness to many people, we recommend that this concept is used more widely as outcome measure in future clinical trials.

Keywords: Parkinson's disease, happiness, Quality of Life, complementary therapies

Quality of Life (QoL) is a commonly used outcome in clinical trials in various fields, including Parkinson's disease (PD) [1]. According to the World Health Organization (WHO), QoL is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" [2]. The term QoL refers to both the positive and negative state of a persons' life [3] and is often equated with happiness or well-being. While QoL metrics are mainly based on motor skills and driven by extrinsic resources, such as income

or employment, happiness is primarily a subjective experience that is pursued intrinsically and that comprises views of persons on their life [4]. Happiness is a part of QoL but does represent a separate construct on its own [5]. QoL entails quality in extrinsic aspects of life, such as environment or performance, whereas happiness is about the intrinsic quality of subjective enjoyment of life [5]. When measuring QoL, the extrinsic factors make it unclear whether intrinsic factors really cause feelings of happiness. Happiness is therefore a valuable concept, above and beyond conventional indicators predicting QoL. And as such, happiness could potentially be considered separately and independently of QoL as a measure of a patient's status, for example, as measured before and after an intervention [6].

Happiness is often measured by the concepts of well-being and self-compassion [7, 8]. Well-being

*Correspondence to: Prof. Bastiaan R. Bloem, MD, PhD, FRCPE, Donders Institute for Brain, Cognition and Behaviour and Department of Neurology, Centre of Expertise for Parkinson and Movement Disorders, Radboud University Medical Centre, PO Box 9101 (947) 6500 HB Nijmegen, Netherlands. Tel.: +31 0243615202; E-mail: Bas.Bloem@radboudumc.nl.

refers to the sense of wellness of an individual [9], while self-compassion is defined as being kind toward oneself in times of failure and challenge [8]. One study suggested that 69% of people rate happiness as the most important thing in life [10]. Happiness was even rated as close to “extraordinarily important and valuable” in 41 countries in a study about subjective well-being and personal perceptions of health [11]. Moreover, the benefits of self-compassion, as an indicator of happiness, are universal despite cultural differences. Levels of self-compassion and its association with well-being were, for example, measured in Taiwan, the United States and Thailand. In all three cultures, greater self-compassion predicted significantly less depression and higher life satisfaction [12].

Because of this apparent importance of happiness to many people, it is remarkable that this concept is not being included as an outcome measure in clinical trials, for example in the field of PD. Currently, the success of clinical trials mostly depends on improvements in motor scores, such as the motor sub-score of the Unified Parkinson Disease Rating Scale. But the value of an intervention cannot always be translated directly into motor improvements, despite obvious personal benefits. Happiness provides a more reliable overview of the patient’s general status, above routinely used parameters. With the complexity that inevitably accompanies a subjective measurement such as happiness, several factors impact its experience and should therefore be considered as well. For example, premorbid personality style and social interactions need to be accommodated when measuring happiness. Also, alongside these influencing factors, we need to realise that happiness is transient and therefore variable in nature [13]. This subjectivity and the many factors influencing happiness make it more difficult to quantify happiness. Qualitative assessments of happiness are therefore valuable in providing specific contextual information, such as the individual nature of positive feelings, as well as the complex interrelationship with factors such as social interaction, creative energy and greater self-worth. As such, qualitative assessments provide valuable complementary information to the quantitative outcome measurements, which can be used to compare effect sizes across interventions in terms of their influence on patients.

For example, a patient who used to love knitting might score high on a QoL scale, despite being unhappy because of the fact that she cannot handle knitting needles anymore. Most questionnaires

or scales do not assess such specific motor impairments. Since this patient could still walk (which the questionnaire did ask for), an acceptable score was obtained on a QoL scale, while this patient nevertheless felt miserable for not being able to knit anymore. This example illustrates that patients may score high on a QoL scale but still have a specific and individually debilitating problem that markedly lowers their actual QoL. Alternative approaches are therefore needed that focus more on the subjective feelings of well-being instead of objective parameters (e.g., walking) that are used as an indicator for well-being.

The capability approach may be a useful alternative, where capability refers to a person’s ability to do specific things. This approach emphasizes the importance of taking someone’s capability to function as a starting point, instead of only looking at scores [14]. Measuring happiness fits well with the capability approach and potentially gives information about otherwise hidden benefits of interventions, which are hard to capture with commonly used questionnaires. Unfortunately, in research, happiness has only scarcely been used as an outcome in clinical trials, even though the subjectively experienced benefits can be very informative and, importantly, can be measured reliably. Specifically, the subjective experience of happiness can be measured precisely and objectively with well-being or self-compassion scales. Examples of measurement scales for subjective well-being are the Satisfaction With Life Scale (SWLS) [15], Positive and Negative Affect Schedule (PANAS) [16], and Scale of Positive and Negative Experience (SPANE) [17]. A measurement scale for happiness with self-compassion is the Self-compassion Scale (SCS) [18–20]. The reliability and validity of these scales have been shown in multiple studies [15–17, 19], although the scales have not yet been validated specifically for PD.

In addition, self-compassion can not only be measured reliably, but it is also a trainable skill that can significantly increase life satisfaction while decreasing depression, anxiety, stress, and emotional avoidance [21]. New non-pharmacological therapies that may potentially have a positive effect on happiness, such as mindfulness [22], dance therapy [23, 24], or music therapy [25], are currently being developed and put to the test in clinical studies. Having reliable scales in these studies that can measure the full impact of such new interventions, well beyond motor scores, may be valuable for patients and timely.

A PubMed search for clinical trials that measured happiness, well-being, or self-compassion in persons

Table 1
Clinical Trials using happiness, self-compassion or well-being

	Study	Total N	Design	Outcome	Results related to happiness and well-being
Happiness	Pacchetti et al., 2000 [26]	32	12 Weeks: Music and physiotherapy group vs. control group Assessment: 0 and 12 weeks	Unified Parkinson Disease Rating Scale (UPDRS), happiness measure (HM), Parkinson's Disease Quality of Life questionnaire (PDQL)	Changes on the Happiness Measure confirmed a beneficial effect of MT on emotional functions
Well-being	Gauthier et al., 1987 [27]	16	5 Weeks: Experimental vs. control group Assessment: 0 and 5 weeks, 6 months and 1 year follow-up	Well-being (via Index of Psychological Well-Being) and motor symptom scales	Subjects of the treated experimental group maintained their functional status after 1 year, demonstrated a significant improvement in their psychological well-being
Well-being	Lindskov et al., 2007 [28]	96	6 Weeks: Intervention (educational program) vs. control group Assessment: 0, 6, and 1 month follow-up	Well-being measured via short-form health survey (SF-12)	Changes in well-being scores at follow-up did not differ between the groups
Well-being	Benninger et al., 2010 [29]	25	2.5 Weeks: tDCS vs. sham stimulation Assessment: 0 and 2.5 weeks, 1 and 3 months follow-up	Change in gait in on and off state, falling, bradykinesia, UPDRS, Beck Depression Inventory (BDI), Well-being measured via Health Survey (SF-12v2)	Changes in well-being did not differ between groups
Well-being	Schröder et al., 2012 [30]	235	8 Months: Pharmacy vs. comparison group Assessment: 0 weeks and 8 months	Well-being via Parkinson's Scale Total Score (PS-23 TS), PDQ-8 Summary Index (SI), EQ-5D Index Score (IS) [23], EQ-5D Visual Analogue Scale (VAS)	Significant benefits in patient health outcomes and age-related quality of drug treatment were gained
Well-being	Allen et al., 2015 [31]	108	6 Months: Exercise vs. control group Assessment: 0 weeks and 6 months	Parkinson's Disease Fall Risk Score, Falls Efficacy Scale-International (FES-I) questionnaire, well-being via SF-36, SF-12v2, SF-6D, Parkinson's Disease Quality of Life Questionnaire (PDQ-39), Positive and Negative Affect Schedule, Frontal Assessment Battery (FAB), Incidental and Planned Exercise Questionnaire, Short Physical Performance Battery	Shorter disease duration, less bodily pain, better self-reported physical well-being (SF-12 physical composite score), and better self-reported health and well-being (SF-6D) were all significantly associated with higher levels of adherence to the exercise program

Table 1
(continued)

Study	Total N	Design	Outcome	Results related to happiness and well-being	
Well-being	Collett et al., 2017 [32]	105	6 Months: Exercise vs. control group Assessment: 0 weeks and 6 months and 3, 6, and 12-months follow-up	2-minute walk, with motor symptoms (UPDRS III), fitness, health and well-being	Some small effects were observed in fitness and well-being measures
Well-being	Dahmen-Zimmer & Jansen, 2017 [33]	37	30 Weeks: Karate vs. dance vs. waiting control group Assessment: 0 and 30 weeks	Well-being was measured with the Multidimensional Mood Questionnaire, Hospital Anxiety and Depression Scale (HADS), CEDS Depression Scale, Short-Form Health Survey, Short Scale of General Self-Efficacy	No decline of emotional well-being took place in the karate group and there was a stable state of emotional well-being in the dance group
Well-being	Kwok, 2019 [34]	187	8 Weeks: Yoga vs. stretching and resistance training exercise (SRTE) group Assessment: 0 and 8 weeks, and 20 weeks follow-up	Hospital Anxiety and Depression Scale (HADS), Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS), Timed Up and Go Test, Holistic Well-being Scale, PDQ-8	Yoga showed, compared to SRTE group, additional benefits on psychological distress, spiritual well-being, and health-related quality of life, with comparable benefits related to motor symptoms and mobility
Well-being	De Luca et al., 2020 [35]	40	8 Weeks: Treadmill integrated with music therapy vs. control group Assessment: 0 and 8 weeks	Psychological General Well-Being Index (PGWBI) and subscales of Brief-COPE	Higher emotional well-being after the musical treadmill training, as shown by the improvement in all subscales of the PGWBI
Well-being	Murdoch et al., 2020 [36]	31	6 Weeks: Counseling vs. delayed control group Assessment: 0 and 6 weeks, and 6 weeks follow-up	PDQ-39, Patient Health Questionnaire (PHQ-9 Depression), Beck Anxiety Inventory (BAI), Well-being via Mental Health Continuum – Short Form (MHC-SF), Self-Efficacy for Managing Chronic Disease scale	Significant effects for time were found for well-being in both Immediate and Delayed conditions

with PD only yielded several small studies: none used self-compassion, one used happiness [26], and ten used well-being as an outcome [27–36] (see Table 1 for more information). Well-being and happiness measurements were used as a primary outcome in five [27, 28, 30, 33, 35] out of eleven clinical trials. Moreover, well-being outcomes were often claimed to be measured, while the scores were derived from QoL questionnaires and not from specific well-being questionnaires. Therefore, we did not include these studies in Table 1 (e.g., [37–48]).

Looking at the studies measuring happiness, we can conclude that happiness or well-being was only included as a primary endpoint in less than half of the studies, and more often, a QoL questionnaire was used to measure well-being. Also, most studies had included only a limited number of participants and used short follow-ups. These considerations emphasise the need for high-quality studies measuring this important construct. Therefore, we argue that happiness, measured as self-compassion or well-being, deserves further exploration in PD research, particularly when considering non-pharmacological therapies, such as dance therapy, music therapy or meditation. To further document the actual benefits of those therapies, happiness may represent a useful and relevant outcome.

ACKNOWLEDGMENTS

Special thanks to Inge Rabeling-Keus for her help and support during this process.

CONFLICT OF INTEREST

Prof. Bloem currently serves as Editor-in-Chief for the Journal of Parkinson's disease, serves on the editorial board of Practical Neurology and Digital Biomarkers, has received honoraria from serving on the scientific advisory board for Zambon, Biogen, UCB and Walk with Path, has received fees for speaking at conferences from AbbVie, Zambon, Roche, GE Healthcare and Bial, and has received research support from the Netherlands Organization for Scientific Research, the Michael J Fox Foundation, UCB, Abbvie, Zambon, the Stichting Parkinson Fonds, the Hersenstichting Nederland, the Parkinson's Foundation, Verily Life Sciences, Horizon 2020, the Topsector Life Sciences and Health, and the Parkinson Vereniging. Dr. De Vries receives research support from The Netherlands Organization

for Health Research and Development and from the Michael J Fox Foundation.

REFERENCES

- [1] van Uem JM, Marinus J, Canning C, van Lummel R, Dodel R, Liepelt-Scarfone I, Berg D, Morris ME, Maetzler W (2016) Health-related quality of life in patients with Parkinson's disease—a systematic review based on the ICF model. *Neurosci Biobehav Rev* **61**, 26-34.
- [2] (1998) The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Sci Med* **46**, 1569-1585.
- [3] Farquhar M (1995) Elderly people's definitions of quality of life. *Soc Sci Med* **41**, 1439-1446.
- [4] Tay L, Kuykendall L, Diener E (2015) Satisfaction and happiness—the bright side of quality of life. In *Global handbook of quality of life*. Springer, Dordrecht, pp. 839-853.
- [5] Veenhoven R (2001) Quality-of-life and happiness: Not quite the same. In *Salute e qualità dell'vida*, DeGirolamo G, ed. Centro Scientifico Editore, Torino, Italia, pp. 67-95.
- [6] Diener E, Seligman ME (2004) Beyond money: Toward an economy of well-being. *Psychol Sci Public Interest* **5**, 1-31.
- [7] Neff KD, Rude SS, Kirkpatrick K (2007) An examination of self-compassion in relation to positive psychological functioning and personality traits. *J Res Pers* **41**, 908–916.
- [8] Ryan RM, Deci EL (2001) On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Ann Rev Psychol* **52**, 141-166.
- [9] Diener E (1984) Subjective well-being. *Psychol Bull* **95**, 542–575.
- [10] Diener E (2000) Subjective well-being: The science of happiness and a proposal for a national index. *Am Psychol* **55**, 34-43.
- [11] Diener E, Sapyta JJ, Suh E (1998) Subjective well-being is essential to well-being. *Psychol Inq* **9**, 33–37.
- [12] Neff KD, Pisitsungkagarn K, Hsieh Y (2008) Self-compassion and self-construal in the United States, Thailand, and Taiwan. *J Cross Cult Psychol* **39**, 267–285.
- [13] Barak Y, Achiron A (2009) Happiness and neurological diseases. *Exp Rev Neurother* **9**, 445-459.
- [14] Canoy M, Faber MJ, Munneke M, Oortwijn W, Nijkrake MJ, Bloem BR (2015) Hidden treasures and secret pitfalls: Application of the capability approach to ParkinsonNet. *J Parkinsons Dis* **5**, 575-580.
- [15] Diener E, Emmons RA, Larsen RJ, Griffin S (1985) The satisfaction with life scale. *J J Pers Assess* **49**, 71–75.
- [16] Watson D, Clark LA (1994) *The PANAS-X: Manual for the positive and negative affect schedule – Expanded form*. The University of Iowa, Ames.
- [17] Diener E, Wirtz D, Tov W, Prieto-Kim C, Choi DW, Oishi S, Biswas-Diener R (2010) New well-being measures: Short scales to assess flourishing and positive and negative feelings. *Soc Indic Res* **97**, 143–156.
- [18] Lyubomirsky S (2001) Why are some people happier than others? The role of cognitive and motivational processes in well-being. *Am Psychol* **56**, 239-249.
- [19] Neff KD (2003) The development and validation of a scale to measure self-compassion. *Self Identity* **2**, 223-250.
- [20] Neff KD, Costigan AP (2014) Self-compassion, well-being, and happiness. *Psychol Österreich* **2**, 114-119.
- [21] Neff KD, Knox MC (2017) Self-compassion. In *Encyclopedia of Personality and Individual Differences*, Zeigler-Hill

- V, Shackelford TK, eds. Springer International Publishing AG, pp. 1-8.
- [22] McLean G, Lawrence M, Simpson R, Mercer SW (2017) Mindfulness-based stress reduction in Parkinson's disease: A systematic review. *BMC Neurol* **17**, 92.
- [23] Bognar S, DeFaria AM, O'Dwyer C, Pankiw E, Simic Bogler J, Teixeira S, Nyhof-Young J, Evans C (2017) More than just dancing: Experiences of people with Parkinson's disease in a therapeutic dance program. *Disabil Rehabil* **39**, 1073-1078.
- [24] Earhart GM (2009) Dance as therapy for individuals with Parkinson disease. *Eur J Phys Rehabil Med* **45**, 231.
- [25] García-Casares N, Martín-Colom JE, García-Arnés JA (2018) Music therapy in Parkinson's disease. *J Am Med Dir Assoc* **19**, 1054-1062.
- [26] Pacchetti C, Mancini F, Aglieri R, Fundarò C, Martignoni E, Nappi G (2000) Active music therapy in Parkinson's disease: An integrative method for motor and emotional rehabilitation. *Psychosom Med* **62**, 386-393.
- [27] Gauthier L, Dalziel S, Gauthier S (1987) The benefits of group occupational therapy for patients with Parkinson's disease. *Am J Occup Ther* **41**, 360-365.
- [28] Lindskov, S, Westergren A, Hagell P (2007) A controlled trial of an educational programme for people with Parkinson's disease. *J Clin Nurs* **16**(11C), 368-376.
- [29] Benninger DH, Lomarev M, Lopez G, Wassermann EM, Li X, Considine E, Hallett M (2010) Transcranial direct current stimulation for the treatment of Parkinson's disease. *J Neurol Neurosurg Psychiatry* **81**, 1105-1111.
- [30] Schröder S, Martus P, Odin P, Schaefer M (2012) Impact of community pharmaceutical care on patient health and quality of drug treatment in Parkinson's disease. *Int J Clin Pharm* **34**, 746-756.
- [31] Allen NE, Song J, Paul SS, Sherrington C, Murray SM, O'Rourke SD, Lord SR, Fung VSC, Close JCT, Howard K, Canning CG (2015) Predictors of adherence to a falls prevention exercise program for people with Parkinson's disease. *Mov Disord Clin Pract* **2**, 395-401.
- [32] Collett J, Franssen M, Meaney A, Wade D, Izadi H, Tims M, Winward C, Bodganovic M, Farmer A, Dawes H (2017) Phase II randomised controlled trial of a 6-month self-managed community exercise programme for people with Parkinson's disease. *J Neurol Neurosurg Psychiatry* **88**, 204-211.
- [33] Dahmen-Zimmer K, Jansen P (2017) Karate and dance training to improve balance and stabilize mood in patients with Parkinson's disease: A feasibility study. *Front Med* **4**, 237.
- [34] Kwok JYY, Kwan JCY, Auyeung M, Mok VCT, Lau CKY, Choi KC, Chan HYL (2019) Effects of mindfulness yoga vs stretching and resistance training exercises on anxiety and depression for people with Parkinson disease: A randomized clinical trial. *JAMA Neurol* **76**, 755-763.
- [35] De Luca R, Latella D, Maggio MG, Leonardi S, Sorbera C, Di Lorenzo G, Balletta T, Cannavò A, Naro A, Impellizzeri F, Calabrò RS (2020) Do patients with PD benefit from music assisted therapy plus treadmill-based gait training? An exploratory study focused on behavioral outcomes. *Int J Neurosci*, doi: 10.1080/00207454.2019.1710147.
- [36] Murdoch KC, Larsen D, Edey W, Arsenault C, Howell A, Joyce A, Sandham T, Miyasaki JM (2020) The efficacy of the Strength, Hope and Resourcefulness Program for people with Parkinson's disease (SHARP-PWP): A mixed methods study. *Parkinsonism Relat Disord* **70**, 7-12.
- [37] Noyes K, Dick AW, Holloway RG, Parkinson Study Group (2006) Pramipexole versus levodopa in patients with early Parkinson's disease: Effect on generic and disease-specific quality of life. *Value Health* **9**, 28-38.
- [38] Zhang Z, Shao M, Chen S, Liu C, Peng R, Li Y, Wang J, Zhu S, Qu Q, Zhang X, Chen H, Sun X, Wang Y, Sun S, Zhang B, Li J, Pan X, Zhao G (2018) Adjunct rasagiline to treat Parkinson's disease with motor fluctuations: A randomized, double-blind study in China. *Transl Neurodegener* **7**, 14.
- [39] Winward C, Sackley C, Meek C, Izadi H, Barker K, Wade D, Dawes H (2012) Weekly exercise does not improve fatigue levels in Parkinson's disease. *Mov Disord* **27**, 143-146.
- [40] Nocera JR, Amano S, Vallabhajosula S, Hass CJ (2013) Tai Chi exercise to improve non-motor symptoms of Parkinson's disease. *J Yoga Phys Ther* **3**, 10.
- [41] Chagas MH, Zuairi AW, Tumas V, Pena-Pereira MA, Sobreira ET, Bergamaschi MM, dos Santos AC, Teixeira AL, Hallak JE, Crippa JA (2014) Effects of cannabidiol in the treatment of patients with Parkinson's disease: An exploratory double-blind trial. *J Psychopharmacol* **28**, 1088-1098.
- [42] Morberg BM, Jensen J, Bode M, Wermuth L (2014) The impact of high intensity physical training on motor and non-motor symptoms in patients with Parkinson's disease (PIP): A preliminary study. *Neurorehabilitation* **35**, 291-298.
- [43] Sheard JM, Ash S, Mellick GD, Silburn PA, Kerr GK (2014) Improved nutritional status is related to improved quality of life in Parkinson's disease. *BMC Neurol* **14**, 212.
- [44] Li M, Yang HM, Luo DX, Chen JZ, Shi HJ (2016) Multi-dimensional analysis on Parkinson's disease questionnaire-39 in Parkinson's patients treated with Bushen Huoxue Granule: A multicenter, randomized, double-blinded and placebo controlled trial. *Complement Ther Med* **29**, 116-120.
- [45] Cattaneo C, Müller T, Bonizzoni E, Lazzeri G, Kottakis I, Keywood C (2017) Long-term effects of safinamide on mood fluctuations in Parkinson's disease. *J Parkinsons Dis* **7**, 629-634.
- [46] Hadinia A, Meyer A, Bruegger V, Hatz F, Nowak K, Taub E, Nyberg E, Stieglitz RD, Fuhr P, Gschwandtner U (2017) Cognitive behavioral group therapy reduces stress and improves the quality of life in patients with Parkinson's disease. *Front Psychol* **7**, 1975.
- [47] Mirabella G, De Vita P, Fragola M, Rampelli S, Lena F, Dilettuso F, Iacopini M, d'Avella R, Borgese MC, Mazzotta S, Lanni D, Grano M, Lubrani S, Modugno N (2017) Theatre is a valid add-on therapeutic intervention for emotional rehabilitation of Parkinson's disease patients. *Parkinsons Dis* **2017**, 7436725.
- [48] Poier D, Rodrigues Recchia D, Ostermann T, Büssing A (2019) A randomized controlled trial to investigate the impact of Tango Argentino versus tai chi on quality of life in patients with Parkinson disease: A short report. *Complement Med Res* **26**, 398-403.