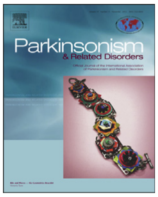
Parkinsonism and Related Disorders 19 (2013) 923–927

Contents lists available at SciVerse ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis



Point of view

Moving from physician-centered care towards patient-centered care for Parkinson's disease patients

Martijn van der Eijk [a], Frouke A.P. Nijhuis [a], Marjan J. Faber [b], Bastiaan R. Bloem [c,*]

[a] Department of Neurology, Nijmegen Centre for Evidence Based Practice, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands
[b] Scientific Institute for Quality of Healthcare (IQ healthcare), Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands
[c] Department of Neurology, Donders Institute for Brain Cognition and Behaviour, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

ARTICLE INFO

Article history:
Received 6 February 2013
Received in revised form
19 April 2013
Accepted 25 April 2013

Keywords:
Patient-centered care
Collaborative care
Health 2.0
Participatory medicine
Parkinson's disease
Chronic disease

ABSTRACT

Today's society is changing rapidly and individuals increasingly favor an active role in designing their own lives. Contemporary patients are no exception, but the present health care system—which is organized primarily from the provider's perspective—is not yet prepared for this development. Here, we argue that an alternative way to organize health care, namely more from the patient's perspective, may help to contain costs, while improving the quality, safety and access to care. This involves a redefinition of the patient—doctor relationship, such that patients are no longer regarded as passive objects, but rather as active subjects who work as partners with health care professionals to optimize health ('participatory medicine'). The opportunities that come with such a collaborative and patient-centered care model are reviewed within the context of patients with Parkinson's disease. We also discuss societal and Parkinson-specific barriers that could impede implementation of this alternative care model to the management of Parkinson's disease and other chronic conditions.

© 2013 Published by Elsevier Ltd.

1. Physician-centered care

Today's society is changing rapidly and individuals increasingly favor an active role in designing their own lives. Internet technology has greatly facilitated this development, with readily available knowledge and interactive communication platforms [1]. Contemporary patients are no exception. They search the internet for medical information, they wish to have open communication channels with their health professionals, and they prefer to actively participate in making important medical decisions [2]. Moreover, they want to be regarded as humans with a health problem, and not as carriers of a disease [3]. Terms that have been coined to describe this alternative health care approach include patient-centered care [2], collaborative care [4], participatory medicine [5] and health 2.0 [6]. This paper reviews the opportunities that come with such a collaborative and patient-centered care model in the context of patients with Parkinson's disease.

The pace of the aforementioned societal developments do not match concurrent health care system reforms. Specifically, the present health care is organized primarily from the 'provider perspective', with professionals taking the lead in deciding about the quality of care, and with a somewhat paternalistic approach to patients [7]. Here, we argue that organizing health care more from the patient's perspective may help to contain costs, while improving the quality, safety and access to care [8–10]. It is interesting to consider that health care is meant to be organized this way; patients already had a central position within the health care team during the times of Hippocrates, the ancient Greek doctor who lived 400 years BC. However, in the centuries following his oath, we inadvertently seem to have lost this view of patients as partners in the health care process [11]. The current challenge is to 'reestablish' a level playing field, in which patients and health professionals are equal members of the health care team. If we want patients to regain their central role, a shift is needed from the classical model of professionalism *('Trust us, we know best what will help you')* towards a more consumerist model *('Let us know what you need and want, and that is what we will offer')* [12,13].

Our current health care system has several drawbacks. First, patients with complex health care needs and chronic conditions such as Parkinson's disease (PD), often receive care that is fragmented, incomplete, inefficient, and ineffective [14]. Particularly in elderly PD patients, this complexity is compounded by co-morbidities and most PD patients acquire relationships with

---

* Corresponding author. Department of Neurology (935), Radboud University Nijmegen Medical Centre, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands. Tel.: +31 24 3615202; fax: +31 24 3541122.
E-mail address: b.bloem@neuro.umcn.nl (B.R. Bloem).

1353-8020/$ – see front matter © 2013 Published by Elsevier Ltd.
http://dx.doi.org/10.1016/j.parkreldis.2013.04.022

multiple professionals and institutions [15,16]. Health care—which initially involved individual consultations for a specific health problem—has gradually evolved into complex multidisciplinary teamwork, with care given by multiple professionals from different backgrounds, and who typically work in different departments and institutions [17]. To manage patients with complicated health problems, professionals must collaborate to make coordinated decisions and share responsibilities [18]. Indeed, for chronic patients, delivery of coordinated and integrated care centered around an individual patient positively affects the clinical outcome, patient functioning and quality of life [17]. However, current multidisciplinary collaboration in health care can still be improved considerably [19].

Second, most chronic patients currently assume a passive role, partially because this is the traditional approach to medicine, but partially also because they lack the tools to self-manage their condition [20]. Moreover, PD patients are increasingly willing to assume a more active role in managing their own care processes [21]. However, physicians are not fully responsive to patient preferences regarding either the degree of communication or the patient's participation in decision making [22].

Third, for complex disorders such as PD, health professionals often lack sufficient experience to address the complex needs of affected patients [15]. This gap between available and required knowledge continues to increase, as our understanding of PD improves. A further problem is the fact that PD patients are often not referred to professionals who do have adequate expertise, likely because referring physicians are unaware where experts can be found [14]. Put simply, there are no 'yellow pages for PD'.

2. Collaborative patient-centered care

An alternative way to organize the care for chronically affected patients is collaborative patient-centered care [4,19,23]. Central elements of this approach are collaborative goal-setting, practical care planning, self-management and monitoring of outcomes within a team of professionals that also involves the patient [24]. Accumulating evidence suggests that collaborative care programs are a cost-effective way to improve the quality of care and lead to better medical outcomes for elderly patients with multiple chronic conditions [24–26].

Patient-centeredness is a crucial element of quality of care and is defined by the Institute of Medicine as: 'providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions' [27]. Contrary to common belief, patient-centeredness requires more than a respectful attitude towards patients or a personalized style of clinical interviewing. It really is about engaging patients to become active participants in their own care, and about improving patient-professional communication [9,28]. Patient-centered care lowers the cost per patient by i.e. a shortened length of stay in the hospital, decreased adverse events or reduced health care utilization [8–10]. Patient-centeredness increases treatment adherence among chronically ill patients and improves job satisfaction among health professionals. Moreover, patient-centeredness is associated with improved quality of life and improved physical health outcomes [9,29]. Despite these apparent advantages, the concept of patient-centeredness remains far from being implemented in everyday clinical practice, even in developed Western countries [30].

Recently, we explored the concept of patient-centered care for PD. These studies showed that patient-centered PD care involves six subscales, each representing a separate dimension of patient-centeredness: patient involvement; provision of tailored information; health care accessibility; empathy and PD expertise; collaboration and continuity of care and emotional support [31,32]. Independent of age, PD patients expressed a desire to be actively involved in the health care process, and were in need of much more medical information, particularly about medication and the various treatment options offered by therapists. Patients wished to be emotionally supported, especially when it comes to disease acceptance and changes in personal relationships [31,32]. Finally, the qualitative study identified a lack of multidisciplinary collaboration among health professionals as an important bottleneck [31].

Delivering collaborative patient-centered care to PD patients is particularly challenging, given the complex and debilitating nature of the disease, which includes a mixture of cognitive, emotional and motor symptoms [33]. In current clinical practice, the primary focus of physicians is on assessing disease severity and evaluating drug effectiveness, but less so on patient involvement or on the specific needs of patients which affect their quality of life [34]. Interestingly, PD patients who did perceive greater involvement in their care were more satisfied with their consultations and tended to be more compliant [21]. A Swedish study demonstrated that neurologists provided only a small proportion of patients with advanced therapy information, despite patients' interest in this issue [35]. Importantly, there are enormous variations in PD patients' expectations of treatment success, and also great inter-individual differences in what patients perceive to be their most troublesome symptoms [36]. These considerations highlight the importance of providing care tailored to each patient's individual preferences.

3. Implementation of collaborative patient-centered care for PD

The implementation of collaborative patient-centered care for PD patients could include several targets that together enclose the whole spectrum of this approach: a broad focus on providing better emotional support and tailored information; implementation of tools that allow better access to health care; active patient involvement and self-management; and reduction of health care fragmentation. Table 1 shows all patient-centered collaborative care initiatives that have thus far been tested for PD, classified by a taxonomy of 'patient focused quality interventions' [37]. In the next paragraphs, we will elaborate on shared decision making, as a promising example of the implementation of patient-centered care which illustrates how PD patients can become actively involved in their own health care process.

3.1. Shared decision making

Shared Decision Making (SDM) is considered especially applicable to specific medical decisions for which—based on the available scientific evidence—there is no distinct preference or obvious superiority for one particular treatment over other treatments. Under such circumstances, it is often the personal preference of the physician that drives the ultimate treatment decision. This is not necessarily wrong, because it is important that physicians feel comfortable with and have experience in the treatments which they prescribe. Ideally, however, the treatment choice should also depend at least on how patients themselves value the risks and benefits of the various treatment options [51]. In other words, a key feature is the process of really making a *shared* decision, with involvement of both the patient and the physician. This SDM process involves information sharing, consensus building about the preferred treatment and reaching an agreement about which treatment to implement [52]. This process does require that patients receive access to unbiased medical information—in layman's terminology, and presented in a comparative and easy to understand format. This information is normally only available to physicians. Depending on the specific context and the patient's wishes

Download English Version:

https://daneshyari.com/en/article/10745700

Download Persian Version:

https://daneshyari.com/article/10745700

Daneshyari.com