

“Where’s the ‘feeling better’ box?” Beyond PDQ-39

Proposing a conversation towards a holistic measurement for Quality of Life in Parkinson’s

In relation to self
Emotional, mental, physical, spiritual

In relation to others

In relation to community
Resources, belonging

The current gold standard quality of life measure for Parkinson’s is the PDQ-39, a health-related quality of life (HRQOL) assessment. Health-related assessments now offer too narrow a definition to support full empowerment of people with Parkinson’s (PwP).

The challenge is to create a broader definition and measure of quality of life with greater meaning for PwP.

Why are QoL measures needed in Parkinson’s?

Health professionals and clinicians need to be able to assess how effective new treatments and interventions are in improving quality of life, given that there is currently no cure for Parkinson’s (Jenkinson & Fitzpatrick 2011).

What is the predominant QoL measure?

The PDQ-39 is the ‘gold standard’ quality of life measure for Parkinson’s patients; a patient-reported outcome measure. Introduced over 20 years ago, it puts ‘patient views [...] truly at the centre of health care evaluation’ (Jenkinson & Fitzpatrick 2011:17).

What’s the problem?

The PDQ-39 (Jenkinson et al 1993) is a HRQOL assessment, in which quality of life and state of health are seen as co-dependent, as deficit. That is: the more advanced the condition, the worse the symptoms; and the worse the symptoms, the worse the quality of life.

There are two problems here:

1. The HRQOL assessment was developed before the importance of patient empowerment gained recognition with emphasis on person-centred practice. It focuses on the impact of state of health, rather than the ‘many ways to have a good life’

2. The health-related focus is reinforced by the measure’s language. Of the 39 questions, 16 ask about ‘difficulty’ or ‘problem’, 15 ask about negative emotions such as ‘anxious’, ‘angry or bitter’, ‘tearful or weepy’, ‘distressing’, ‘depressed’, ‘worried’. The remaining 8 questions are more neutral, for example asking about physical sensations and muscle cramps.

This means that the PDQ39 can be seen as a list of expectations, suggestions and, potentially, instructions about how a PwP’s Parkinson’s should develop, and how they should feel about it. As the condition progresses, the PwP’s attitude to it, and therefore their quality of life, is expected to deteriorate.

The placebo effect is very strong in Parkinson’s, as is the nocebo effect, its ‘evil twin’. Going through these questions, phrased in this way, risks reinforcing the very things that it is trying to tackle.

“[T]here is one way to be healthy, while there are many ways to have a good life.”
Hausman (2015)

Where’s the feeling better box?

During the PDQ-39’s development one version included a question about overall health now, as opposed to six months previously. The options were ‘a lot better’, ‘a little better’, ‘the same’, ‘a little worse’, or ‘a lot worse’.

3.7% - 13.0% of people in this sample reported a change for the better, while over a quarter of the sample reported

they felt ‘a little worse’. The writers, citing evidence that a small positive or negative change from baseline can be treated as equivalent (Jaeschke et al 1989), removed the ‘feeling better’ boxes (Jenkinson & Fitzpatrick 2011).

Removing the questions about feeling a lot or a little better effectively removed those possibilities for the person filling in the questionnaire.

A starting point for the conversation:

Michael Roy suggests examining the ‘potential strengths of individuals [...] rather than focusing on individual risk factors’.

A quality of life measure that is not directly or solely health-related needs an alternative value base to support it. A framework based on the values of a person-centred approach puts the PwP at the centre of the quality of life assessment, looking at each individual in three ways – in relation to themselves, in relation to other people, and in relation to their communities.

Three assessment approaches, each based on different values, and complementary to a HRQOL, are offered as a starting point:

- Asset-based: Measuring Humanity. de Andrade (2017)
- Capability-based: Sen (1999). Quoted Canoy et al (2015)
- Capability Wellbeing-based ICECAP-O & ICECAP-A: Al-Janabi & Coast (2012)

Next? A special interest group?



	PwP in relation to self:				PwP in relation to others	PwP in relation to community:	
	Emotional	Physical	Mental	Spiritual		Resources	Belonging
Asset-based: Measuring Humanity Marisa de Andrade (2017)	Happiness: Benefits interpersonal relationships, creativity, sociability, and productivity. Fosters resilience. Optimism: Individuals have positive expectations about their future. And engage in efforts towards desired goals.	Physical health: Individuals lead healthy lives and are able to have optimal levels of wellbeing	Self-determination: Individuals experience greater autonomy in their everyday life. They can express their individuality and self-identity, regulating their behaviour in congruence to their values and needs. Individuals can make informed decisions about the best services for their health and wellbeing. They can maintain their independence as they get older and are able to access appropriate support when they need it.	Personal meaning: Individuals have a purpose in life which is determined by their personal meaning and values. Spirituality: Individuals construct their own spirituality which help them cope with stressful and threatening situations.	Empathy: Individuals are able to exert perspective taking in interactions with others Trust: Individuals are trustful. They are able to build different social relationships Interpersonal relationships: Individuals benefit from functional aspects such as emotional support, companionship, advice, in experiences of adverse stress. A change in behaviour in one individual is likely to produce a change in behaviour of the other. Individuals are involved in community activities which contribute to the improvement of their health and wellbeing.	Access to resources: Individuals have opportunities to access different forms of social capital through organisations. Healthy environments: Health promoting amenities and resources enable individuals to maintain healthy lives	Culture: Individuals have a sense of identity and culture. They are free to express and live according to their cultural values and norms, including freedom of religious expression. Helpfulness: Individuals have positive attitudes to helping others.
Capability-based: Sen (1999) quoted Canoy et al (2015)		Health, longevity: Life expectancy, good health gauged by subjective and objective health indicators (including mental health). Access to good quality information on health.	Basic rights: Basic rights: political (freedom of speech); religion + religious expression; freedom to decide about one’s own body; and freedom to move			Safety: Feeling safe and being safe. Standard of living Living income; choice and control over where and how you live Productive and valued activities: Employment opportunities; no discrimination; good working conditions, and leisure time; caring for others. Environment: Good quality of local and global environment and can control one’s environment.	Culture and entertainment: Quality of cultural ‘supply’ and opportunities to participate. Social cohesion and civil participation: Quality of social networks; feelings of justice; civil participation (voting, volunteer work); developing moral outlook & other beliefs.
Capability/Wellbeing-based: ICECAP-O & ICECAP-A Al-Janabi & Coast (2010)	Enjoyment: Can experience enjoyment and pleasure. Security: Can think about the future without concern. Attachment: Can have love, friendship and support.		Being independent: From: Completely independent - unable to be independent Control: Independence Autonomy: An ability to be independent. Achievement and progress: From: Achieve and progress in all aspects of life - cannot achieve in any. Role: Doing things that make you feel valued)		Love, friendship and support: From: A lot/ quite a lot/a little/cannot have any Attachment: Love and friendship.		Feeling settled and secure: From: In all areas of life -unable to feel settled and secure in any areas of life Stability: An ability to feel settled and secure.
Functionality/Health-based: PDQ39 Jenkinson, Fitzpatrick & Peto (1993) Due to having Parkinson’s Disease, how often in the past month have you...	Felt worried about your future?	Had problems walking half a mile? 100 yards? Getting around in public? Fear of falling over in public? Unexpectedly fallen asleep during the day? Problems with concentration? Memory? Distressing dreams or hallucinations? Speech difficulties? Painful muscle cramps or spasms? Aches and pains in your joints or body?	Had problems getting around the house easily? Needed an escort to go out? Or been confined to the house more than you would like? Had difficulty washing or dressing yourself, cutting up your food? Or holding a drink without spilling it?		Felt you had to hide your Parkinson’s? Avoided having to eat or drink in public? Felt embarrassed in public? Or worried by other people’s reaction to you? Had problems with close personal relationships? Or lacked support in the ways you need from your spouse or partner? Felt unable to communicate with people properly? Or ignored? Difficulty writing clearly? Speech difficulty?	Had difficulty looking after your home, e.g. DIY, housework, cooking? Carrying bags of shopping?	

References: Al-Janabi H., Flynn T. N. & Coast J. (2012) Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. Quality of Life Research 21:167–176 / de Andrade M. (2017) Measuring Humanity. <https://measuringhumanity.org/> asset-based-indicator-framework / de Andrade (2018). Measuring Humanity: hip-hop as evidence for health inequalities. The Lancet Vol. 391 (April 7, 2018) 1340–1341 / Canoya, M., Faber, M. J., Munneke, M., Oortwijn, W., Nijkrakeb, M.J and Bloem, B. R. (2015) Hidden Treasures and Secret Pitfalls: Application of the Capability Approach to ParkinsonNet. Journal of Parkinson’s Disease 5 575–580. / Hausman, D. M. (2015). Valuing Health: Well-Being, Freedom, and Suffering. Oxford: Oxford University Press. / Jaeschke, R., Singer, J., Guyatt, G. H. (1989). Measurements of health status: ascertaining the minimal clinically important difference. Control Clin Trials 1989; 10: 407–415. / C. Jenkinson, Michele Peters, & Mark B. Bromberg, (Eds.) Quality of Life Measurement in Neurodegenerative and Related Conditions. Cambridge: Cambridge University Press. / Jenkinson, C. & Fitzpatrick, R. (2011). The development and validation of the Parkinson’s Disease Questionnaire and related measures. In: C. Jenkinson, Michele Peters, & Mark B. Bromberg (Eds.) Quality of Life Measurement in Neurodegenerative and Related Conditions. Cambridge: Cambridge University Press. / Jenkinson C., Fitzpatrick, R., & Peto, V. (1993) PDQ-39. Isis Innovation Ltd. 1998. / Roy M. J. (2017). The assets-based approach: furthering a neoliberal agenda or rediscovering the old public. Critical Public Health 2017; 27: 455–64. / Sen, A. K. (1999). Development as freedom. Oxford University Press, Oxford.

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