



Development and evaluation of a dyadic intervention for elderly couples living with moderate-stage Parkinson disease[☆]



Line Beaudet, RN, Ph.D.^{a,b,*}, Francine Ducharme, RN, Ph.D.^b, Nathalie L'Écuyer, RN, B.Sc.N.^a, Sylvain Chouinard, MD, FRCPC^{b,c}, Nicolas Jodoin, MD, FRCPC^{b,c}, Michel Panisset, MD, FRCPC^{b,c}

^a Neurology, Centre hospitalier de l'Université de Montréal, H2L 4M1 Montréal, Canada

^b Faculty of Nursing, Université de Montréal, H3C 3J7 Montréal, Canada

^c Faculty of Medicine, Université de Montréal, H3C 3J7 Montréal, Canada

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ABSTRACT

Purpose: The purpose of this qualitative study was to develop, test and evaluate a dyadic intervention for elderly couples living with moderate-stage Parkinson disease.

Methods: Based on Meleis's theory of transitions and following systemic and participatory approaches, the study comprised four steps informed by the intervention mapping process: 1) assessing couples' intervention needs, preferences and objectives; 2) developing and validating a dyadic intervention proposal; 3) formalizing the dyadic intervention; and 4) testing and evaluating the dyadic intervention.

Results: The dyadic intervention consisted of seven 90-minutes sessions held every other week. Intervention content and strategies used were based on couples' needs, preferences and objectives, as well as specific theories, models and empirical findings.

Conclusion: This study can assist nurses involved in different domains of practice and interested in developing and evaluating theoretically based dyadic interventions.

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1. Introduction

Parkinson disease (PD) is a common chronic condition and a leading cause of disability among elderly persons (Canadian Institute for Health Information, 2007). Worldwide, this degenerative disease affects more than 6.3 million persons (European Parkinson's Disease Association, 2013), the majority of which are community-living seniors cared for by an elderly spouse (American Parkinson's Disease Association, 2010). It is at the moderate stage that persons with PD (PWPD) require assistance and their spouses begin to assume their caregiver role (Bogard, 2010). This transition alters the functioning and quality of life of couples, who generally assert being ill-prepared for the multiple changes they must deal with PD progression (Roger & Medved, 2010). Because of the aging population, an expected increase of 50% in the incidence rate of PD over the coming decades (Neurological Health Charities Canada, 2014) will be translated into a greater number of couples requiring specific support interventions.

In a systematic review of the literature, Hempel, Norman, Golder, Aguiar-Ibanez, and Eastwood (2008) showed that caregivers of

PWPD were typically attributed the role of adjunctive therapist and expected to perform the activities of a daily living coach, such as for physical exercises and negative thought management. These authors recommended that future studies develop and evaluate theory-based interventions centered on the specific needs of PWPD and their caregivers. Moreover, given that PD progresses across various stages and affects individuals differently, it is necessary to take into account the stage of the illness, the age of the PWPD and the caregivers, as well as their kinship tie. Finally, as Hempel et al. (2008) pointed out that, given the nature of PD, it is surprising that no systemic approach and no family intervention had been identified.

A meta-analysis by Martire, Schulz, Helgeson, Small, and Saghaifi (2010) confirmed the promise held by interventions centered on couples living with a chronic disease. According to these authors, these couple-oriented interventions contributed, among other things, to improve spousal coping strategies, dyadic functioning, and the experience of the disease, particularly in terms of stress and anxiety management, self-efficacy, and control over changes caused by the disease. The findings of this meta-analysis suggested, also, that the most successful interventions might be those tailored to the needs of individual couples. Finally, the authors recommended that investigators explicitly reference the theories or models underpinning the development and evaluation of interventions and identify the targets for change. As noted by other researchers (Sidani &

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* Corresponding author at: Centre hospitalier de l'Université de Montréal, 1560, rue Sherbrooke Est, local GR-1184, Montréal, (Québec), Canada, H2L 4M1. Tel.: +1 5148908000x26395; fax: +1 5144127139.

E-mail address: line.beaudet.chum@ssss.gouv.qc.ca (L. Beaudet).

Braden, 2011), the design of theory-based interventions allows elucidating their essential components.

2. Purpose

Against this backdrop, a pilot study with the aim of developing, implementing and qualitatively evaluating a dyadic nursing intervention for elderly couples living with moderate-stage PD was conducted with a view to promote positive functioning between spouses and facilitate their transition experience. The primary focus was on examining the acceptability of the dyadic intervention (content, structure, process) and its usefulness for these couples seen in clinical practice.

The transitions theory developed by Meleis, Sawyer, Im, Hilfinger Messias, and Schumacher (2000) was selected as this middle range theory allows exploring and understanding health and illness transition experiences, transition facilitators and constraints, and the outcomes of successful transitions, which include coping, self-efficacy, and satisfactory relations with family, friends and formal services. However, as transitions theory does not consider dyadic transitions specifically, we also used the systemic approach developed by Wright and Leahey (2009). Consistent with transitions theory (Ducharme et al., 2009), this approach affords strategic points of reference useful for the conceptualization and evaluation of a dyadic intervention that targets better spousal functioning principally in the areas of communication, problem solving, and role adjustment. Transitions theory and the systemic approach also served to design the study's data collection tools.

3. Method and results

This qualitative study comprised four steps that drew on the intervention mapping (IM) process developed by Bartholomew, Parcel, Kok, and Gottlieb (2006): 1) assessing couples' intervention needs, preferences and objectives; 2) developing and validating a dyadic intervention proposal; 3) formalizing the dyadic intervention; and 4) testing and evaluating the dyadic intervention.

IM is a logical, rigorous, participative, reflective and iterative process that serves to guide intervention planning and evaluation (Bartholomew et al., 2006). It incorporates experiential data derived from the views of the target population and other stakeholders (e.g., service providers), different theories and models, and empirical evidence in intervention development and examination (Sidani & Braden, 2011). The target population's intervention needs, preferences and objectives guide the selection of relevant theories or models, the choice of intervention methods and strategies to achieve these objectives, and the specification of the intervention's content, structure and process (Bartholomew et al., 2006).

The study's couples were recruited with the help of a nurse case manager and three neurologists in a movement disorders clinic in the province of Quebec, Canada. The couples signed a consent form approved by the research ethics board of a tertiary hospital.

3.1. Step 1—Assessing couples' intervention needs, preferences and objectives

The intervention needs, preferences and objectives of elderly couples at the moderate stage of PD were explored to develop and validate a dyadic intervention proposal.

3.1.1. Sample and procedure

Couples were selected following a purposive sampling method based on theoretical criteria to facilitate transferability of the intervention to a larger number of dyads who visit the clinical setting. In order to obtain a sample of couples exhibiting typical variations

seen in clinical settings, the selection criteria were that the person affected be 65 years old or over and living with moderate-stage PD. Participants were men and women with high educational level (>12 years of schooling) and low educational level (\leq 12 years of schooling). Finally, couples where at least one member was clinically diagnosed with anxiety or depression, by a neurologist or a family doctor, were recruited as well.

The number of couples ($N = 10$) was determined by data saturation, that is, a redundancy of themes (Morse, 2000) to emerge from dyadic interviews (i.e. needs, preferences and objectives in this study). The PWPD (six men, four women) had a mean age of 69 years, as did the spouse-caregivers, and had about 12 years of schooling. Finally, one-half of the couples presented with anxiety or depression. The nurse case manager (B.Sc.N. and 6 years' experience in neurosciences and geriatrics) and the three neurologists (specialized in movement disorders with more than 15 years' experience with PD) who helped with recruitment also took part in a focus group at this step of the study to corroborate the emerging themes with experiential data from their clinical practice and to point out the strengths, resources (e.g., professional, material) and limitations (time, space) of the clinical setting for enhancement of capacity in the intervention development (Bartholomew et al., 2006).

3.1.2. Data collection and analysis

Semi-structured interview guides were designed to explore the intervention needs, preferences and objectives shared by the couples, and to validate these with the service providers' perspective. Mean duration of joint interviews was 90 minutes with the couples and 45 minutes with the service providers. Each of the interviews with the couples was recorded and transcribed verbatim. The transcripts were read, revised, analyzed, interpreted, categorized and coded by the first two authors. The case-oriented approach proposed by Miles and Huberman (2003) was selected for cross-case or cross-dyad analysis. Intra- and inter-dyad matrices were completed in order to identify, compare and group the couples' main intervention needs, preferences and objectives. The matrices allowed systematic visualization of all the condensed cases at once. The findings from the cross-case comparisons were shared with the service providers. Finally, regarding the group interview with the service providers, the transcript was analyzed following the previously mentioned process.

3.1.3. Results

Six recurring themes related to intervention needs emerged from the data analysis (see Table 1, column 1): 1) recognize the importance of changes and challenges faced with PD; 2) take care of one's health, well-being and quality of life as a couple; 3) solve various problems associated with PD effectively and prevent conflicts; 4) establish links with community groups and service providers; 5) develop skills to communicate effectively (between spouses, with family, friends, healthcare service providers, and others); and 6) adjust, assume and master different roles. The participating couples also identified specific objectives (see Table 1, column 3). These referred to behavioral outcomes that they expected to achieve after each session or at the end of the intervention. When asked about their preferences regarding the structure and process of a possible intervention, the majority of the couples expressed a preference for being met as a couple rather than separately or in a group with others. They recommended six dyadic or joint sessions with a nurse, each 60 minutes long, once every 2 weeks, at home or in clinical setting, at the couple's convenience.

The service providers recognized the importance of the intervention needs and objectives identified by the participating couples and all responded favorably to the preferences expressed regarding the number, duration, frequency and location of nurse-couple sessions.

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