

RESEARCH ARTICLE

Effects of self-management education for persons with Parkinson's disease and their care partners: A qualitative observational study in clinical care

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Abstract

Persons with Parkinson's disease and their care partners want support from health care to develop the skills to handle everyday life with the long-term condition. Earlier findings indicate that participants of the self-management program Swedish National Parkinson School experience several benefits of the program. The purpose of this qualitative observational study was to explore if participants had implemented the strategies of self-monitoring included in the program and use them to communicate health care status and needs in clinical encounters. Data were collected 3 to 15 months after participation in the program and analyzed using constant comparative analysis. Three categories were evident: "Self-observation in everyday life," "Self-care activities to promote health," and "Managing emotional impact of Parkinson's Disease." Categories were linked together in a core category that highlight the use of self-management strategies described by participants during clinical encounters. Results confirmed that persons with Parkinson's disease and care partners use the techniques of self-observation in their everyday lives. Observations of effects in clinical care can be a valuable approach to evaluate the outcomes educational interventions and their benefits for individuals and health care.

KEYWORDS

clinical care, follow-up studies, Parkinson's disease, patient education, qualitative research, self-management

1 | INTRODUCTION

Parkinson's disease (PD) is a neurodegenerative disorder affecting about 1% of the population over 60 years old. Diagnosis increases with advancing age and peaks around the age of 80. With longer life expectancy in the general population as well as improved treatments for PD, the prevalence of persons affected is expected to double over the coming decades (Ascherio & Schwarzschild, 2016; Dorsey &

Bloem, 2018; Kalla & Lang, 2015). PD is a disease with both physical and mental symptoms that will affect many aspects of everyday life not only for the person affected by disease but also for the care partners (Kalla & Lang, 2015; Schapira, Chaudhuri, & Jenner, 2017). Persons with PD (PwPD) and their care partners have a long-term need for close and regular contact with health care but daily treatment and care is performed mainly by PwPD themselves and the care partners at home and in community as a part of everyday life (Baudet

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et al., 2015). Accordingly, PwPD and their care partners want support from health care to develop emotional and cognitive strategies and skills to deal with fear of the future, to adjust to life with chronic disease and live well despite PD.

1.1 | Background

PwPD will experience motor symptoms, that is, slowing of movements, rigidity, resting tremors, balance and gait problems due to degeneration of dopaminergic neurons in the brain (Kalla & Lang, 2015). PD also generates nonmotor symptoms, that is, depression, anxiety, cognitive impairment, constipation, pain, sleep disturbances, and orthostatic hypotension (Schapira et al., 2017). These symptoms have a negative impact on the quality of life for PwPD and cause strain to their family (Kadastik-Eerme, Rosenthal, Muldmaa, & Taba, 2015; Mosely, Moodie, & Dissanayaka, 2017).

Good medical treatment is available but only symptomatic and will not stop or halt the progression of the disease (Schaeffer & Berg, 2017). As the disease progresses, the burden of symptoms increases, and symptoms will be more unpredictable (Kadastik-Eerme, Taba, Asser, & Taba, 2017). Although PwPD need regular health care visits, including evaluation of symptoms and adjustment of medical treatment the majority of care and management of disease is performed by the person themselves and their family in in everyday life (Baudet et al., 2015; Lageman, Mickens, & Cash, 2015). PwPD and their care partners want help and support from health care in order to develop emotional, cognitive, and practical skills to handle everyday life and maintain life satisfaction (Berger et al., 2017; Sturm, Folkerts, & Kalbe, 2019; Vlaanderen et al., 2019).

Patient education strengthen a person's abilities and boost self-efficacy to become actively involved in self-care (Grey, Schulman-Green, Knafel, & Reynolds, 2015). Self-management is defined as the ability of a person, in collaboration with family, society and health care, to handle symptoms, treatments, lifestyle changes, psychosocial strain, and other consequences of disease (Wilde & Garvin, 2007). Self-management interventions are designed to help persons with long-term conditions deal with different aspects of disease in everyday life such as symptom control, medication and emotional reactions. Interventions targeting cognitive processes and inner motivation can boost self-efficacy and improve self-management skills more than educational approaches alone (Van Hooft, Been-Dahmen, Ista, Van Staa, & Boeijeh, 2016). Self-monitoring refers to cognitive processes including observation and assessment of symptoms or activities of daily living leading to self-awareness. Techniques to enhance self-monitoring are often part of the skills included in self-management interventions. (Wilde & Garvin, 2007).

In 2002, EduPark, a European collaboration, initiated development of a standardized education for PwPD and care partners. This resulted in a self-management program called "Patient education for persons with PD and their carers" (PEPP). It is based on knowledge and experiences from cognitive behavioral therapy. The purpose was to provide PwPD and their care partners with tools and strategies to increase their ability to manage everyday life with PD and to promote

life satisfaction (Smith & Simons, 2006). The program was tested and evaluated in seven European countries but it has not been evaluated clinically how the participants use the learned strategies in everyday life after attending the program (A'Campo, Spliethoff-Kamminga, & Roos, 2011; A'Campo, Spliethoff-Kamminga, et al., 2010; A'Campo, Wekking, Spliethoff-Kamminga, Le Cessie, & Roos, 2010). Inspired by the PEPP, a Swedish program, the National Parkinson School (NPS), was developed in 2013. NPS is a dyadic self-management program and self-monitoring as well as self-management are central concepts of the program (see Supporting Information Appendix 1).

The NPS has been implemented in clinical practice in Sweden since 2014. A previous study indicated that the participants experienced several benefits including support from people in the same situation and improved social connection to family, society and health care as well as improved knowledge of strategies and cognitive techniques to monitor symptoms and change behaviors to understand, adapt to and handle PD better. It also increased awareness of the need to adapt a positive mindset and outlook on life and to prioritize activities that promote feelings of well-being and satisfaction with life (Blinded for Hellqvist, Dizdar, Hagell, Berterö & Sund-Levander, 2018).

2 | PURPOSE

The purpose was to study whether PwPD and care partners implemented the strategies of self-monitoring included in the self-management intervention NPS and use them in clinical encounters with health care professionals.

3 | METHODS

3.1 | Design

This was a qualitative inductive study using observation and follow-up interviews and analyzed using constant comparative analysis.

This study is the first to our knowledge to study effects and outcomes of a self-management educational program for PwPD through observations in a clinical practice setting. Previous studies evaluating outcomes of self-management programs for PwPD either report the participant's view and experience through qualitative interviews or evaluate outcomes using scales measuring, for example, quality of life, mood and everyday functioning (A'Campo et al., 2011; Baudet et al., 2015; A'Campo, Spliethoff-Kamminga, et al., 2010; A'Campo, Spliethoff-Kamminga, Stijnen, & Roos, 2012; A'Campo, Wekking, et al., 2010; Hellqvist et al., 2018; Macht et al., 2007).

3.2 | Participants

PwPD who had previously attended the self-management intervention NPS and were cared for at the neurologic or geriatric outpatient clinics of a Swedish university hospital were asked to participate in

the study. Participants were informed that the clinical encounter between the PwPD, care partner and treating physician was in focus. Purposeful and consecutive sampling was used. Two PwPD declined to participate due to a heavy symptom burden. Three geriatric and five neurologic physicians gave permission for observations during a routine visit. All PwPD were familiar with their physician and they had met several times before. All data were collected in an outpatient clinical setting at the hospital. The length of time that had passed from participation in the NPS to the time the data was collected varied between three to 15 months. The duration of disease varied between one to nine years with a range of severity according to Hoehn and Yahr (1967) with participants in stage I ($n = 2$), stage II ($n = 2$), stage III ($n = 5$), and stage IV ($n = 1$). In total, 10 PwPD and three care partners participated in the study.

3.3 | Data collection

Data was collected through observations and interviews between April 2016 and January 2019. The first author was responsible for all data collection, both observations and interviews. Before the consultation, the first author would briefly greet the participants and again inform them about the purpose of the study and the two-part method of data collection, with observation followed by a short interview. Data collected was transcribed as close to the time of collection as possible.

The clinical encounters observed always included some common processes and actions. The initial phase of the visit lasted for about 10 min and included greetings and reconnection both on an intrapersonal level as well as to review what had been discussed last time. Next, physicians invited PwPD and care partners to share their perspective on life and symptoms of disease by asking them "How are you feeling?" Physicians listened carefully and asked questions to clarify or get further information. This phase was 20 to 30 min long and followed by a review of the current medication and a physical examination including PD-specific tests of motor function. At the end of the visit, the physicians summarized the main points of what was said during the visit, including eventual changes in medical treatment. The physicians also informed patients when to expect the next visit or phone contact for evaluation. Each visit observed lasted about 45 to 60 min. The first author collected observational data as a silent observer, writing down information with pen on paper as the clinical encounter unfolded. To reduce the influence on the interaction between physician and PwPD, the first author was sitting in a chair in a corner of the examination room. An observational guide was designed for this study, focusing on the relational interaction and social processes and the content of the topics discussed during the consultation. Immediately following the consultation with the physician, the first author collected the participants' views of the meeting through a short interview. An interview guide was designed for this purpose. Probing questions were used to explore answers further if needed. The interviews were conducted in a separate room at the outpatient clinic without the physician present. The interviews varied

in length between 3 and 22 min. Most of them were about 15 min long.

3.4 | Ethical considerations

The study was approved by the regional ethical review board (EPN) in Linköping, Sweden (reg. no 2014/497-31) and conducted in accordance with the guidelines in the declaration of Helsinki (World Medical Association, 2013) including written and oral information about the study as well as the collection of written consent from all participants.

3.5 | Data analysis

Data were analyzed using constant comparative analysis that focuses on the general processes in a meeting rather than on the experiences of individuals (Glaser, 1965; Glaser, 1978; Glaser & Strauss, 1967; Heath & Cowley, 2004). This method was suitable because the focus of this study was to identify and analyze how participants used the learned self-management strategies in the clinical encounter rather than exploring the individual strategies to handle specific situations in everyday life.

Three researchers were involved in the analysis. All data with the same participant were considered as one dataset and analyzed as such. In the first step, all the transcribed data from observations, interviews, and field notes were compared to the raw material to ensure accuracy.

Through an open coding procedure, each dataset was examined thoroughly to identify words or phrases of importance to answer the research question. Meaningful parts were extracted from the text to form substantive codes. The substantive codes from each set of data were then compared to the substantive codes from all other sets of data. Through this comparison, patterns and similarities amongst the codes were found, resulting in the formation of conceptual categories at a more abstract level. The categories were compared with the substantive codes and transcribed data to confirm relevance. The relations between categories were investigated through comparison and theoretical coding.

Finally the comparison of categories and the relations among them resulted in identification of a core category.

3.6 | Validity and reliability

The first author was responsible for all data collection and transcription to ensure the similarity of the procedure and limit the researchers own preunderstanding of the topic to affect data. When data were collected and transcribed all three researchers first analyzed data independently. To ensure reliability of the analysis, comparisons were then made of the three researchers' coding and categorization. Discrepancies were discussed and resolved. This form of researcher

triangulation strengthens the validity and rigor of the findings of this study (Patton, 2002).

4 | RESULTS

Three distinct categories were evident and constructed from the data: "Self-observation in everyday life," "Self-care activities to promote health," and "Managing the emotional impact of PD." These categories are linked together in the core-category: "Awareness of own abilities strengthens mutual understanding and communication in the health care encounter." The core category is the essence of all data brought together and answering the research question. The categories and core category are at an abstract level and the examples of quotations and excerpts provided for each of them are grounded in empirical raw data (see supporting information Appendix 2).

4.1 | Core category: "Awareness of own abilities strengthens mutual understanding and communication in the health care encounter"

As a starting point of the clinical encounter, all physicians would ask PwPD and care partners to talk about how they experienced and handled symptoms of PD in everyday life. With the basis in this personal narrative physician, PwPD and care partners then collaborated during the visit to find a common understanding of the situation. This mutual understanding functioned as a platform that justified any changes in medication or treatment suggested during the visit. The personal narrative stood out as fundamental for the quality of contact and communication in the encounter as well as the medical outcome of the visit.

The awareness of PwPD and care partners of the challenges of living with PD as well as their own abilities and strategies to handle them was key to self-management of the disease in everyday life. In the clinical encounter the understanding of what is important information to share with a physician was crucial. In the clinical encounter, PwPD would look to the physician for expert advice about medical treatment and PD-related questions concerning facts and knowledge at a more general level. The physicians would in turn look to the PwPD for the specific knowledge and understanding of the life situation and symptoms of the particular person in front of them.

The observational as well as the interview data revealed that many PwPD themselves had good knowledge and understanding of the complexity of the disease and the diversity of symptoms. They understood the challenge faced by physicians in treating and relieving symptoms and recognized the need for medication to be tailored to the specific person and the person's specific symptoms.

According to the participants, there were several aspects of great importance for the quality and satisfaction with the consultation. The continuity of contact with the same physician was much appreciated since building trust and confidence in a relationship was considered a gradually developing thing. To find the right connection during the

encounter, not only as physician and patient, but between two humans at a more personal level was stressed by many participants as valuable.

Being listened to and having the opportunity to tell the physician about how life with PD was experienced was key. To be able to ask and get answers to questions about PD and medication was important. The physician's genuine interest and efforts in trying to figure out problems and also to suggest a strategy for help or relief was central. Having enough time with the physician to explain one's life situation was a prerequisite for a fruitful meeting.

The process of the physician as the expert in medical knowledge, and the person as the expert of living with PD exchanging information to form a common ground and understanding is fundamental to achieving a better medical regimen and symptom control. It also boosts motivation and confidence to perform self-care activities for PwPD. Awareness of one's own abilities and the ability to communicate this will strengthen the therapeutic relationship and trust between PwPD and physician. It is a prerequisite for high quality and person-centered care.

4.2 | Self-observation in everyday life

During a clinical consultation, PwPD would frequently share multiple examples of self-observation performed in everyday life. Most of these self-observations were related to symptoms of disease and intake of anti-Parkinsonian medicine. The description of symptoms included both motor symptoms, that is, stiffness, tremors and other problems with movement, as well as neuropsychiatric and cognitive symptoms, sleep disorders, pain, and symptoms related to food intake and obstipation. PwPD noticed that their symptoms would fluctuate throughout the day, often with a distinct pattern repeating itself. Participants would tell about specific times and hours of the day when they would feel better or worse in their PD symptoms. There were also descriptions of self-observation of symptoms and well-being in relation to time of medicine intake, the dosage of medicine and time of food intake.

PwPD presented several descriptions of how different activities performed in everyday life affected their emotional state and well-being in different ways. They had also observed changes in their personality due to PD including being more emotional and less tolerant of stressors occurring in everyday life. Care partners also shared their observations of PD symptoms they had noticed in their partner.

4.3 | Self-care activities to promote health

PwPD themselves or together with their care partner engaged in several types of self-care activities. Activities were carried out to avoid worsening of the symptoms and progress of the disease but also to promote feelings of well-being and happiness. Most PwPD had worked out a schedule for intake of medicines, and self-adjusted the medication times so they would not interfere with intake of food.

Other self-care activities concerning medicine were to set mobile phones with an alarm that would go off at every medication time and to take pills with yoghurt instead of water to make swallowing easier. As PD and medication will often lead to problems with orthostatic hypotension, several patients had blood pressure monitors and would regularly check their blood pressure at home. Constipation was handled and avoided by drinking extra liquids, eating particular types of laxative foods, and drinking coffee.

PwPD had worked out their own strategies to help facilitate chores that were challenging in terms of motor difficulties, such as turning in bed at night, getting out of a car seat or putting socks on. They would sometimes also show the physician what the strategy was during a consultation.

All PwPD engaged in some form of physical activity in everyday life, such as walking, gardening, or biking, to maintain muscle strength, balance and mobility. Some participants also attended classes with targeted training to cope with the specific symptoms of Parkinson's disease. PwPD stated they gained feelings of both physical and psychological well-being from being physically active.

Self-care activities were not only targeted toward medical treatment or controlling the physical symptoms of disease. Several participants described the psychological impact of disease and the importance of trying to keep a positive mindset to relieve feelings of downheartedness or anxiety. They had recognized a need to prioritize activities that they enjoyed, such as painting, meeting friends and family, spending time with pets, woodworking, listening to music, and birdwatching.

Seeking information was also a self-care strategy for PwPD. Sources of information were the Internet, books, and exchanging experiences with other persons also affected by PD, such as people in a patient organization.

4.4 | Managing the emotional impact of PD

Although they tried to keep a positive mindset and outlook on life, participants described feelings and emotional reactions related to their disease. They felt anxious thinking about the future, being afraid that their symptoms would increase over time, eventually hindering them from keeping up the activities they enjoyed in life. Several participants said that they had already had to adjust their activities as a result of the disease and were afraid that eventually they would not be able to continue at all. Fears also included worsening of memory problems and not being able to manage in their own home anymore. PD had also led to changes in personality and mood evident to PwPD themselves and their family and friends. PwPD mentioned increased sensitivity and decreased ability to handle stressful situations, greater frequency of emotions like sadness and worry, and a decreased ability to multitask or be in environments with a lot of stimuli. Some felt that performing the actions required to handle the symptoms of disease was becoming more and more like a full-time job and that PD had taken over life totally. There was no time left in life to do anything else but try to cope with disease all day and all night. Strategies to lift

themselves up included downward comparison to the situations of others. To cope with the own life situation it was a comfort for PwPD and care partners to know there was always someone else even worse off. A comforting thought was also that there were all kinds of other diseases with a worse prognostic outcome, and PD was at least a disease that worsened only slowly.

5 | DISCUSSION

The core category "Awareness of own abilities strengthen mutual understanding and communication in the health care encounter" point out that educational interventions can have an impact on participants own understanding of PD and the abilities available to handle everyday life. The value of educational interventions for PwPD are evident for both health care professionals providing this kind of support in clinical care as well as for the participants, but the research evidence for effects of this type of interventions are scarce (A'Campo, Spliethoff-Kammaing, et al., 2010; A'Campo, Wekking, et al., 2010; Chenoweth, Gallagher, Sheriff, Donoghue, & Stein-Parbury, 2008; Kessler & Liddy, 2017). Measuring the long-term effects and efficacy of educational interventions for PwPD has proved to be difficult. Studies using traditional outcome measures such as HRQoL or depression scales have shown short-term improvements but have failed to show long-term effects with repeated measures 6 to 12 months post intervention (A'Campo et al., 2012; Nelson, Wong, & Lai, 2011). Failure to measure long-term effects could have several reasons. Possibly the scales used have not been suitable to measure outcomes of educational interventions and/or too blunt and imprecise to measure effects, and due to the design of many studies not looking at long-term effects. In some cases, not being able to detect significant outcome may also be due to progression of PD over time or the effect of confounders (Kessler & Liddy, 2017). In an attempt to evaluate effects from a different angle, this study set out to see if the effects of the self-management program NPS could be detected in observations of routine clinical consultations.

This observational study of the clinical encounters confirmed that PwPD and care partners had adopted the techniques of self-observation, introduced during the NPS, in their lives. Self-monitoring was used as a strategy to motivate acts of self-management in order to improve symptom control and satisfaction in life. The use of self-monitoring to gather information was also employed as a strategy to communicate PD-related symptoms to the physician during consultations. Knowing and using techniques of self-monitoring and ability to communicate self-observations during clinical encounters provide a one way for PwPD and care partners to be actively involved in decisions about care and medical treatment. The wish of PwPD to be involved in decisions concerning their own care has been recognized in several studies (Eygelshoven et al., 2017; Grosset & Grosset, 2005; Weernink et al., 2016). Self-monitoring as a cognitive tool has been used for many years in cognitive behavioral therapy to help people handle psychiatric disorders, leading to a better understanding of the self and of emotional reactions (Cohen, Edmunds, Brodman,

Benjamin, & Kendall, 2013; King & Boswell, 2019) and has been helpful in managing other types of chronic physical diseases as well (Andersson & Oakinci, 2018). The results suggest that teaching self-monitoring also to PwPD and their care partners helps them with handling the symptoms of disease. Even 3 to 15 months after participation in the NPS this strategy was still used very frequently in everyday life.

Abilities and skills in self-monitoring in combination with knowledge about PD and the strategies of medical treatment discussed in the NPS increased the courage and motivation of PwPD and care partners to engage in self-management activities in everyday life. This promoted self-efficacy and feelings of being in control of their own lives. Several self-management strategies were used to handle both physical as well as psychological symptoms of disease in everyday life. PD will affect life not only for the person affected by the disease but also their whole family. In this study, care partners were often present during clinical encounters and involved in discussions about symptoms and treatment. An educational approach for PwPD, like the NPS, that will also include family members can be helpful to improve understanding of symptoms, acceptance of the disease, and the family's commitment to finding strategies to cope with the symptoms of disease in everyday life. Involvement and educational interventions for care partners and family have also been recognized as an area of improvement and have been found beneficial in previous studies (A'Campo, Spliethoff-Kamminga, et al., 2010; Baudet et al., 2015; Berger et al., 2017; Fereshrehnejad, 2019; Kessler & Liddy, 2017; Schwartz, Zulman, Gray, Goldstein, & Trivedi, 2018).

In this study, PwPD and care partners expressed feelings about changes in life as a result of PD during the clinical encounters with physicians. Several previous studies have shown that PD non-motor symptoms such as loss of memory, frequent falls, and changed personality and mood are associated with a reduced quality of life for both PwPD and family (Fereshrehnejad, 2019; Sjö Dahl Hammarlund, Westergren, Åström, Edberg, & Hagell, 2018; Hiseman & Fackrell, 2017). These symptoms are often difficult to treat with medications, and PwPD as well as the family need to find ways to adapt to and cope with these changes caused by the disease (Berger et al., 2017; Sjö Dahl Hammarlund et al., 2018; Kleiner-Fisman, Gryfe, & Naglie, 2013). Previous studies have also identified wishes and unmet needs for PwPD and care partners for emotional support, as well as strategies to cope with these aspects of disease in medical care (Kleiner-Fisman et al., 2013; Hellqvist & Berterö, 2015; Vlaanderen et al., 2019; Van der Eijk, Faber, Al, Munneke, & Bloem, 2011). The NPS includes strategies to handle emotional strain caused by PD and this could be one intervention offered by health care to address these unmet needs.

Introducing techniques of self-monitoring is an approach that could be helpful to PwPD in order to understand and sort symptoms and reactions of disease. Self-monitoring can help PwPD to gain information and insight into their own reactions and symptoms and can function as a motivator for self-care actions and to evaluate the effects of these actions. This can help PwPD regain some feelings of control and boost self-efficacy and ability to handle everyday life.

6 | CONCLUSION

Awareness of one's own abilities strengthens mutual understanding and communication in the health care encounter point out that educational intervention can have a positive impact on participants. A fruitful exchange of information between medical expert and patient expert is crucial for providing every PwPD with high-quality, personally tailored care. When designing self-management programs for PwPD and care partners the inclusion of self-monitoring techniques is beneficial. Studying the effects of patient education through observations in clinical care is one approach to evaluate these interventions. Although observational studies using a qualitative approach will include a relatively small number of participants this method will result in rich and extensive data describing real-world interactions. Observations as a way of collecting data is valuable as it will allow the researcher to witness processes and interactions directly as they occur in the intended setting and study how it is actually done in practice. Observations can highlight disparities between reported practice and actual practice and deepen understanding of what works in clinical care and what does not. This approach might be a useful in generating additional scientific proof of the benefits and outcomes of patient education. The results show that NPS as a self-management intervention for PwPD and care partners is valuable. The NPS has an impact on participants on a personal level as well as on the outcomes of medical care. Although this study is restricted to a small number of participants, it adds valuable insights in the use of self-management strategies in everyday life of PwPD and their families. This study contributes to the limited evidence in research supporting the value and effectiveness of self-management interventions for PwPD and their families.

7 | RELEVANCE FOR CLINICAL PRACTICE

Self-management interventions are beneficial for PwPD and care partners as they can boost self-efficacy and function as a motivator to engage in self-care activities in daily life. Educational interventions like the NPS that focus on self-monitoring and self-management of symptoms in everyday life should be offered as a part of routine clinical care. Studies and evaluations of these types of programs not only show benefits for PwPD and family in terms of managing everyday life but also lead to improved communication of patient needs and thereby the ability provide high quality, personally tailored care in clinical consultations. Self-management interventions should be designed to be easily implemented into clinical care, considering the amount of time and resources available. Nurses working to support this group should make educational interventions a priority.

CONFLICT OF INTEREST

No conflicts of interest.

AUTHOR CONTRIBUTIONS

Idea for study: C.H. and C.B.

Study design: C.H. and C.B.

Data collection: C.H.

Data analysis: C.H., C.B. and M.S.-L.

Manuscript writing: C.H., C.B., N.D., P.H., and M.S.-L.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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