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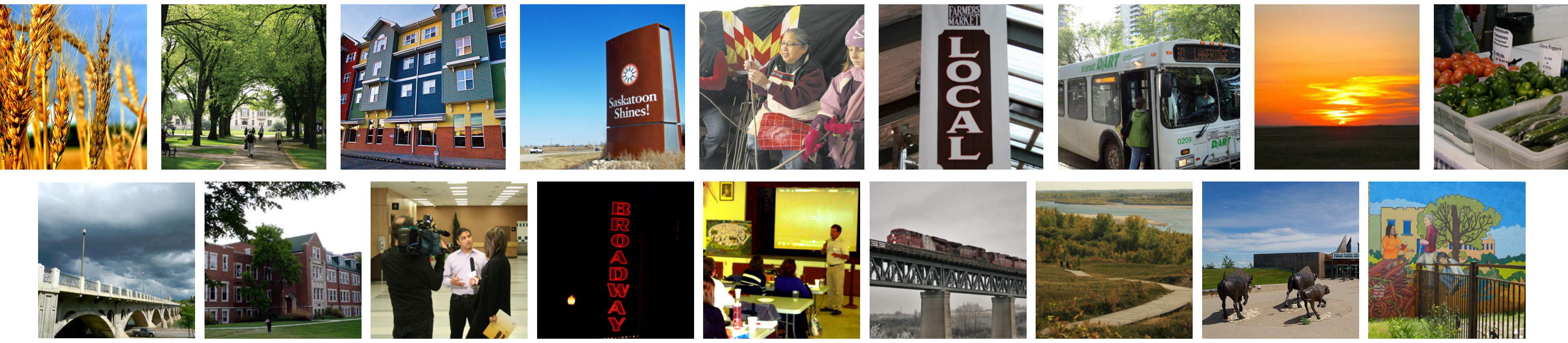
Parkinson Society Saskatchewan: Working Together to Meet Member Needs

A Research Report

Tamara Chambers-Richards, Rawia Ahmed, and Isobel M. Findlay



Community-University Institute for Social Research

Building healthy, sustainable communities

Since 1999, the Community-University Institute for Social Research (CUISR)—formally established as a university-wide interdisciplinary research centre in 2000—has remained true to its mission of facilitating “partnerships between the university and the larger community in order to engage in relevant social research that supports a deeper understanding of our communities and that reveals opportunities for improving our quality of life.”

Strategic Research Directions

CUISR is committed to collaborative research and to accurate, objective reporting of research results in the public domain, taking into account the needs for confidentiality in gathering, disseminating, and storing information. In 2007 CUISR adopted five interdisciplinary strategies:

1. Saskatoon Community Sustainability
2. Social Economy
3. Rural-Urban Community Links
4. Building Alliances for Indigenous Women’s Community Development
5. Analysis of community-university partnerships

These strategic directions extend our research organized until 2007 in three modules—quality of life indicators, community health determinants and health policy, and community economic development—the result of efforts to address health, quality of life, and poverty that led to the formation of CUISR to build capacity among researchers, CBOs, and citizenry.

CUISR research projects are funded largely by SSHRC, local CBOs, provincial associations, and municipal, provincial, and federal governments. Beginning in 2007, CUISR’s reputation for high quality community-based participatory research (CBPR) enabled us to diversify our funding by responding to community agency requests to conduct research projects for them for a fee.

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Knowledge mobilization: CUISR disseminates research through newsletters, brown bag luncheons, reports, journal articles, monographs, videos, arts-based methods, listserv, website.

Portal bringing university and community together to address social issues: CUISR facilitates partnerships with community agencies.

Public policy: CUISR supports evidence-based practice and policy at these tables: provincial Advisory Table on Individualized Funding for People with Intellectual Disabilities, Saskatoon Poverty Reduction Partnership, and Saskatoon Regional Intersectoral Committee (RIC).

Student training: CUISR provides training and guidance to undergraduate and graduate students and encourages community agencies to provide community orientation in order to promote positive experiences with evaluators and researchers.

PARKINSON SOCIETY SASKATCHEWAN: WORKING TOGETHER TO MEET MEMBER NEEDS

A RESEARCH REPORT

TAMARA CHAMBERS-RICHARDS, RAWIA AHMED, AND
ISOBEL M. FINDLAY

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ACKNOWLEDGEMENTS

WE ACKNOWLEDGE THE PARKINSON SOCIETY SASKATCHEWAN (PSS) for initiating and providing the funding to undertake this project and the generous support and direction of Executive Director Travis Low throughout the process. We thank the many participants who gave of their time and shared their experiences by completing surveys, participating in focus group discussions, and engaging in personal interviews. We are grateful too to Pat Duggleby and the PSS board for their valuable feedback on report drafts.

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ABSTRACT

A progressive neurodegenerative disease impacting 4,000 people, their families and friends, in Saskatchewan as well as 100,000 Canadians (85 percent over the age of 65), Parkinson's is expected to double in incidence by 2025 (with related increases in social and economic costs) in the context of an aging Canadian population. With no cure currently, Parkinson's progresses at different rates requiring various treatments and therapies and the interventions of diverse health professionals to manage and to support people's quality of life. Parkinson Society Saskatchewan (PSS) as part of a national federation of Parkinson societies is "the voice of people living with Parkinson's" committed to improving quality of life through its four service pillars: advocacy, education, research, and support. Understanding better its members' needs is a critical part of PSS efforts to increase awareness, enhance outreach, improve operations and services, and fulfil its mission.

Against this background, the aim of this research study was to evaluate PSS programming to identify program and service gaps, understand stakeholder needs across diverse communities in Saskatchewan, and recommend where services and service delivery might be improved within the mandate of the organization. The evaluation focused on the experience of PSS members and caregivers.

Data were collected throughout the province of Saskatchewan from September to December 2013 through the completion of 40 questionnaires administered online and in print to people living with Parkinson's and care partners, four focus group discussions, an interview of a person living with early onset Parkinson's, and four key informant interviews. The focus group discussions were conducted with 5-15 people living with Parkinson's and their care partners and support group facilitators as a means of capturing additional data that may not have been gathered by the surveys.

The following services of PSS were found by participants to be vital to coping with the disease: support groups which are well supported, information package, the Parkinson Press newsletter and the website: parkinsonsaskatchewan.ca. The strengths of PSS included a passionate board; professional, helpful, and knowledgeable staff; numerous current educational resources; and a strategic national research agenda program helping to raise the profile of Parkinson's. However, there are several areas in which improvement to services would

heighten PSS's ability to achieve desired outcomes. The major areas include increasing capacity and enhancing visibility and reach of PSS; organizing educational and resource materials according to the needs of people living with Parkinson's and care partner and disease progression; directly enriching quality of life by providing and/or improving services to those whose disease has significantly progressed; enhancing advocacy as well as care partner support; establishing more support groups across the province; and increasing collaboration with health professionals.

In conclusion, PSS has clearly defined mission, vision, and goals. PSS should continue to build on what it does well and map out a clear strategy for increasing its capacity to support member needs. It is prudent for PSS to use its mandate as a tool for developing organizational processes that will ensure that services are consistent with the needs of the entire population it seeks to serve, and which will translate into established and measurable outcomes.

INTRODUCTION

Parkinson's, a degenerative brain disease prevalent in developed countries associated with longer life spans, impacts the lives of 100,000 Canadians, 85 percent of whom are over the age of 65, as well as 4,000 people, their families and friends, in Saskatchewan. In an aging Canadian population, Parkinson's is expected to double in incidence by 2025 to 23.6 percent of the population (Parkinson Society Canada, 2003), increasing the social and economic costs of the disease by some estimates to as much as $1 billion within decades (Kleiner-Fisman, Gryfe, & Naglie, 2013). With no cure currently, Parkinson's progresses at different rates requiring various treatments and therapies and the interventions of diverse health professionals to manage and to support people's quality of life. The Parkinson Society Saskatchewan (PSS) mission is to be "the voice of people living with Parkinson's" committed to improving quality of life through its four service pillars: advocacy, education, research, and support (Parkinson Society Saskatchewan, 2014). Understanding better its members' needs is a critical part of PSS ongoing efforts to increase awareness, enhance outreach, improve operations and services, and fulfil its mission.

Incorporated in 1972, PSS is one of the regional partners of Parkinson Society Canada, the national not for profit volunteer-based charity acting as the voice of people with Parkinson's in Canada by providing education, support, and advocacy services (Parkinson Society Canada, 2014). In its mission to improve quality of life, PSS is guided by its vision--"Together we will create a better life with a brighter future for people living with Parkinson's today and a world without Parkinson's tomorrow"—and its four foundational pillars of service (Parkinson Society Saskatchewan, 2012). Moreover, along with all other regional partners of Parkinson Society Canada, PSS is committed to these values: "People with Parkinson's first, collaboration, compassion, creativity, transparency, and empowerment" (Parkinson Society Canada, 2012).

To determine if it is meeting its challenges and addressing the needs of its members, PSS took the initiative to partner with Community University Institute for Social Research (CUISR) in evaluating its current programming offered to people with Parkinson's (PWP) and their care partners in Saskatchewan.

The purpose of this evaluation is to understand stakeholders' needs across diverse communities (urban and rural, small and large) and identify service and service delivery gaps so that PSS can better serve PWP and fully meet its mandate of improving quality of life of PWP and their care partners. The study was guided by these research questions:

- Is there consistency between services and service delivery and the mission and goals of PSS?
- Is the population being served that needs to be served?
- Are populations in small and large centres served equitably?
- Do processes contribute to desired outcomes?

- Are the desired outcomes being achieved?

This report presents the context and background for the evaluation of the PSS programming, includes a literature review and environmental scan covering the best practices adopted by different organizations providing services to PWP and care partners, a methodology section explaining primary and secondary research conducted, as well as the research findings and conclusions.

LITERATURE REVIEW

The Parkinson Society Canada (PSC) (2014) defines Parkinson's as "a neurodegenerative disease," adding, "Movement is normally controlled by dopamine, a chemical that carries signals between the nerves in the brain. When cells that normally produce dopamine die, the symptoms of Parkinson's appear." When 70% of these cells are lost, symptoms start to reveal themselves. Research has not yet discovered why these nerve cells die, but it is known that dopamine levels continue to decline over years leading to appearance of new symptoms (Heisters, 2011). Gazewood, Richards, and Clebak (2013) describe the "cardinal features" of Parkinson's as "bradykinesia, rigidity, tremor, and postural instability" (p. 267); in other words, it "can cause shaking and stiffness, and make you move more slowly" (p. 267). PSC (2014) lists other symptoms: fatigue, soft speech, problems with handwriting, stooped posture, constipation, and sleep disturbances.

About 70% develop tremors (Heisters, 2011). Extreme sleepiness and related accident risk (Breen, Williams-Gray, Mason, Foltynie, & Barker, 2013), depression impacting 35 percent of PWP (Leentjens, A. F. G., et al., 2013), and memory loss are among other "debilitating" symptoms. To manage these symptoms, PWP are usually administered "a carefully balanced combination of medication. The timing of this medication is crucial" for PWP to avoid the risk of symptoms worsening (Heisters, 2011, p. 182). The second most common neurodegenerative disease, the subtleties of differential symptoms can make diagnosis difficult (Alves, Forsaa, Pedersen, Gjerstad, & Larsen, 2008).

According to PSC (2014), the average age of Parkinson's onset is 60 years; however, young onset (before the age of 40) of the disease occurs in 5% - 10% of those diagnosed and 20 percent are under 50. A diagnosis of early onset can produce "shock, fear and confusion" at an "unexpected life hurdle," and the beginning of a difficult journey to take "charge of [the] disease" and know what you can control so that you can be active and proactive in "optimiz[ing] your health" and learning "to live well with this disease" (Dr. Soania Mathur; cited in Ravenek, 2014, p. 3).

A critical part of gaining control is becoming informed about the disease, learning from the professional experts as well as PWPs, keeping records of symptoms and medications, participating in trials, and exercising for "self-care" (Mathur; cited in Ravenek, 2014, p. 4). Even if people often don't want to know, "read as much as you can about the disease" in good, credible sources, never fear asking questions or looking stupid—"If you've got a questions, it's a legitimate question"—and keep a positive perspective so that you can "explore potentials . . . that you never explored before" with the right supports in place (Ravenek, 2014, pp. 13-19).

Many of the characteristics of Parkinson's in young onset differ with the onset age; for example, the impairment progresses more slowly, young onset are "more sensitive" to medications, but "less likely" to progress to dementia, and more likely to continue to work for years. If the physical challenges can be taxing, PWP (25-35 percent of whom are active in the workforce) also face a range of professional, personal, and financial issues impacting the whole family. In these cases, support groups can prove enabling (PSC, Young Onset, 2014). And disclosing to your family helps with planning for your collective futures, while talking to a lawyer can be helpful on employment rights and counselling can help navigate change (Ravenek, 2014). According to one study participant, exercise can make a huge difference: "Exercise, exercise, exercise, I can't say that enough. Find something you like and just do it. . . . I'm so much more positive when I exercise . . . and just feel great." Another claimed, "Exercise is my new drug for Parkinson's" (Ravenek, 2014, p. 35).

Prevalence and Risk Factors of Parkinson's

The development of PD is thought to be influenced not by "a single factor, but by "a complex interaction of genetic and environmental factors" (Göbel, et al., 2012). Multiple risk factors include age, gender (especially in males over 60 in the West), genetic, and non-genetic (occupational, environmental, and lifestyle) factors (Alves et al., 2008; Kieburtz & Wunderle, 2012; Schapira & Jenner, 2011). According to Alves, et al. (2008), Parkinson's "is found in all ethnic groups," although differently prevalent geographically and especially associated with developed countries (p. 19). Alves et al. state that about 1-2% of people aged 65 are PD patients, while 3 - 5% of people aged 85 or older have the disease, numbers predicted to grow in an aging Canadian population (PSC, 2014). Lix, Hobson, Azimaee, Leslie, Burchill, & Hobson (2010) found in their Manitoba study a 66.6 percent increase in PD cases between 1987-1988 and 2006-2007.

Additionally, prevalence and incidence rates for PD are associated with lower socioeconomic status. In fact, common to all chronic diseases, the rate at which PD is increasing is considerably higher in the lowest income groups in both urban and rural areas (though "less apparent in rural regions"). Thus "equity-oriented policies about access to healthcare resources" are critical (Lix, et al., 2010, p. 335). Studies suggest a link between PD, rural living and pesticide exposure, especially among younger people (Costello, Cockburn, Bronstein, Zhang, & Ritz, 2009; Narayan, S., et al., 2013; Wang, Cockburn, Ly, Bronstein, & Ritz, 2014). Costello, et al. (2009) argue that "the critical window of exposure to toxicants may be years before the onset of motor symptoms which lead to diagnosis" (p. 922). Other risk factors include traumatic brain injury with particular risks associated with the number and duration of injuries, although divergent study results suggest a need for further research (Kieburtz & Wunderle, 2013; Morley & Duda, 2013).

Access to Services

The increase in the number of Canadians diagnosed with Parkinson's is matched by an increase in service for PWP and their care partners. Today, the medical care of PWP across Canada is managed by doctors specializing in family medicine, geriatrics, general neurology, and movement disorder neurology (Burkholder & Mortensen, 2006). Medical care is supplemented by social and allied health services. Both disease-specific education and "multidisciplinary intervention programs" have proven especially effective in improving quality of life (Kleiner-Fisman, Gryfe, & Naglie, 2013). However, according to Burkholder and Mortensen (2006), access to social workers, physiotherapists, occupational therapists, speech therapists, and counsellors is dependent on the capacity of the existing services; and access to specialized care in rural and/or remote areas has always been difficult for those coping with Parkinson's. In keeping with this challenge, despite the key roles of PSC and its regional partners, they state that there is a "growing concern that there will not be enough specialists and healthcare providers in Canada" to provide adequate care for PWP in the next twenty years (p. 9).

In addition, gaps in services experienced by PWP are not so much associated with treating physical symptoms of the disease as with emotional and social difficulties as well as the legal and financial worries experienced by those living with the disease. Although online access to information can be beneficial, only 1 percent of the top 100 of 4.6 million webpages on Parkinson's have been found understandable for the average person (Kleiner-Fisman, et al., 2013). Inequalities also exist in these areas: "access to specialist Parkinson's nurses; long waits to see a specialist; poor access to therapy services; lack of support for carers of people with Parkinson's; poor access to mental health services for those that need them; and social care support that is inadequate and hard to access" (Parkinson's UK, 2009). Other gaps identified involve education on the dosage and timing of medications, the relationship between diet and medications, and management of common drug side-effects (Kleiner-Fisman et al, 2013). The Parkinson's Disease Foundation of the US (2014), in a statement on Managing your Medications, also suggests that PWP receiving treatment for five years or more may find it complicated to monitor medication doses and schedules. This is because as the disease progresses, PWP need to track more medications and closely monitor schedule of doses to provide effective relief of symptoms.

There is also a deficiency in meeting the palliative care needs in the current Canadian health-care model and an over-estimation of physician "time spent on educating patients." There is evidence to suggest that these services should be both multi-disciplinary and team-based so that PWP and their families can receive comprehensive and effective support tailored to their needs (Giles & Miyasaki, 2009, p. 124). Many support associations and Parkinson's organizations have provided recommendations for services to be utilized by PWP whose healthcare utilization is higher as the disease progresses (Hobson et al, 2012). People with Parkinson's and their care partners have stated consistently the ways in which they may be better served through services such as “financial support in terms of pension, equipment and home modification; respite and home support for carers; transport; access to allied health services; regular contact with associations particularly in rural areas; information about condition and treatment; education of service providers; improved public understanding and awareness; and for dedicated programs for these special conditions” (Aoun, Kristjanson, & Oldham, 2006, p.17).

Challenges with Parkinson’s are faced not only by PWP but also by clinicians faced with management of the disease. These include “the need to be more skilled in responding to varying patient expectations and values, readiness to meet a more diverse, aging and chronically ill patient, and an expectation to work in teams despite not being trained in team-based skills” (National Parkinson Foundation, Allied Team Training for Parkinson’s, n.d.).

ENVIRONMENTAL SCAN OF PARKINSON’S ORGANIZATIONS

In July 2012, Parkinson Society Canada, movement disorder specialists from major Canadian movement disorder centres, including functional surgery specialists, family physicians, nurses, physiotherapists, and methodologists combined efforts to produce the Canadian guidelines on Parkinson’s Disease for health care professionals to promote the standard of, and access to, care for Parkinson’s disease patients across Canada (Grimes et al., 2012). The guidelines covering four areas—“Communication,” “Diagnosis and Progression,” “General Treatment Considerations,” and “Non-motor Features of PD- Mental Health”— founded on the “best published evidence” are suitable for the Canadian Health Care system, “policy makers, funding bodies”, PD patients, and their caregivers (Grimes et al., 2012, p. 1).

In addition to this Canadian effort, to be reviewed in 2014, organizing bodies in many countries arrange conferences hosting experts and speakers to share information about the latest news and medical research about Parkinson’s. Among the major organizing bodies is the World Parkinson Coalition Inc. which is “a non-profit organization dedicated to providing an international forum to learn about the latest scientific discoveries, medical practices, caregiver initiatives and advocacy work related to Parkinson’s disease” (World Parkinson Coalition, 2014). Over 3300 people from 64 countries gathered to attend the latest World Parkinson Congress (WPC) 2013 in Montreal (earlier congresses were held in Washington and Glasgow). They left with increased knowledge about ongoing scientific and clinical research as well as new friendships and many opportunities for socializing with people around the world who experience similar challenges. Barker (2013) reported on the Montreal congress’s mission “to enable the dialogue and better understanding of the diseases by linking those with the condition and those seeking to help treat it at whatever level” (p.1). He continued, “the programme is an interesting mix – ranging from detailed science to live performances of patient inspired artistic endeavours” (p.1). Some of the 120 educational sessions topics covered were Parkinson's disease and cancer, new genes and risk factors of PD, non-motor manifestations of Parkinson's disease, music, creativity and Parkinson's, and benefits and risks of genetic testing (World Parkinson Coalition, 2014).

One of the major organizations serving PWP and their care partners is the National Parkinson Foundation (NPF) based in the USA. It adopts many practices that could be implemented in Canadian organizations serving PWP with many services that are perceived as "needed" by PWP interviewed in the focus groups during the research process of this report. With a mission "to improve the quality of care for people with Parkinson's disease through research, education and outreach" (NPF, 2014) and many programs similar to those offered by the PSC, NPF has nevertheless some unique services to offer. In 2011, as a consequence of the release of its Parkinson's Toolkit, a smart application offering evidence-based data on Parkinson's targeted at healthcare professionals, Parkinson's Central was launched to offer PD patients and their caregivers information related to Parkinson's diagnosis: the "ins and outs of medication management," "getting the most of the doctor's visit," living well with Parkinson's, finance and insurance, and a special section for caregivers (NPF, 2014, Parkinson's Central Smartphone App, p.1-2). In addition to these features, the "Near me" feature makes it possible for PD patients to know where to find support groups and healthcare professionals in their community . The Parkinson's Toolkit and Parkinson's Central are among the valuable educational tools of the NPF.

According to Tarsy (2012), the uncertainties associated with the diagnosis of a chronic illness are frightening. In the early period of the diagnosis, the PD patient should collect data about the symptoms and available treatment alternatives. As the literature suggests, it is also common that PD patients worry about financial matters and their social well-being (Tarsy, 2012). On the NPF website, a PD patient can get information on treatment options, including motor symptoms medications, surgical treatment, complementary therapies such as supplements and herbs, exercise, and telemedicine care (a popular option for patients in remote, rural, and underserved areas). In addition to conferences, workshops, webinars, the Allied Team Training for Parkinson program, and the Aware in Care kit, special sections on the NPF website are dedicated to educate PD patients about their legal rights, financial planning, and insurance products and options.

As medical sciences advance, and the potential increases to identify "specific genetic markers implicated in various diseases," experts in Canada are concerned that those medical advances could result in the withholding of coverage and benefits by insurance companies and employers (Weeks, 2012, para.16). While Canadian legislation along with the Canadian Human Rights Act has protections for people with disabilities, there are no protections for "future disability. . . . Nor does it prevent discrimination from taking place; rather, it offers remedies after discrimination has occurred" (Watton, 2009). In a Canadian study, Bombard et al. (2009) reported 39.9 percent of people at risk of Huntington's disease had experienced discrimination: 29.2 percent in insurance, 15.5 in family, 12.4 in social settings, 6.9 in employment, 8.6 in health care, and 3.9 percent in public sector, although family history rather than genetic testing was the main source of discrimination. The current situation in Canada which is expected to worsen with the increasing availability of genetic tests has brought together 15 organizations including the Parkinson Society Canada in the Canadian Coalition for Genetic Fairness (2009) to educate and to lobby governments for change. They are confident that they have Canadians behind them when a 2003 poll found 91% agree that insurance companies should have no access to “their genetic information for insurance assessment.” Additionally, 90% of Canadians believe that employers shouldn’t access this type of information of existing or potential employees (Watton, 2009).

By contrast, under the Americans with Disability Act (ADA), Parkinson’s patients who meet the definition of disabled are protected by the ADA (Michael J. Fox Foundation, 2014). The Genetic Information Non-Discrimination Act (GINA) is a federal law that protects Americans from being discriminated against based on DNA genes that might affect their health. The law protects people from being unfairly treated on the basis of gene differences by health insurers and employers, although it “does not cover life insurance, disability insurance and long-term care insurance” (National Human Genome Research Institute, 2014). Although under this law and other American laws there is no discrimination on grounds of race, gender, age or disability, Parkinson’s patients may lose their jobs, if they cannot perform their jobs competently. According to The Michael J. Fox Foundation, a PD employees therefore “may not want to ‘come out’ at work until [they are] ready to ask for accommodation, as outlined in the ADA” (2014, para.5).

These are among the issues that Parkinson Society Canada, the national voice of PWP in Canada, and its regional partners address in advocacy, education, research and support to PWP. In Saskatchewan, in 2003, the Saskatoon Health Region announced the opening of Saskatchewan Centre for Parkinson’s Disease and Movement Disorder to offer PD patients outstanding patient care and carry on the research activities on Parkinson’s and movement diseases (Saskatoon Health Region, 2003). Dr. Rajput, director of the Centre, described the Centre as “unique” for the number of medical doctors and PhDs who collaborate within the centre to better patient care and to further understand these illnesses (Saskatoon Health Region, 2003). Live Well Parkinson is another program organized by the Saskatoon Health Region among other health regions to help people with Parkinson exercise and improve their quality of life (Saskatoon Health Region, 2014, Live Well Parkinson’s).

In addition to those services, each regional partner offers extra unique services and/or programs. Parkinson Society of British Columbia (PSBC) (2014), for example, is mainly concerned with the “personal and social consequences of Parkinson’s disease through education, community outreach, scientific research, advocacy and public awareness.” The website includes educational material addressing personal and social aspects of the disease. For example, to help PWP maintain their cognitive health, a separate section on the website details definitive activities and games to be exercised by PWP to maintain the language, speech, visual scanning, multitasking, planning, problem solving, memory, calculation and coordination of diagnosed people. Another example is the website section designed for caregivers. Ample recommendations are presented to caregivers either specific to caregiver type (family, friend, health care professional) or generic information to help them cope, avoid burnout, and plan care for the future. Moreover, nine support groups are uniquely developed for caregivers. For those who want to help, there are many different possibilities for donating money, stock or securities, creating a fundraising event and including the organization in one’s will, or making a gift in honor or memory of a beloved one and/or becoming a member and volunteer.

The PD Link program offered by PSBC connects PWP or their care partners, who prefer not to or are unable to attend the support groups, and/or who want to get in contact with persons in the same situation but live far from a support group or prefer one to one conversations with other volunteers who have similar experiences.

Parkinson Society of Eastern Ontario (PSEO) – Ottawa, Cornwall, Gananoque, Perth, and Pembroke—has exclusive services such as annual comedy nights (Parkinson Society of Eastern Ontario, 2014). As well, PSEO developed a survey for health care professionals to gauge their awareness of the Canadian Guidelines on Parkinson's disease. An eight-week speech and swallowing program is also developed by PSEO to assist PWP in enunciation, volume and energy of speech, and swallowing issues.

Parkinson Society of Southwestern Ontario (PSSO)—Essex, Chatham-Kent, Lambton, Elgin, Middlesex, Huron, Perth, Bruce, Grey, Oxford, Waterloo, Dufferin, Brant, Norfolk, and Haldimand and area of Wellington County extending east to Highway 18—has special PWP and care partner services such as "train the trainer" Parkinson Education Program (PEP) for community care givers to help PWP to enjoy a better quality of life, reduce hospital stay periods, have PWP with advanced symptoms stay longer in their homes, and make the caring easier on caregivers. Additionally, monthly facilitators' E-Newsletters are published by PSSO for support group facilitators to share with their support groups. Moreover, PSSO provides consultation services either in person or by phone to PWP or their caregivers who need to talk with someone knowledgeable about Parkinson's and be compassionate about their concerns (PSSO, 2014).

Parkinson Society Central and Northern Ontario (PSCNO)—areas west to Niagara Falls, east to Kingston and regions north of this area including Guelph, Peterborough, Barrie, Collingwood, Sudbury, Manitoulin Island, Timmins, Kirkland Lake, Sault Ste. Marie and Thunder Bay— shares advocacy priorities with the rest of Ontario: interdisciplinary care, caregiver support, access to drug therapy, and income security. As part of its fundraising efforts, it offers a wedding favor program through which couples can donate on behalf of their wedding guests. Through choosing among tent cards, large inserts, and thank you letters or certificates, they can communicate their donation to their guests on their wedding day (PSNO, 2014).

The Parkinson Society Manitoba website (PSM) informs PWP and their caregivers about their possible eligibility for tax credits and disability benefits. Detailed explanation and contact information are provided. PSM has created free DVDs with information collected from actual support group meetings and regional conference specifically for those who cannot attend the support group meetings or who do not have support groups nearby. Topics include an introduction to Parkinson's, drug therapies, exercise, nutrition, and caregiving.

Parkinson Alberta has unique services such as singing sessions, dancing, bowling, massage, and social programs for PD patients. "Research indicates that singing may help improve some of the speech problems commonly associated with PD; it is also a great mood lifter" (Parkinson Alberta, 2014). In addition, Parkinson Alberta has a counselling service that helps PD patients feel in control of their situation and to help them develop management strategies (Parkinson Alberta, 2014).

Parkinson Society Maritime Region offers the option for businesses to advertise on its website. Similarly, volunteers are offered the opportunity to participate in research about Parkinson's (Parkinson Society Maritime Region, 2014).

Parkinson Society Quebec uniquely presents a variety of fundraising events, such as circus acrobats evenings, Great Hiking Parkinson to raise funds for research and support services, Charity Challenge Scotiabank, and the Parkinson Bike Challenge that is devoted to raise funds for educational tools for PWP and healthcare professionals to name some (Parkinson Society Quebec, 2014).

Parkinson Society of Newfoundland & Labrador provides very similar services to those offered by Parkinson Society Saskatchewan.

Canadian Health Care Public Policy

In terms of public policy, specifically Canadian health care policy, the Canadian Healthcare Association (CHA) argued for government funding of facility-based long-term care as a significant part of the health care system, underlining the growing numbers of Canadians being diagnosed with degenerative brain illnesses such as Alzheimer's and Parkinson's who have to pay for long-term care facilities should they need them (CHA, 2009). The CHA (2009) was critical of the fact that Canadians suffering from acute illnesses such as heart disease and cancer receive full insurance for hospital and physician services, while Canadians who suffer from chronic illnesses or have disabilities and who may need long-term care facilities rather than hospital services must pay for this service. This extra financial burden in addition to the chronic disease- related financial commitments as well as an example of "bias by disease type" that "has evolved in public policy development" (CHA, 2009).

METHODOLOGY

This study commenced in September 2013 after obtaining ethics approval from the University of Saskatchewan's Behavioural Research Ethics Board (Beh-REB). The applications are evaluated based on the extent to which matters of informed consent of participants, voluntary participation of participants, and protection of individual privacy are met. The population of this study were people with Parkinson's and their care partners, and data were collected through an online questionnaire that was based on a survey developed by PSS's counterpart in British Columbia. Forty people with Parkinson's and care partner participants responded. Four focus groups were held in large urban as well as smaller rural communities. As well, there were in depth interviews with key informants. In the beginning, the surveys were available only online to those participants interested in taking them. Later, the process was adjusted to accommodate potential participants who may not have had access to computers or the internet. Therefore, surveys were printed, and the voluntary involvement of possible participants was solicited, either in focus groups or in support group meetings. The research team contacted the organizer of the Parkinson's exercise group at one exercise facility for permission to administer the surveys to PWP (Appendix A) and their care partners (Appendix B). This new approach proved to be successful in increasing the number of survey respondents.

The focus groups were conducted across the province, took approximately 90 minutes and were attended by 5-15 participants each. The first focus group participants were support group facilitators who were invited by the Executive Director of Parkinson Society Saskatchewan. They represented 10 support groups throughout the province. The second focus group was arranged by contacting large urban centre support group facilitators who encouraged PWP and their care partners to attend. The third and fourth focus groups took place in two smaller communities in Saskatchewan and were arranged by communicating with their support group facilitators. The focus group discussions were conducted using a general guide that was developed by CUISR researchers in collaboration with PSS (Appendix C).

The key informant interviews took approximately 45-60 minutes each following a key informant interview guide that was created by the CUISR research team (Appendix D). The selection of key informants was partially based on the background of each key informant participant, the recommendation of community partners at PSS, the availability of key informants for interview, and the nature of information needed for the study. The results of the audio-taped interviews are represented in this report in aggregate form with no personal reference to any participant.

The analysis process started with the coding of the survey questions and the survey data were analyzed using the Statistical Package for Social Sciences (SPSS) software program. The audio- taped focus groups and key informant interviews discussions were transcribed and their findings analyzed and discussed together with the findings of the surveys in the "Findings" section of the report.

FINDINGS

A total of forty (40) surveys were completed. Twenty-three (23) surveys were completed by people living with Parkinson's and seventeen (17) by care partners. The survey for People with Parkinson's was divided into four (4) sections:

1. Demographic Information
2. Parkinson's and You
3. Services and Information
4. Parkinson Society Saskatchewan (PSS) and You

The survey for care partners of people with Parkinson's was similarly organized into four (4) sections:

1. Demographic Information
2. Parkinson's and You:
    a. Parkinson's and Care Provision
    b. Impact of Parkinson's on Care Partners
3. Services and Information
4. Parkinson Society Saskatchewan and You

A Survey for People with Parkinson's

Demographic Information

The participants were mostly male, with 73% men and 27% women responding. Their ages ranged from between 50 and 89 years; 41% of respondents were between 70-79 years, 36 % between 60-69 years, while the remainder were between 50-59 years (9%) and 80-89 years (14%). The majority (91%) of participants lived with spouse/partner while the remaining lived with other family members or in a care home. Regarding employment status, 80% were retired, while 10% each were on long-term disability due to Parkinson's, or were employed part time. The average annual household income was $60,000.00.

Parkinson's and You

The majority of participants (95%) reported having Parkinson's disease only while the remaining 5% also had transient epileptic amnesia and peripheral vascular disease. Participants had been living with Parkinson's for a range of 1 – 21 years with the mean number of years being 7. Participants were diagnosed with Parkinson's as young as 40 years and as old as 83 years. The average age of diagnosis was 58 years. On average, people living with Parkinson's generally experience mild to moderate impairment (85%), while 5% experienced no impairment and 10% significant impairment.

In regard to motor symptoms, a significant proportion of participants were finding it a little more difficult to walk (65%), balance (60%), dress (71%), write (40%), speak (61%), swallow (56%), eat (66%), maintain posture (50%), and maintain muscle coordination (58%). Whenever improvements in motor symptoms were noted, they were due to exercise, medication, speech therapy, and deep brain stimulation. Participants also found the following non-motor symptoms a little more difficult since diagnosis with the disease: concentration (88%), memory (82%), emotional balance (77%), independence (77%), social conduct (67%) and motivation (69%). It was found that these symptoms generally improved with medication, taking ownership of the disease, or participating in exercise and support group activities. The majority (95%) of the participants were taking medications for their conditions. The average monthly cost of medications before insurance was $95.59, while the average monthly cost to participants was $29.80.

Services and Information

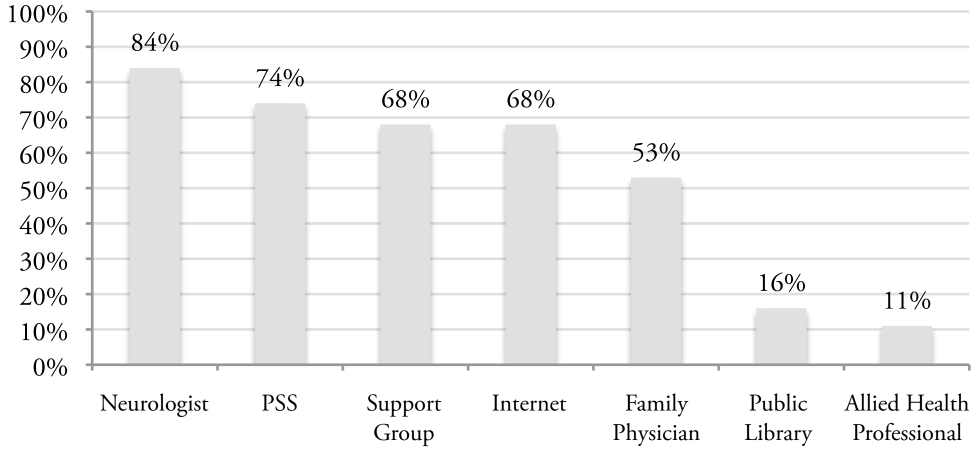
The health-related service that participants found most helpful (Table 1) was that of a physical therapist (72%). They also found the services of a massage therapist to be somewhat helpful (50%) and very helpful (10%). The other services—dietician/nutritionist, occupational therapist, speech and language therapist, swallowing therapist, public health nurse, psychologist and psychiatrist—were also found to be unavailable, not helpful at all or posed no interest to participants.

Table 1. Relative Importance of Services

Services	**Not Available**	**Very helpful**	**Somewhat helpful**	**Not helpful**	**Not interested**
Dietician/Nutritionist	14%	__	14%	29%	43%
Massage Therapist	10%	50%	10%	30%	__
Occupational Therapist	16%	17%	17%	__	50%
Physical therapist	9%	37%	36%	__	18%
Speech & Language Therapist	16%	__	17%	17%	50%
Swallowing Therapist	20%	__	__	__	80%
Public Health Nurse	20%	__	20%	__	60%
Psychologist	33%	__	__	17%	50%
Psychiatrist	40%	__	__	__	60%

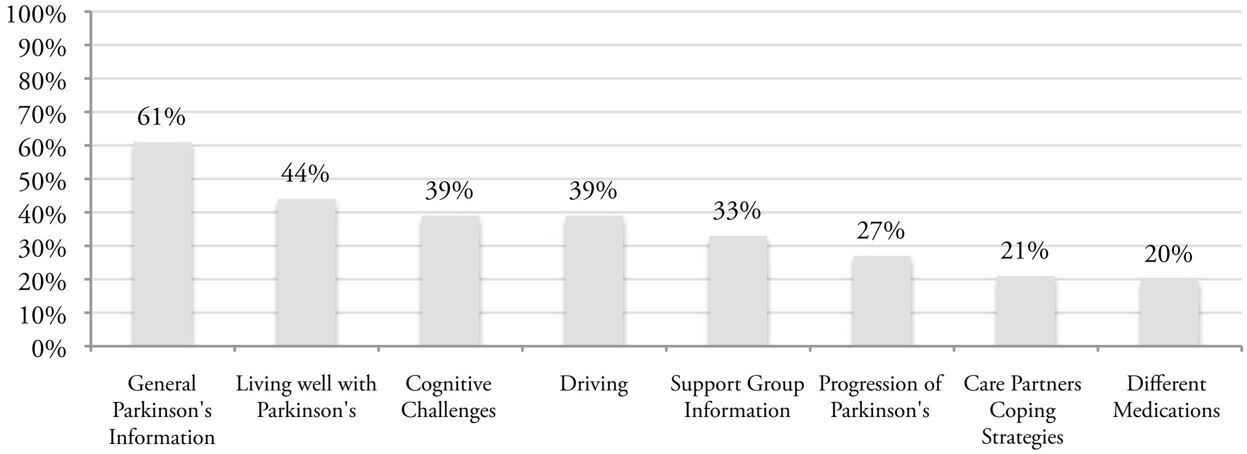
Participants obtained information (Figure 1) about Parkinson's disease predominantly from neurologists, Parkinson Society Saskatchewan, support groups, and the internet.

Figure 1. Where Participants Get Information about Parkinson's



The information which was most important or valuable to participants with Parkinson's (Figure 2) was general information on Parkinson's—the latest research, treatments, and symptoms (61%). The following topics comprise information that participants felt was important in helping them to cope: living well with Parkinson's—exercise and nutrition; cognitive challenges and driving; support group contact information, tips for progression of Parkinson's; care partner self-care or coping strategies, and types of Parkinson's medications.

Figure 2: Importance of Information about Parkinson's to PWP



There was variance in responses to satisfaction with healthcare staff's (barring neurologists) level of knowledge of Parkinson's disease—68% did not respond, while 23% were very satisfied and 9% were somewhat satisfied.

Parkinson Society Saskatchewan and You

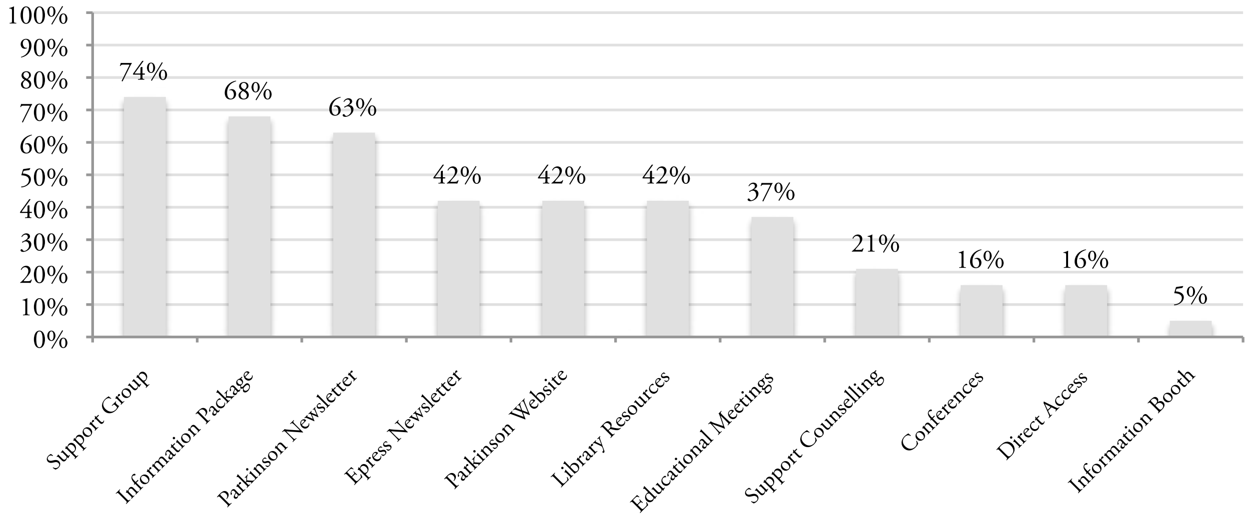
a. Awareness of PSS

The majority (95%) of participants were not aware of PSS before diagnosis while 33% first became aware of the organization through referral by a physician or healthcare professional. Other sources of initial awareness included support group (28%), relative or friend (17%), PSS member, newspaper or magazine (11% each). A large percentage (63%) of participants had never contacted PSS while of the 37% who had made contact, 60% used the telephone, 53% email, and 33% made contact in person.

b. Value of PSS Services to Participants

In reference to the services and activities provided by the PSS (Figure 3), more than half of the participants ranked the following services as very valuable or somewhat valuable: support groups (74%), information package (68%), and Parkinson Press newsletter (63%); while the following services were mostly ranked as not valuable at all or not applicable: information booth at fundraisers, direct access to information and referral service, education conference, support counselling, and educational meetings and conferences.

Figure 3: Value of Services and Activities Provided by PSS



The participants suggested that services could be improved if PSS could be more visible allowing them to rely less on their own initiative to educate and inform themselves. They further suggested that PSS could devise ways of reaching clientele in their communities rather than expecting them to travel to meetings. They also felt that PSS could play a role in educating general practitioners on Parkinson's; get brochures on display in neurologists' offices; and assign staff members to attend monthly support group meetings to address new developments. Topics that were suggested for future educational meetings or conferences were information about the latest research findings, positive encouragement such as exercise ideas, coping strategies for various activities or jobs, recipes and advice on food, help with the issue of protein and medication, and information on focused ultrasound.

c. Attendance at Support Group Meetings

Support groups are well-supported: attendance reported in 2013 being 53% attending 6-8 meetings, 26% attending 2-5, 11% attending 10 or more, and 10% attending 0-1. The factors influencing attendance at meetings were ranked as follows: choice of topic (47%), group dynamic (42%), time conflicts with other commitments (42%), and proximity of meeting (32%).

d. Quarterly Parkinson Press Newsletter Access and Use

When asked about use of the quarterly Parkinson Press newsletter, 24% stated that they did not receive it; an additional 24% read only articles that caught their interest while 35% read it cover to cover. Participants would like to read about success stories, local research and the opportunity to participate in trials, recent research findings, as well as useful physical exercise regimens, relevant activities that can be engaged, and more about the link between protein, swallowing, and absorption of medications.

e. Parkinson Society Canada Fundraising Initiatives

Fundraising activities are undertaken by Parkinson Society Canada, in part, to support its national research program. There is inconsistency in regards to the level of awareness of the Parkinson Society Canada National Research Program as 59% stated they were not aware of this program while 41% stated that they were aware. Of the 58% that participate in PSS fundraising activities, 47% support SuperWalk (the largest Canadian fundraiser with walks in over thirty communities in Saskatchewan), 11% support Lows in Motion (entertainment activities suitable for all ages), 6% Shake, Rattle and Roll (a one-day motorcycle rally event), and 18% other activities such as Step and Stride (Alberta's annual walk) and tulip sales (the red Parkinson tulip is the national symbol for Parkinson's disease). Fifty-six percent felt that volunteering/donating to PSS compared with other charitable donations was something of a priority while 22% felt that supporting PSS was their first priority.

f. Access to Public Programs and Services

Sixty percent of the participants felt that access to public programs and services for Parkinson's had greatly improved or somewhat improved over the past three years while 40% felt the services had stayed the same.

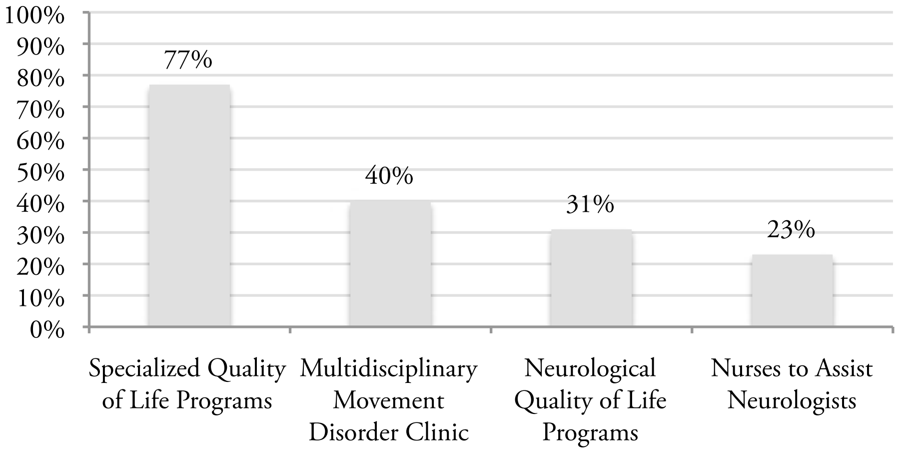
g. Participant Advice to Newly-diagnosed Parkinson Patients

Participants would advise those newly diagnosed with Parkinson's not to panic, "be informed," "stay active," "don't despair," "attend support group meetings," "get comfortable medical help," "use the PSS website," "participate in exercise programs where available," and "do online research." Additionally, participants were interested in information about a possible cure, pleased with the committed staff at the provincial office and expressed satisfaction with the provincial conference held in Regina in April 2013. These participants reported that the best ways to receive communication from PSS was via email (72%), phone (22%), and mail (6%).

h. Rank of Quality of Life Issues

The following issues were ranked by PWP as number one or being most important (Figure 4): access to specialized Parkinson's specific quality of life programs and a Multidisciplinary Movement Disorder Clinic, access to general neurological quality of life programs, and nurses to assist neurologists throughout the province.

Figure 4: Importance of Quality of Life Programs to Persons with Parkinson's



Satisfaction with PSS

In regard to overall level of satisfaction with PSS 84% were very satisfied or somewhat satisfied. Most participants are satisfied with PSS governance and organizational structure (Table 2). Only 7% of the participants were not satisfied with the professionalism, knowledge, and helpfulness of PSS staff, while 77% were satisfied that PSS policies and governance are transparent, sensible, and clearly communicated. Participants expressed high levels of trust in the organization (93%), and in the Board of Directors of PSS (93%).

Table 2: Levels of Satisfaction with PSS Governance and Organizational Structure

Levels of Satisfaction	**Highly satisfied**	**Very satisfied**	**Somewhat satisfied**	**Not satisfied**
PSS Support	50%	14%	29%	7%
Board of Directors	54%	8%	31%	7%
Policies and Governance	23%	31%	23%	23%
PSS Staff	50%	36%	7%	7%

A Survey for Care Partners of People with Parkinson's

Demographic Information

The participants were mostly female, with 18% men and 82% women taking part. Their age ranged from between 50 and 89 years; 29% of respondents were between 70-79 years, and 60-69 years respectively, while 35% were between 50-59 years and 6 % between 80-89 years. The majority (88%) of participants lived with a spouse/partner while the remaining 6% lived with other family members or in their own home.

Regarding employment status, 76% were retired, while 6% were employed either full time or part time self-employed, and 12% were employed part time. The average annual household income among care partners was $60,000.00.

Parkinson's and You

a. Parkinson's and Care Provision

The majority of participants (82%) reported that the person that they cared for was their spouse/partner while 12% cared for a parent and 6% had another relationship with the person with Parkinson's. The average length of time spent caring for a person since diagnosis with Parkinson's was 12 years and the average age of diagnosis of the persons cared for was 63 years. The following are tasks that caregivers help with or perform for persons living with Parkinson's: carrying objects, cutting toenails, helping out of a chair, administering medications, and pushing wheelchair (35%); dressing and undressing (29%); bathing and/or showering (18%); toileting (12%); and eating and drinking (6%).

b. Care Partners' Responsibilities and Concerns

Caregivers have taken on new responsibilities since diagnosis of persons living with Parkinson's. The primary ones are driving (65%); taking to medical appointments (59%); obtaining prescriptions (47%); dealing with finances (35%); taking to other appointments (35%); and other activities such as assisting with walking, cleaning teeth, and loading into vehicles (35%). Only 47% of caregivers were very comfortable leaving people living with Parkinson's alone for a full day. Concerns about leaving the persons alone include fear of them falling or wandering, dementia and inability to complete basic tasks or call for help. The majority of caregivers (88%) do not usually have someone else stay with the person with Parkinson's, while 59% are unsure of respite care available in their area and no one had used respite care since the person living with Parkinson's had been diagnosed. Seventy-seven percent of caregivers were not sure if there were groups or activities provided specifically for care partners.

c. Impact of Parkinson's on Care Partners

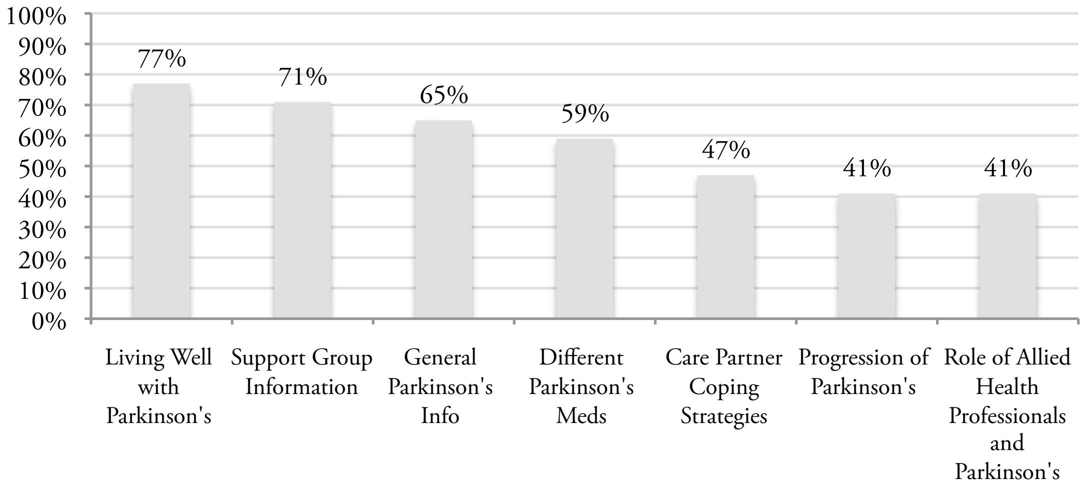
A significant number of care partners (41%) agreed that living with and/or looking after someone with Parkinson's had affected both their mental and physical health. Caring for someone living with Parkinson's affected the health of caregivers because they constantly worried, are sometimes depressed, have to do more of the housework as spouse tires easily, feel confined, and spend less time socializing because it's difficult getting around. Caregivers also reported that they experience more stress and coping is needed.

However, aspects of caregiving were reported to be rewarding: "being together," "helping someone in need of living normally," "developing a positive attitude towards spouse," "being a motivator," and "learning a lot about the disease while sharing experiences."

Services and Information

Care partners obtained information about Parkinson's disease predominantly from the following sources: internet (71%), support group (65%), neurologist (53%), Parkinson Society Saskatchewan (41%), family physician and other allied health professionals (35% respectively). Twelve percent obtained information from books and magazines. The information which was most important or valuable to care partners (Figure 5) was living well with Parkinson's – exercise and nutrition, support group information, general information on Parkinson's – the latest research, treatments and symptoms, different Parkinson's medications, care partner self-care or coping strategies, progression of Parkinson's, and the role of allied health professionals and Parkinson's disease.

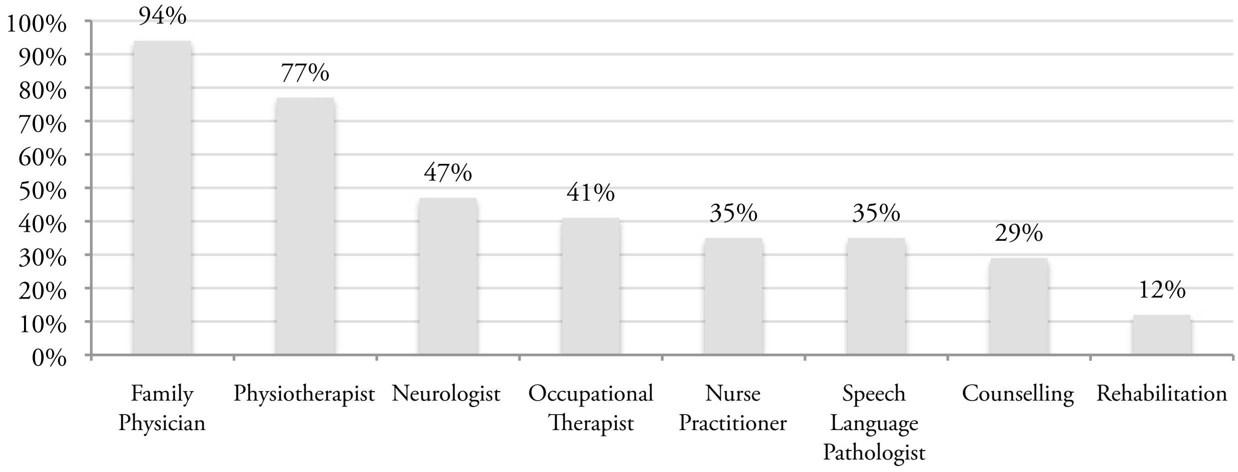
Figure 5: Valuable Information for Care Partners



Availability and Accessibility of Services

Family physician services were reported by the majority as participants and most available and accessible (Figure 6). A significant proportion felt that physiotherapy services were accessible while less than half had access to neurologists, occupational therapists, nurse practitioners, and speech language pathologists. Less than one third reported that counselling and rehabilitation services were accessible.

Figure 6: Availability and Accessibility of Services for PWP



Parkinson Society Saskatchewan and You

The majority (82%) of participants were not aware of PSS before diagnosis of their care partners while 88% first became aware of the organization through a PSS member. Other sources of initial awareness included support group (41%), relative or friend (29%), referral by a physician or healthcare professional, internet or website and SuperWalk (12% respectively). A large proportion of care partners (59%) had never contacted PSS while of those who had made contact, 24% used the telephone, 18% emailed, and 12% was in person.

a. Value of PSS Services to Care Partners

In reference to the services and activities provided by the PSS, the following services were cumulatively ranked as very valuable and somewhat valuable: support groups (59%), information package (47%), library books and DVDs (41%), while the following services were mostly ranked as not applicable to care partners: direct access to information and referral service (100%), education conference (94%), support counselling and information booth at fundraisers (88%), website: parkinsonsaskatchewan.ca, ePress newsletter-email, and educational meetings and conferences (82% respectively), and the Parkinson Press newsletter (65%).

b. Support Group Participation

Support groups meetings are considered a vital part of care partners' lives, with attendance in the past year being 31% respectively attending 6-8 or 2-5 meetings, 25% attending 10 or more, and 13% attending 0-1. The factors influencing meeting attendance were ranked as follows: choice of topic and group dynamic (29% each), and time conflicts with other commitments (24%). Suggestions of topics for support group presentations and/or future educational meetings included how to cope with symptoms, the benefits of seeing a physiotherapist, vital support for caregivers, variety and stages of Parkinson's, and directory of neurologists and physical therapists.

c. Quarterly Parkinson Press Newsletter Access and Use by Care Partners

Fifty percent stated that they did not receive the quarterly Parkinson Press newsletter; an additional 31% read only articles that caught their interest while 19% read it cover to cover. Participants would like to read about "success stories," recent research findings and how those affect the next generation, support for all involved with Parkinson's, as well as nutritional, medical and exercise information, and question and answer segments.

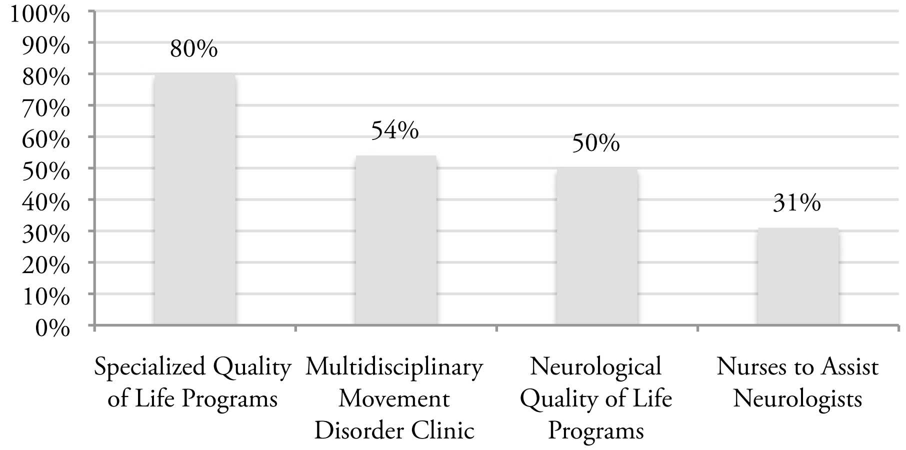
d. Awareness and Support of Parkinson Society Canada National Research Program

In regard to the level of awareness of the Parkinson Society Canada National Research Program, 59% were aware of this program while 41% stated that they were not aware. However, 65% of care partners participate in PSS fundraising activities—41% support SuperWalk, 18% support Lows in Motion, and 24% support other activities such as tulip sales and pledging donations. Twenty seven percent were neutral toward volunteering/donating to PSS compared with other charitable donations while 27% felt that it was somewhat of a priority and 13% felt that supporting PSS was their first priority. One third of participants would give some support but are not overly committed. These participants also reported that the best ways to receive communication from PSS was via email (77%), mail (35%), and phone (29%).

e. Importance of Quality of Life Issues

Quality of life issues were ranked by care partners as most important (Figure 7) in the following order: access to specialized Parkinson's-specific quality of life programs and a Multidisciplinary Movement Disorder Clinic, access to general neurological quality of life programs and nurses to assist neurologists throughout the province.

Figure 7: Importance of Quality of Life Programs to Care Partners for PWP



f. Satisfaction with PSS

In regard to the overall level of satisfaction with PSS, 82% were very satisfied or somewhat satisfied, while 67% had not sought the services of the PSS as they were not applicable. All the care partners were either highly satisfied or very satisfied with their trust in and support of PSS while 91% trusted and supported the Board of Directors of PSS. All were highly satisfied that PSS staff was professional, knowledgeable, and helpful, and 82% were either highly satisfied or very satisfied that PSS policies and governance are transparent, sensible, and clearly communicated.

Focus Groups

Persons living with Parkinson's and Care Partners

These focus group discussions were a means of capturing additional information that may not have been gathered by the survey. Groups which included persons living with Parkinson's and their care partners spoke generally about their experiences with Parkinson's, from diagnosis to the challenges they face daily and what they believe can be done by PSS to improve their quality of life. They also discussed whether or not the services of PSS were meeting their needs and made suggestions for activities and programs that they would appreciate.

Diagnosis with Parkinson's

For people diagnosed with Parkinson's, the general impression was that there is a familial link associated with the disease as evidenced by the following participant quotes: "I was diagnosed with stage 2…my mom had it," "I have two sisters with Parkinson's and one has had it 20 years," "my husband had Parkinson's…his brother had Parkinson's, they were not twins," "I was 55 when I was diagnosed…I had a sister and a brother with Parkinson's". One participant questioned the link between occupational exposure and Parkinson's:

> I felt it a strange thing that I had Parkinson's…in my area, within six square miles are six cases of Parkinson's. I was in contact with a million chemicals and probably had a couple of mishaps and never thought anything about it. Scientists say there's not much you can do about it, but I can't help thinking, is it too late for the linking there with pollutants or could there be a link genetically?

There is little certainty about Parkinson's and limited awareness of where to get information about the disease upon initial diagnosis. To the person first diagnosed with the disease, it is a feeling of loss and loneliness compounded by knowing very little about the disease. According to one participant, "I was diagnosed and I was really shocked. I was standing in the parking lot thinking, what do I know about Parkinson's? …and really nothing. I think most of us know that this person has tremors or could have tremors, but beyond that we had no idea."

One of the major themes repeated at each focus group was the impression that formal diagnosis of Parkinson's is not standardized among family physicians. This adds to the uncertainty that participants and their care partners face as they try to cope with the disease. The following quotes highlight the prolonged uncertainty and stress associated with delayed or incorrect diagnosis:

> I thought I had a physical problem, other than that they didn't seem to know, kept sending me back.

> First time I went for a diagnosis, they said, well, we know one thing, you don't have Parkinson's. The following year I was diagnosed with it.

> My neurologist referred me to another neurologist who said, 'I don't think you have difficult Parkinson's... here we go again…so he's having me reassessed.
>
> My family doctor didn't initiate the referral; I had to suggest that he have me referred to a Parkinson's specialist.

Challenges experienced with Parkinson's

Persons living with Parkinson's and care partners agree that life has drastically changed and become more challenging with the diagnosis. Impacts on lifestyle for participants include the inability to carry out previous work functions and reduced participation in social activities. One participant commented, "It definitely changes your lifestyle. I can't do the work I was doing," while another stated, "We don't go out quite as often as we used to." Another commented on the challenge of knowing no improvement can be expected: "it is difficult waking up every morning knowing it isn't going to be better the next day." Even medication may not bring relief: "I've never been able to tolerate the medication which brought confusion. All the others always have had bad effects."

Furthermore, persons with Parkinson's and their caregivers expressed difficulty in adjusting their medications, doses, and administration. "Trying to figure out the medication that works best and what isn't needed… if it should be changed." Another reported, "I sometimes just think that if these doctors had to put up with some of the side-effects of the things they prescribe, they wouldn't so much". There is also concern about Parkinson's medications being administered on time to persons in a care facility. The following quotes (highlighted from different participants) make it clear how extensive is this challenge and how difficult to take is the apparent inflexibility or even indifference of medical personnel:

> It's a fight, you literally feel like you're fighting with them…one lady at a hospital said he will get his drugs when we dispense them and we have a certain hour.
>
> Oh my goodness, he'll be given medications you're supposed to have in the morning at 8 at 12 when he's had his last one at 7 at night. Useless!
>
> We found…they were just going to discontinue the Parkinson's meds for a while.
>
> They were doing a whole bunch of tests and the doctor said it doesn't matter if you don't take your meds for two days.
>
> I don't think they think it's that important. In the hospital they were understaffed, they were running slow.

One person expressed outrage at the idea that health workers may not think that it is important for medications to be administered on time to persons with Parkinson's: "If you're going to do it, why not do it right? [They are] going to get it to you sometime, so why not do it on time? We really shouldn't let them get away with it."

Concerns were also repeated about a lack of neurologists to meet the needs of people with Parkinson's. This was particularly conspicuous in the rural areas of Saskatchewan. One participant stated, "Neurologist isn't doing much at all. We're frustrated with that. As far as we know, how many neurologists do we have in Saskatchewan?" Other participants expressed frustration about delayed appointments due to the limited number of neurologists: "haven't heard for an appointment yet either and I'm thinking if I don't hear pretty soon, I'm going to phone…over a year, the last three times, I had to phone." Yet another feared that research appointments were more attractive than clinical care: "nobody wants to take on the job of working with Parkinson's as a neurologist rather than the ones that we have in research".

Access to Services

Specific services geared toward the improvement in the quality of life of persons living with Parkinson's were especially scarce in the rural areas. One participant commented, "I don't think there are any out here. There could be home care but I'm not sure," while another added, "If there could be therapy for swallowing and trouble walking, maybe ¾ of an hour." Another participant was more pragmatic about the specialized services available: "We have to be practical about this. There aren't enough experts around to service everyone equally. That's just the way it is. You know what's out there and it's up to you really to take advantage of it…like nobody says we will be for Parkinson's at such a time for exercise but you have to kind of do it yourself. You know it's there but you have to more or less let yourself do it."

Consequently, those in rural areas rely heavily on their support groups: "I felt quite isolated in the very beginning, all I had was the packet of information and it was like, anything you want, you dig it up. This group has been wonderful. It's worth the drive for sure [110km]." One participant commented, "I find being out in rural, this is where we come, our group"; another added, "This support group has been great. We've compared medications and wondered why and know there's quite a few different guides out there."

However, in general, they find the services or support they need in exercise groups, local support groups, and utilize educational services such as resource lists, literature and recorded information from PSS. They explained that they have had "speakers – pharmacists, speech pathologists, yoga, tai chi." "We have a wellness walking trail," "there's physiotherapy…involvement in church, and neighbours". Participants also engage in scheduled health promotion activities and are content that information is available: "there are resources, literature, CDs; there's quite a lot of literature we can get." In spite of these available resources, participants expressed that additional expert support is necessary when there are delays between appointments with neurologists. One participant commented, "a helpline possibly run by persons who have experience with Parkinson's." Another agreed, "maybe a [support] group like this, those who've been there and are willing to field calls." "If you don't get to see your neurologist for a year… [you can call] just to say I have questions."

Participants were generally satisfied with their experiences with PSS: "the entire staff at PSS deserves credit for being positive and eager to help." They were especially pleased with the newsletter generated by PSS and felt that it was commendable that it could be accessed online: "I would rate my experiences with PSS very good, especially the newsletter that's probably printed, but I read it online. I am encouraged that there are people promoting awareness, promoting research, promoting services around the province that people with Parkinson's can use." Participants were also pleased that through PSS they had established friendships: "the friendships that we've developed with [others] going through the same thing is important." There is a young onset group and the opportunity to have caregiver group discussions: "as a caregiver, I think the caregiver discussions are very, very useful." They also commended the conference that was staged in Regina: "the conference that was organized in Regina was very useful. It was excellent, the keynote speaker, the information and workshops were good too."

Achievement of PSS Mandate

Participants were generally unaware of the PSS mandate or whether it was being met. It was stated that this was because the mandate had been insufficiently promoted. An annual report listing PSS goals and achievement was deemed necessary in this regard. One participant stated, "PSS is relatively new…so really…other than information on paper that we've got at the last couple meetings, really we haven't had any support from them." One rural participant suggested:

> This support group is really important. I guess I don't know what percentage of people that have Parkinson's in the province are in a support group; likely very low, maybe 20/30%. I'm wondering if we could increase that; then we could have a support group. In an ideal world if everyone that has Parkinson's in our town would be part of a support group, we'd be enough to meet and then travelling is less of an issue.

Once the mandate was shared, there was a general consensus that the mandate of education had improved in the last year. However, participants felt that though persons with Parkinson's were being educated, there is a gap in the health system. Supported by nods of agreement, one participant stated:

> Before I was admitted, I phoned the hospital and I said I have Parkinson's. Is your staff aware of people with Parkinson's, what their needs are? They said, "yes they've attended clinics, no problem." A high percentage of trained personnel, I was told…but my experience was exactly the opposite of that.

Another participant agreed citing the need for a centralized formal program for Parkinson's:

> There's a pile of information out there. I don't think there's a lack of information. What I would like to see is health professionals – doctors, nurses and so on, more knowledgeable about Parkinson's and I would like to see therapy where we could go for specialized care specific to the symptoms. I think that would be a very big thing in controlling and keeping Parkinson's at bay for longer.

Regarding research funding and dissemination of research findings, participants were aware of some of the fundraising events but were not absolutely sure about how research was funded or if they were being benefited at all. They feel they would be better served if they were involved as research subjects. One participant commented, "It's sort of very complex…the money is going to various studies to treat and find a cure which is very interesting, but I would like to know the findings of the latest research or even be involved in a clinical trial." In reference to participation in fundraising events, a care partner had this to say: "SuperWalk is absolutely fantastic. We had 10 at the [recent] SuperWalk which is exciting, fun and wonderful….doing a really good job with that."

Service Improvements

Participants felt that PSS had improved its services in the last two years. However, there was consensus that services could be improved in a variety of ways to meet direct needs and improve quality of life for persons living with Parkinson's and their care partners. One participant considered that some of the challenges common to aging make it difficult for some people living with Parkinson's to benefit optimally from educational meetings and conferences. It would therefore be justified for PSS to provide access to technology enhanced learning resources supported by introductory computer courses (perhaps in partnership with public libraries):

> It seems to me that another thing that goes with Parkinson's and aging is inexperience with accessing information on line. So to whatever extent the society can encourage and facilitate access on the part of people who are living with Parkinson's in their 70s and 80s…like a basic computer course at the [PSS] office… sometimes researchers who are not public speakers are nervous about speaking and tend to mumble. Simply recording that so that I could play it back like a YouTube video makes a huge difference in what I get out of it…I suppose it's reasonable to expect that PSS could broadcast events for like the conference in Regina for those of us who live elsewhere.

PSS could also employ an interactive team approach in meeting education and social needs:

> I think it's always helpful to have new information shared by someone that's more knowledgeable than us… we are just sharing our experiences with each other but we really haven't got any authority or schooling in what we are talking about.

Another participant added:

> One of the main jobs of the provincial organization is supporting the support groups. An example of that is helping us to find out about the disability tax credit, sharing information and possibly helping with the application.

Participants suggested that PSS could create a registry of resource personnel who focus on Parkinson's while advocating for increased access to specialized healthcare delivery:

> We need specialized services. We come from a small town and we don't have any services about anything.

> It might be helpful to have nurse practitioners become involved in that area.

> It would be very helpful instead of having to make the trek to see a specialist.

Participants also highlighted the need for PSS to advocate for improved services in the health care system, and increased dissemination of information on treatment innovation and research:

> It's [PSS] just not meeting the needs of some right now. I think they are doing a lot. I wish I had more information of what works best. They would get done if they are [known to be] successful.
>
> I appreciate all the information but I'm greedy about knowing when there's a cure and how much further to go before they find it.
>
> If there was that person between you and the nursing staff [they carry more weight too] is better than us saying this isn't working.

Support Group Facilitators

Support group facilitators participated in a discussion on their experiences with Parkinson's, their facilitation of support groups, and their perspectives of PSS services.

Experiences with Parkinson's

Participants were excited about support groups being established in their areas to increase information on Parkinson's. One participant explained that when medical knowledge is lacking, progression of Parkinson's may lead to isolation. It was reported that this is more common in patients who do not exhibit constant shaking but experience other symptoms such as trouble swallowing and breathing, rigidity and inability to move, especially in the absence of medication. "It's a different process in terms of therapies and medicine and the doctor we are seeing admitted not knowing much about it." The need for formal and sustained dialogue about the disease is captured by this facilitator: "they need to listen to somebody who says I know what you are going through… I understand, I feel the same way, you are not alone – so, that's my excitement about the support group."

Interest in Providing Support

There is much interest in setting up support groups. Despite the wide range of information available online and through PSS, it is felt that the personal connection with people who have Parkinson's is necessary. A participant supported this need for support groups: "I can see how much benefit there is, [Parkinson's is] hard on everybody, not understanding the disease, not knowing where to get any kind of information, the resource of having only the doctor is very tricky; they don't have the time to spend with you and…it's a little bit discouraging."

Resource Materials

Communication is maintained between the PSS office and the group facilitators who have access to a wide range of resources. Facilitators mentioned that they receive support group manuals as well as pamphlets, DVDs, and books supplied by PSS personnel who visit the support groups. However, training of facilitators in the appropriate use of resources for the benefit of support group participants is warranted. Facilitators reported information overload with "binders and binders" of paper to digest. They explained that there is such a variety of resources available for sharing with support groups that they are not sure how to use them: "I don't know what to do with them because I've got so many different books and things like that."

Promotion of Support Groups

Facilitators engage in promotion of support groups. They do this through letters containing contact and background information about the support group, and an invitation to interested persons. Facilitators reported that it is sometimes difficult to recruit members who have been diagnosed with Parkinson's at a younger age: "some people don't show up to the support group because they don't want other people to see them in that way or because they don't want to see people whose symptoms have progressed." Participants agreed that confidentiality made it more difficult to recruit these members because there is no registry of persons living with Parkinson's, and doctors can't be asked to provide the information.

It was recommended that people diagnosed with early onset Parkinson's be targeted directly through the PSS office, and community events advertised in community centres, local newspapers, public library advertisements, posters around towns, word of mouth, and the PSS website. Support group facilitators also suggested that to boost awareness among all groups, an increased effort is needed to distribute brochures or pamphlets with information about PSS and support group meeting times and locations. These pamphlets would be placed at neurologists' offices or pharmacies for distribution along with medications.

Motivation to join Support Groups

Participants agreed that they were motivated by information needs, emotional support and socialization to join support groups. It was also about belonging, learning from each other, and sharing fear and grief. The availability of information from PSS, promotional materials created by facilitators, and testimonials are the main tools used to get people to join and remain in support groups: "the hook to get people to join the support group is the information." Another participant mentioned, "When people are diagnosed they don't know anything about Parkinson's, so when they attend the support group they see people who have experiences to share."It was also reported that people with Parkinson's join support groups and are reassured by shared experiences when they hear about it through established programs. "Three to four times a year, we go out for lunch together, and people get comfortable in coming because lots of us don't like to eat in public when we are the only ones shaking." Togetherness increases comfort and cohesion. One participant shared, "We all meet together and we all eat together and all shake together."

Support Group Facilitation

Most support groups meet monthly. The facilitator advertises the topic/activity each month, “so they know what to look forward [to] there and I get some answers through the paper in the community events… then they come and they are their own experts.” Facilitators reported that groups in the urban areas are very active and it is a delight for members to participate each month. However there is not full attendance each month: “usually 6 or 7, sometimes just me, but sometimes just 2 or 3.”

Support groups can also build capacity, not just among those living with Parkinson’s, but also among professionals who attend and present at meetings. A schedule of topics is compiled for the year by the facilitators and members of the group. Also, because people sometimes, especially at the beginning, may feel uncomfortable talking to each other, speakers are invited. “Slowly, they get comfortable with sharing their own experiences and have a lot of interaction between members.” Speakers have included dieticians, occupational health specialists, physiotherapists and home care staff. As a direct result, other professionals of the community become more knowledgeable about Parkinson’s: “The physiotherapist who had to research the topic to make the presentation to the support group got interested and ran a program at the local hospital in the summer for people with movement disorders.”

In large centres, support groups may be very large compared to those in rural centres: “around 70 people consisting of a mix of people with Parkinson’s and their care givers.” The facilitators administer surveys in order to identify people’s information needs and then select speakers. Facilitators mentioned that in the past, as a group activity, they had viewed webcasts of well-known Parkinson’s associations. Support group facilitators also reported that, sometimes, attendance allows for splitting groups into care partners and PWP who collaboratively decide on the topics to be discussed. Each group is then guided by a facilitator. A support group coordinator testified that “people like it when the support group is organized this way,” a view supported by testimonials from people with Parkinson’s.

Challenges/Concerns

Coordination with health care workers to attract members to support groups is a common issue that facilitators faced with the sustainability of support groups. One participant stated, “One of the frustrating things was trying to coordinate knowledge or the fact that there is a support group in the community or with other health care professionals.”

Facilitators were under the impression that information about support groups is not being shared by health professionals especially in the case of confidentiality concerns related to patients newly diagnosed with Parkinson’s. The participant further stated, “this past spring there [were] some health videos that were video conferenced through health districts, and the only way we found out about it [was that] fortunately [the Community Outreach Coordinator] e-mailed me.”

In regard to dissemination of information, it is perceived that health care professionals may be too exclusive. This is viewed as a gap by support group facilitators and members who feel that there should be better coordination through the health care system to create open forums for the sharing of information which may be helpful to care givers or PWP:

> There seems to be kind of a gap…by the time you get [the information], it's not timely because we only meet once a month and in order to share the information not all of our members have got e-mail or have computers; that means calling people which adds more time.

One participant mentioned that this is compounded by the fact that there are hardly any advertisements about PSS in the media to sensitize people to its existence and information about Parkinson's. An additional concern is the seeming lack of continuity between the PSS groups and a past group which was established by "a major researcher in the world of Parkinson's."

Facilitators were also concerned about the notable absence of pamphlets about Parkinson's at doctors' offices in comparison to pamphlets about other diseases, while some participants agreed that these resources were in their possession and could be easily made available.

Improvement of PSS Services

- Participants recommended the following improvements to access to PSS programs:
- Arranging a formal system of transport (a van) for at least some of the meetings: "more people will come (10-15) if we can get them there."
- Training professionals such as nurses, physiotherapists, and other public health professionals to provide support to rural communities and to spread awareness about Parkinson's and available services .
- Developing outreach programs for caregivers because they feel isolated, and in some instances have no one to talk to who is experiencing similar circumstances.
- Producing a phone directory of doctors who are knowledgeable about Parkinson's. This will alleviate the uncertainty faced during the waiting times to see a neurologist, as the family doctor is hesitant in advising Parkinson's patients because of lack of expertise.
- Offering an alternative form of support to people who used to attend the support group, but can't continue to do so because of progression of the disease or for those who don't want to show up in the support group because they don't want to identify themselves with the group.
- Coordinating public awareness campaigns.
- Hosting more telehealth presentations.

Key Informant Interviews

Key informant interviews were conducted with individuals, who have or have had direct involvement in the directorate of PSS to deepen understanding of PSS and the experiences of those directly living with or dealing with Parkinson's.

The board members' experiences with Parkinson's were both personal (impacting a spouse) and professional. One board member understood well care partner difficulty coping with the disease especially at initial diagnosis: "It was an emotional draining time, not quite emotional for me but it was difficult."

Board members learned about PSS through local support group meetings and by seeking out the organization for professional reasons. Through these means they were recruited and volunteered to sit on the board, a big part of whose mandate is education about Parkinson's symptoms, and the importance of getting medication on time. This education is delivered to people with Parkinson's, the general public, and health care professionals through various media including print, online, presentations to the individual support groups and to professionals. PSS also arranges support groups and there are plans to expand services to larger communities and to southern communities.

Although access is not yet province-wide, it is hoped that "Someday there will be and …advocacy for people with Parkinson's whether that means lobbying governments as well as supporting professionals that are working with Parkinson's to understand best practices for working with people with Parkinson's."

Strengths of PSS

The strengths of PSS from the board members' perspectives were:

- Having a passionate and dynamic board that is knowledgeable about Parkinson's: "I think people walk away feeling there is positivity in their future."
- The personal contact with persons with Parkinson's and the support of professionals and nursing homes
- Having up to date resources
- Supporting the national research program helping to raise the profile of Parkinson's
- Acting as central governing body coordinating for Parkinson's throughout the province.

While recognizing the passion of board members as one of the strengths of PSS, one participant was concerned that this could lead to discouragement: "there's a lot of passion in PSS and it's very positive that people are putting a lot of work into it but I'm also wondering about burn out within PSS because of that. Things move slowly, so then you work harder but it doesn't move much faster and so I can see that people might get really frustrated."

Increasingly, PSS is recognized for centralizing and coordinating services: "I don't know if that's happened before. I think that the word is getting out there more…so that people are starting to look to PSS for information. Instead of stumbling across it, they're told about it."

Issues of access and equity across the province remain works in progress, both a challenge and an opportunity:

> I think that there is quite a concentration of service in [larger urban centres]…and then there's always difficulty getting to the rural areas because there's just so much more logistical difficulty and I guess there's still a lot of transformative work that needs to be done to going towards a more centralized body….looking for a direction, getting bylaws set up how we are going to deal with this situation. That is a weakness but it's also a chance to get it right.

Is PSS meeting its mandate?

It is felt that PSS could be more visible and better communicate its mandate where "the general impression of health professionals [is that PSS] is a support group and that's not PSS's mandate. It's much more complex than that, more far reaching than a support group." Notwithstanding,

Board members agreed that PSS was meeting its mandate "quite well" in terms of the "get it on time" program to educate health professionals on the need for timely medication. It was also reported that PSS services of education, support, and research are valued by people with Parkinson's: "This is what they see and experience when they see our educational materials…it's something physical they can see." While "they also value research," they don't "necessarily understand research…they indirectly value research as they'd love to see a cure one day."

PSS could also do more in terms of sharing research findings and encouraging Parkinson's Society Canada to educate members on the direct link between research funding and findings' impact on their quality of life. According to one participant, it would be potentially useful for PSS "to translate research and best practices to front line work." Research can increase awareness and improve treatment where "if you have a multidisciplinary centre, the big focus is going to be Parkinson's. I think there would start to be better awareness of the best way to treat people and so I do think that would be helpful."

The directorate of PSS believes that it is succeeding at improving quality of life by explaining the importance of exercise and nutrition and indirectly through promoting the different resources in the community: "We don't provide direct services. Someone who is recently diagnosed contacts us to find the different resources available in the community." The exceptional educational materials and fundraising promote independence: "I would say that without the services of our organization, a lot of people would have just sat in silence and wouldn't know where to turn."

Gaps in Services

Board members reported that identifying the gaps will enable PSS to develop a three to five year strategic focus that will allow the "champions both in the Parkinson's communities and health care professionals who are willing to fight for the cause understand what we are trying to accomplish." There are likely not enough professionals available to deal with Parkinson's but PSS could have a role in increasing awareness of the efficacy of treatments if they are done intensively over a short period of time rather than spaced over a long period. According to one participant, "there is a real gap between what the research says and I think what a lot of the therapeutic professionals know about how to treat Parkinson's." PSS might also have a role in promoting positive research findings of treatment modalities. This role could not be maximized with only one person as the liaison to the communities in such "a big territory where more health region access in terms of professionals can help with the knowledge."

It was deemed beneficial for PSS to provide support in training health professionals to promote changing the way that treatment is delivered to people with Parkinson's: "I don't think that's a giant role for PSS, just assisting, making sure that whatever these professionals need to get going, there's some support there." There is need for PSS to expand its advocacy role in support of care partners:

> Care partners don't have much support; they have no support from the health region. Women are mostly the care partners, so we have to figure out a way to support care partners and how to help PWP when care partners get older. Health region and provincial government they have the care plan, but they are looking at acute care not long-term care. We should make health regions and health ministries aware through advocacy that they have this issue; it has been on our list for few years.

The role of PSS is insufficiently appreciated and there are limits to what it can achieve:

> Having worked in the field and knowing somewhat of the business side and coming from the medical side of it…they [PSS] are doing what they can do. On the [other] end of it, the reality is it's a very isolating disease. My experience is that when they are mobile and able to function and go to support groups and utilize PSS, great! But when they have progressed and require caregiving, that to me is where the line is somewhat drawn because of the fact that they're on their own and that's when you tend to use the health districts and services that's provided there. I really have experienced the fact that people move on. You don't even see them at support groups because they progress so much.

PSS could have a role in bridging this particular gap in public health services, but could only intervene if its capacity increased. Within current resources, PSS is meeting its objectives, but it is envisioned that in the future there would be support throughout all the stages of the disease, improving quality of life for those "people who actually can't exercise, that's part of the treatment but you get to the point where that's not an option." However such intervention may demand too much of PSS: "I think the issue is that Parkinson's is a very cruel degenerative disease and I think that's where the picture is so much larger than what PSS can do…maybe that's where PSS draws the line and the hospital system steps up."

It was reported that because Parkinson's is not a short term disease, people living with the disease manage independently as long as they are able: "People have it for twenty some years and they learn to cope with it. It is up to the person to be responsible to connect with PSS, but there comes a time where they don't and they can't." It would be bonus "if a society could cope with the progressed people if they require it or request it, but typically they do not. They don't even have the energy to go to a support group."

One participant felt that by establishing a movement disorder clinic, PSS could impact a wide range of people living with the different forms and stages of Parkinson's:

> I just felt that if it could evolve and be the medical society that is there for people with these movement disorders, I think it would put them on the map. I doubt you'd ever want to have the disease but you'd be able to say, I can rely on PSS and even though I'm at this stage there is a representative maybe that even can come into the hospital and provide the service that's required. I really believe in a movement disorder clinic…I definitely believe in it.

Young Onset Participant Interview

From the perspective of member of the young onset group, the experience of diagnosis was extremely confusing as the symptoms could not be related to the general aging process. One individual has had the disease for four years and was diagnosed when training for a sporting event highlighted symptoms: "the harder I trained, the slower I got." The major challenge highlighted by the participant is that life has become much slower and calculated with dexterity and movement being most affected. Exercise, diet, naturopathic, and brain-training interventions are helpful in coping while positive attitude is an advantage.

The major strength of PSS was its continued efforts to improve programming, and achieving its mandate. PSS services are used for networking while general information is found by this group to be the most useful service PSS has to offer. PSS has a role, but not an exclusive one, in improving quality of life: "If you seek help it is a great place to find support and info. I find you need to seek and help yourself; they are just another tool." The experiences with PSS were given a score of 7 out of 10 because the services were timely and the information sought was found, although more educational sessions and speakers, and greater availability and visibility to all persons affected by Parkinson's would be an improvement.

CONCLUSION

A diagnosis of Parkinson's disease is accompanied by feelings of isolation and uncertainty with all individuals feeling the need to know more about the disease. As with other chronic illnesses, the lives of those with this disease and their care partners are forever changed. People living with Parkinson's (PWP) learn new ways of coping with their circumstances and care partners take on additional responsibilities and devote most of their time to care for PWP who are usually spouses/partners. PWP rely heavily upon physical and massage therapy services as a valuable method of coping with their condition. Overall, information about Parkinson's is predominantly sourced from neurologists, PSS, and support groups.

The following services of PSS are a vital aspect of coping with the disease: support groups, information package, the Parkinson Press newsletter, and the website: parkinsonsaskatchewan.ca. PSS has many strengths including a professional, helpful and knowledgeable staff, a passionate board, solid support of local organizations, numerous current educational resources, and strategic national research agenda program helping to raise the profile of Parkinson's.

While the directorate of PSS is satisfied that it is meeting its mandate of increasing awareness through the "get it on time program," it was evident from numerous comments that wide-scale education of healthcare personnel would positively impact quality of life. Service areas that need strengthening include advocacy and support for people living with progressed Parkinson's, caregiver support, and helpline services. The following were recurring themes of future directions that PSS could explore: capacity building, creating a registry of health professionals, computer classes, live streaming of events, interactive team approach to increased specialized services, and establishing a multidisciplinary movement disorder centre.

Summary of Findings

PSS has clearly defined mission, vision, and goals. There is consensus that PSS is achieving some level of success and is relevant.

Meeting missions and goals

In keeping with its mission and goal to improve quality of life through advocacy, education, research, and support services, PSS consistently provides education through publications in the print and online media, and presentations to PWP at support groups and to health care professionals, while establishing and sustaining support groups across the province. However, it is not clear to the PSS clients exactly how research is conducted and how the findings will translate into an improved quality of life for PWP and their care partners.

There is a clear call among the PWP population for PSS to assume a strong advocacy role vis-a-vis health regions and ministries on matters such as public education campaigns, treatment innovations, and long-term care. Advocacy is necessary for strengthening and expansion of respite services for care partners who have indicated that their stress level has increased as they take on additional responsibilities and devote most of their time to care for PWP.

Though the vision of PSS is clear and well-articulated, the processes of the organization were not well-defined and are still being developed. Findings of this project can help to shape these processes for outcomes that improve quality of life for PWP and their care partners. Establishing clearly defined organizational processes and increasing capacity will allow the PSS to improve its service delivery and mission.

Meeting the needs of the population

While PSS is impacting a portion of its target population through various media, it is also evident that the population being served, though appreciative of the services, have more needs than PSS in its current capacity is able to meet. The needs are differing among the PWP population, and the current approach of PSS is more suited to meeting the needs of the younger population of PWP who are more active and independent and whose disease has not significantly progressed. Even so, that group is advocating for improved access to neurological and physiotherapy services.

The fact that publications of PSS are widely read by persons trying to cope with Parkinson's is an indication that individuals are constantly seeking new information. Participants would be better served by publications that met with their interest and in their words would like to read about "success stories", "recent research findings and how those affect the next generation", "support for all involved with Parkinson's" as well as "nutritional, medical and exercise information" and "question and answer segments."

Given the specialized needs of the older PWP whose disease is more progressed and who may be immobile, it is not certain that PSS in its current scope is meeting (or even that it can meet) those specialized palliative needs of that population.

Support groups, though attended by care partners, focus mostly on the needs of the PWP and only on rare occasions are large support groups in urban centres able to facilitate meetings for care partners' needs for counselling and psychological services.

Services in rural versus urban centres

There is a disparity in services available in large urban centres and those in rural areas where PWP and their care partners in some instances have access only to support groups some distance away and therefore struggle to remain active. There is a demand in these areas for the presence and participation of community outreach coordinators to ensure that the groups remain viable over time. Also, where other services such as exercise groups do exist, there may be difficulty of access for many in the smaller towns because these services are not offered at convenient times and are still clustered around larger centres.

Stakeholders and clients of PSS are generally satisfied with PSS programing given its current capacity. The organization aims to improve quality of life through four pillars: advocacy, education, research and support services. In testament to this aim, the camaraderie and motivation experienced at support groups are by far the most cited reasons for PSS success. Support groups maximize independence and provide a place for networking and having a voice: "I felt quite isolated in the very beginning, all I had was the packet of information and it was like, anything you want, you dig it up. This group has been wonderful. It's worth the drive for sure [110km]."

The following section summarizes participants' views on ways in which PSS can better achieve the four pillars of service and its vision to create a better life with a brighter future for people living with Parkinson's today and a world without Parkinson's tomorrow:

Building Capacity

- Increase the number of Community Outreach Coordinators (which may also include nursing practitioners) in an effort to improve the interactive team approach between PSS and support groups by having staff representatives at support groups.
- Deploy human resources to improve visibility and access to services in rural areas especially in the farming areas.

Enhancing Visibility and Reach of PSS

- Continue to coordinate public education campaigns and fundraising activities that raise awareness about Parkinson's.
- Circulate annual reports inclusive of PSS activities and achievement of goals/targets, direct link to research findings and treatment options.
- Create a registry of health professionals who specialize in Parkinson's.
- Facilitate introductory computer courses by partnering with public libraries to increase the number of PWP and care partners who access information electronically.
- Promote the existing helpline which could be facilitated by persons who have experience with Parkinson's and will help to alleviate the anxiety of having to wait long periods to have discussions with neurologists.
- Prepare fact sheets that promote positive research findings in order to improve awareness of treatment modalities that are effective when done intensively over a short period of time.
- Acquire vehicles marked with the PSS logo for increased visibility and to provide a formal system of transport to meetings and events.

Improving Educational and Resource Materials

- Provide a directory or access to resource persons to help with access to social services and understanding benefits e.g. disability tax credit.
- Deliver content of conference presentations by live streaming, podcasts, or videos so that those not in attendance or with hearing loss can have access for later viewing and assimilation.
- Prepare a list from feedback of "hot topics" and categorize resources according to what PWP and care partners need to know as they progress through each stage of Parkinson's to reduce the perception of

information overload.

Supporting Caregivers

- Develop outreach programs for caregivers such as in the beginning with respite for care partners for possibly two hours per month.
- Develop a plan to explore ways of supporting care partners and how to help PWP access long-term care when care partners get older.

Enhancing Quality of Life

- Develop a plan to provide services to those whose disease has progressed and who are immobile and are unable to participate in exercise and/or support groups.
- Continue to plan strategically for becoming the centre of excellence which will provide specialized and widespread care and be designed to meet all the needs of PWP and care partners in a centralized, coordinated and collaborative manner.

Expanding Advocacy

- Continue to provide advocacy in the health care system, pushing for more neurologists and public education campaigns in the hospitals and healthcare facilities.
- Advocate for and disseminate information on treatment innovation and research. PSS can be the driving force behind Parkinson Society Canada helping members to understand the direct link between their funding research studies and their improved quality of life.
- Engage health regions and health ministries on behalf of PWP whose care partners become unable to provide long-term care due to aging.

Facilitating Support Groups

- Continue to establish more support groups across the province
- Propose alternative forms of support to people who no longer attend support groups because of progression of the disease or for those who choose not to join these groups because of fear of being identified with people with Parkinson's.
- Collaborating with Health Professionals

- Establish a scholarship fund aimed at providing specialized training of neurologists and other health care professionals in Parkinson's who will be retained to serve the PWP population. This will ensure the education necessary for general practitioners and allied health professionals to provide quality services to PWP while reducing the shortage of these professionals. As one participant stated, "It would be very helpful instead of having to make the trek to see a specialist."
- Establish networks of allied health care professionals who will commit to working very closely with Parkinson's on a regular basis. In the words of one participant, "If there could be therapy for swallowing and trouble walking, maybe ¾ of an hour."

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APPENDIX A: A Survey for People with Parkinson's

The Community-University Institute for Social Research (CUISR) is undertaking a study, funded by the Parkinson Society Saskatchewan (PSS), to evaluate the PSS by learning about your experience of living with Parkinson's disease and your experience with PSS services. The results of the survey to be published by CUISR will assist PSS in planning support services and programs in the coming years. The PSS will not be engaging in this kind of study every year, but does plan to touch base with their membership every two or three years to ensure the membership's needs are fulfilled.

By filling in and submitting this online survey, you are providing your consent for the information contained in the survey to be used in this study. The results of the survey will be confidential and are subject to the ethical guidelines of the Research Ethics Board at the University of Saskatchewan. In order to maintain confidentiality, any identifying information will be removed before the results are analyzed and reported. The data will be reported in aggregated form. Some direct quotes may be included, with all identifying information removed. The data from the survey will be stored securely at CUISR for seven years (according to ethical protocol) and then destroyed.

Participation in the survey is voluntary and if there are questions that you do not feel comfortable answering, please feel free skip to the next question. Due to the nature of an online survey, your right to withdraw from the study will apply until you have submitted the survey.

If you have questions regarding this survey, your participation in the study or regarding the research results, please contact CUISR:

Martha Robbins – Strategic Research Coordinator
(306)966-2120
Cuisr.research@usask.ca

Principal Investigator: Dr. Isobel M. Findlay
Professor, Management and Marketing
Edwards School of Business
University of Saskatchewan
(Tel): 306-966-2385; Findlay@edwards.usask.ca)

This project was reviewed on ethical grounds by the U of S Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to the Research Ethics Office toll free at 1-888-966-2975 or ethics.office@usask.ca.

The survey should take approximately 20 minutes to complete.

Thank you for your time and interest in participating in this survey

Sections of the survey:

I About You
II Parkinson's and You
III Services and Information
IV Parkinson Society Saskatchewan and You

Adapted from the Parkinson Society British Columbia 2009 Survey for People with Parkinson's and their Carepartners, with thanks.

I About You

1. What is your gender?

   Male
   Female

2. How old are you?

   29 or under
   30 – 39
   40 – 49
   50 – 59
   60 – 69
   70 – 79
   80 – 89
   90 or above

3. Which of the following best describes your current living arrangement?

   Live with spouse/partner
   Live with other family member
   Live on my own (in my own home, apt, etc.)
   Other:
   Seniors Residence
   Assisted Living
   Long-Term Care

4. Do you currently have an <u>unpaid</u> care provider, such as a spouse or partner, family member or friend, whom you rely on, to assist you with daily activities?

   Yes
   No

5. What is your current employment status?

Employed full-time
Employed part-time
On long-term disability due to Parkinson's
On long-term disability due to another condition
Unemployed
Retired
Other:

6. Please indicate your annual household income. Please remember that this survey will remain strictly anonymous.

Less than $30,000
$30,000 to just under $50,000
$50,000 to just under $70,000
Over $70,000
Prefer to not answer this question

7. Please provide the six characters of your postal code. These will be used only for statistical purposes to understand differences by region and geography. They will not be used to identify you in any way. Your anonymity will be preserved.

Thank you for completing this section.

II Parkinson's and You

We are asking these questions to better understand the effect Parkinson's has on your day-to-day life.

8. What Parkinson's or Parkinson's Plus conditions do you have?

Parkinson's disease, only
Cortico Basal Degeneration
Lewy Body Dementia
Multiple Systems Atrophy
Progressive Supranuclear Palsy
Other (please specify):

9. How many years ago were you diagnosed with Parkinson's?

10. How old were you when diagnosed with Parkinson's?

11. The following question refers to the degree to which Parkinson's affects you at this time. On average, do you experience:

No impairment
Mild to moderate impairment
Significant impairment

12. Please list the changes you have seen in the past year to your motor and non-motor symptoms.

Motor symptoms

Activity	Observation					
	A lot more difficult	**More difficult**	**A little more difficult**	**A little mprovement**	**Some improvement**	**A lot of improvement**
Walking						
Balance						
Dressing						
Writing						
Speaking						
Swallowing						
Eating						
Muscles						
Posture						

If you noticed any improvements, please say why you think there have been improvements in the physical symptoms.

Non-motor symptoms

Activity	Observation					
	A lot more difficult	**More difficult**	**A little more difficult**	**A little improvement**	**Some improvement**	**A lot of improvement**
Concentration						
Memory						
Emotional balance						
Independence						
Social contact						
Motivation						

If you noticed any improvements, please say why you think there have been improvements in the physical symptoms.

____

____

13. Are you currently taking any medication(s) for Parkinson's?

Yes No

14. What is the total average monthly cost of Parkinson's medications, **before** SaskHealth coverage, and/or insurance claims?

15. On average, how much do you personally pay out-of pocket for Parkinson's medications per month **after** SaskHealth coverage and/or insurance payments?

16. Have you been hospitalized in the past 12 months?

Yes No

17. Do you feel the healthcare staff was well informed about Parkinson's and related symptoms?

Yes No

Thank you for completing this section.

III. Services and Information

18. Please indicate if you have used any of the healthcare providers or services listed below. Please also indicate how helpful you have found these services.

Services Used	Not Available (as far as you know)	Very Helpful	Somewhat helpful	Not very helpful	Not helpful at all	Not Interested
Dietitian/ Nutritionist						
Massage therapist						
Occupational therapist						
Physical therapist						
Speech and language therapist						
Swallowing therapist						
Public health nurse						
Psychologist						
Psychiatrist						

20. Where, or to whom, do you go to obtain information on Parkinson's disease? Please check all that apply.

Family physician
Walk-in clinic
Neurologist
Public Library
Allied health professional (physio/occupational therapist, speech therapist, etc.)

Support Group
Internet
Parkinson Society Saskatchewan

Other (please specify):

21. Please rank the following by which information is most valuable to you, where 1 means most important and 11 least important.

___ General Information on Parkinson`s: latest research, treatments and symptoms
___ Different Parkinson's Medications
___ Support group information
___ Home care and/or continuing care/assisted living information
___ Living well with Parkinson's: exercise and nutrition
___ Progression of Parkinson's
___ Care partner self-care or coping strategies
___ Cognitive challenges
___ Driving
___ Assisted devices (walkers, chair lifts, wheel chairs, assisted speech device, etc.)
___ Role of Allied health professionals and PD (physio, occupational therapist, speech therapist, etc.)
___ Other (please specify):

Please answer the following question **ONLY if you currently live in a care home or other long-term care facility.** If not, please move on to Section C "Parkinson Society Saskatchewan and You".

22. How satisfied are you with the healthcare staff's level of knowledge of Parkinson's disease and the related needs of Parkinson's patients?

Very satisfied
Somewhat satisfied
Not at all satisfied
Not sure

Please explain.

Thank you for completing this section.

IV. Parkinson Society Saskatchewan and You

We are asking the following questions to learn how widely PSS services are used and how PSS services can be improved to better assist those affected by Parkinson's.

23. Were you aware of PSS prior to diagnosis?

Yes No

24. How did you first become aware of PSS?

Referral by a physician or healthcare professional
A PSS member
A relative or friend
Newspaper
Magazine
Radio
TV
Parkinson Press newsletter
Other, please specify:

Support group
Internet or website
Taking this survey
SuperWalk
Lows in Motion
Shake, Rattle & Roll

25. Have you ever contacted PSS?

Yes No

26. If yes, by which method?

○ Telephone
○ E-mail
○ In person
○ Through the board of directors

27. Listed below are activities and services currently provided by PSS. Which of the following activities and/or services have you used in the past 2 years? Please indicate how valuable the activities and/or services have been to you.

Services Used	**Very valuable**	**Somewhat valuable**	**Not very valuable**	**Not valuable at all**	**Not Applicable**
Information package					
Direct access to information and referral service (via toll free 1-800 number or e-mail)					
Support counselling					
Educational meetings and conferences					
Support Group					
ePress newsletter (Email)					
ParkinsonPress newsletter					
Library – books and DVDs					
Information booths at various fundraisers					
Education Conference					
Website: parkinsonsaskatchewan.ca					

28. Do you have any suggestions on how to expand the PSS services listed above?

29. What topics or speakers would you suggest for future educational meetings or conferences?

30. How many support group meetings have you attended in the past year?

○ 0-1

○ 2-5

○ 6-8

○ 10+

31. What factors influence your attendance?

○ Group Dynamic
○ Choice of topic
○ Proximity of meeting
○ Time conflicts with other commitments
○ Not a priority

32. What best describes your use of the Quarterly Parkinson Press newsletter?

○ Share it with my friends and family
○ Read it cover to cover
○ Skim from page to page
○ Only read articles that catch my interest
○ Don't read it
○ Don't receive it

33. What topics/information would you like to read about in Parkinson Press? Please explain.

34. Are you aware of the Parkinson Society Canada National Research Program?

Yes No

35. Do you or have you participated in PSS fundraising activities?

Yes No

If so, which ones?

○ SuperWalk
○ Lows in Motion
○ Shake, Rattle, and Roll
○ Other: ________

36. What is your preference for volunteering/donating to PSS as compared with other charitable organizations?

- ○ First priority
- ○ Somewhat of a priority
- ○ Neutral
- ○ Some support but not overly committed
- ○ Do not support PSS

37. Over the past 3 years, how has access to public programs and services for Parkinson's changed?

- ○ Greatly improved
- ○ Somewhat improved
- ○ Stayed the same
- ○ Somewhat declined
- ○ Declined significantly

38. Rank the following issues from 1-4 (1 being most important to 4 being least)

___ Multidisciplinary Movement Disorder Clinic
___ Nurse to assist Neurologists throughout province
___ Access to specialized Parkinson's specific quality of life programs (Exercise, voice treatment, dance, yoga, etc.)
___ Access to general neurological quality of life programs (chair yoga, aquasize classes, etc.)

39. What advice would you give to a newly diagnosed person with Parkinson's?

40. What are the best ways for PSS to communicate with you?

Email
Phone
Mail
Blogs
Facebook
Twitter
Other:

41. What is your overall level of satisfaction with PSS?

    Very satisfied
    Somewhat satisfied
    Not very satisfied
    Not at all satisfied
    N/A I have not sought the services of PSS

42. Please rate your satisfaction with each of the following areas on a scale of 1-5 (1 as highest satisfaction, 5 as lowest) :

    ___ PSS has my trust and support
    ___ PSS Board of Directors has my trust and support
    ___ PSS policies and governance are transparent, sensible and clearly communicated
    ___ Staff is professional knowledgeable and helpful

43. Please feel free to add any additional comments regarding any aspect of PSS including the support group networks, fundraising events, awareness, availability of staff, information materials, etc. Your comments are appreciated!

Thank you for completing this section

Thank you for taking the time to complete this survey. Your answers are extremely valuable in this study and will help Parkinson Society Saskatchewan to better understand and serve your needs.

If you would like information about Parkinson Society Saskatchewan or other services available, please contact:

Travis Low, Executive Director
Office: 306-933-4455
Toll Free: 1-888-685-0059
Fax: 888-775-1402
E-mail: travis.low@parkinson.ca

Website: www.parkinsonsaskatchewan.ca

APPENDIX B: A Survey for Care Partners of People with Parkinson's

The Community-University Institute for Social Research (CUISR) is undertaking a study, funded by the Parkinson Society Saskatchewan (PSS), to evaluate the PSS by learning about your experience of caring for someone living with Parkinson's disease and your experience with PSS services. The results of the survey to be published by CUISR will assist PSS in planning support services and programs in the coming years. The PSS will not be engaging in this kind of study every year, but does plan to touch base with their membership every two or three years to ensure the membership's needs are fulfilled.

By filling in and submitting this online survey, you are providing your consent for the information contained in the survey to be used in this study. The results of the survey will be confidential and are subject to the ethical guidelines of the Research Ethics Board at the University of Saskatchewan. In order to maintain confidentiality, any identifying information will be removed before the results are analyzed and reported. The data will be reported in aggregated form. Some direct quotes may be included, with all identifying information removed. The data from the survey will be stored securely at CUISR for seven years (according to ethical protocol) and then destroyed.

Participation in the survey is voluntary and if there are questions that you do not feel comfortable answering, please feel free skip to the next question. Due to the nature of an online survey, your right to withdraw from the study will apply until you have submitted the survey.
If you have questions regarding this survey, your participation in the study or regarding the research results, please contact CUISR:

Martha Robbins – Strategic Research Coordinator
(306)966-2120
Cuisr.research@usask.ca

Principal Investigator: Dr. Isobel M. Findlay
Professor, Management and Marketing
Edwards School of Business, University of Saskatchewan
(tel: 306-966-2385; Findlay@edwards.usask.ca)

This project was reviewed on ethical grounds by the U of S Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to the Research Ethics Office toll free at 1-888-966-2975 or ethics.office@usask.ca.

The survey should take approximately 20 minutes to complete.

Thank you for your time and interest in participating in this survey

Sections of the survey:

I	**About You**
II	**Parkinson's and You**
III	**Services and Information**
IV	**Parkinson Society Saskatchewan and You**

Adapted from the Parkinson Society British Columbia 2009 Survey for People with Parkinson's and their Carepartners, with Thanks.

* A care partner is a spouse, friend and/or adult child caring for a person with Parkinson's (PWP).

I About You

The following questions will enable us to develop a better understanding of our care partner demographic. Please feel free to be honest, as this survey is confidential.

1. What is your gender?

Male
Female

2. How old are you?

29 or under
30 – 39
40 – 49
50 – 59
60 – 69
70 – 79
80 – 89
90 or above

3. Which of the following best describes your current arrangement?

Live with spouse/partner
Live with other family member
Live on my own (in my own home, apt, etc.)
Other:
Seniors Residence
Assisted Living
Long-Term Care

4. What is your current employment status?

   Employed full-time
   Employed part-time
   On long-term disability
   Unemployed
   Retired
   Other:

5. Please indicate your annual household income. Please remember that this survey will remain strictly confidential.

   Less than $30,000
   $30,000 to just under $50,000
   $50,000 to just under $70,000
   Over $70,000
   Prefer to not answer this question

6. Please provide the six characters of your postal code. These will be used only for statistical purposes to understand differences by region and geography. They will not be used to identify you in any way. Your anonymity will be preserved.

II Parkinson's and You

a) Parkinson's and Care Provision

We are asking these questions to help us better understand your daily involvement with a person with Parkinson's disease.

7. The person for whom you are a care partner is a:

   Spouse/partner
   Parent
   Child (son or daughter)
   Sibling
   Another relative
   Friend
   Neighbour
   Other (please specify):

8. When was this person diagnosed with Parkinson's? (looking for # of years or year diagnosed)

9. How old was this person when diagnosed with Parkinson's?

10. Do you help the person with Parkinson's with any of the following personal tasks? Check all that apply.

    Bathing and/or showering
    Dressing and undressing
    Eating and Drinking
    Toileting
    Other (please specify):

11. What new responsibilities have you taken on since diagnosis (responsibilities that you previously did not have)?

    Obtain prescriptions
    Deal with finances
    Drive
    Give medication
    Yard work
    Grocery shopping
    Other shopping (clothing, special occasions etc)
    Prepare meals
    Run errands
    Take to medical appointments
    Laundry
    Take to other appointments (dental, hair cut, legal etc)

12. How comfortable are you leaving the person with Parkinson's alone?

    ○ Very comfortable

    ○ Fairly comfortable

    ○ Somewhat comfortable

    ○ Not at all comfortable

13. How many hours per day are you comfortable leaving the person with Parkinson’s alone?

24 hours
12–23 hours
4–11 hours
1–3 hours
0 hours

What are your concerns if you leave the person with Parkinson’s alone?
____
____

14. Approximately how many hours <u>per day</u> does someone other than yourself stay with the person with Parkinson’s?

0 hours
1–2 hours
3–4 hours
5–8 hours
9–12 hours
24 hours

15. What type of respite care is available in your area?

Family/Friends Health Region Not Available Private Service Unsure

16. Have you used or do you use respite care?

Yes No

Comments: ______________________________

17. In your community, are there any groups or activities provided <u>specifically for care partners</u>?

No
Not sure
Yes (Please specify):
Yes, but I do not attend.

b) **Impact of Care Partners and Parkinson's**

We are asking these questions to understand how the impact of caregiving described in Section a affects you now or has affected you in the past.

18. The health of people living with/looking after someone with Parkinson's is important. Do you feel that living with, and/or looking after someone with Parkinson's has affected your own mental health?

    Yes No

    If you have answered "yes", do you have any additional comments?

19. The health of people living with/looking after someone with Parkinson's is important. Do you feel that living with, and/or looking after someone with Parkinson's has affected your own physical health?

    Yes No

    If you have answered "yes", do you have any additional comments?

20. What is the most rewarding aspect of caring for a person with Parkinson's?

21. What is the biggest challenge you face when caring for a person with Parkinson's? Please explain.

Thank you for completing this section.

III Services and Information

22. Where, or to whom, do you go to obtain information on Parkinson’s disease? Please check all that apply.

Family physician
Walk-in clinic
Neurologist
Public Library
Support Group
Internet
Parkinson Society Saskatchewan
Allied health professional (physio/occupational therapist, speech therapist, etc.)
Other (please specify):

23. What information do you or would you find valuable? Please check all that apply.

- ○ General Information on Parkinson’s:
  - ○ Latest Research
  - ○ Treatment
  - ○ Symptoms
- ○ Different Medications
- ○ Support group information
- ○ Home care and/or continuing care/assisted living information
- ○ Living well with Parkinson’s
  - ○ Exercise
  - ○ Nutrition
- ○ Progression of Parkinson’s
- ○ Care partner self-care or coping strategies
- ○ Cognitive challenges
- ○ Driving
- ○ Assisted devices (walkers, chair lifts, wheel chairs, assisted speech device, etc.)
- ○ Role of Allied health professionals and PD (physio, occupational therapist, speech therapist, etc.)
- ○ Other (please specify):

24. Please check the services accessible to you in your area:

- ○ Family physician
- ○ Nurse practitioner
- ○ Neurologist
- ○ Physiotherapist

- Occupational therapist
- Speech Language Pathologist
- Rehabilitation services
- Counselling services
- Other (please specify):

Thank you for completing this section.

IV Parkinson Society Saskatchewan and You

We are asking the following questions to learn how widely PSS services are used and how PSS services can be improved to help those affected by Parkinson's.

25. Were you aware of PSS prior to diagnosis?

Yes
No

26. How did you first become aware of PSS?

Referral by a physician or healthcare professional
A PSS member
A relative or friend
Newspaper
Magazine
Radio
TV
Parkinson Press newsletter
Other, please specify:

Support group
Internet or website
Taking this survey
SuperWalk
Lows in Motion
Shake, Rattle & Roll

27. Have you ever contacted PSS?

Yes
No

28. If yes, by which method?

- ○ Telephone
- ○ E-mail
- ○ In person
- ○ Through the board of directors

29. Listed below are activities and services currently provided by PSS. Which PSS activities and/or services have you used in the past 2 years? Please indicate how valuable the activities and/or services have been to you.

Services Used	**Very valuable**	**Somewhat valuable**	**Not very valuable**	**Not valuable at all**	**Not Applicable**
Information package					
Direct access to information and referral service (via toll free 1-800 number or e-mail)					
Support Counselling					
Educational meetings and conferences					
Support Group					
ePress newsletter (Email)					
ParkinsonPress newsletter					
Library – books and DVDs					
Information booths at various fundraisers					
Education Conference					
Website: parkinsonsaskatchewan.ca					

30. What topics or speakers would you suggest for future educational meetings, support group presentations or conferences?

31. How many support group meetings have you attended in the past year?

○ 0-1
○ 2-5
○ 6-8
○ 10+

32. What factors influence your attendance?

○ Group Dynamic
○ Choice of topic
○ Proximity of meeting
○ Availability of support care
○ Time conflicts with other commitments
○ Not a priority

33. What best describes your use of the Quarterly Parkinson Press newsletter?

○ Share it with my friends and family
○ Read it cover to cover
○ Skim from page to page
○ Only read articles that catch my interest
○ Don't read it
○ Don't receive it

34. What types of information would you like to read about in *Parkinson Press*? Please explain.

35. Are you aware of the Parkinson Society Canada National Research Program?

Yes No

36. Do you or have you participated in PSS fundraising activities?

Yes No

If so, which ones?

- ○ SuperWalk
- ○ Lows in Motion
- ○ Shake, Rattle, and Roll
- ○ Other: ________

37. What is your preference for volunteering/donating to PSS as compared with other charitable organizations?

- ○ First priority
- ○ Somewhat of a priority
- ○ Neutral
- ○ Some support but not overly committed
- ○ Do not support PSS

38. PSS is committed to advocating on behalf of people living with Parkinson's in Saskatchewan.

Rank the following issues from 1-4 (1 being most important to 4 being least)

___ Multidisciplinary Movement Disorder Clinic
___ Nurse to assist Neurologists throughout province
___ Access to specialized Parkinson's specific quality of life programs (Exercise, voice treatment, dance, yoga, etc.)
___ Access to general neurological quality of life programs (chair yoga, aquasize classes, etc.)

39. What are the best ways for PSS to communicate with you? (Check all that apply)

Email
Blogs
Facebook
Twitter
Phone
Mail
Other:

40. What is your overall level of satisfaction with the services provided by PSS?

Very satisfied
Somewhat satisfied
Not very satisfied
Not at all satisfied
N/A I have not sought the services of PSS

41. Please rate your satisfaction with each of the following areas on a scale of 1-5, where 1 indicates highest satisfaction and 5 lowest:

___ PSS has my trust and support
___ PSS Board of Directors has my trust and support
___ Policies and governance are transparent, sensible and clearly communicated
___ Staff is professional knowledgeable and helpful

42. Please feel free to add additional comments regarding any aspect of PSS including the support group networks, fundraising events, awareness, availability of staff, information materials, etc. Your comments are appreciated!

Thank you for completing this section.

Thank you for taking the time to complete this survey. Thank you for taking the time to complete this survey. Your answers are extremely valuable in this study and will help Parkinson Society Saskatchewan to better understand and serve your needs.

If you would like information about Parkinson Society Saskatchewan or other services available, please contact:

Travis Low, Executive Director
Office: 306-933-4455
Toll Free: 1-888-685-0059
Fax: 888-775-1402
E-mail: travis.low@parkinson.ca
Website: www.parkinsonsaskatchewan.ca

APPENDIX C: Focus Group Guide

I. Steps to be covered before the interview

a) Introduction

- Introduce yourself as a CUISR researcher.
- Explain purpose of the focus group – the purpose is to collect information about their experience living with Parkinson's disease or being a care partner for someone who is living with Parkinson's and the services they use or would find useful. The information will be used to inform the programming at Parkinson's Society Saskatchewan (PSS).
- Go over the consent form – if each individual consents to participate, get the individuals to sign the forms and give them a copy for their records.
- Go over the focus group guidelines – responses are confidential, identifying information will be removed before information is published in the final report; the recorder can be turned off at any time; you do not have to answer a question if you don't want to; you can leave the focus group at any time for whatever reason, there is no penalty for choosing to leave the focus group early.
- Explain what will happen to information from focus group – i.e. all the information collected will be put together into a report published by CUISR for PSS. The report will be made public. The goal of the research is to examine the gaps and potential improvements to PSS programming.
- Thank them for participating in the focus group.

b) Getting to know the group (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask everyone for a general brief overview about themselves e.g. their relationship to Parkinson's – person with Parkinson's, care partner, relative, etc.

II. Interview Guide (TURN ON THE RECORDER IF PERMISSION IS GIVEN)

Section 1: Your experience with Parkinson's

1. As part of the evaluation for Parkinson Society Saskatchewan, we would like to know about your experience with Parkinson's. Can you tell us a little bit about your story and your experience of Parkinson's?
    a. Probe: When were you/the person you care for diagnosed? How old were you/they?
2. How has life changed since diagnosis? What has been challenging? What has been useful in managing Parkinson's?
3. What type of services and supports have you taken advantage of?
    a. Probe: Do you have help from anyone outside your friends and family? A 'formal' support network?

Section 2: Your interactions with Parkinson Society Saskatchewan

1. How and when did you learn about Parkinson Society Saskatchewan?
2. What types of services and activities does PSS offer?

    a. Probe: Fundraising activities, support groups, information sharing…

3. Do you access or participate in any of the programming offered by PSS? If so, which ones?
4. What do you find most useful or interesting in what PSS has to offer? Why?
5. How has the program helped (or not) your quality of life or that of someone you know?
    a. Probe: Has PSS helped you live more independently (if you are living with Parkinson's)? Or provided important information or a place to share with others?
6. How would you rate your experiences with PSS?
    a. Probe: Would you say your experiences have been very good, good, bad, very bad? And why?
7. Have you benefitted from PSS programming in ways that you were not expecting?
    a. Probe: What were the benefits that you received that you were not expecting?
8. Have your expectations for the various services been met?
    a. Yes Probe: Would you mind explaining what your expectations were that were met?
    b. No Probe: Can you give us examples of expectations that you had, but that were not met?
9. What do you most enjoy about PSS services and activities?
10. What could be improved in PSS's current programs?
11. What is missing from PSS that would improve your quality of life? What could PSS offer that would be helpful in addressing your needs?
12. What about PSS programming do you least enjoy?
13. In your view, what are the strengths of PSS? (How the programs operate)
14. In your view, what are the weaknesses of PSS? (How the programs operate)
15. If you had the opportunity to improve the services offered by PSS, what would you change?
16. The mandate of PSS is to "to promote excellence in patient care, education and research in Parkinson's disease and related disorders in the province." How well do you feel PSS meets its mandate?
17. Is there anything else that you think we should know about your experience with PSS?

III. Wrap-up

Thank you for taking the time to talk to me/us today. Is there anything else you would like to add? Thanks, and have a good day.

APPENDIX D: Key Informant Interview Guide

I. <u>Steps to be covered before the interview</u>

a) Introduction

- Introduce yourself as a CUISR researcher.
- Explain purpose of interview – the purpose of the interview is to collect information about their experience living with Parkinson's disease or being a care partner for someone who is living with Parkinson's and the services they use or would find useful. The information will be used to inform the programming at Parkinson's Society Saskatchewan (PSS).
- Go over the consent form – if the individual consents to participate, get the individual to sign the forms and give them a copy for their records.
- Go over the interview guidelines – responses are confidential, identifying information will be removed before information is published in the final report; the recorder can be turned off at any time, the interview does not have to be recorded; you do not have to answer a question if you don't want to; you can finish the interview at any time for whatever reason, there is no penalty for choosing to end the interview at any time.
- Explain what will happen to information from interview – i.e. all the information collected will be put together into a report published by CUISR for PSS. The report will be made public. The goal of the research is to examine the gaps and potential improvements to PSS programming.
- Thank them for participating in the interview.

b) Getting to know the individual (DO NOT RECORD THIS PORTION OF THE INTERVIEW)

- Ask the individual for a general brief overview about themselves e.g. age, living arrangements, day time activities

II. <u>Interview Guide</u> (TURN ON THE RECORDER IF PERMISSION IS GIVEN)

<u>Section 1: Your experience with Parkinson's</u>

1. As part of the evaluation for Parkinson Society Saskatchewan, we would like to know about your experience with Parkinson's. Are you or someone you know affected by Parkinson's disease?
2. Can you tell us a little bit about your story and your experience of Parkinson's?
    a. Probe: When were you/the person you care for diagnosed? How old were you/they?
3. How has life changed since diagnosis? What has been challenging? What has been useful in managing Parkinson's?
4. What type of services and supports have you taken advantage of?
    b. Probe: Do you have help from anyone outside your friends and family? A 'formal' support network?

Section 2: Your interactions with Parkinson Society Saskatchewan

1. How and when did you learn about Parkinson Society Saskatchewan?
2. What types of services and activities does PSS offer?
    b. Probe: Fundraising activities, support groups, information sharing…
3. Do you access or participate in any of the programming offered by PSS? If so, which ones?
4. What do you find most useful or interesting in what PSS has to offer? Why?
5. How has PSS programming impacted the quality of life of those with Parkinson's Disease?
    a. Probe: Has PSS promoted independence of people living with Parkinson's)? Or provided important information or a place to share with others?
6. How would you rate your experiences with PSS?
    a. Probe: Would you say your experiences have been very good, good, bad, very bad? And why?
7. What could be improved in PSS's current programs?
8. What is missing from PSS that would improve your quality of life? What could PSS offer that would be helpful in addressing the major needs of the Parkinson's Disease community?
9. In your view, what are the strengths of PSS? (How the programs operate)
10. In your view, what are the weaknesses of PSS? (How the programs operate)
11. If you had the opportunity to improve the services offered by PSS, what would you change?
12. How well do you feel PSS meets its mandate "to promote excellence in patient care, education and research in Parkinson's disease and related disorders in the province?" Give specific examples.

III. Is there anything else that you would like to add? **Wrap-up**

Thank you for taking the time to talk to me/us today. Is there anything else you would like to add? Thanks, and have a good day.

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