

'Adults with Parkinson's disease and hallucinations or delusions can have treatment with clozapine if they need to'[†]

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SUMMARY

Clozapine is the only antipsychotic licensed for treatment of Parkinson's disease psychosis (PDP) but is infrequently used in the National Health Service because of obstacles to the integration of hospital-based neurological/geriatric services with clozapine clinics run by community mental health teams. This commentary points out the mismatch between NICE quality standards on antipsychotic treatment for PDP and current clinical practice. It suggests that forthcoming integrated care systems should be able to overcome these obstacles, enabling innovative models for providing clozapine treatment for PDP such as those described by Taylor et al, so that clozapine treatment becomes a right for patients and their families.

KEYWORDS

Parkinson's disease; psychosis; clozapine; model of care; service integration.

Parkinson's disease is classified as a neurological disorder (World Health Organization 2018: 8A00) but in practice can be viewed as a neuropsychiatric illness. This is because the movement abnormalities are frequently accompanied by psychiatric symptoms reflecting either the underlying neuropathology of Parkinson's disease or the action of medication prescribed for motor control. From the onset and throughout the course of Parkinson's disease, mental disorders commonly arise, including depression, anxiety, impulse control disorder, psychosis and dementia.

Neurologists or geriatricians are commissioned to manage the motor symptoms of people with Parkinson's disease but there is no care pathway mandating access to psychiatric and psychological services and there are too few neuropsychiatrists and neuropsychologists to make such specialist care feasible. In 2019, The Neurological Alliance's 2018–2019 Patient Experience Survey reported

that 40% of patients with a neurological condition felt that their mental health needs were not being met (Neurological Alliance 2019). Nowhere is there a starker example of the inequity of access to mental health services than that of the provision of clozapine for people with Parkinson's disease psychosis (PDP). As pointed out in the article by Taylor et al (2021) in this journal, PDP is common, developing in about 60% of patients at some point during their illness. Not all will require intervention with antipsychotic medication, but this is often the last recourse because of the failure of other approaches, the distress of the patient, the strain on the family and the attendant risks.

NICE guidelines

Randomised controlled trials (RCTs) of antipsychotic medication for PDP have demonstrated unequivocally that low-dose clozapine significantly alleviates psychosis without worsening motor symptoms (Kyle 2020). As a consequence, clozapine treatment allows anti-parkinsonian medication to be increased as motor symptoms worsen with disease progression and it can even alleviate parkinsonian tremor and levodopa-induced dyskinesia (Yaw 2015). RCTs of other antipsychotics showed little or no antipsychotic potency at the doses prescribed and/or worsened motor function (Kyle 2020). Guidelines from the National Institute for Health and Care Excellence (NICE) recommend that the unlicensed use of quetiapine should be considered as 'standard' treatment for PDP (NICE, 2017), despite a literature review showing that all but one placebo-controlled trials were negative (Shotbolt 2010). This decision was based on low-quality evidence of efficacy and the observation that it does not worsen motor symptoms. Clozapine is the only antipsychotic licensed for PDP in the UK and NICE recommends that this is offered only if quetiapine is ineffective.

Another NICE consideration was that clozapine is impractical as a first-line antipsychotic. Clozapine

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has potentially life-threatening adverse effects, mainly agranulocytosis and myocarditis, and because of these the National Health Service has a well-established, effective and safe system for administering and monitoring clozapine for patients with a primary psychosis. So why is there a problem with access to this service for people with PDP? The answer is that initiating clozapine and sustaining safe monitoring requires the will and determination to embark on a process that requires integration across medical disciplines and services, and is effortful and resource demanding. Initiating treatment requires patients to be admitted to hospital or intensely monitored in the community. This is particularly important for patients with PDP, who tend to be older and frailer than patients with primary psychosis. Mental health beds for this group are difficult to come by and, as mentioned by Taylor et al, admission to a psychiatric bed usually only occurs when a crisis develops. Community initiation of clozapine is more common these days but is resource demanding and mental health teams may not be confident working with people with Parkinson's disease. Another difficulty is the lack of cross-talk between hospital neurological/geriatric medical services and community mental health services, which have different budgets and commissioning processes.

NICE quality standards

NICE Quality Standards (QS164 2018), In recognition of the practical difficulties of prescribing clozapine, NICE Quality Standard QS164 establishes a very important principle: 'Adults with Parkinson's disease and hallucinations or delusions can have treatment with clozapine if they need to' (NICE 2018: Quality Statement 5). It exhorts commissioners to 'encourage joint working between services to ensure that the specific needs of adults with Parkinson's disease are understood and met... this may mean joint arrangements with mental health services are needed'. Unfortunately, this guidance has got off to a slow start. In 2019, Parkinson's Disease UK undertook a survey of neurology and geriatric services and found that 71% do not prescribe clozapine for PDP, yet over 90% of respondents said they would like their patients to have access to this medication (S Carney, personal communication, 2020). The main reason stated for lack of progress in this initiative was that they had no safe system for initiation, monitoring and dispensing clozapine. Taylor et al have shown in their article that this obstacle can be overcome with innovative approaches. One important component of all three services that they describe is that the consultant neurologist or geriatrician has overcome the

usual stipulation that only consultant psychiatrists can prescribe clozapine by becoming prescribers themselves. This enables them to manage both the psychotic and physical symptoms of their own patients. A second important element is the ability to initiate clozapine, monitor symptoms and look out for potential adverse effects in a community setting. A third is 'buy-in' from mental health services (clozapine clinics for blood tests and health monitoring led by community psychiatric nurses) and/or primary care (district nurses for blood tests and health monitoring). The input of a specialist pharmacist to track blood results and prescriptions is also invaluable. These three services are successful but each one is different because they have adapted to their local context and circumstances. Therefore, it is highly likely that around the UK clozapine services will adopt different models of care that work in their catchment areas.

Will integrated care systems make a difference?

Management of PDP requires the input of neurological, psychological and psychiatric services to optimise motor and mental function, which can be a fine balancing act. The time is now ripe for the commissioning of clozapine care systems for PDP that work flexibly within the local landscape of community mental health and hospital physical health services. In England, clinical commissioning groups (CCGs) are being subsumed into single regional integrated care systems (ICSs) that will come into action very soon. A main aim is 'to deliver joined-up support for growing numbers of older people and people living with long-term conditions' (King's Fund 2020). In practice this will bring together CCGs, general practitioners, hospitals and mental health services, hopefully breaking down the purchaser-provider split to provide integrated care. There should be no barrier now, funding or otherwise, to the provision of a clozapine service that will keep families together and improve the quality of life and well-being of people with Parkinson's disease.

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Declaration of interest

None.

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