

Parkinson's Disease and Quality of Life – A Patient's Perspective

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Abstract

Quality of life (QoL) for the person with Parkinson's disease (PD) relies heavily on the effectiveness of communication between patient and healthcare providers. It is only through a successful interaction between clinical expertise and patient experience together with lifestyle choice that the most appropriate management strategies for a person with PD can be devised and implemented. The concept of QoL, however, is neither something that can be applied generically nor even defined generically. In PD it is true to say that both motor and non-motor symptoms may impact on QoL, but it may also be necessary to look at more over-arching aspects of life and how individuals differ in their approach to it, their future expectations and the manner in which they react or respond to circumstance. While these may be difficult to quantify, it is important that the patient's perception of their QoL plays a more fundamental role in the overall assessment of QoL in PD and the impact of treatment. The simple step of improving knowledge of PD among patients and involving them in management decisions can improve QoL, regardless of any actual changes to the patient's treatment. Communication is therefore a key factor, and this should involve the patient, their spouse or partner, the neurologist and other members of the multi-disciplinary healthcare team. Such cooperation will lead to a greater understanding of patient needs, which will surely help in tackling the growing challenge of PD.

Keywords

Parkinson's disease, quality of life, patient's perception, shared decision-making

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Parkinson's disease (PD) is a journey and like all journeys it is not about the destination, but about how you get there. Quality of life (QoL) with PD varies depending on where you live and who you are. It is all very well to say, as this article says later, that attitude is everything, but if you are stuck in a fine art auction room with uncontrollable tremor, a good attitude will not help you. Although stated lightly here, this point is a serious one; QoL varies from country to country and from situation to situation to an alarming degree. These issues are too complex to tackle in a paper such as this – they comprise a much wider socioeconomic problem which none of us can materially affect – so instead we should concentrate on issues where we can and do have an influence.

Symptoms and Quality of Life

Most readers of this article will be aware of the symptoms of PD, and a simple account of my personal symptoms would provide nothing new to this supplement. Here are some facts that may be typical of many patients with PD (or if not typical, not likely to surprise a neurologist who treats many patients with PD):

- I was diagnosed at 27 years of age.
- I have been frozen rigid to the spot in the middle of a busy street.
- I have had flamboyant dyskinesias that have led to taxi drivers thinking I am either drunk or deranged and refusing to pick me up.
- I can have long, hot and sweaty sessions of bat-wing tremor

while the pills kick in or wear off, and when the muscle spasms are so painful, all anyone can do is scream for help.

Neurologists see and hear these things every day and patients experience them frequently. Similarly, the psychological effect that the diagnosis of PD has in the early years, the more recent lack of sleep, the inability to organise oneself, and periods of obsessive behaviour, are all real problems that many people with PD encounter.

The combination of these problems would, one may expect, have a profound and negative effect on my QoL during the last 15 years since my diagnosis. And yet, it may surprise the reader to learn that my perception is that my QoL is currently better than it was 15 years ago – indeed it is probably better than it has ever been.

Perceptions of Quality of Life

So how could 15 years of PD have improved somebody's QoL? Firstly, one person's perception of QoL is likely to be entirely different to another person's. When I think of QoL, I think of travelling, enjoying my work, playing golf, seeing friends and sharing good times with my wife. In general, I measure my own QoL in terms of a sense of fulfilment or a sense of worth in what I am doing. This is probably different to a patient's QoL as perceived by a neurologist or other healthcare professional – they are more likely to think of QoL in terms of health-specific rating scales and their

appropriate application to the people in their care (perhaps in relation to clinical trials).

Given the different interpretations of QoL, can a definition for QoL be found that combines a specific health-related, and therefore more tangible and measurable, element with something of real meaning to the person with PD? Undoubtedly the best definition I have found is by researchers at the University of Toronto's Quality of Life Research Unit, who say, "Quality of life is the degree to which a person enjoys the important possibilities of his or her life".¹ Their Quality of Life Model is based around the categories 'being', 'belonging' and 'becoming' – in other words who one is, how one is connected to one's environment and whether one achieves one's personal goals, hopes and aspirations, respectively (see *Figure 1*).¹ As a patient, I can relate to these separate compartments of QoL very easily. The three different values of who I am, how I interact with the world and my sense of what the future holds define my attitude to living.

With such varying perceptions, how can QoL be measured, assessed and quantified? There is a lovely saying, "The greater part of our happiness or misery depends on our dispositions, and not our circumstances" (Martha Washington, 1731–1802, wife of US president George Washington). This leads one to ask whether QoL in its purest sense and in the context of PD has got anything to do with the assessment of physical symptoms? Are the physical manifestations of PD not better described as precursors or contributing factors that will likely influence QoL, but that do not provide a measure in themselves? QoL assessment that relies heavily on visual analysis of patients should be treated with great caution. My own personal experiences give backing to this statement – the severity of my PD symptoms can be shocking to those not used to them, and yet my perception of my life and QoL is probably as positive as anybody reading this article.

My positive perception can be explained if we return to the concept of 'being', 'belonging'- and 'becoming'. After 15 years of living with PD, I have got used to the idea and have become accustomed to the symptoms. Immersing myself in the business of PD has offset the negative effects of these symptoms. Before I had the condition, the only purpose of my day-to-day work was to make money for already wealthy people – now I have a far greater sense of fulfilment in my working life, which in turn gives me a greater sense of identity and greater belief and commitment in everything I do. Therefore, despite living with an incurable degenerative and highly disabling movement disorder for 15 years, I feel good about who I am (about 'being').

PD is an isolating disease with an associated stigma. People with PD get stared at and are treated differently as a result of this pronounced movement disorder. This is not an enjoyable experience, but I have overcome the feelings of isolation by engaging myself in all things related to PD. By working in the world of PD I am not ostracised. More than this, the PD community embraces me as one of its own and it is a place in which I can thrive – perhaps even flourish. Through this, I am connected to my environment and my sense of 'belonging' is satisfied.

Thirdly, with the diagnosis of PD there comes uncertainty in one's future and a sense of having no control. By co-founding an organisation which

Figure 1: Being, Belonging, Becoming



seeks to cure PD, I know that there is science out there that will soon bring improved treatments. Armed with this information, I can drive on with optimism, belief and a sense of purpose, because The Cure Parkinson's Trust and the EPDA may have a role in accelerating a brighter future, not just for me, but for everyone with PD. This optimism satisfies the 'becoming' aspect of my QoL concept.

These three aspects of life, along with other more personal influences, result in a good QoL. This description is given for one reason, to illustrate the important point that a patient-focused assessment of QoL can give very different results to a health-related QoL assessment tool.

Patient Perceptions of Quality of Life and How They Influence Management Decisions

It would be wrong to suggest that patients alone should make decisions on the management of their PD, but it is accurate to say that the only person that can fully assess the QoL of an individual patient, is the patient himself or herself. This emphasises the importance of communication between patients and their managing physicians. Unless there is adequate communication, there is little chance of tailoring treatment to suit that person's lifestyle and their personality. For example, how would my consultant know that my ability to speak was one of the most important aspects of my life, unless I told him? The importance of this information when choosing the right course of treatment could make a dramatic difference on my day-to-day life. To a neurologist or neurosurgeon observing my dyskinesias, the option of deep brain stimulation (DBS) may seem like a logical choice. However, any procedure that could potentially compromise my ability to communicate is not worth the risk for me, even if it benefits my motor symptoms.

Examples such as this highlight the importance of personalised medicine and shared decision-making. Communication between doctors and patients and joint decision making, is not only about discussing treatment options. Engaging patients to increase their understanding of PD and how it may affect them in the future is also of key importance to improving QoL. A Japanese study in 2004 showed that there was a clear correlation between patient QoL and patient knowledge about PD.² It seems logical to conclude from this study that patient education can positively affect attitude to life. Similarly, Donald and Katherine Grosset at the Institute of Neurological Sciences, Glasgow, identified a significant positive correlation between QoL and the satisfaction of a patient – and the more involved a patient is in the administration of their own treatment, the more satisfied they are.³

So by encouraging better communication with patients, and by engaging their interest in their health and in PD, not only will the right therapeutic decisions be made for the individual, but also the very act of involving the patient could have an immense impact on their QoL.

Assessing Quality of Life in the Future

What changes can be made in assessing QoL in PD that reflect the issues raised here? How can the concepts of 'being', 'belonging' and 'becoming' be introduced in the measurement of QoL in clinical trials? It may be useful to move away from the physician's perception of the patient's QoL to actual changes in QoL, and this can be achieved by involving four individuals (or groups of individuals):

- the patient;
- the spouse or partner of the patient;
- the PD specialist nurse or research nurse; and
- the neurologist.

An amalgamation of the perception from these four people/groups may give a more rounded, and consequently a more accurate measure, of QoL. Such an approach may be more consistently accurate than having to rely on the more limited scope and characteristics of the current rating scales.

The spouse or partner plays a particularly important role in observing symptoms and behaviour that healthcare professionals and even the patient are unaware of. This may be particularly true of some non-motor symptoms of PD. Furthermore, the QoL of the partner and other family members should be considered in management decisions and in the development of new pharmacological agents.

All the points raised in this article about patient perspectives of QoL do, of course, have to be balanced with the real benefits of using clinical assessment of QoL when the cost-benefits of different treatments for different conditions are being compared. Such comparisons are needed when considering the impact of diseases and treatments at the level of the whole society, and individuals' needs cannot be the primary consideration. However, at the same time, everyday management decisions must have more focus on the patient's perception of their own QoL and on the factors that affect their QoL – and the only way to make the healthcare teams aware of such factors is by open and honest communication between the patient and the team. ■

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