Parkinsonism and Related Disorders 20S1 (2014) S174–S179

Contents lists available at SciVerse ScienceDirect

Parkinsonism and Related Disorders

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

Parkinson patients as partners in care

Mark A. Hirsch[a,*], Mohammed Sanjak[b,c], Danielle Englert[b], Sanjay Iyer[b], Margaret M. Quinlan[d]

[a] *Carolinas Rehabilitation, Department of Physical Medicine and Rehabilitation, Charlotte, NC, USA*

[b] *Center for Parkinson's Disease and Movement Disorders, Carolinas Medical Center,* [c] *University of North Carolina at Charlotte, Department of Kinesiology,* [d] *University of North Carolina at Charlotte, Department of Communication Studies, Charlotte, NC, USA*

ARTICLE INFO

Keywords:
Parkinson's disease
Patient-centered
Exercise
Physical therapy
Social capital

SUMMARY

Increasing physical activity, as part of an active lifestyle, is an important health goal for individuals with Parkinson's disease (PD). Exercise can positively impact health related quality of life. Given this, how can we promote physically active lifestyles among PD patients (most of whom are sedentary)? Here we suggest that health care professionals could significantly expand their impact by collaborating with PD patients and their spouses (or caregivers) as *partners-in-care*. We outline reasons why partners-in-care approaches are important in PD, including the need to increase *social capital*, which deals with issues of trust and the value of social networks in linking members of a community. We then present results of a qualitative study involving partners-in-care exercise beliefs among 19 PD patients and spouses, and conclude with our perspective on future benefits of this approach.

1. Introduction

Increasing physical activity (PA), as part of an active lifestyle, is an important health goal for individuals with Parkinson's disease (PD) [1,2]. Inactivity, which characterizes most PD patients, is prodegenerative, at least in animal models of PD [3]; higher intensity activity is thought to be protective [3,4]. Given this, how can we promote a long term, physically active lifestyle, among PD patients?

Current approaches to neurological rehabilitation involve highly trained multi-disciplinary teams. This assigns health care advisors and individuals with PD to two, non-overlapping groups: individuals with PD are "objects" or "subjects" of care, not "colleagues", "collaborators" or "partners". We believe allied health care professionals can significantly expand their health impact by inviting individuals with PD and their family members to become "partners-in-care" which, incidentally, breaks down some barriers between the medical community and patients [5]. We suggest that a partners-in-care approach can be clinically important in PD because it increases both PA and social capital of patients. We present results of a qualitative study assessing Parkinson patient and spouse beliefs about leading exercise using the partners-in-care model in which we interviewed participants with PD and spouses about the partners-in-care approach. We conclude with a future direction.

2. Patients as partners

Parkinson patients are the most underutilized resource in health care today (attributed to [5]). The proof-of-principle of involving patients with PD as partners in (exercise) care has been demonstrated (Fig. 1) [6]. In a randomized controlled trial led by the

Fig. 1. Two partners-in-care. Trainers with PD (Hoehn and Yahr stage I/II) from the first author's randomized controlled trial [6] (reproduced with permission; [7]).

---

[*] Corresponding author. Carolinas Rehabilitation, Dept. of Physical Medicine and Rehabilitation, 1100 Blythe Blvd., Charlotte, NC 28203, USA. Tel.: +1 704 355 7673; fax: +1 704 355 0709.
E-mail address: Mark.hirsch@carolinashealthcare.org (M.A. Hirsch).

first author [6] the treatment (high intensity resistance and balance training) was administered by patients with PD and care-partners (spouses of patients with PD) and produced measurable changes in PD impairment, including improved postural control, and muscle strength, reduced falls on a standardized test of equilibrium, with no worsening in quality of life [6]. Here we present reasons why partners-in-care approaches (using PD patients and/or their spouses as health coaches), would be a logical "next step" in the evolution of neurorehabilitation, and would enhance the impact of health professionals while serving both PD patients and their spouses.

2.1. Shortage of rehabilitation professionals

Shortages of neurologists, PD nurse-specialists (RN) and physical therapists (PT), concurrent with increases in demand for their services, may reduce the quality of PD care [8–10]. Shortages in the number of neurologists, now at 11% in the United States, are expected to reach 19% within the next 10 years [8]. Similarly, shortages in skilled rehabilitation personnel, including RNs and PTs, are likely to increase both in the USA and internationally [11]. In the USA shortages in PT are expected to exceed 140,000 by 2030, particularly in skilled nursing facility settings, acute care hospitals and outpatient PT clinics [10]; these shortages will affect outpatient clinics where most of the PD rehabilitation now occurs [12]. Given projections, whom can individuals with PD turn to in order to continue to receive high quality care?

2.2. Increased number of patients

The number of PD patients will double by 2040, with concomitant increases in PD medical expenditures (currently $12,800 per capita) and reduced PD patient employability [13]. Shortages in the supply of health care professionals, who have less time for patient encounters, and increases in the number of patients with PD will likely reduce the overall quality of PD care.

2.3. Care-partner health

Spouses serving as care partners of individuals with PD, who currently receive little or no training, display high levels of depression, anxiety and reduced health related quality of life; these factors become magnified with increasing disease burden [14]. Including care partners in the partners-in-care approach, and providing them with sufficient training, may have positive effects on both the PD patient and the care-giving spouse; we propose these benefits would include reduced mortality, reduced depression and anxiety, reduced care-partner burden and improved relationship satisfaction [15].

2.4. Social capital: Parkinson patients as health coaches

Since exercise has positive medicinal properties, while a sedentary lifestyle can enhance the degenerative process (at least in animal models), we need a big "evolutionary change" in how patients with PD participate in their treatment so that they take their "exercise medicine" on a regular basis. We think that our idea of promoting PD patients as health coaches will be a significant step in that direction. There is an additional, significant benefit to this innovation. To discuss this we introduce the concept of "social capital".

Social capital relates to the value of networks in linking individuals within communities, and issues of trust [16]. In our case, the community consists of the multi-disciplinary collaborating health care teams, patients with PD, and their spouses and families seeking physical activity (PA). We suggest that increases in social capital will promote PA of this community. But how can we help PD patients build social capital?

Here we argue that a PD patient leading exercise in a social setting, such as a fitness center, can build new connections within the community that support his or her efforts, and come to trust peers who exercise at this setting. This is likely to motivate living a more physically active life and promote positive health outcomes such as sustained increases in the amount of physical activity: a program to build such social capital needs to be developed.

3. Physical inactivity

It is becoming clear that exercise can become part of the treatment at all stages of PD. Unfortunately, up to 82% of individuals with PD demonstrate continuous low PA levels after diagnosis [17,18], and individuals with PD are 29% less physically active than healthy controls [19]. (Activity levels are lower for females than for males.)

Plausible activity reducing factors include problems with gait, advancing PD stage, anxiety, falls and fear-of-falling, impaired executive function, depression, and disability in daily activities or low outcome expectations [17–22]. However, in one study only 24% of the variability in PA was explained by various combinations of the above listed demographic and disease-related factors, leaving a large amount (~80%) of the variability unexplained [19].

In an attempt to increase PA and fitness, van Nimwegen and colleagues enrolled sedentary individuals with PD into a multimodal behavioral change program (ParkFit) [21]. In this large scale, rigorous, double-blind study they randomly assigned PD patients (N = 586) to two groups: (ParkSafe – physiotherapy aimed at moving safely and ParkFit – PT plus behavior change techniques, in which coaches used motivational strategies and ambulatory feedback to enhance the amount of PA). They used a standardized 7-day recall instrument over a long (24 month) follow-up period (loss to follow-up was low, 7.8%). Physical fitness parameters increased in ParkFit participants, with no significant change in the time spent on PA (ParkFit 7% increase; ParkSafe, 1% decrease, $p = 0.19$) or improvement in quality of life.

We suggest two reasons why there was no significant change in the proportion of sedentary PD patients in either group. First, trainers were all physical therapists working in a PT clinic so there was no opportunity for patients to acquire "lay role models". Second, training was in a clinical setting and not in a public social setting, making it unlikely social capital increased. PD patients who exercise in public fitness centers report that, while they started exercising to improve balance, walking and muscle strength, they continued mainly because of exercise-related social support [23].

PD patients might become more active if they have a supportive home environment (e.g., spouses who favor exercise) and/or if exercising provides peer-support opportunities (e.g. PD support groups that convene at fitness facilities). There are currently no data to support this. We have now created a Parkinson alliance center in partnership with fitness centers in Mecklenburg County, North Carolina, which have begun to host PD patient support group meetings at select YMCAs (fitness centers) to boost adherence to physical activity. An evaluation of this concept is expected in 2015.

4. How do patients with PD envision their participation in health care?

Despite attention given to exercise and health promotion in PD over the last decades, what is appropriate and optimal care for patients and spouses of patients with PD is often filtered through the voices of the biomedical community "experts". As a result we have learned little about how patients with PD envision shaping the future of health care.

4.1. Participants, data collection and analysis

We assessed PD patients' beliefs about exercising with either their spouse or another PD patient. The study was approved by the institutional review board and a convenience sample of individuals with PD (confirmed diagnosis of PD according to established criteria,