
CONFERENCE ABSTRACT

Integrated care for people and families living with Parkinson's, Huntington's and Multiple Sclerosis: A systematic review

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People living with long term neurological conditions have complex needs that demand coordination of care across different health and social care sectors, however there is uncertainty in how to deliver integrated care and its impact on people.

Our research is focused on patients and caregivers living with long term neurological conditions, specifically with Parkinson's disease (PD), Multiple Sclerosis (MS) and Huntington's Disease (HD).

We developed the review questions and interpreted the results of the review with a patient and public involvement group composed of people with lived experience of long term conditions. The group identified three important problems with their care: fragmentation (services are not joined-up missing important needs), duplication (repetition of assessments) and lack of continuity (changes in staff and difficulty in knowing who to contact). These areas prompted us to identify the key characteristics of successful integrated care programmes in the literature and which benefits were brought to people.

We undertook a systematic review of the literature searching CINAHL, Cochrane, Embase, PsycINFO, Medline, Web of Science and Google Scholar of all published studies (from Jan 1, 2000 to Sep 30, 2021) testing multisectoral integrated care interventions in people living with PD, MS and HD. Articles published in English, Portuguese, Spanish and German were considered. We supplemented this with snowballing technique, hand and grey literature searches. Evidence was graded for strength (or certainty) for each outcome measure.

Our review identified 15 papers across 5 countries and a total of 2095 patients and caregivers were included. Analysis indicated that multisectoral integrated care programmes can improve people's access to resources and patients' mood (by reducing depression). UK studies indicated improvements in patients' quality of life, although the international literature was inconclusive. To date, few programmes considered benefits for caregivers; studies that did, reported no differences or even a decline on caregivers' outcomes. Evidence identified was inconsistent or limited regarding all other outcomes reported. Overall, the literature has a limited consideration of effects on people living with PD and MS, namely, needs being met and continuity of care; to date, no empirical

research has focussed on people living with HD. Successful programmes for people with PD and MS were characterised by four facilitating factors:

- Expert knowledge
- Multi-sectoral care coordination
- Care continuity
- Person-centred approach

Hindering factors were related to logistics for care delivery, such as issues with data access and care transition between different providers.

To date, limited evidence exists to support the benefits of multisectoral integrate care programmes from the perspective of patients and caregivers. By focusing on metrics that do not reflect people's experiences and how well people's needs are being met, the true impact of these programmes is lost, and with it, the opportunity to advise policies for best service delivery in practice.

Future studies should investigate integrated care from the perspective of patients and caregivers, to measure impact at user-level. This is relevant across all conditions. Furthermore, more research is needed in vulnerable groups and people living with rare complex conditions such as HD.