

# Health and Support Services Access and Use by Persons with Parkinson Disease: An Alberta, Canada Case Study

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## ABSTRACT

In Alberta, Canada, over 8500 people have Parkinson Disease (PD). While health and support services do not cure the disease, they help to maintain health status and quality of life, as well as delay or prevent costly institutionalization. In 2008, Alberta Health Services was created, shifting care to a more centralized delivery system. What is the impact? This Case Study explores this, utilizing a phased approach with mixed and multiple methods to survey and interview persons with PD, their caregivers, service providers and decision makers, and explore changes, if any, in the availability, accessibility and costs of health and support services. Survey, interview and focus group instruments were developed for each group. Participant recruitment was through various means. Limitations were noted in the study with sampling and access to participants across Alberta. Descriptive statistical analysis was used with quantitative data, and qualitative interview/focus group data was thematically analyzed. The results will be triangulated to support identified satisfaction or challenges in services available and accessible by persons with PD and their caregivers as well as service providers. Recommendations are proposed from this case study. Knowledge Translation is far reaching including the application of this Case Study design and mixed methods approach.

**Keywords: Case Study, Mixed and Multiple Methods, Surveys, Interviews, Focus Groups, Parkinson Disease, Multiple Perspectives**

## INTRODUCTION

Currently in Alberta, Canada there are more than 8500 persons diagnosed with Parkinson Disease [1]. While health services, physiotherapy, movement disorder clinics and exercise therapy, do not cure the disease nor prolong life, they do help to maintain health status and quality of life, as well as to potentially delay or prevent costly institutionalization [2]. A 2006 Alberta study [2] [3] with persons with Parkinson Disease (PD) and their caregivers reported out-of-pocket costs of medications and therapies to be about \$1000 per month. Some health care and

support services were used and valued more because of their positive outcomes than other services, particularly seeing the neurologist or specialist, and accessing various therapies such as physiotherapy, exercise and speech. Home care services were valued but difficult to access. Since that study, in 2008 Alberta moved towards centralization of services and to one health system from nine regional health authorities, each with considerable autonomy. What impact has this shift to a centralized delivery system had for people with PD? What health and support services have become more available and easily accessed, and where are there more challenges for persons with Parkinson Disease and their caregivers as they attempt to access needed health and support services? These latter questions formed the basis for a study to examine the changes in health and social services following the formation of Alberta Health Services in 2008, and what impact these changes are having on persons affected by PD and others with similar health challenges.

## DESIGN AND METHODOLOGY

A case study design was selected to explore the proposed questions, based on the approach recommended by Yin [3] and the case study application by Tellis [4]. With the focus on Alberta Canada, its reformed health care system, and Albertans living with Parkinson Disease and their caregivers, this study like others involving chronic diseases or conditions and access to health and support services, is best approached as a case study. There are many advantages to the case study design. It supports mixed or multiple methods for data collection so that there is comprehensive investigation of the research question(s) for the targeted population with the identified condition. There is also support for gathering the perspectives of multiple stakeholders affected by the identified condition and therefore, having multiple sources of data which can be independently analyzed by stakeholder group or aggregated to get an overall perspective on key issues or recommendations. In this case study regarding all those affected by Parkinson Disease, there are multiple perspectives (persons with PD, their caregivers, health and support care providers, and

administrators or decision makers) which are essential to consider when talking about what health and support services are available or not, their accessibility or not, their need and benefit, as well as how they are delivered, changes in delivery, and recommendations to improve service access and delivery across rural and urban centres in Alberta. These different perspectives will be gathered in multiple ways - through surveys, interviews and focus groups - which provides richer and more comprehensive data from which to draw conclusions and make recommendations. This is suggested by Yin [3] as the best way to ensure triangulation and therefore, reliability and validity of the the study findings.

The purpose of this proposed Parkinson Disease case study is to explore and share information about changes in the availability and accessibility of health and support services specifically for persons with Parkinson Disease (PD) and their caregivers, as well as changes in resources and costs to them.

The case study includes three phases and three sets of data sources for triangulation [5]:

1. Analysis of health and social policies and services, and any documents regarding changes in parts or across Alberta between 2006 and 2012;
2. Exploration and sharing of perceptions and experiences of Persons with PD, their caregivers and service providers regarding service needs, availability and access, and related costs, as well as perceived and actual impacts of changes within the health system from 2006 to present;
3. Translation of study findings and recommendations with all impacted by PD including decision/policy makers for their perspectives and potential strategies to 'problem solve'.

### **Mixed and Multiple Methodology**

This study focusing on Parkinson Disease and health and support services across the province of Alberta is a good choice for a case study design and mixed and multiple methodology. The questions and objectives identified also support a case study approach with the methodology selected. Mixed methods are suggested because one method is not adequate in getting to the evidence that would comprehensively analyze the research questions or issues identified [6]. Starting with one method to gather initial data, and using those findings to elicit a second more in-depth set of data or confirming the first set of data, is critical in mixed methods. Otherwise, using different methods will be considered multiple methods which is also appropriate in case studies.

Ethics approval is required for this type of study which if needed for many different ethics committees in different institutions, can be a challenge. In the Parkinson study,

not only is ethics approval to be obtained from the University Health Research Ethics Board, but also those in Alberta Health Services and different institutions which are access points for persons with PD as well as health care and social support providers and administrators or decision makers.

**Phase 1: Document Analysis:** Policy and program documents or reports are searched across Alberta related to health and support services between 2006 and 2012. This is a grey literature search conducted through Google and MSN search engines, as well as manual searches of known websites and organizations. Key terms used for searches included Parkinson Disease, health services (including medical care and treatment, physiotherapy, physical therapy, mental health and psychology/psychiatry, speech therapy nutrition services, other therapies), support services (including peer support groups, counseling, financial planning, social work support, and occupational therapy), Parkinson Society, Alberta Health Services, and other related terms. Inclusion criteria and worksheets are similar to search terms and also include policies, services and programs provided by location for each year starting 2006 to 2012. Findings are presented in tabular format for ease of analysis.

**Phase 2: Quantitative Methods – Surveys:** Survey instruments were developed for the three targeted groups of participants - persons with PD, their caregivers, and service or care providers and administrators. Survey questions for persons with PD and their caregivers were based on the 2006 survey as well as Phase I document and program analysis. Table 1 summarizes the topic areas for the survey. Generally, questions focused on personal demographics, health and employment status, impact of PD on daily living and quality of life, economic or other costs, access and use of health care and support services as well as home care and long-term or continuing care, transportation and mobility, and information access including awareness and use of the Parkinson Society.

The proposed survey used with Caregivers of persons with PD focused on demographics, their experiences in supporting persons with PD and their caregivers, impact of PD, services and information they need and access, and awareness and use of the Parkinson Society (See Table 1).

The survey for the Service Providers and Administrators in Health care and support covered their roles in service provision and talking about services needed or challenges experienced by persons with PD and their caregivers, location of service, accessibility and impact for persons with PD, and perceived affiliation with the Parkinson society or other referral institutions (See Table 1).

**Table 1: Survey Topic areas for the three targeted groups – Persons with Parkinson Disease, their Caregivers, and Service Providers and Administrators (Decision Makers)**

Targeted Groups	Survey Focus – Topic areas
<b>Persons with Parkinson Disease (PD)</b>	<ul style="list-style-type: none"> <li>I. Information about the person with PD or PD like conditions</li> <li>II. Health and employment status</li> <li>III. Impact of PD or related conditions on daily living and life</li> <li>IV. Health care and support services</li> <li>V. Care in the community – home care, long-term care, continuing care</li> <li>VI. Economic costs and related expenses</li> <li>VII. Quality of Life</li> <li>VIII. Transportation and Mobility</li> <li>IX. Services that may be needed by People with PD</li> <li>X. Parkinson Society and services available</li> </ul>
<b>Caregivers of Persons with PD</b>	<ul style="list-style-type: none"> <li>I. Information about the Caregiver</li> <li>II. Caregiving Experience</li> <li>III. Impact of PD on Caregiver</li> <li>IV. Services needed by persons with PD</li> <li>V. Parkinson Society and services available</li> </ul>
<b>Service Providers &amp; Administrators</b>	<ul style="list-style-type: none"> <li>I. Role in Service Provision for person with PD</li> <li>II. Location of Service, Accessibility and Impact for person with P</li> <li>III. Perceived role of Parkinson society.</li> <li>IV. Perceived areas of improvement</li> </ul>

Participant recruitment was through several means, including the Parkinson Alberta Society support groups, information articles in weekly newspapers, Movement Disorder Clinics, therapy clinics in Alberta Health Services, physicians’ offices and continuing care/long term care facilities. Service providers and Administrators were accessed through centralized Alberta Health Services clinics, home care services or office listings, and through snow-balling or word-of-mouth recommendations.

Information on the study was provided along with the surveys which were gathered as paper, on-line or phone surveys. Because of the mixed methods used in gathering the survey data, quantitative data was inputted into

databases to be analyzed using SPSS for descriptive and inferential statistical analysis, while qualitative data was set up for thematic analysis.

**Phase 3 - Qualitative Methods (Targeted Interviews and Focus Groups):** The

Interview and focus group questions were framed around the results of Phase 1 and the survey responses in Phase 2. Questions were semi-structured, focusing on the participants’ perceptions regarding the survey findings as well as the impact of changes in services or related costs, if any, or perceived need for changes to service availability, access, and related policies. The participants were also asked what they felt would be recommendations to improve health and support services availability and access by persons with PD and their caregivers.

Recruitment for targeted interviews and focus groups included persons with PD or their caregivers as well as with Administrators/Decision Makers occurred in different ways. Some individuals self-identified by contacting the research contacts provided at the end of the survey or responded to ads in newspapers, while in other cases, service providers provided persons with PD and their caregivers information and invitations to participate. Administrators and Decision Makers were sent information and invitations, and were followed up by phone. Interviews were conducted in person and by phone, usually taking 1 to 1.5 hours, while focus groups averaged 1.5 hours and usually involved 10 people (mixed persons with PD and caregivers) in each group. Main inclusion criteria was that they be English speaking.

Interviews and focus groups were audiotaped and transcribed for ease of categorization, coding and thematic analysis. These various tasks including emergent thematic determination and analysis was conducted by two researchers – the inter-rater agreement scores demonstrated reliability of the process credibility for the theme outcomes.

**EXPECTED OUTCOMES FROM THE CASE STUDY**

There are several key outcomes which can come from this Case Study. Aside from individual reports of the results from each of the three phases, there will also be an overall study report. In addition, a recommendations briefing note or position paper may arise from the findings of this case study. The triangulation of data sources and the mixed and multiple methods used in gathering the different data strengthens the results for advocacy regarding service availability, access, delivery and gaps or needs. One major outcome based on the data is the mapping of services to where people with PD and their caregivers reside across Alberta. This mapping can illustrate where there is a need for services to be made available and delivered. The overall outcome is the translation and mobilization of the results with the Knowledge Users so they can benefit directly from the

information or use the information to advocate for changes.

## KNOWLEDGE TRANSLATION

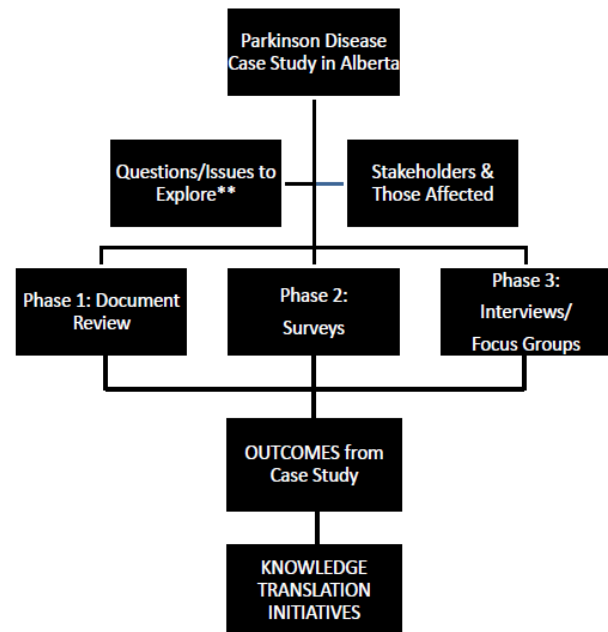
Based on the way in which this case study is designed with the three phases, there is knowledge translation from one phase to the next. For example, findings from the Phase 1 document scan is translated for use by or with knowledge users and researchers in their creation of surveys and interview or focus group questions for Phase 2. The results from the surveys gathered from the targeted groups as part of Phase 2 are used to develop interview and focus group questions with not only persons with PD, their caregivers, service providers and administrators but also with decision/policy makers. These knowledge users are part of the study planning and discussions. The dissemination and KT plans throughout the study include the education of various knowledge users about the findings, with the intention of further exploring potential strategies to address any inequities in availability and accessibility of services across rural and urban Alberta.

The case study approach is very conducive to Knowledge Translation of findings not only within and between phases and elements of the study but also for education and follow through with the Knowledge Users – Persons with PD, their caregivers, service providers, administrators and other decision makers. The Knowledge Users are involved in the study design and as participants throughout the study.

## ANALYSIS AND DISCUSSION OF THE CASE STUDY

The Case Study approach provides all the advantages for this proposed study on Parkinson Disease and Service Access or Utilization in Alberta. Figure 1 illustrates the different features of a Case Study as captured in the Parkinson Study. The study's research questions or issues to explore become the focus of the study with all other elements aligned to provide recommendations to address the questions or issues. There are many elements to this Case Study which enriches the findings and therefore supports any conclusions or recommendations made.

**Figure 1: Flow Diagram or Framework for the Case Study elements as supported in the Parkinson Study.**



\*\* The questions/issues are as proposed for the study.

It is clear from the Flow Diagram or Framework for this Case Study, the processes are equally as important as the outcomes for each step and for the study as a whole. The interconnectedness between Phases 1 and 2 as well as between Phases 2 and 3 results from the planned triangulation of the three sources of data. The outcomes in this case are fairly traditional but could be more innovative as could the Knowledge Translation initiatives. There are potential innovative ways to think about different ways to analyze the data from each of the three phases as well as for the overall study.

Considerations for limitations are noted in the study with sampling and access to participants across Alberta. A lot of effort was put into various means to recruit persons with PD and their caregivers, to ensure there were adequate numbers for significant statistical analysis in particular. Advice on recommendations for alternative ways to recruit participants can be made from this case study for other similar case studies.

The triangulation of results from the three phases clearly indicate changes have occurred since 2008, in services available and accessible by persons with PD and their caregivers. Although this paper is about the Case Study design and methodology used, the results are a product of this approach and indicate the need for follow up. For example, centralization, as noted by care or service providers, has altered availability and accessibility in rural and urban areas across the province, some good and some worse than before the reform. People indicated driving distances for appointments to specialists or therapists. Wait times to doctors or services increased for many people, especially for specialists in clinics. Participants

generally agreed that better coordination of services was needed (“one-stop shopping approach”), and that a team-based approach was best for ensuring services could be provided to persons with PD and their caregivers when they needed them most. A mix of centralized and community-based care was seen as most accommodating, particularly with home care services expanding, along with telehealth and possible Primary Care Networks and Family Community Care Centers across Alberta. These are some preliminary results from this Case Study on Parkinson Disease in Alberta. This information will be disseminated broadly and actively translated or mobilized as part of the Knowledge Translation planning.

## CONCLUSIONS

Looking at Parkinson Disease and the people affected by it as part of the Alberta Parkinson Case Study will provide a clear description of the services delivered by care providers and their experiences working with persons with PD, as well as those services used, needed and valued by people with PD and their caregivers. This case study will also provide the gaps, challenges and barriers experienced by all affected by PD including persons living with it, their caregivers, service providers and administrators or decision makers in Alberta Health Services as well as other service organizations.

Through the translation of the findings, the knowledge users who are primarily the persons with PD, their caregivers and service providers, indicate an increased understanding of the impact of the changes in service availability and access because of the centralization of services in Alberta in 2008. These stakeholders need to be engaged in collaborative discussion and strategic planning to identify actions, or “problem solve” strategies to address issues with current service access and related costs.

This case study is a good example of how evidence can be gathered and presented to support or challenge policy and service utilization and gaps. This approach that would be of interest to other disease groups, particularly as the information can be the evidence to support reform or status quo in terms of service availability in rural and urban centres, as well as accessibility, costs, and service or program delivery planning. The approach and methodology used in the Parkinson case study is also transferable to other chronic conditions with similar or different health and social support service needs in rural and urban centres. The case study approach is flexible for single or multiple cases as well – for example, if the Parkinson case study data as collected is used as a template for other neurological conditions, then multiple case studies could be analyzed under one larger neurological case study. The learnings from this case study approach has been immense.

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