Out of Hours Mental health and Parkinson's disease:

from the cradle to the grave

INTRODUCTION

With advances seen in medical imaging (for example, functional magnetic resonance imaging), and development of new drugs and breakthroughs in molecular medicine (for example, neuroprotective agents for Parkinson's disease [PD]), many clinicians may become caught up in the idea that PD is merely a movement disorder with motor symptoms only. However, research has shown that patients with PD suffer from non-motor symptoms (including mental comorbidities), just as they do from motor symptoms. This article sheds light on mental health and PD; it provides a concise background on issues related to mental welfare from pre-diagnosis to the end of life.

PD is a neuropsychiatric disorder characterised by motor symptoms, postural instability as well as non-motor symptoms. Non-motor symptoms are usually categorised into sensory, autonomic, cognitive-behavioural, and sleep-related symptoms.¹ Of these, cognitive-behavioural symptoms are of special importance, due to their insidious onset, relative difficulty in diagnosis and treatment, and significant impact on both patients with PD and their caregivers. Mental health care in patients with PD should be a continuum of care from prediagnosis through to the patient's last days, and extending further to their caregivers. However, research into PD-related cognitivebehavioural comorbidities as well as appropriate evidence-based mental health care in patients with PD has been fairly limited to date; and new research has not yet been assembled for proper clinical use and discussion. This article explores recent published research in the field of mental health and PD in a chronological sequence; from pre-diagnosis through to death as well as the ongoing effects on caregivers.

PRE-DIAGNOSIS

There has been accumulating evidence that mental and psychiatric disturbances start to appear before the patient shows any motor symptoms and well before the clinical diagnosis of PD.²⁻⁴ In a recent study, the investigators observed that the population who went on to develop PD were more likely to have had lifetime diagnoses of major depressive disorder, generalised anxiety disorder, and psychological distress than those who did not.³ In another study, patients with PD were observed to have had a sharp

increase in the use of mental health services 5 years before the diagnosis, peaking around the time of diagnosis.⁴ Both studies suggest a common pathway in the pathophysiology of PD and these mental illnesses. Such data can be used to guide clinicians to the introduction of an early detection approach of PD in demographically-susceptible groups.

AFTER THE CLINICAL DIAGNOSIS

Many studies now show that patients with PD have a poorer health-related quality of life than their age- and sex- matched peers.^{1,5,6} Not only does this perceived poor quality of life stem from the chronic nature of PD, but also cognitive-behavioural comorbidities such as depression and apathy play a major role in the life quality of patients with PD.^{1,5,6} A recent review has shown that moderate exercise was beneficial for mental health.7 However, due to the motor disability resulting from PD, a vicious cycle of lesser exercise and a lower quality of life is created. Moreover, dopaminergic medications used to treat motor symptoms of PD can precipitate or exacerbate these mental problems, thus treatment requires a fine balance between motor and cognitive-behavioural benefits; and evidence-based guidance on such dilemmas is unfortunately lacking.¹

END OF LIFE

End-of-life issues in patients with PD is a relatively new arena of research, partially due to the fact that a number of expert reviews do not consider PD as a cause of death.⁸ In another study, caregivers described confusion as the most frequent and severe of psychiatric symptoms during the last weeks of life in patients with PD.⁸ Furthermore, compared with end-of-life psychological experiences for patients with amvotrophic lateral sclerosis (ALS), patients with PD had diminished social interactions and were more isolated from loved ones.⁸ This can be attributed to patients with PD being older compared to patients with ALS, having been through a longer and more chronic disease, and were more likely to be institutionalised.8 In terms of caregiver experiences, bereavement was significantly longer in caregivers of patients with ALS than in patients with PD.8 However, caregivers for patients with PD were less likely to know their loved one's treatment goals, which could be a source of additional unwarranted anxiety to them. Furthermore, when compared with families and friends of patients with multiple

sclerosis (MS), families and friends of patients with PD were found to spend more on their loved one's care (financially), with the cost increasing as the disease progressed.⁹

FUTURE DIRECTIONS

Many clinicians may find it easier to deal with the 'organic' (meaning the 'apparent' symptoms, for example, tremor and rigidity) parts of PD while ignoring other parts, which could be just as distressing to the patient. Rising utilisation of mental healthcare facilities should be critically evaluated and used, if appropriate, as a screening tool for early preclinical diagnosis of PD. Once PD is diagnosed, careful psychological monitoring should be exercised to avoid any significant fluctuations in the patient's perception of his or her quality of life. Tools such as PD Questionnaire (PDQ-39) or personality assessment instruments could be of considerable help in achieving this goal. If a mental illness has been detected, proper early treatment should commence only after discussing the patient's preferences and goals of treatment both with the patient and their caregivers. Group education and personal rehabilitation of patients with idiopathic PD can be added to the treatment regimen; for example, a trial of group education conducted by a group of Japanese specialists in PD resulted in significant improvement in quality of life reported by the patients, and mood elevations reported by their caregivers.¹⁰ Finally, end-of-life care should be part of the routine care of patients with PD. In the last months of life, palliative care, pain management, and social wellbeing are of special importance to the patient; health care costs, and the ability to cope after a loved one's death become more important issues to the caregivers.

PD is no longer thought of as a movementonly disorder. Increasingly available evidence is showing that non-motor symptoms can be just as disabling to patients with PD as motor symptoms; and can be the result of the disease itself, its medications, or due to the on-off fluctuations in motor status due to the effects of the drugs wearing off.¹ Cognitive-behavioural comorbidities associated with PD necessitate a watchful eye to diagnose and treat. They can be difficult to recognise since they can mimic the physical features of PD; and can be difficult to treat due to adverse interactions of various PD medications. Moreover, most studies

Out of Hours Books

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on the mental health in patients with PD have been of an observational nature which are not uncommonly subject to biases and pitfalls. Higher quality research is therefore warranted in early recognition of mental illnesses in PD, in finding better or alternative treatments, and in reaching evidence-based guidelines for mental health wellbeing for patients with PD.

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LITTLE PIECES OF THE WRECKAGE A Flourishing Practice?

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Doctors don't seem to be flourishing right now. GPs live in a world of multiple statutory, regulatory, and disciplinary perils, 5-yearly revalidation, deprofessionalisation, and who knows how many years to a pension. A world where doctors' interests seem often to be pitted against patients' interests in a zero sum game. Peter Toon offers us no sticking plasters or quick fixes. This book starts with the metaphor of society clinging to the wreckage of a past shared-moral vision. Our little pieces of the wreckage are precious as they keep us afloat. But might there be any way of building a shared vision of social cohesion in the medical world once again?

Toon's argument builds on Alasdair MacIntyre's account of virtue theory from his ground-breaking work *After Virtue*, which Toon outlines in his opening chapters. Virtue ethics is an increasingly important area, and Toon's work locates GP ethics again in the forefront of medical ethical thinking. Toon rejects both rule-based and consequence-oriented guides. Instead he roots moral discourse in our own nature, asking whether an action or outcome helps or hinders human flourishing.

How to tie the goals of medicine to a model of human flourishing is much harder than following a biomedical model that simply aims for a list of biomedical norms. But if our medicine is to be good for patients then serving human flourishing is key. And what of our own flourishing? The beauty of Toon's approach is that it rejects the zero sum game and shows how both sides can win. Toon reflects on our distinctive professional virtues. He gives us an intellectually credible analysis of the 'ordinary' and humane work of a doctor; no longer just the antique domain of *Dr Finlay*. Compassion is a prime example of what both biomedicine and traditional ethics leaves out and yet is so very important to patients. Toon examines this in particular detail. He advocates the professional virtue of temperance as a deeper model than 'work life balance'. Toon examines how the virtues of integrity, honour, and altruism act as more effective guarantors of our practice than regulation.

This is a trailblazing and vital contribution to our craft. It is deeply relevant to the current debate as to what medicine is for and how it should be provided and controlled. I hope that it may influence our current arid policy discourses and will certainly help our own professional life to flourish. Don't just cling to the wreckage, read this lifeboat construction manual now!

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