

Clinical and Scientific Challenges to Multispecialty Team Care

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The complex nature of many neurodegenerative disorders warrants the need for multi-component interventions. These disorders, like Alzheimer's disease and Parkinson's disease, are typically characterized by a broad range of symptoms. Because of this, these disorders pose a significant challenge to medical specialists, not only for adequate diagnosis but also for the management of the wide array of symptoms. An additional difficulty is the fact that the clinical presentation is highly variable across individuals, in terms of disease manifestation and progression, as well as the individual perception of most troublesome problems [1]. This great inter-individual variation creates an even greater challenge to optimize treatment tailored to each individual patient's needs and priorities. Due to this complexity, treatment by health care professionals from multiple complementary disciplines seems warranted. Here, some examples will be described to illustrate the complexity of designing and evaluating these multidisciplinary team approaches.

Parkinson's Disease: A Multidimensional Disorder

An example of a complex disorder is Parkinson's disease. Although, typically known for its motor features, a range of non-motor symptoms are increasingly recognized as a substantial part of Parkinson's disease [2]. These non-motor features (including gastrointestinal, mood, attention and sleep problems) have a negative impact on quality of life, in fact, even greater than motor symptoms [3]. Therefore, multidisciplinary treatment seems preferable over a single-clinician approach to satisfactorily manage this broad disorder. Indeed, guidelines for Parkinson's disease recommend that patients should have access to several health care professionals [4,5]. Yet, these guidelines do not provide an evidence-based template on how to best organize such care.

No Standard Template

There is no standard available on how to best organize these approaches, in terms of which specialist should be involved or the optimal way to implement team approaches into everyday healthcare settings [6]. Subsequently, many Parkinson centers worldwide offer team-based care, but their approaches vary widely regarding the disciplines and number of specialists involved, and the type of collaboration between these team members [6,7]. In addition, the implementation of team approaches within current health care systems vary; some centers offer their team approaches as inpatient services (e.g. to fine-tune therapeutic effects of medications during intensive treatment), while others have implemented outpatient services [7]. These outpatient services might be located in one single center where both diagnostics and treatment are provided by the same team [8]. Alternatively, care might be provided as an integrated approach of complementary elements. For example, as a Dutch model of Parkinson care that has been put to the test recently [9]. Here, patients are referred to a tertiary referral center for an individually tailored multidisciplinary assessment. After integration of treatment recommendations from all disciplines, treatment is initiated by medical specialists and allied health therapists who collaborate within regional expert networks (the so-called Parkinson Net networks), providing specialized care in the patients' own vicinity [9,10].

The scientific literature on effectiveness of multispecialty

interventions in the management of Parkinson's disease is limited to a few controlled trials [6]. Although, some of these trials have shown beneficial effects of multidisciplinary team care, results are inconsistent. The heterogeneity among these trials, in terms of study design, treatment arms, and choice of outcome measures make direct comparison difficult. Interventions also differ in frequency, duration and combination of treatments. Additionally, the disciplines and number of health professionals involved vary widely among these trials [6]. This is however not surprising, because over 20 disciplines have been identified that might have a potential value in Parkinson care [4]. This list includes medical specialist (like neurologist, rehabilitation specialist, and geriatricians), specialized Parkinson's disease nurses, and a range of allied health care professionals, including physiotherapists, occupational therapists, speech-language therapists, social workers, and dieticians [4]. The best combination of these disciplines is however not known, nor is the relative contribution of each of these disciplines within a team. In fact, the possible merits for most of these 'monodisciplinary' interventions are still largely based on clinical experience rather than on scientific evidence. Fortunately, allied health care is increasingly developing into an evidence-based profession and evidence is growing [11-13].

A Multidisciplinary Approach for Alzheimer's Disease

Also, for other neurodegenerative diseases like Alzheimer's disease-which also typically requires a multidisciplinary approach-it is unknown which format works best. Memory clinics have been set up, but similar as with Parkinson's disease, these clinics operate in various settings and include a diverse range of different professions [14]. Promising results on behavioral and psychosocial symptoms have been shown for collaborative primary dementia care involving an advanced practice nurse working together with families with dementia [15]. However, other studies failed to show positive effects for post-diagnosis treatment and coordinated care in memory clinics on health outcomes in dementia patients [16-18]. In the Netherlands, dementia care is highly fragmented and collaboration between health care professionals is still mainly scheduled on an incidental base rather than as structural collaboration.

Evaluating Clinical Effectiveness: Some of the Lessons Learned

Organizing multispecialty team care involves a wide array of considerations, as to which disciplines should be involved, how team members should collaborate, at what stage team care should be

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implemented, and how team models can be designed within current health care systems [6]. Additionally (and, in fact, also subsequently) such complex interventions provide significant challenges to research on clinical effectiveness and researchers will be faced with several methodological and practical problems.

For example, randomized controlled designs are regarded as the highest level of evidence for clinical trials. Yet, randomization between study arms might not always be feasible, especially when interventions are evaluated as part of clinical care. In the IMPACT trial [9], where we evaluated the previous mentioned Dutch health care approach in Parkinson's disease, a controlled design was used as randomization was impossible. Here, patients were selected based on the region they participated; regions where the expert center and regional network care were available versus control regions that administered usual care. Randomization within one region was not feasible, as this would have led to contamination of the control arm, as control patients would have gained access to parts of the intervention.

Unlike drugs trials, where a single intervention is taken to the test, multispecialty approaches typically comprise several interconnecting elements [19]. For complex interventions it is impossible to apply the same standardisation as in drugs trials, in particular when care is delivered in a tailored fashion providing an individual package for each patient, adapted to their own individual needs and priorities. Drugs trials are simpler in design because study medication is often provided at a specific dose, frequency and timeframe. In contrast, evaluation studies of multidisciplinary interventions are bound to more complex and variable designs due to the variety of disciplines and interventions involved, including a diverse set of therapies at a variable intensity, frequency, and duration of treatment [6].

Another difficulty in this area of research is the choice of outcome measures. As multidisciplinary interventions include different components, it is very difficult to assess the effectiveness using one overarching outcome. The focus of one primary outcome will likely be insufficient to determine the full extent of treatment effects and individual improvements of complex healthcare. Perhaps, a better alternative would be to include a combination of multiple outcome measures [20,21]. Additionally, mixed methods designs, including both quantitative and qualitative methods, might offer a more suitable methodology to evaluate complex healthcare interventions.

Another important consideration is the fact that the evaluation of the effectiveness of healthcare interventions must be implemented and evaluated within constantly changing healthcare settings. For example, in Alzheimer's disease, the importance of the choice of healthcare setting has been shown recently when evaluating the effectiveness of the Dutch community occupational therapy in dementia. While effects were seen after implementation in the Netherlands, applying this complex intervention in German healthcare setting lead to unexpected intervention failure [22]. Possible explanations for these differences in effectiveness were explored by Voigt-Radloff and colleagues [22], including differences in study populations, variations between intervention and utilization of healthcare resources, and differences in study design and primary outcome between the Dutch and German trial. Although, patient characteristics and implementation of some active elements of the intervention existed varied to some extent, these variables could not explain the varying outcomes between the two studies. Yet, usual care differed between the trials: in contrast to the Dutch waiting-control group, control patients in the German trial received a comprehensive consultation. Although, this represented non-pharmacological standard care in Germany, it served as an

active control intervention [22]. This might have diluted the contrast between the intervention and control treatment. This limited contrast was also a possible explanation for the small effect size found for the integrated, multidisciplinary care approach for Parkinson's disease [9]. Here, information on health care use showed that usual care in the Netherlands often includes a multidisciplinary approach. Therefore, results from standard multispecialty care might have only improved marginally by the more intensive integrated care tested in this study. Implementation of the same intervention within another country might have achieved larger improvements.

A Challenging Field!

Although multispecialty approaches are increasingly acknowledged as preferred treatment of complex disorders like Alzheimer's disease and Parkinson's disease, there is no known standard or best template for organizing these team models of health care. The aforementioned difficulties underline the complexity to organize these multidisciplinary interventions and to provide solid evidence on clinical effectiveness. Although, results of trials thus far have not provided the final answer on how to optimally design team-based care, they provide an initial inventory for future work. Hopefully, the many challenges to scientific research, of which some illustrated here, will above all inspire to explore other ways to design research that provide a better fit to evaluate these complex interventions. It is an emerging and exciting field that offers many challenges to both clinical practice and scientific research, and which hopefully leads to better treatment for patients, not only in neurodegenerative disorders, but also for other chronic diseases.

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