Assessing quality of life in Parkinson’s in routine clinical settings

For people with Parkinson’s, quality of life (QoL) is affected by many factors that are dependent on motor and non-motor symptoms, social support, activity, and environment – making it a difficult subject for clinicians to discuss fully with their patients in a standard outpatient clinic visit. Various definitions for QoL exist, but most recent definitions broadly define QoL as the patient’s perception of their life in the context of their environment. Physical health remains important, but as part of a broader picture.

Following the principles of patient-centred care, clinicians should also allow their patients the opportunity to discuss their health beliefs, concerns and preferences to inform their individualised care. However, pressures such as limitations on the time allowed for each visit (often only 15–30 minutes), and the intervals between follow-up appointments (average 6–12 months) mean that it is very challenging for clinicians to capture a broad sense of how patients are doing and also focus on specific changes in disease-related issues in an efficient fashion without missing something which may be important to patient care and QoL. While this is the case for other chronic diseases, matters can be even more challenging in Parkinson’s as the clinical examination findings are dependent on medication timing and the clinic environment, and therefore may not reflect out of clinic function. In addition, there is often a difference between the carer’s and the patient’s perspective, which may be confounded by mood and cognitive function.

Continuity of care is also important and it is vital that clinicians document how the patient’s health status changes over time; one way to do this would be to assess and record patient-reported changes in their symptoms and how these impact their daily life at each appointment. Many QoL scales and tools, including the PDQ-39 and its shorter version the PDQ-8 have been developed, but are not routinely used in most clinical practices, mainly due to length and often perceived lack of user-friendliness. These scales were designed for use in clinical trials where the aim is to collect information systematically and reproducibly. Moreover, in clinical practice, the broad range of detailed questions may distract from a much smaller number of issues of greater relative importance to the patient.

Using their consultation skills, most clinicians will start the conversation with an open question, although it can often take repeated prompting to get to the troublesome issues and some may still be missed. It can be especially difficult to identify the most important issues and subsequently as a successful clinician should also allow their patients the opportunity to discuss their health beliefs, concerns and preferences to inform their individualised care. However, pressures such as limitations on the time allowed for each visit (often only 15–30 minutes), and the intervals between follow-up appointments (average 6–12 months) mean that it is very challenging for clinicians to capture a broad sense of how patients are doing and also focus on specific changes in disease-related issues in an efficient fashion without missing something which may be important to patient care and QoL. While this is the case for other chronic diseases, matters can be even more challenging in Parkinson’s as the clinical examination findings are dependent on medication timing and the clinic environment, and therefore may not reflect out of clinic function. In addition, there is often a difference between the carer’s and the patient’s perspective, which may be confounded by mood and cognitive function.

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than having the time to establish what is most important to the patient’s function and QoL.

In the case of a Parkinson’s consultation, simple opening questions such as ‘What has changed since we last discussed your Parkinson’s?’ and ‘Have these changes caused you or your family any particular problems?’ might be effective in starting to tease out the problems that are troubling patients as well as establishing any other changes in social circumstances and environment likely to impact on function and QoL. This approach is also more likely to pick up non-motor symptoms, which the patient and/or carer may have not realised were part of Parkinson’s. This approach would go hand in hand with patient education regarding the wide range of signs and symptoms that are characteristic of Parkinson’s and will in turn maximise the usefulness of future consultations, as both physician and patient/carer will be better prepared to identify and discuss their most troublesome symptoms. In this respect, pioneering studies in the Netherlands show that proper patient (and carer) education can itself significantly improve QoL in Parkinson’s.

One simple approach to improving the efficiency of the consultation is to ask patients to prepare for their next appointment by considering what they want to talk about before they come. Patient diaries are available for motivated patients to capture both motor and non-motor symptoms over the course of several days, but this may provide reams of information over months which may not be easy to analyse in the consultation, only looked at in a cursory fashion or put to one side with patients disappointed that their efforts have not been useful. Instead, it may be easier in the first instance for patients simply to list symptoms that bother them. They should also be directed to symptoms that may be related to disease and likely to affect QoL, but that they may not have linked to their Parkinson’s and so not mentioned. In order to help address patients’ most important symptoms and QoL concerns, and to try to bring some structure to the consultation and thereby get the most out of the limited time available, a group of experts set out to design a simple consultation aid that could facilitate a patient’s preparation for, and participation in their routine clinic visits. The group included a range of Parkinson’s specialists including Neurologists, Geriatricians, Parkinson’s Nurse Specialists and representatives of CPT and Parkinson’s Movement (including an expert patient, JS).

The Parkinson’s QoL Consultation Aid includes 17 prompts or domains/groups of symptoms, relating to Parkinson’s itself, and its potential impact on activities of daily living and QoL. These domains were identified through review and discussion of the domains captured in available QoL of life tools (both disease specific and generic), and were also informed by a CPT survey highlighting factors that typically more strongly determine QoL measures. The domains are not exhaustive, and the tool was purposely not designed to be a list of symptoms. Instead, the Consultation Aid guides the patient to think about the areas of life that Parkinson’s can affect and encourages them to think beyond pure motor function. The arrangements of the prompts are deliberately disjointed such that patients can think of them independently and not necessarily make links implying association or cause between certain symptoms and functions/activities. The graphic use of the clock provides a way of discussing both change over time, either positively or negatively, reflecting both a progressive neurodegenerative disease but also response to treatments and also to help with prompting the clinician to ask whether the symptoms change over 24 hours leading to identification of wearing off. Where appropriate or relevant, patients are encouraged to consider the prompts with carers which provides a way of discussing factors influencing both the patients and carers perspectives on QoL. After this patients are asked to consider the three most important areas for discussion with their clinician. The Consultation Aid can be sent to patients in advance of the consultation, filled out just prior to the consultation or use during the consultation itself.

The carers perspective is crucial to QoL discussions. Members of the development group have ‘road-tested’ the Consultation Aid and used it during the outpatient clinic visit itself to act as a series of prompts for facilitating QoL discussions with the carer present. This has improved the quality of the conversation with both patients and carers leading to greater consultation satisfaction without necessarily increasing the time of the consultation. Indeed, the Consultation Aid provides a way of accessing important information in a more time efficient and patient-centred fashion. In the majority of cases, use of the
Consultation Aid provided important information that would not otherwise have been volunteered. These ‘hidden’ symptoms typically include fatigue, pain, communication, sexual dysfunction and mild cognitive symptoms and also provide broader understanding of the impact of Parkinson’s on social function and sense of isolation. Alternatively, the Consultation Aid can be used in advance of the outpatient visit, in which case patients have been informed that they may find it helpful to review some of the prompts with their carer/partner as well. The use of the Consultation Aid given immediately in advance of the appointment to be considered in a busy waiting area has proven to be of less utility in this regard. The relatively small number of patients and carers on which this aid has been tested have found the Consultation Aid easy to understand, the rationale easy to comprehend, and have reacted positively with almost universal approval. The use of the Consultation Aid does not seem to have generated undue distress at prompts, which are mentioned on the aid but not yet experienced by the patient.

Of course, doctors will continue to ask about all aspects of Parkinson’s as part of good consultation practice. Many tools are available to assess specific aspects of a patient’s condition for example NMS-QUEST or NMSS14 to hospital non-motor symptoms and WOQ-19 to assess wear-off. The Consultation Aid is not designed to replace these but rather to engage the patient in a prioritised conversation around QoL. When reviewed with local patient support groups, the Consultation Aid was perceived favourably as helping facilitate a patient and carer centred consultation.

Copies of the Parkinson’s QoL Consultation Aid in both colour and black and white are freely available and can be printed via Parkinson’s Movement at www.cureparkinsons.org.uk/sites/parkinsonsmovement/pages/qol-aid-tool. It is recognised that each clinician will have a different consulting style and technique and the use of such a consultation aid will depend on both patient factors and clinical settings. However, in the experience of those who have used it, it has proved to be a valuable adjunct to consultations with Parkinson’s nurses, elderly care specialists and neurolologists. Any meaningful improvement in the consultation will underpin better patient care in a resource effective fashion.

The use of the Consultation Aid can be audited by using the standard Royal College of Physicians or General Medical Council outpatient consultation patient satisfaction questionnaires (commonly used by UK physicians as part of their appraisal and revalidation requirements), and although this may help indicate patient satisfaction with the consultation it may not necessarily measure the impact on QoL. To audit this a validated measure such as the PDQ-39 questionnaire would need to be used both at baseline and after any changes in management that follow the use of the Consultation Aid. This would then need to be compared to a cohort of patients in whom the Consultation Aid was not used. This would be a major undertaking and the more pragmatic step adopted has been to undertake a standard consultation and then use the Consultation Aid at the end of the consultation discussions to see if any additional information comes to light which may positively influence QoL conversations.

Expert working group who were involved in the design and testing of the Consultation Aid:

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• Dr Paul Worth, Consultant Neurologist, Cambridge University Hospitals NHS Foundation
• Helen Matthews, The Cure Parkinson’s Trust, www.cureparkinsons.org.uk/
• Dr Pete’s Fletcher, Consultant Physician in Elderly Care, Gloucestershire Hospitals NHS Foundation Trust
• Dr Doug MacMahon, Consultant Physician, University Hospitals Coventry and Warwickshire
• Annette Hand, Nurse Consultant, Northumbria Healthcare NHS Foundation Trust
• Anne Martin, PDNS Kings College Hospital Parkinson’s Centre of Excellence, London.

REFERENCES
2. University of Toronto. The Quality of Life Model http://www.utoronto.ca/qol/qol_model.htm
10. The Cure Parkinson’s Trust survey. Available at: https://healthunlocked.com/parkinsonsmovement/poll/100029884/Do-you-feel-your-priorities-were-listened-to-by-your-parkinsons-specialistsresult
tion-skills-control-length-consultation/

UCL Institute of Neurology
in association with The National Hospital for Neurology & Neurosurgery
NEUROLOGY 2015: leading edge neurology for the practising clinician
Wednesday 25th March 2015 (half day)
Thursday 26th March 2015 and Friday 27th March 2015
Course organiser: Professor Simon Shorvon
This course, which will take place on an annual basis, is for consultants and clinical trainees in neurology and other neuroscience specialties in the UK, Europe and internationally. The course is designed to provide a comprehensive update on the practical hospital management of common neurological diseases, with an emphasis on modern techniques and therapies. The course aims to be didactic, but also entertaining and informative, and should become an annual highlight of the British neurological calendar.

The half day event on Wednesday 25th March 2015 is open to Clinical Trainees and Research Fellows in Neurology and associated specialties. It is a precursor to the full course, taking place on Thursday 26th and Friday 27th March 2015.

VENUES
Wednesday 25th March.
Wolfson Lecture Theatre, NHNN, Queen Square, London WC1N 3BG
Thursday 26th & Friday 27th March.
Logan Hall, Institute of Education, 20 Bedford Way, London WC1H 0AL

COST
Consultant and associate specialists: £190 for two days OR £140 per day
Clinical trainees and research fellows: £130 for two days OR £80 per day, £50 for half day on Wednesday only

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