CLIENT-CENTRED CARE EXPERIENCES IN ADULT REHABILITATION

EXPLORING CLIENT-CENTRED CARE EXPERIENCES IN ADULT

REHABILITATION SETTINGS: HEALTH CARE PROFESSIONALS',

PATIENTS', AND THEIR FAMILIES' EXPERIENCES

BY

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Abstract

Introduction: Client-Centred Care (CCC) is emerging as a best practice in health care organizations around the world. Partnerships between patient, family, and health professionals in planning and delivery of health care services are known to improve outcomes and satisfaction with care. Studies report lack of understanding of the elements involved in creating this partnership, and identify the need for valid and reliable measures of client-centredness for adults

Objectives: 1) To explore the historical evolution and current state of CCC as these were used in adult health care settings; 2) to evaluate the performance of the adapted MPOC for Adults (MPOC-A) and MPOC-SP (A) as measures of client-centredness from the perspectives of adult clients and their HCPs, respectively; and 3) to develop an in-depth understanding of health professionals' and clients' experiences of engaging in CCC.

Methods: A narrative review was completed to explore the development and conceptualization of CCC. Two validation studies looked at psychometric properties of the Measure of Processes of Care for Adults (MPOC-A) in orthopedic surgery and in-patient neurological rehabilitation settings, and the Measure of Processes of Care for Service Providers working with Adults (MPOC-SP (A)) in in-patient neurological rehabilitation programs. A qualitative study using Grounded Theory methodology explored experiences of CCC, barriers, and supports to developing successful partnerships from patients', families', and health care professionals' perspectives.

Results: The narrative review presented theoretical conceptualizations and definitions of CCC and identified areas that needed further development, e.g., clinical implementation of CCC principles into adult health care, development of valid and reliable outcome measures for adult clients, etc. In the validation studies, good to excellent internal consistency and moderate to good correlations between domains supported internal reliability of the tools. Results of confirmatory factor analysis of MPOC-SP (A) supported the original multi-dimensional structure of the tool.

Being on common ground was the main category identified by both clients and HCPs in the qualitative study. All participants repeatedly highlighted the importance of good communication and information flow among all the parties.

Conclusions: The MPOC-A and MPOC-SP (A) will be useful in assisting with program evaluation and quality control. The qualitative components of this study will help to improve our understanding of attributes of programs and health professionals that clients consider important for good quality care, and will provide some practical recommendations for clinicians on implementation of CCC into practice.

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I dedicate this work to my husband Vladimir. Thank you for your kindness, love, and support, without which none of this would be possible.

Preface

This thesis includes manuscripts of four studies. Chapters 2 and 3 have already

been published in peer-reviewed journals, and the remaining two have been

submitted for publication. The following summary details all authors'

contribution to each of the manuscripts included.

For all the manuscripts: Elena Bamm conceived the research questions, conducted

literature searches and synthesised background information, developed the study

plan, drafted applications to the Ethics Review Committee, collected and analysed

data, and drafted the manuscripts. Dr. Peter Rosenbaum helped with formulating

the research question and defining the population of interest, approaching

potential sites, reviewing study proposals and ethics applications, applying for a

grant to secure funding, and editing drafts of all the manuscripts.

For the manuscript entitled Validation of the Measure of Processes of Care for

Adults: A measure of client-centred care, Prof. Paul Stratford assisted with data

analysis and interpretation of the results, and reviewed final drafts of the

manuscript.

For the manuscript entitled Performance of the Measures of Processes of Care for

Adults (MPOC-A) and Service Providers (MPOC-A (SP)) in Rehabilitation

Settings, Dr. Seanne Wilkins provided editorial assistance with the manuscript

preparation, and Prof. Paul Stratford assisted with data analysis and interpretation of the results, and reviewed final drafts of the manuscript.

For the manuscript entitled <u>Exploring Client-Centred Care Experiences in In-patient Rehabilitation Settings</u>, Dr. Seanne Wilkins assisted with formulating the study questions, provided guidance and mentorship on analysis and interpretation of the results using Grounded Theory methodology, and assisted with drafting the final manuscript. Prof. Paul Stratford reviewed final drafts of the manuscript. Nadilein Mahlberg assisted with recruitment, data collection and management, and coding of the transcripts.

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Chapter 1

Introduction

Technological progress has changed our lives significantly over the last few centuries. Medicine has seen advantages through technology and science, such that many formerly terminal diseases can now be managed by therapy and appropriate adjustments to life style. The roles of health care providers (HCPs) have also undergone significant changes, from the doctor being the 'centre of the universe' in the medical model, to the partnerships between HCPs and clients that are promoted today (Bamm & Rosenbaum, 2008; MacKean, Thurston, & Scott, 2005; Schoot, Proot, ter Meulen, & de Witte, 2005). Of course this transition has been gradual. The movement towards care that puts the client in the centre was started over 50 years ago by parents of children with disabilities. They argued that as they were mostly responsible for the care of their child, knew their child's abilities and needs, and were overall invested in the child's physical and mental wellbeing they were entitled to reciprocity in information sharing and having their opinions considered in all decisions (Law et al., 2005; Lawlor & Mattingly, 1998; Rosenbaum, King, Law, King, & Evans, 1998).

Since that time, Family-Centred Care (FCC) has become the main model of practice in pediatric settings (Lawlor & Mattingly, 1998; Rosenbaum et al., 1998). The implementation of this new model of care was significantly helped by researchers exploring the pros and cons of FCC, developing outcome measures, and increasing clinicians' and the public's awareness by publications and

information packages. *CanChild* Centre for Childhood Disability Research in Canada and *NetChild* (Network for Childhood Disability Research) in the Netherlands are among the leading research groups that have helped to promote FCC in child care (*CanChild* Centre for Childhood Disability Research, 2003; Network for Childhood Disability Research in The Netherlands, 2009)

CanChild defines FCC as a service that "… is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered" (*CanChild* Centre for Childhood Disability Research, 2003). Similar ideas are present in virtually all definitions and conceptualizations of FCC (Bamm & Rosenbaum, 2008). Over the years, FCC has been linked with improvement in treatment outcomes, increased satisfaction with services and decreased anxiety and stress in patients and families (Rosenbaum et al., 1998).

In recent years client- and family-centred care principles have gradually been introduced into adult health care. Initially, the family's involvement in intensive care was considered essential (Giuliano, Giuliano, Bloniasz, Quirk, & Wood, 2000; Pryzby, 2005). Later, the idea of patient and family as members of rehabilitation team was introduced (Bright, Boland, Rutherford, Kayes, &

McPherson, 2012; Klein & Liu, 2010; Nieuwenhuijsen, 2009). Recently, client- and family-centred care has been adopted as the universal model of care in many developed countries (Abley, 2012; Hunt, Moore, & Sherriff, 2012; Kjörnsberg, Karlsson, Babra, & Wadensten, 2010; National Research Council, 2001; Ontario Medical Association, 2010). Although the main concepts of this new approach were developed through extensive research with patients, families, and HCPs, and Client-Centred Care (CCC) was said to be implemented in a variety of health care settings, reports were not always encouraging. Clients repeatedly reported unsatisfactory information flow and poor communication; HCPs in turn were not sure about actual involvement in the partnerships with the clients (Atwal et al., 2007; Krevers, Narvanen, & Oberg, 2002; MacKean et al., 2005; Morris, Payne, & Lambert, 2007). In order to promote implementation, there was a need for valid and reliable outcome measures that could capture the experiences of clients and HCPs. Researchers from *CanChild* Centre developed such a family of tools. The Measure of Processes of Care (MPOC) captures the experiences of partnerships between parents and HCPs from the parent perspective, while the Measure of Processes of Care for Service Providers (MPOC-SP) does that from the HCPs' point of view. Both measures are among the most often used worldwide for evaluation of FCC (*CanChild* Centre for Childhood Disability Research, 2003; Dyke, Buttigieg, Blackmore, & Ghose, 2006).

Working as a community and home care physiotherapist, I was able to see firsthand the importance of a patient's and family's involvement and engagement

in care, and the challenges of my inter-professional team to maintain similar levels of involvement, coordination, and communication. Unfortunately, the literature on CCC in adult health care settings was scarce, and I could not identify any tools that could help to assess current levels of client-centredness in my particular context. Consequently seven years ago I approached Dr. Rosenbaum to enquire about whether any work had been done on CCC for adult clients. I was hoping to build upon experience and expertise of the whole *CanChild* team and Dr. Rosenbaum to be able to transfer the ideas developed by them into adult health care.

Conceptual Framework

There are many definitions and conceptualizations of CCC available today, all of which support the multi-dimensionality of the construct. All studies completed during this thesis followed the framework developed by the *CanChild* group (*CanChild* Centre for Childhood Disability Research, 2003). Although the original MPOC was developed inductively based on the extensive interviews of parents of children with disability, the same concepts were found to be applicable in adult health care settings. (Please see Chapter 2 for further discussion). The framework includes five main domains:

1.   The Enabling and Partnership domain focuses on patients' and families' involvement in their care process, particularly in decision-making. Providing appropriate support in the form of information, encouragement, and respect of clients' expertise and experiences is vital.

2.   The Providing General Information domain is looking at how clients'

general information needs are being addressed by the health-care providers.

General information needs include, but are not limited to, general progression of

the condition, alternative treatment options, and support available in the

community. The information should also be available in different formats (e.g.,

brochures, videos, internet sources, etc.).

3.   Providing Specific Information focuses on provision of specific

information about a client's condition, progress and prognosis. This includes test

results, specific goal achievement, and overall prognosis for each particular client.

4.   Coordinated and Comprehensive Care is focusing on concerns of

continuity and consistency of care over time, settings and people. In other words,

it refers to holistic care that is tailored to each client's needs and life situation,

where all health care team members share information and are consistent in their

recommendations.

5.   Respectful and Supportive Care looks for relationships between clients

and HCPs in which the clients are treated with respect as individuals, equal and

expert. There should be enough time for the clients to voice their questions or

concerns, so that they do not feel rushed or brushed off. (For examples of MPOC-

A and MPOC-SP(A) items as they relate to the framework and further description

of the tools please refer to Chapters 3 and 5.)

Available Outcome Measures

Until recently, satisfaction with care was one of the most often used outcomes to evaluate the quality of care from a client's perspective (Atwal et al., 2007b; Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The majority of these outcomes ask for the overall rating of satisfaction across several aspects of care. The advantages of the satisfaction measures are their ease in administration and scoring, and their simplicity makes it easier for the client to understand the questions and provide a response. However, it remains to be seen how useful the information collected with the help of satisfaction measures might be. In fact, several studies reported on disadvantages of these measures, including significant ceiling effects and high levels of overall satisfaction reported, especially by older clients. Moreover, even when lower levels of satisfaction are reported, there is no usable detailed information to inform the clinicians and researches on what specific aspects of care are in need of improvement (see Chapter 3 for more details) (Atwal et al., 2007b; Williams, 1994). Consequentially, following adoption of CCC, the need for outcome measures assessing concepts identified as important by the clients and HCPs was recognized. In the last five years many tools have been developed, ranging from disease-specific to more general measures, asking patients, families, and HCPs to share their experiences (Edvardsson & Innes, 2010). However, to date the MPOC family remains the most widely used in clinical settings worldwide. It has been translated into several languages, and tested in a variety of health care settings. Its main advantage is

probably in the way the scores are calculated: the results are presented as sub-scale scores, without calculation of the overall score. Thus problematic areas can be easily identified and addressed. (For more details please refer to Chapter 4.)

Client-Centred Care Today

Looking at the body of literature on CCC, it becomes clear that we have a strong theoretical grounding for this new model of care. The HCP factors known to be essential for practicing true CCC are a clear understanding of the concept, support by general and local policies, and personal willingness and skills to engage in partnerships with clients (Litchfield & MacDougall, 2002). It is important now to evaluate the translation of the theoretical knowledge into clinical practice. In 2007 Morris and colleagues conducted focus groups with patients, families, and staff of acute and rehabilitation stroke units in a major city in England (Morris, Payne, & Lambert, 2007). The objective of their study was to learn and link the experiences of care of all the parties. They identified several important themes. Patients' and caregivers' themes included information (with specific information about condition and prognosis identified as problematic area), staff attitudes (reported as very positive), availability of care/treatment, and consideration of the whole person in context. Caregivers described two additional themes: accommodation of patients' individual needs and burden of care (they felt that they had to step in to assist the client with basic functions due to shortage of staff). Staff also identified six themes. Although some themes identified by clients and staff corresponded, the main focus of the clients was on personal and social indicators, while staff

highlighted the specialty and technical aspects of care. It would be important to explore whether there is more concordance in clients' and clinicians' experiences five years later. Hence, the objective of this thesis work was not only to allow quantitative assessment of client-centredness (Chapters 3 and 4), but also to explore the experiences of patients, families, and clinicians of CCC in in-patient stroke rehabilitation (Chapter 5).

The overall objectives of my work were:

1. To explore the historical evolution and current state of CCC as these were used in adult health care settings;

2. To evaluate the performance of adapted MPOC for Adults (MPOC-A) and MPOC-SP(A) as measures of client-centredness from the perspectives of adult clients and their HCPs;

3. To develop an in-depth understanding of health professionals' and clients' experiences of engaging in CCC;

4. To explore the needs of patients and families in terms of ways in which partnerships could be improved; and

5. To explore potential partnership barriers experienced by health professionals, patients, and their families.

This work is presented in this dissertation with publications and includes four manuscripts. A brief overview of each manuscript is presented below.

Overview of chapters

Chapter 2: Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine.

To better understand the state of CCC in adult health care settings I undertook a narrative review, the purpose of which was to present the development and evolution of family-centred theory as an underlying conceptual foundation of contemporary health care. The review focused on describing the key concepts, accepted definitions, barriers and supports to implementation, and measurement tools available for assessment of client and family-centred principles. Briefly, the review identified multiple conceptualizations and definitions of CCC, but found no generic valid and reliable outcome measure to assess CCC in adult health care settings. This work was published in the Archives of Physical Medicine and Rehabilitation in August of 2008, and forms Chapter 2 of this dissertation (Bamm & Rosenbaum, 2008).

Chapter 3: Validation of the Measure of Processes of Care for Adults: A measure of client-centred care.

Following on the results of the narrative review (Bamm & Rosenbaum, 2008), it was decided to adapt the original MPOC for use in adult care. Chapter 3 of the thesis includes the report of the study entitled 'Validation of the Measure of Processes of Care for adults: a measure of client-centredness of care' published in the International Journal for Quality in Health Care in June 2010 (Bamm, Rosenbaum, & Stratford, 2010). The purpose of the study was to assess the

psychometric properties of the adapted version of the tool, the MPOC-A, with clients undergoing elective joint replacement surgery. Although MPOC-A demonstrated good psychometric properties, the study was limited by the relatively small sample size and respondents' short-term experiences of the orthopedic unit that rendered many of the response options 'not applicable' to the study population. Many participants provided additional comments in the margins of the questionnaires, which although extremely valuable, were beyond the scope of the proposed study. Hence a decision was made to expand the study to include quantitative and qualitative components and to engage clients and HCPs from the in-patient rehabilitation units in which people often can experience richer and longer care-giving partnerships. The results of this two-part study form the next two chapters of the thesis.

Chapter 4: Performance of the Measures of Processes of Care for Adults (MPOC-A) and Service Providers (MPOC-SP (A)) in Rehabilitation Settings.

Chapter 4 of the dissertation reports on the performance of the MPOC-A and the MPOC-SP (A) (an adaptation of the original MPOC-SP) in adult in-patient rehabilitation settings. The patients, family members and HCPs on rehabilitation units were invited to respond to the respective questionnaires. Both questionnaires demonstrated promising results, however the limited sample size of the client group prevented us from carrying out all the planned analyses and, pending further studies, limited the generalizability of the outcomes. The

manuscript of this work was submitted for publication to the BMJ: Quality and Safety in September 2013.

Chapter 5: Exploring Client-Centred Care Experiences in In-patient Rehabilitation Settings

The study entitled 'Exploring Client-Centred Care Experiences in In-patient Rehabilitation Settings' forms Chapter 5 of the dissertation. Clients and HCPs from the previous study were asked to share their experiences in semi-structured interviews. The participants were selected based on their responses on MPOC-A or MPOC-SP(A), respectively. We hypothesized that the perspectives of people who rated the services as highly client-centred might differ substantially from those whose needs are not being met by their service providers. The study, following the Grounded Theory methodology developed by Strauss and Corbin (1998), uncovered many important categories and provided some helpful ideas on how to support implementation of CCC principles in practice. This work was submitted for publication to the Qualitative Health Research in September 2013.

Chapter 6: Discussion

Chapter 6 of the thesis provides an overview of the lessons learned, describes limitation of the studies, outlines potential further directions for both research and implementation of the best evidence-based information resulting from the studies, and summarizes clinical significance of the studies' outcomes.

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Chapter 2

Title of Paper: Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine.

Authors: Elena Bamm, Peter Rosenbaum

Abstract

The concept of Family-Centered Care (FCC) was introduced to the public more than four decades ago stressing the importance of the family in children's well-being. Since then family-centered values and practices have been widely implemented in child health. The purpose of this paper is to offer an overview of the development and evolution of Family-Centered Theory as an underlying conceptual foundation for contemporary health services. The focus includes key concepts, accepted definitions, barriers and supports that can influence successful implementation, and discussion of the valid quantitative measures of family-centeredness currently available to evaluate service delivery. The paper also provides the foundation, and proposes questions, for future research.

Key words: Family-centered; client-centered care; theory; rehabilitation; service evaluation.

"Nothing is so practical as a good theory"

(Kurt Lewin as quoted in Rogers[1] (p 15))

In the past century there have been revolutionary transformations in political, social, and scientific aspects of human life. The health care system is no exception. The transition from medically focused to client-and family-centered models of service delivery has its roots in perceptional transformation of humanity. Political agendas regarding family rights have been introduced. For example, 1994 was pronounced the United Nations International Year of the Family,[2] and academic publications have led to increased public awareness.[3-10] People have better access to information, and their higher expectations of service provision, as well as increased life-expectancy, require well developed and coordinated health services.

The purpose of this paper is to offer a presentation of the development and evolution of Family-Centered Theory as an underlying conceptual foundation for contemporary health care. The focus will include key concepts, accepted definitions, barriers and supports that can influence successful implementation, and then discuss valid quantitative measures of family-centeredness currently available to evaluate service delivery.

History

When a discipline experiences a paradigm shift, it often takes years, sometimes decades, until the theory gains substantial ground to become generally accepted and implemented in the field. The theory undergoes modifications and adaptations; it is influenced by cultural and political factors, and interacts with other philosophies in the area of interest. Its evolution is a dynamic process of development and growth.

The starting point of Family-Centered Theory can be traced back to when Carl Rogers began practicing Client-Centered Therapy in psychiatry almost 70 years ago. He saw Client-Centered Therapy as a continuing process, in which the therapist treats the individual as a person of worth and significance, and respects their capacity and right to self-direction. Presenting "Newer Concepts in Psychotherapy" as a guest lecturer at the University of Minnesota in 1940, Rogers was surprised by the interest his ideas evoked.[11] In 1959, Rogers diagrammatically presented the implications of a therapeutic relationship on family life and society. The key idea was mutual influence of the treatment process, family dynamics, and individual function and participation in social life.[11]

In the mid-1960s Rogers's ideas were embraced by the Association for the Care of Children in Hospital (subsequently the Association for the Care of Children's Health). This parent advocacy movement took client-centeredness to

the next level by stressing the importance of the family in children's well being.[12] It took almost 20 years until the Education for All Handicapped Children Amendments of 1986 in the United States of America (USA) (Public Law 99-457) granted families of children with special needs legal power to become an equal partner in the health care team.[7, 12]

The Ecological Theory of Child Development outlined by Bronfenbrenner in 1979 stressed the importance of considering not only the immediate family, but extended family and environment as well, when working with children.[5] The inclusion of the family in care decision-making has been expanded in North America's paediatric settings in the last 20 years.[10, 12-17]

The recent shift from client-centeredness to family-centeredness in the care of the adult population was probably initiated by the recognition of the significance of treating the patient in the context of the family and the general perception of the family as the basic social unit – the main educator, supporter, and shaper of each individual.[2, 17-20] The Universal Declaration of Human Rights (UDHR Article 16/3), presented by the United Nations General Assembly in 1948, states that: "The family is the natural and fundamental group unit of society and is entitled to protection by society and the state".[21] This systemic view of the family initiated the development of Family Systems Theory, derived from General Systems Theory presented by Von Bertalanffy in 1968.[17,18,22] The main principle of General Systems Theory that is applicable for systems in general is the

importance of seeing any system as a whole. Von Bertalanffy stated that a system and the behavior of its elements can only be explained when addressing all the parts in their mutual interaction and influence. The sum of parts independently described is not equal to the general picture of the system they form.[23] Thus, in the health care field, the family represents one of the most valuable sources of support and important insights on behavior and coping strategies of the individual.[5, 19,20]

Serious illness or injury brings with it an inevitable distortion of family dynamics and fine equilibrium. The ability of the family to reorganize and reduce the stress, in order to provide a healthy environment for all members of the family and initiate the healing process, differs from one family to another. This unique pattern has to be respected and addressed appropriately. Friedman's Family Assessment Model provides a useful tool that takes into account a family's stressors, strengths, perceptions, coping and adaptation strategies. According to assessment outcomes, specific family concerns and problems can be addressed and timely help offered.[24]

With an aging population and a larger proportion of people living with chronic diseases and disabilities, the main objective of the health care system has been shifting from providing curative treatments to providing support and remediation, improving function and health-related quality of life.[25] To improve quality of life and increase life span of families dealing with serious health

conditions, all possible supportive systems have to be employed: the social system by encouraging participation in the community life; the political system by providing financial support, as well as promoting policies to remove environmental barriers that limit participation; emotional and spiritual support systems provided by extended families, friends, and religion; and the health care system by maintaining the best possible function given the limitations of the illness. A family-centered approach provides an important conceptual foundation for a contemporary model of health service delivery, as is evident from numerous publications of the last decade, not only in professional journals, but also in the public press.[3, 4, 12, 19, 22, 24,26-28]

Definition and main principles

In order for a theory to become accepted and implemented in the field, it has to be clearly defined and its main principles must be outlined. Explicit definition of the concepts provides common language for inter-professional communication and proper interpretation of the ideas by service providers. In 2001 Briar-Lawson et al.[2] published an international interdisciplinary conceptual framework for building family-centered policies and practices. It states that "as diverse as they may be, all family-centered policies and practices share the following five important features:

1. *Families are considered experts in what helps and hurts them.*

2. *Families are indispensable, invaluable partners for policy makers, helping professionals, and advocates.*

3. *Families are not called, or treated as, dependent clients. Helping professionals and policy makers view families as equals, as citizens, with whom they collaborate, and whom they empower.*

4. *Family-centered policies and practices… promote family-to-family and community-based systems of care and mutual support.*

5. *Family-centered policies and practices promote democratization and gender equity*".[2 (pp 185-86)]

However, as function and perception of "family" vary according to the cultural and political environment, such a definition of Family-Centeredness might differ from country to country and from one setting to another. The definitions found in the literature range from study-specific[19, 29, 30] to age- or diagnosis-specific,[31] to comprehensive definitions introduced in recent years.[32] To illustrate, consider two of many existing definitions:

CanChild Centre for Childhood Disability Research describes family-centered service as an approach to providing services for children with special needs:

Family-centred service is a philosophy and method of service delivery that:

- *recognizes parents as the experts on their child's needs*

- *promotes partnership between parents and service providers, and*

- *supports the family's role in decision making about services for their child.*[31]

According to the Institute for Family-Centered Care:

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnership among patients, families, and providers. It applies to patients of all ages, and it may be practiced in any health care setting.[32]

Though different according to the populations they serve, the main concepts in these definitions (family as expert, and the importance of partnership during the whole interaction) appear to be very similar.

MacKean et al.[9] conducted a comprehensive literature review to condense the main concepts of Family-Centered Care most frequently described in the child health literature. These are as follows:

1. *"Recognizing the family as central to and/or the constant in the [child's] life, and the [child's] primary source of strength and support;*

2. *Acknowledging the uniqueness and diversity of [children] and families;*

3. *Acknowledging that [parents] bring expertise to both the individual care-giving level and the systems level;*

4. *Recognizing that family-centred care is competency enhancing rather than weakness focused;*

5. *Encouraging the development of true collaborative relationships between families and health-care providers, and partnership; and*

6. *Facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families.* "[9(p.75)]

While this framework represents pediatric care perspectives, it describes the same ideas (such as the family as expert and source of support, uniqueness and partnership) that form the core of a general Family-Centered approach.

Although the definitions of the main concepts of this approach such as dignity and respect, information sharing, participation, and collaboration have become clearer over the years,[19, 29-32] practical implementation of a theory represents the real challenge faced by every innovation in the field. The questions addressed by this narrative literature review are as follows: How is the Family-Centered Theory put into practice? What are the barriers and supports that affect the implementation of this theory? Is it testable?

Literature review

Search strategy:

In preparing this narrative review we have attempted to portray the contemporary state of the Family-Centered Theory as it appears in scientific publications, specific commentaries, official websites, textbooks, and documentary books. A

literature search was conducted between November 2006 and March of 2007 in

Medline (looking at the literature from 1966 to October 2006), Embase (1980 to

2006 week 42), PubMed (published at any date), and CINAHL (1982 to March

2007). The main keywords used were: Family-centered/centred, client centered,

rehabilitation, theory, measures. The references of the articles retrieved were also

examined to extract other publications of interest. Moreover, the websites of the

Institute for Family-Centered Care and the Picker Foundation were searched for

additional references. A total of 85 publications were reviewed, and 50 were

selected for inclusion, based on the following criteria: Randomized Controlled

Trials on comparison of conventional with family-centered treatments; historical

development of the theory; systematic reviews on family-centered programs and

interventions; use of outcome measures of family-centeredness in different

settings and age groups; English language. Publications were excluded if they

described family-centered interventions rather than family-centered care;

investigated individual aspects of family-centered care without referring to

Family-Centered Service per se; concentrated on the physical aspects of the

intervention, such as architectural adaptations, day-to-day care, and financial

support without considering psychosocial facets of care; or focused on the patient

without considering the context of the family.

Theory use

Most literature existing today on Family-Centered Care is drawn from the field of child health; the interest in new approaches in adult health care has only become apparent in recent publications.[12, 20, 28, 33, 34] Although research conducted by different disciplines [9,22,26,35,36-38] identified important domains and definitions of family-centeredness [9,12,31] (see "Definition and main principles" section), professionals in various fields of the health care system are experiencing an ongoing struggle with the implementation of the concepts of Family-Centered Care into practice.[7,9,17,35] Questions raised by these professionals include: how do they provide essential information to each individual family? How can they avoid being just "the expert" and become a partner? How will they know when they are expected to guide and when just to listen? As an example, MacKean et al.[9] explored utilization of Family-Centered concepts by developmental services at a children's hospital in Alberta, Canada. Focus groups and individual interviews were conducted with parents and service providers. The findings suggested that while families were very interested in working collaboratively with service providers, professionals still tend to prescribe the role of the parents in the interaction. In some cases families felt that they had more responsibilities than they could manage. Similarly, mothers of young children with disabilities communicated identical problems with the implementation of a Family-Centered approach.[17] Analysis of interviews and observational data collected for that study showed that some mothers felt that appearing as a "good mother" in the health

provider perspective by sharing the responsibility for the treatment could jeopardize their role as a mother. Moreover, many expressed apprehension about being unqualified to fulfill the role of the therapist.[17] More research is required to understand how professionals and families can work in collaboration.

Based upon previously outlined concepts and theoretical frameworks of Family-Centered Care,[1, 2, 9, 11] several new programs have been developed to enhance family-centeredness in different settings. Giuliano et al.,[28] working with critically ill adults, and Madigan et al.[33] working with children undergoing heart surgery, presented programs specifically developed to improve family-staff communication in Intensive Care Units. The basic components of the programs included appointment of a staff member to guide and support the family throughout hospitalization, as well as constant communication between primary physician and family, and timely provision of information. The evaluation of the programs was done by administering the Critical Care Family Needs Inventory in the former study and the Parent Satisfaction Survey in the latter program. Overall improvement in timely information provision and communication between families and care providers was demonstrated in both studies; however no statistical significance was reported, making it difficult to estimate the efficacy of the programs.[28, 33]

Visser-Meily et al.[39] in the Netherlands and Van Horn et al.[27] in the USA conducted systematic reviews examining interventions for caregivers of patients

post-stroke and patients with cardiovascular diseases, respectively. In the studies reviewed, the interventions included information and educational sessions, client-specific goal settings, and psychological and emotional support. Although most studies reviewed in Visser-Meily et al.[39] and Van Horn et al.[27] (14 of 22 and 9 of 13, respectively) had a randomized control trial design, the variety of interventions and outcome measures used and the small sample sizes did not allow any clear conclusions to be drawn. In general, most studies demonstrated that the caregiver interventions implemented had decreased depression rates, improved satisfaction with care and health-related quality of life, as well as led to more active participation in community life, and overall reported better family dynamics for patients and caregivers.

Litchfield and MacDougall[35] described professionals' understanding of the main concepts of family/client-centered care, how they see themselves implementing it in practice, and the main skills that are required for successful accomplishment. They explored perspectives of physiotherapists working in family-centered settings in Australia. Semistructured interviews were conducted with 10 physiotherapists. The main characteristics of the interaction involved setting family-specific goals, providing education and counseling, and enabling informed decision making. The participants emphasized the importance of policies (at the federal or local levels) to facilitate acceptance of family-centered care as a new approach to service delivery. In addition the physiotherapy

participants expressed concerns regarding the change in their professional roles, credibility, and skills required to implement Family-Centered Care.[35]

Several articles offer an insight into how patients and families understand Family-Centered Care and what professional competencies are required from the health care providers in order to meet their expectations. Attree[36] and Little et al.[30] in United Kingdom, Epstein[37] and King and Semik[38] in the USA, and Wachters-Kaufmann et al.[40] and Shoot et al.[26] in the Netherlands explored patients' and families' requirements for "good" care. The results were similar across these qualitative studies. Participants stated that the most important issues in health care services were individualized, patient-centered care, clients' involvement in their care, availability and accessibility of the staff, inter-professional communication, and relevant and timely information provision, which are the main components of Family-Centered Care.[2, 9] The most interesting finding, however, was that participants rated human qualities of the professionals, such as kindness, concern, compassion, sensitivity, and approachability as being of much higher importance than technical competencies.

Lanza's[41] personal story demonstrated a valuable experience of crossing the line: a nurse who suffered massive stroke presented a list of lessons to help nurses better understand stroke survivors. The most important messages were: allow control over the "little things", and encourage advocacy by family members on behalf of patients.

Although carried out in different countries, qualitative studies by MacKean et al.[9] and Morris et al.[42] report similar attitudes by clients and health professionals, respectively. What makes these studies of high informational value is their two-sided perspective investigation performed under the same conditions. Morris et al.[42] explored patient, carer, and staff experiences of in-hospital rehabilitation following stroke, while MacKean et al.[9] were interested in how understanding of family-centered care varied among families and health professionals in paediatric settings. Core themes identified by all participants were similar across these studies and consisted of personalized care, timely information provision, staff competency and expertise, and efficient inter-professional communication. While patients and carers saw the former three as being the most important aspect of good care, health professionals tended to stress the importance of medical competencies over the informing the families on all the aspect of care. The results of these studies correspond to outcomes of research described in previous sections of this review.

Although recent qualitative studies have identified the same main concepts of family-centeredness by clients and health care providers, the discrepancy between patients', families', and professionals' perspectives becomes apparent if the issues described in the publications are summarized as embraced by each group.[9,26,28,30,33,35-38,40-43] Families view availability, accessibility, and communication as the most important issues for collaborative relationships, while professionals see their primary responsibility as providing education, counseling,

and information (Appendix 1). Moreover, partnership was the one criterion most often identified by the patients and families that was not mentioned by health care providers at all. As stated by MacKean et al.[9 (p. 81)]: "Family-centered care is beginning to sound like something that is being defined by experts and then carried out to families, which is ironic given that the concept of family-centered care emerged from a strong family advocacy movement".

Barriers and supports to implementation of family-centered theory

The implementation and acceptance of a theory can take years and even decades.[12] For the most part barriers and supports to implementation of any innovation can be divided into political, conceptual, financial, and attitudinal factors. [6,7,9, 32,35]

Political and conceptual factors: Professionals are usually more willing to accept changes when managers and leaders of the organization they work for provide personal example and guidance, or when the new approach is enforced by legislation and policies.[6] Johnson[6 (p.19)] states that in order for Family-centered Care to be embraced by the health providers "Family-centered values must be articulated in the organization's philosophy of care, mission statement, or strategic plan". Friedemann et al.[22] indicated that in nursing homes with family-oriented nursing home policies and practices families were more likely to report actual involvement in the care of their loved ones than families from facilities that did not encourage family involvement. However, legislation by itself does not

make the transition process easier. For example, Litchfield and MacDougall[35] described the main concerns of physiotherapists working for organizations with a family-centered approach as losing their professional credibility, diminished recognition by other physiotherapists, and as a consequence, fear for future employment. Despite increased awareness of the importance of involving patients and their families in their own health care, many health professionals still feel more comfortable practicing in a biomedical model.[12, 34]

Different models of family-professional interaction have been presented over the last 20 years. [34, 35, 43] A seven-level hierarchy model of family-therapist involvement has been proposed by Brown et al. [43] The levels were based on analysis of occupational therapist-family interaction outcomes expressed by the therapists in the open-ended interviews. The collected data also allowed researchers to outline technical and personal qualities required from therapists for successful collaboration. In this model levels 1 to 3 represent no to little involvement of the family in the treatment process, levels 4 and 5 show some involvement as co-client or consultant, and levels 6 and 7 represent true family-centered collaboration. Litchfield and MacDougall[35] later investigated practical implementation of the model by physiotherapists working in family-centered and community-based settings. The study revealed that most physiotherapists were comfortable working with families as assistants and consultants, but felt threatened by sharing power and responsibilities with the families.[35]

These outcomes raise other factors that might act as barriers to implementation, such as competency and confidence of the health professionals. After practicing in a paternalistic model for many years it is not easy for people to move to a new way of providing care, even if the concepts are clear and relevant.[12] Though the differences between patient-centered and family-centered care do not appear at first sight to be substantial, the family issues cannot just be added to previous models. The whole conceptual framework has to be reorganized to become both patient- and family-centered.[6, 7] However, many professionals do not feel confident enough to become engaged in family-centered care.[6,12,35] Collaborating with families as well as with clients presents specialists with new challenges professional had not necessarily had to face before.[6] Emotional and social involvement with families requires competency in addressing psychological issues, and interpersonal communication skills such as honesty, respect, tolerance, and flexibility.[7] In addition, the specialist has to be confident enough not to feel threatened by the power shift and the change in their professional role.[6, 7, 34, 35] Moreover, based on recent qualitative studies conducted in different rehabilitation settings, it still appears to be unclear to health professionals and families what real collaboration is and how to make it work.[9, 35, 42]

Financial factors: One of the frequently asked questions is: Does patient- and family-centered care cost more?[32] Recent qualitative studies have indicated that although it requires an initial investment for education of the staff and development of the new strategies, at the end the benefits outweigh the

expenses.[19,29, 35,38,39,44] Mant et al.[45] conducted a randomized control trial to assess the impact of a family support program for stroke survivors and their families. The results were lower depression and anxiety rates (p-values 0.01-0.04), and less utilization of specialist services (p-value 0.04). In agreement with Mant et al.[45], several other studies indicated clinically important improvement in treatment outcomes (both functionally and with respect to time), satisfaction with care, and quality of life of entire family;[30, 38, 44] and decrease in depression rates and burden in carers.[19,37,38] These findings support the idea that in the long term Family-Centered Care may improve effectiveness and efficiency of the health services, and reduce financial burden on the system. However, more research is needed to explore direct financial benefits of a Family-Centered approach.

Attitudinal factors: According to Attree: "… caring is as much a social as a physical process".[36 (p. 462)] Nevertheless, attitudinal issues are probably the least explored of all the aspects of family-centered services. As every individual is unique, so are the attitudes towards any aspect of the surrounding world, including health care system. Health service providers' attitudes are represented by three main points of view: some believe that they have always practiced Family-Centered Care and thus do not require any change; others are confused and frightened by the changes the new approach brings, and uncertain what would be the best way to make the transformation happen; and last, the minority do not want any change and are satisfied with the authoritarian status they have enjoyed for many years of practicing in a medical model.[4,6,12] The reasons for these

disparities in perspectives are probably lack of educational programs and implementation strategies,[46] and the scarcity of research to support effectiveness and efficacy of practicing Family-Centered Care as opposed to a biomedical approach.[6,9] In 1988 a postgraduate course for teaching patient- and family-centered medicine to family medicine residents was developed in Ben Gurion University of the Negev in Israel. The course was based on the main concepts of Family Systems Theory and has been reported as a valuable educational experience by most graduates. Participants expressed that the program helped them to understand and implement important aspects of physician-family interaction, and provided practical tools to deal with complex situations.[46] Development and evaluation of effectiveness of inter-professional educational programs is an essential step in converting family-centeredness from theory to practical ideas.

Apart from the individuality of attitudes and wishes of each person/family, there appear to be other determinants that may influence client-health care provider interaction. Gender and age, cultural values, economic status, race, acute versus chronic illness differences in attitudes towards family-centered care have all been pointed out as potential variables in many recent publications.[5,8,19,26,27,29,37-40,47] Several publications indicated that differences in the course of psychological and physiological recovery, family and social support systems, and outcome expectations in men, women, and younger versus older adults, were responsible for different attitudes towards family centeredness of

care.[27,38] In general, women and/or older patients tend to be more satisfied with medical care. However, no evidence is available to date regarding relationships between demographic characteristics of patients and families, satisfaction, and different domains of the family-centeredness of care.

Cultural differences were interestingly addressed by ethnographic research methods in a publication by Hammer.[5] Families and therapists from different cultural backgrounds may hold distinct beliefs and attitudes towards the whole intervention. As an example, the importance of medical care can come as patients' last priority after all other social and family responsibilities. Families might prefer not to have the responsibility of choosing the best treatment option, or may entrust decisions to the health professional as "an expert" to make all the decisions. The key point is that family should have a choice; respecting every family's wishes requires exceptional flexibility and open-mindedness from health professionals. Hammer suggested that literature reviews, written documents, interviews, and observation can be employed by the therapist to understand and embrace families' perspectives. This in turn will allow real collaboration to take place between two partners who share common values and goals.[5]

Measures: One of the essential characteristics of a theory is its testability. Valid and reliable quantitative measures are essential for evaluation of a theory's utility, research development, and knowledge transfer. The development of measures of processes of human interaction is especially difficult given that so

many factors have to be taken into account.[47,48] There are several quantitative

measures of family-centeredness described in the literature.[10, 49-52] The Measure of

Processes of Care (MPOC) developed for families of children with disabilities by

King et al. in 1996[49] has demonstrated good validity and reliability.[10, 49,50]

Cronbach's alpha coefficients ranged from 0.81 to 0.96 for the five domains, and

intraclass correlation coefficients (ICCs) of the test-retest reliability ranged from

0.78 to 0.88 demonstrating good stability. For construct validation MPOC scores

were hypothesized to be negatively correlated with parental stress level and

positively with satisfaction with care. Spearman Rank Correlation Coefficients (r_s)

for association between stress and MPOC scores ranged from -0.47 to -0.55 and

Pearson Correlation Coefficient (r) for association between satisfaction and

MPOC scores ranged from 0.40 to 0.64.[49] Over the years MPOC has given rise to

several modifications: MPOC-56 is the original version; MPOC-20 is the shorter

20-question format that covers the same main aspects; MPOC-SP is a

complementary form used in combination with MPOC to measure service

providers' (SP) perspectives of Family-Centered Care. The five domains of

MPOC are: Enabling and partnership, Providing general information, Providing

specific information, Coordinated and comprehensive care, and Respectful and

supportive care.[10, 49,50]

Give Youth a Voice (GYV) is an additional adaptation of MPOC,

developed by Campbell et al. to reflect the special perspectives of adolescents'

experiences of family-centered care.[52] Family-Centered Care Survey (FCCS) is

20-item questionnaire to measure adult patients' satisfaction and family-centeredness of the care. Although it has demonstrated good face validity, its overall validity and reliability have not been reported yet.[50]

Previously, when trying to assess subjective outcomes of interventions, global satisfaction was considered as the best measure. Though satisfaction with care and family-centeredness are interrelated (r ranging from 0.40 to 0.64),[31,49] the complexity of the factors that were identified by patients as essential components of Family-Centered Care requires a measure that will be able to quantify and differentiate all aspects of the service. This in turn will allow effective reflection, knowledge transfer, and quality improvement of successful and problematic areas of specific programs or facilities.[30, 36-40, 49] Although MPOC has been proved to be a reliable measure in children's health settings, based on the present literature review no similar properly validated measures of family-centeredness for an adult population were identified. Thus, it is important to develop and validate a generic measure that will be able to assess to what extent adult patients and their families experience Family-Centered Care.

Conclusion

Family-Centered Theory forms the foundation for delivery of health care services in a manner alternative to that provided by the existing biomedical model.[12] The ideas of family-centeredness were introduced more then 40 years ago and have been widely implemented in the field of child health.[1,7, 10, 12-16] The

subjective outcome measures developed for evaluation of parents' perspective of the services (e.g., MPOC) demonstrate statistically significant moderately positive correlations with satisfaction with services (r from 0.40 to 0.64) and negative correlations with stress levels of caregivers (r_s from -0.47 to -0.55).[10,14,15,31,49,50] Although many concepts and principles of Family-Centered Theory have been transferred from child health to adult care practice, more research is needed in different populations and settings to ensure the applicability of the model to different age groups. Development of trustworthy methods for evaluating or assessing the family-centeredness of care in the adult population is essential for research, knowledge transfer, evaluation of change initiatives and better understanding of the barriers and supports to implementation. These measures will also provide the evidence to support or reject the concepts of Family-Centered Theory. Important issues such as the development of new policies and competencies, educational programs, and organizational frameworks have to be addressed, as well as the interpersonal and cultural differences embedded in any human relationship that make the implementation of the theory extremely difficult.

Family-centered theory is continuing to develop, but is yet to be fully understood, implemented, and effectively evaluated in order that it can be universally adopted as 'best practice'. Opportunities abound to move this exciting field forward with research and model practices.

Acknowledgments

Appendix 1: Main aspects of Family-Centered Care in clients' and health professionals' perspectives.

Clients' perception[9, 26, 30, 36-38, 40-43]	Professionals' perception[9, 28, 33, 35, 43]
• Availability and accessibility • Communication • Partnership • Information (timely and situation-specific) • Advocacy and coordination • Education and counseling	• Education and counseling • Information • Policies • Emotional support • Common goals setting • Coordination

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Chapter 3

Title of Paper: Validation of the Measure of Processes of Care for Adults: a measure of client-centred care

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Abstract

Objective: To assess the psychometric properties of the Measure of Processes of Care for Adults (MPOC-A), an adapted measure of client-centredness of care for adult health care settings.

Design: A validation study.

Setting: Regional orthopaedic service of a university-affiliated hospital in Ontario, Canada.

Participants: All patients and families who had had joint replacement surgery (Knee or Hip) between January and August of 2007.

Main Outcome Measures: MPOC-A and the Client Satisfaction Questionnaire (CSQ).

Results: 176 questionnaires filled out by patients and 81 by family members were analysed. Scales demonstrated high internal consistency (Cronbach's Alpha varying from 0.81 to 0.93 for patients and from 0.88 to 0.96 for family members). MPOC-A domain scores were moderately correlated with CSQ total scores (Pearson coefficients varying from 0.44 to 0.66 for patients and from 0.53 to 0.72 for family members). Moderate to good inter-rater agreement (ICC from 0.50 to 0.74) and high test-retest reliability were found (ICCs varying from 0.73 to 0.83 for patients and from 0.75 to 0.91 for family members).

Conclusions: MPOC-A has demonstrated good psychometric properties. As general satisfaction scores are notoriously poor indicators of the quality of care, this measure can help us understand the elements that contribute to overall judgments of satisfaction and provide a level of understanding that is important to improving service quality and delivery.

Key words: Family/client-centred care; measures; service evaluation; rehabilitation.

Introduction

Family-Centred Care has been implemented as a 'best practice' in many child health care settings around the world [1-7]. Recent qualitative studies conducted with adult patients and their families have identified important aspects of client/service provider interaction similar to studies in the paediatric field [7-16]. Information provision, respectful and supportive care, personalized, and coordinated care were identified by clients as being of equal importance to the technical medical skills of the health care team. However, they also reported dissatisfaction with the degree to which these behaviours were actually demonstrated by health professionals [9, 10, 12, 17-19]. Specifically, patients and carers expressed the need for more timely information on etiology and prevention of the disease, as well as coordinated updates on their current condition and future perspectives. Personalized care and psychological support were other aspects of interpersonal relationships that did not meet patients' and families' expectations [9,10,12]. There is considerable work in the field of child health exploring and measuring family-centred service and this work has been replicated across countries and languages [1-7]. On the other hand a detailed overview of the state of the field identified a dearth of valid and reliable measures of client-centredness in adult medicine [7]. Psychometrically sound tools are needed that will allow systematic exploration of client-centred service from the adult clients' perspectives.

Satisfaction measures have been widely used in an attempt to evaluate the quality of health care from the client's perspective. A variety of measures has been employed, starting from global satisfaction questions and evolving into multidimensional measures meant to capture different important aspects of services [20-24]. In general, patients tended to report very high satisfaction with health services, reaching as high as 93% in older clients [8,21,25,26]. However, extensive interviews have revealed serious underlying problems in provider-client interactions, often excused by understaffed health teams and low expectations from the clients [9,19,21,25]. It can be argued, then, that global satisfaction does not adequately describe the process of client/health provider interaction, and merely presents an overall impression of the experience as a summary outcome [2,25,27]. Moreover, since most measures of quality of health services have been constructed without direct involvement of the consumer, and have often been concerned with aspects of services that could be relatively easily modified (waiting times, appointment scheduling), patients' and families' preferences were often missed [8,19,22,28]. The complexity of the factors that have been identified by patients as essential components of client-centred service requires a measure that will be able to quantify and differentiate various aspects of the care. This in turn will allow effective reflection, knowledge transfer, and quality control of successful and problematic areas of specific programs or facilities.

The measure used most frequently in paediatric settings to assess client/family-centredness is the Measure of Processes of Care (MPOC), '…

developed to meet the need for a rigorously designed measure of parents'

perceptions of the care they and their children receive from rehabilitation

treatment centres' [27]. As described in detail in the many publications about the

development of MPOC [2, 30] large numbers of parents were intimately involved

in an iterative quantitative-qualitative-quantitative process to develop and field

test the measure. All the items in the current version of MPOC are worded as

parents reported them to the developers, of which the second author was a part. It

has been used worldwide and has demonstrated strong psychometric properties

[2,5,29-31]. Recently, the Measure of Processes of Care for Adults (MPOC-A)

was adapted from MPOC with data from 130 adults and seniors who participated

in field testing of the original measure. The adaptation was carried out by two

Occupational Therapy students working with the second author (one of the

developers of MPOC). The measurement properties of MPOC-A were sound

(unpublished data) but it was recognized that further data collection was needed in

order to complete the psychometric evaluation of this new tool.

The purpose of this study was to assess the measurement properties of the

Measure of Processes of Care for Adults (MPOC-A) with clients who have

received an elective Total Joint Replacement (TJR) surgery (hip or knee). Based

on experience with the development and use of MPOC and on the body of

qualitative research conducted to date in adult settings, the following

characteristics of MPOC-A were tested:

1. High internal consistency (Cronbach's $\alpha \geq 0.80$) of each scale was expected if the items were measuring the same domain.

2. A moderate correlation (Pearson Product-Moment Correlations of 0.5-0.7) was expected between MPOC-A scale scores and a measure of general satisfaction with treatment.

3. A moderate inter-rater reliability correlation (ICCs between 0.5-0.7) was expected between patients' and families' scores on MPOC-A

4. A high test-retest reliability correlation (ICCs between 0.70-0.90) was expected in test-retest MPOC-A scale scores.

Methods

Sample and Setting:

The study was carried out through the regional orthopaedic services of a university-affiliated hospital in Ontario, Canada. All patients and families who had been treated for planned joint replacement surgery (Knee or Hip) and had received immediate post-surgical acute rehabilitation services from a variety of health professionals (physicians, nursing staff, physiotherapy, etc) in the hospital between January and August of 2007 were invited to take part in the study. The only exclusion criterion was lack of English fluency (as all the questionnaires are currently available in English only).

<u>Design:</u>

Figure 1 provides a depiction of the study design. Time 1 data (6 months post-surgery) were used to estimate internal consistency and cross-sectional convergent construct validity of the MPOC-A. Cross-sectional validity was assessed by comparing MPOC-A scores to CSQ scores. This study also assessed inter-rater and test-retest reliability of the MPOC-A. Inter-rater reliability was assessed at Time 1. Test-retest reliability of the MPOC-A was assessed by comparing Time 1 and Time 2 scores (2-4 weeks after Time 1).

Figure 1: Study design-Measurment and analysis time line.
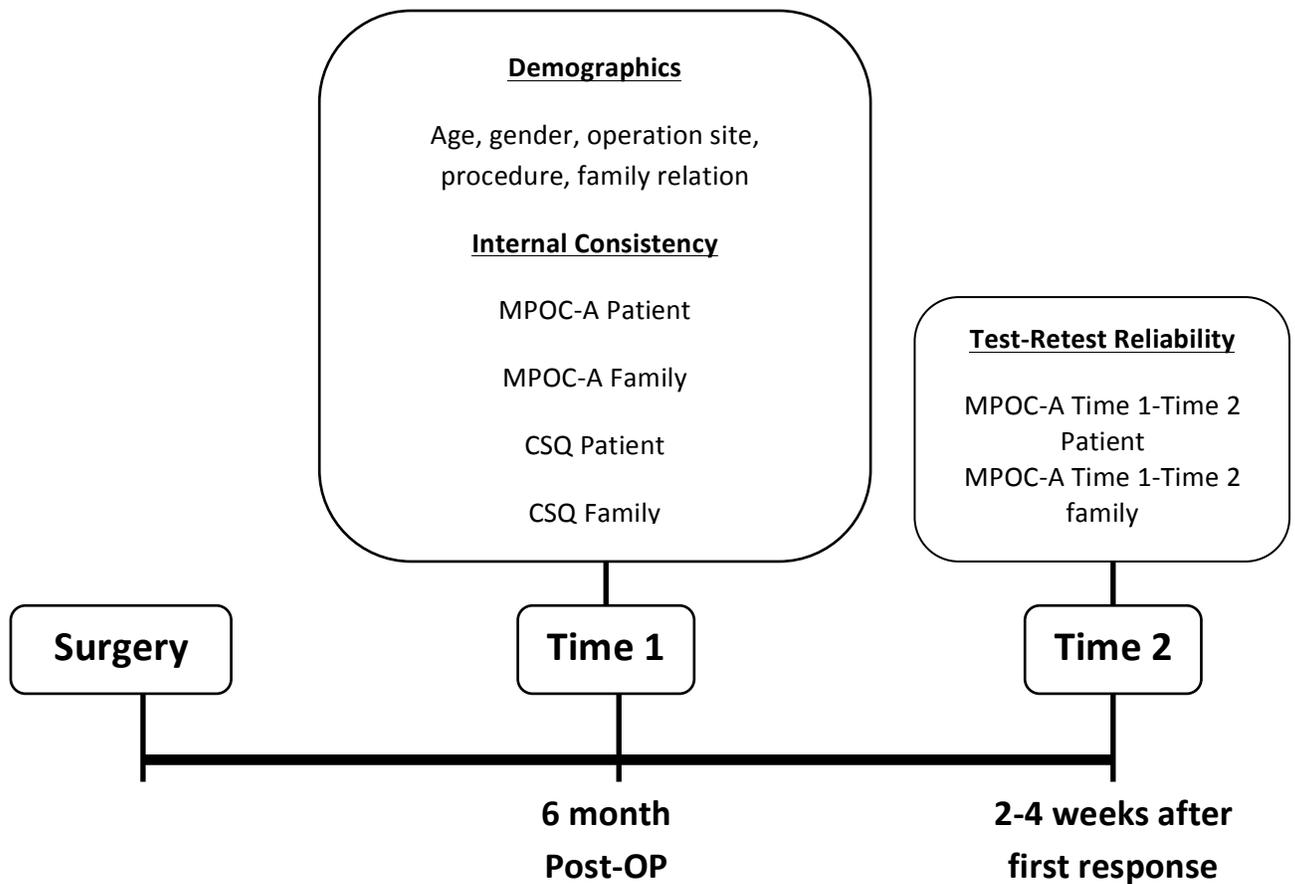
Procedures:

A package of materials was prepared, including a consent form, a demographic sheet, two copies of MPOC-A (one each for the patient and a family member), two Client Satisfaction Questionnaires (CSQ) [20], and a stamped self-addressed envelope. The 'patient' participants were asked in the information letter to identify a family member who was closely involved in their care and to invite them to participate in the study. To assess respondents' experiences of services, as evaluated by MPOC-A, the package was sent at 6 months post-surgery. It was assumed that by that time the patients had settled after this traumatic experience, completed their rehabilitation, and would not have any new health care experiences that might influence test-retest scores.

The second package containing two MPOC-As and two CSQs was sent to randomly chosen responders 2-4 weeks later to evaluate MPOC-A's test-retest reliability [32]. One of the goals of this study was to undertake a factor analysis of data, to understand the factor structure of the measure. The recommended rule for this procedure is to have a minimum of 5, and preferably 10, subject per item.[33]. The sample of 350 participants was planned for this study. Sample size required to support test-retest reliability of the measure was calculated based on expected reliabily of 0.80, one-sided 95% Confidence Interval, and lower limit of 0.70 (Confidence Interval width of 0.10) [34]. This calculation identified that 52

participants were required for the test, and when adjusted to expected 50%

response rate from the second administration, a total of 100 packages were sent.

The protocol of the study was approved by the Hamilton Health Science

Research Ethics Board.

Measurement instruments

The **Measure of Processes of Care for Adults (MPOC-A)** is an

adaptation of MPOC-56. It is a self-administered 34-item questionnaire with

positively worded short statements and a 7-point Likert response scale. The stem

question for all items is: 'To what extent do health care providers who work with

you…'. The answer scale varies from 'To a Very Great Extent' to 'Not At All'

(from 7 to 1, respectively), and a 'Not applicable' box is also provided (rated as

0). Five main domains have been identified for MPOC-A based on extensive

literature review and previous work in pediatric settings. The *Enabling and

Partnership* domain focuses on patients' and families' involvement in their care

process, particularly in decision making (e.g., provide opportunities for you to

make decisions about treatment/services?). *Providing General Information*

domain is looking at how clients' general information needs are being addressed

by the health care providers (e.g., have information available to you in various

forms such as a booklet, kit, video?). *Providing Specific Information* focuses on

provision of specific information about client's condition, progress, and prognosis

(e.g., provide you with written information about your progress?). *Coordinated*

and Comprehensive Care is focusing on continuity and consistency of care over time, settings, and people (e.g., plan together so they are all working in the same direction?). *Respectful and Supportive Care* looks for relationships between clients and health providers in which the client is treated with respect as individual, equal, and expert (e.g., provide enough time to talk so you don't feel rushed?) (Appendix 1). Each domain score, varying from 1.0 to 7.0, is computed by averaging the ratings for the items of that domain. The "Not applicable" responses are treated as missing data and the questionnaires that have more than 50% missing and 'not applicable' answers combined are discarded. To be able to calculate the mean of the scale at least two-thirds of valid responses for that domain's items have to be present [29].

The Client Satisfaction Questionnaire (CSQ) is an 8-item global satisfaction measure with proven psychometric properties (coefficient alpha 0.92, Pearson correlation of 0.56, p<0.01 for estimates of client satisfaction by health provider) [20]. CSQ was administered along with MPOC-A.

Statistical Analysis:

The data were analysed using SPSS (version 15.0 for Windows). The data were analysed to assess whether responders differed in any demographic characteristics from the non-responders.

Descriptive statistics for MPOC-A and CSQ scores including means and standard deviations were calculated to check that patients were using the full range of scores, and that there was no ceiling effect or extreme skewedness of the scores. Internal consistency was assessed using Cronbach's alpha. The correlation between sub-scales of MPOC-A and CSQ was calculated using Pearson product-moment correlations. Reliability was assessed using a Shrout and Fleiss type 2,1 intraclass correlation coefficient (ICC) [35].

Results

Of the 800 packages sent out to patients and families after Total Joint replacement who fit the inclusion criteria but had no previous knowledge of the study, 192 were returned (response rate 24%). 176 questionnaires (91.7%) filled out by patients were analysed. Reasons for excluding the other 16 questionnaires from data analysis were as follows: only demographic sheet completed (1); more than 50% of the answers were missing or marked as not applicable (3); relocation/death of the participant (7); or explicit wish not to participate in the study (5). A total of 84 questionnaires were received from family members and 81 retained for analysis (3 were excluded due to more than 50% missing or not applicable responses). Respondents were assigned consecutive numbers, the files were rearranged randomly using random list generator, and all odd-numbered respondents were sent the test-retest package approximately 4 weeks from the date of first response (min-max 14-30 days). A total of 100 questionnaires were

sent. The response rate for the re-test was 76% for patients (all analysed) and 35% for family members (30 analysed, 5 had more than 50% missing or not applicable responses and were excluded from the analysis).

Table 1 displays the demographic characteristics of participants and family members. Small but significant differences were found when respondents' age and gender were compared to those of non-respondents. Participants who returned valid questionnaires tended to be slightly younger (mean difference = 2.6 years, p=0.003) and had larger percentage of male patients (48%, p=0.029) compared to non-responders or those who declined participation (39%). No significant differences were found in responses across the domains in different age, gender, and procedure groups (all p>0.05).

The data were analysed to detect patterns of missing data; more than 5 % responses were missing or 'Not applicable' for questions 7, 11, 20, 23, 25, 33, 34 (Appendix 1). Analysis of missing data was performed by each domain and in cases where missing items did not exceed two-thirds of the questions, estimated scores for missing values (but not for 'Not applicable') were calculated by averaging scores of the domain for that respondent. Descriptive analysis showed that the whole available range of answers was used by participants. Although scale scores tended towards the higher end of the scale (Table 2), the data were consistent with a normal distribution, which allowed use of parametric statistics for the data analysis.

Scales also demonstrated high internal consistency, varying from 0.81 to 0.93 (Cronbach's Alpha) (Table 2) and moderate to good correlation between the scales (Pearson Correlation coefficient varying from 0.64 to 0.92; all correlations were significant at p=0.01 level). Similar patterns were found in family member responses, where the full range of scores was used. Internal consistency varied from 0.88 to 0.96, and Pearson correlations between the domains varied from 0.53 to 0.94. Since only 144 questionnaires were eligible for the factor analysis (with a minimum of 170 needed given the conventional rule of at least 5 cases per item) [33], no results on factor structure of MPOC-A could be reported.

MPOC-A domain scores were moderately correlated with CSQ total scores (Pearson coefficients varied from 0.44 to 0.66). Family members' data showed slightly higher CSQ and MPOC-A domains correlations (Pearson correlations varied from 0.53-0.72) preserving the pattern with MPOC for lower correlation between domains 2 and 3 and the global satisfaction measure (Table 3). Moderate to good inter-rater agreement (ICC varied from 0.50 to 0.74) and high test-retest reliability were found (ICCs varied from 0.73 to 0.83 for patients and from 0.75 to 0.91 for family members) as reported in table 4.

Discussion

In order to plan and deliver health services effectively it is essential to understand the processes of care that are important from clients' perspectives. Researchers and policy makers are looking for reliable measures that will make it possible to capture the extent to which patients' and families' wishes and needs are addressed. The present study indicates that MPOC-A has appropriate psychometric properties. The wide range of mean scores across the various scales demonstrated that patients and their family members were able to differentiate across the proposed domains (Table 2). High Cronbach's alphas (0.80-0.93), as well as good inter-item correlation within each scale and moderate to good correlations between scales, support internal consistency of the domains. However, correlations higher than 0.9 also suggest that several items are tapping into the same features, and it may be possible to extract a shorter version of MPOC-A with fewer questions without sacrificing psychometric qualities of the measure [2]. This will be the focus of planned future exploration and development of MPOC-A.

Previous studies have demonstrated that implementing client/family-centred intervention strategies is associated with patient higher satisfaction scores [36-38]. Since no 'gold standard' measure for client/family-centredness is available, MPOC-A scores were expected to correlate positively with total score of CSQ if the construct indeed was valid. The scores were found to be moderately

correlated (Pearson coefficients varied from 0.44 to 0.66) supporting the idea that MPOC-A domains provide a related but broader and more detailed description of processes of client-health provider interaction than clients' satisfaction scores alone. It is recognized that general satisfaction scores are notoriously poor indicators of the quality of care; this is why measures like MPOC and MPOC-A are important additions to the toolbox. If these latter measures can help people 'get under the surface' of satisfaction and help us understand the elements that contribute to overall judgments of satisfaction, they will provide a level of understanding that is important to improving service quality and delivery. In the original validation of MPOC it was hypothesized that there would be important correlations between the five scales of MPOC and an overall measure of 'satisfaction' – a finding which was found in that work and has been replicated [2].

The authors hypothesized that patients' responses would correlate moderately with those provided by family members who have been involved in the same client-health provider interactions. Moderate to good agreement (ICC varying from 0.50-0.74) between patient and family member scores supported the assumption. These findings were also consistent with results of previous research conducted by Lobchuk et al. in 2007. That study showed that even with a neutral approach (when they were neither encouraged nor discouraged to take the patient's perspective) caregivers were able reliably to report patients' experiences (ICCs as high as 0.87) [39]. These findings are especially important in situations

where patients are unable (due to poor health or other reasons) to answer for themselves. Under these circumstances carers' reports can provide clinicians with additional information not only from the patient's perspective, but also identify specific family needs that might differ substantially from those of the patient [8,11,12,31].

This study also provided excellent support for stability of the measure over time. High to excellent agreement between two scores administered approximately 4 weeks apart (ICCs varying from 0.73 to 0.83 for patients and from 0.75 to 0.91 for family members) provided good evidence of test-retest reliability of the new measure.

Several demographic factors that tend to affect clients' satisfaction ratings have been identified in the literature. Older patients, especially women, tend to report high satisfaction with health care services regardless of the settings [8,19,21,24,25]. Health status has also been pointed out as a potential factor in satisfaction reports [21,24]. The present study, however, did not identify any significant relationship between age, gender, operation site, or procedure (primary or revision) and MPOC-A or CSQ scores. Although small but statistically significant age and gender differences between responders and non-responders were found, the authors believe that the sample was clinically representative of the whole population of people receiving total joint replacements. The wide range of ages and the absence of any statistical relationship between demographics and

response scores supports that idea. Further investigation of possible covariates will allow clearer understanding of specific needs of different age and gender groups and possibly shape new tailored intervention strategies to improve their experiences with health services.

Although this project identified good psychometric properties of the new client-centred measure, some limitations of the study have to be noted. The relatively low response rate (24%, although considered good for one-time mailed contact), along with missing values and 'Not applicable' responses for some of the items, could have underpowered the analysis. Future studies with other populations can determine whether a refined and shortened version of the existing measure will be more user-friendly and efficient, while still retaining good psychometric qualities, a task that was beyond the scope of this project. At present, lower endorsement of several items can be explained by different needs and wishes of patients and families in acute versus chronic rehabilitation settings. Partnership in care, continuity, and information on available resources can be especially important in long-term relationships between clients and health service providers [13]. Exploring long-term relationships between patients, families, and health professionals with the help of MPOC-A will help not only to further develop the measure, but also to improve our understanding of specific needs of clients who live with chronic illness and disability, and of their families.

It can be argued that due to the long period between actual experience and survey time there might have been different services and health professionals involved in the care of the participants which might have biased their answer. We believe, however, that since this study did not intend to evaluate specific programs, service providers or hospitals, and was focused on testing the psychometric properties of the measure, the population of participants can be considered to consist of people with similar overall experiences, and respondents who are representative of populations with whom MPOC-A might be used in future.

Conclusions

To improve planning and delivery of health care services researchers, clinicians, and stakeholders need reliable measures that will allow simple and effective gathering of information about the experiences of the services from patients' and families' perspectives. This study was a first step in validation of a new, generic measure of family-centredness. Overall, MPOC-A has demonstrated good psychometric properties and with some refinement should be tested in additional health care settings and with a variety of populations around the world.

Acknowledgments

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Table 1. Demographic characteristics of responders.

Age, mean (Min-Max) in years	66.5 (36-88)
Gender, n (%)	
Female	90 (51)
Male	86 (49)
Operation site, n (%)	
Total Hip Replacement	70 (40)
Total Knee Replacement	101 (57)
Bilateral Knee Replacement	5 (3)
Procedure, n (%)	
Primary surgery	166 (94)
Revision surgery	10 (6)
Relation to the patient, n (%)*	
Wife	37 (45)
Husband	20 (25)
Daughter	10 (12)
Son	3 (4)
Sister	3 (4)
Friend	2 (2)
Mother	1 (1)

*The cumulative percent does not add to 100% due to missing data.

Table 2: Descriptive statistics and internal consistency as assessed by Cronbach's Coefficient Alpha of MPOC-A domains.

Domain name (number of items)	Patient response (n=176)				Family member response (n=81)			
	Mean	SD	Range	Cronbach's α	Mean	SD	Range	Cronbach's α
Enabling and Partnership (9)	5.54	1.12	5.50	0.93	5.18	1.29	6.00	0.96
Providing General Information (5)	4.60	1.37	5.60	0.81	4.61	1.59	6.00	0.88
Providing Specific Information (5)	4.43	1.62	6.00	0.84	4.47	1.63	6.00	0.87
Coordinated and Comprehensive Care (9)	5.25	1.26	5.56	0.93	5.03	1.40	5.89	0.96
Respectful and Supportive Care (6)	5.56	1.22	5.83	0.93	5.30	1.44	6.00	0.95
Global Satisfaction (8)	27.53	4.33	22.00	0.92	27.01	4.82	24.00	0.91

Table 3: Pearson Product-Moment Correlation Coefficients of MPOC-A Domain Scores with Client Satisfaction Scores.

Domain name	Patient Global Satisfaction (95% CI)	Family member Global Satisfaction (95% CI)
Enabling and Partnership	0.65 (0.56-0.73)	0.68 (0.54-0.78)
Providing General Information	0.45 (0.32-0.56)	0.53 (0.35-0.67)
Providing Specific Information	0.44 (0.31-0.55)	0.54 (0.36-0.68)
Coordinated and Comprehensive Care	0.66 (0.57-0.74)	0.72 (0.59-0.81)
Respectful and Supportive Care	0.64 (0.54-0.72)	0.71 (0.58-0.80)

Table 4: Patient-Family Member (Inter-Rater) and Test-Retest Reliability as Assessed by Intraclass Correlation Coefficients (ICC)

Domain name	Inter-rater reliability (ICC) (95% CI) (n=80)	Test-retest reliability (ICC)	
		Patient responses (95% CI) (n=76)	Family responses (95% CI) (n=30)
Enabling and Partnership	0.50 (0.28-0.66)	0.77 (0.66-0.85)	0.89 (0.79-0.95)
Providing General Information	0.74 (0.62-0.83)	0.73 (0.60-0.82)	0.75 (0.52-0.88)
Providing Specific Information	0.67 (0.51-0.78)	0.73 (0.61-0.82)	0.86 (0.70-0.93)
Coordinated and Comprehensive Care	0.55 (0.36-0.69)	0.83 (0.75-0.89)	0.91 (0.82-0.95)
Respectful and Supportive Care	0.61 (0.42-0.74)	0.77 (0.65-0.85)	0.90 (0.79-0.95)

Appendix 1

To what extent do health care providers who work with you …

1. help you to feel competent in managing your own care?
2. make sure you have a chance to say what is important to you?
3. provide you with written information on what you are doing in therapy?
4. trust you as the person who knows yourself best?
5. provide a caring atmosphere rather than just give you information?
6. make sure that your health history is known to all persons working with you so that information is carried across services and service providers?
7. let you choose when to receive information and the type of information you want?
8. tell you about the options for treatments or services?
9. look at the needs of your 'whole' self (e.g. at mental, emotional, and social needs) instead of just at physical needs?
10. offer you positive feedback and encouragement?
11. make sure that at least one team member is someone who works with you and your family over a long period of time?
12. are polite and friendly to you and your family?
13. fully explain treatment choices to you?
14. provide opportunities for you to make decisions about treatment?
15. appear aware of your needs as your health changes?
16. provide enough time for you to talk so you don't feel rushed?
17. display honesty about your condition and how it may affect your life?
18. plan together so they are all working in the same direction?
19. explain things to you in a way that you understand?
20. provide opportunities for your entire family to obtain information?
21. treat you as an <u>equal</u> rather than just as the patient?
22. give you information that is consistent from person to person?
23. make themselves available to you as a resource (e.g. emotional support, advocacy, information)?
24. suggest therapy/treatment plans that fit with your needs and lifestyle?
25. provide opportunities for your family to participate in decisions about your care?
26. treat you as an individual rather than as a 'typical' patient?
27. provide you with written information about your progress?
28. have information available about your condition (e.g. its causes, how it progresses, future outlook)?
29. provide you with written information about your medications (i.e. purpose, side effects, risks)?
30. tell you about the results from tests/assessments?
31. have information available to you in various forms such as a booklet, video?
32. give you information about the types of services offered at the health care facility or in your community?

33. provide advice on how to contact other people with the same condition?
34. provide opportunities for your family to receive information about your progress?

Chapter 4

Title of Paper: Performance of the Measures of Processes of Care for Adults (MPOC-A) and Service Providers (MPOC-A(SP)) in Rehabilitation Settings.

Authors: Elena Bamm, Peter Rosenbaum, Seanne Wilkins, Paul Stratford

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Abstract

Introduction: In recent years Client-Centred Care has been embraced as a new philosophy of care by many organizations around the world. Clinicians and researchers have identified the need for valid, reliable, and outcome measures that are easy to use to evaluate success of implementation of new concepts. The Measure of Processes of Care provides a means to capture families' and clinicians' perspectives of client-centredness in pediatric settings.

The objective: The current study was developed to complete adaptation and field testing of the companion Measures of Processes of Care for Adults (MPOC-A) and Service Providers working with adult clients (MPOC-A(SP)).

Settings: In-patient rehabilitation facilities.

Results: Three hundred and eighty-four health care providers, 61 patients, and 16 family members completed the questionnaires. Good to excellent internal consistency (0.71-0.88 for HCPs, 0.82-0.90 for patients, and 0.87-0.94 for family members), as well as moderate to good correlations between domains (0.40-0.78 for HCPs, and 0.52-0.84 for clients) supported internal reliability of the tools. Exploratory Factor Analysis of the MPOC-SP (A) responses supported the multi-dimensionality of the questionnaire.

Conclusions: Exploring long-term relationships among patients, families, and HCPs with the help of MPOC-A and MPOC-SP (A) will assist with further

development of the measures and improve our understanding of specific needs of clients. Both the MPOC-SP (A) and MPOC-A demonstrated promising psychometric properties in the adult rehabilitation settings.

Introduction

In the past decade researchers and clinicians around the world have begun systematically to ask their clients about the important aspects of health care that make the processes and experiences easier and more helpful to them. Not surprisingly, patients and their families want to be sufficiently informed about the illness and their progress to be able to participate in what is happening to them; to be treated respectfully and with dignity; to be confident that they receive comprehensive and well-coordinated care; and to feel good about asking questions. Based on what people have reported many frameworks have been developed of what now we call Client or Person-Centred Care.[1-4] In recent years this new philosophy has been embraced by many organizations around the world. The need for valid, reliable, and easy outcome measures to evaluate success of implementation of new concepts has been identified in the literature.[5-7] Moreover, measures are needed that will allow clients to evaluate the quality of care, and enable clinicians to be able to reflect on their practices and beliefs and identify areas that require attention.

In 2010 we published an article describing validation of the adapted Measure of Processes of Care from the perspectives (MPOC-A) of adult clients undergoing elective joint replacement.[8] At the time of that study the measure was the only available generic tool that allowed evaluation of client and family-centredness of care in adults. In the last decade several new measures have been developed and implemented in research studies, ranging from disease-specific

tools to questionnaires applied in specific health care settings. Examples of these new tools for clients include the Person-Centred Climate Questionnaire, available in Swedish- and English-Patient version;[5, 6] Client-Centred Care Questionnaire (CCCQ) developed for use in home care;[9] Client-Centred Rehabilitation Questionnaire (CCRQ);[10] and Patient-Centredness Questionnaire-Infertility.[11] Similar tools were also developed to assess health care professionals' experiences: the Person-Centred Care Assessment Tool (P-CAT) developed by Edwardsson et al. and validated in several languages;[12, 13] Patient-Practitioner Orientation Scale (PPOS);[14] and the Nursing Context Index.[15] The strengths and limitations of some of the tools mentioned above were well described in the comparative review of published tools completed by Edvardsson and Innes in 2010.[16]

Despite many new tools available today we believe that the MPOC family of measures provides several advantages.[17] First, unlike any other tool, the multi-dimensionality of client-centredness is preserved by presenting the results of each domain separately with no composite score. Second, the perspectives of all the participants in the health care encounter can be assessed simultaneously with client and service provider versions that were developed based on the same theoretical framework. Third, unlike most tools that were developed for research purposes, the original Measure of Processes of Care (MPOC) and the Measure of Processes of Care for Service Providers (MPOC-SP) have been translated to many languages and used to assess the quality of care in child programs in many countries.[17] The adult versions adapted in this research program, although still

under development, have already been used in several countries for program evaluation (personal communication Carmen Hall, Julie Evans).

CanChild Centre for Childhood Disability Research has developed a family of self-report outcome measures that assess family-centred experiences of parents of children with disabilities (MPOC) and of service providers (MPOC-SP). The psychometric properties of these tools are well documented in a variety of paediatric settings and countries around the world and they have been translated into several languages (i.e., French, Danish, Japanese, Arabic, Hebrew, and Portuguese).[17-20] A complete manual for use and interpretation of the MPOC is available for open use from the *CanChild* website.[20]

In the past decade adaptation of the MPOC for adults was undertaken as part of an occupational therapy student project under the supervision of one of the developers of the original version. In 2008, the MPOC-A was field-tested with patients and families after elective hip or knee replacement surgery.[8] Following publication of the results of that pilot study, inquiries about administration, scoring, and interpretation of the tool were received from across Canada (Quebec, Alberta) and abroad (Netherlands, USA, Italy, Brazil, Australia). In addition, researchers and clinicians were asking if the companion measure, similar to the MPOC-SP, was available for use with service providers caring for the adult population.

The objective of the current study was to complete adaptation and field testing of the companion Measures of Processes of Care for Service Providers

working with adult clients (MPOC-A(SP)) and Adults (MPOC-A). These clinical measures capture 'the extent to which' patients, their families, and health professionals experience partnerships.[20] To assess the measurement properties and performance of these tools the following hypotheses were tested:

1. Internal consistency: Cronbach's $\alpha \geq 0.7$ was expected for each scale of the measure if the items are measuring the same domain.

2. Construct Validity: Pearson Product-Moment Correlations of 0.5-0.7 were expected between MPOC-A scale scores and a standardized measure of general satisfaction with treatment.

3. Inter-rater reliability: ICCs between 0.5-0.7 were expected between patients' and families' scores on MPOC-A.

4. Exploratory Factor Analysis would support the four-factor structure of MPOC-A (SP).

5. MPOC-SP (A) would be able to detect differences across programs.

Methods

The data used in this study have been collected in three recent projects (over the past three years). First, all health care professionals (HCPs) and clients (patients and family members collectively) of four in-patient stroke rehabilitation units across South-Central Ontario, Canada were invited to respond to MPOC-SP(A) and MPOC-A, respectively. HCPs were included if they had been practicing in the facility for at least three months. Clients were included if they were expected to remain within the program for at least 2 weeks, and had been

receiving treatment for at least two weeks. Exclusion criteria included lack of English fluency (as all questionnaires are currently available in English only), and severe cognitive impairment as assessed by the Montreal Cognitive Assessment (MoCA<19) or the Mini-Mental State Examination (MMSE<21) (routine outcome measures used by stroke centres).

Second, data from the use of MPOC-SP(A) were collected during Speech-Language Demonstration Project Person, Child and Family-Centred Care Committee, Alberta Health Services. All Speech Language Pathologists (SLPs) practicing in the province of Alberta were invited to respond to a survey that included MPOC-SP(A). The responses of SLPs working with adult clients were identified and included in the current study.

The third study was conducted by the Veterans Affairs in United States. Clinical staff in the Polytrauma Network Sites and Polytrauma Support Clinical Teams were invited to participate. The results pertaining to MPOC-SP (A) were included in the present study.

The rationale for combining the studies was grounded in the belief that since all three settings share a similar philosophy of care, similar trends in responses can be expected. However, we would also expect certain dissimilarities due to different settings and professionals involved, allowing testing of construct validity by exploring correlations between scores from different locations.

All appropriate Research Ethics Committees approved the protocols of the studies.

Instruments:

The Measure of Processes of Care for Adults (MPOC-A) is a self-administered 34-item questionnaire with positively worded short statements and a 7-point Likert-type response scale. MPOC-A has demonstrated strong psychometric properties in the previous study.[8] The stem question for all items is: "To what extent do health care providers who work with you…". The response scale ranges from "To a Very Great Extent" to "Not At All" (from 7 to 1, respectively), and a "Not applicable" box is also provided (rated as 0). Five main domains have been identified for MPOC-A based on extensive literature review and previous work in pediatric settings.[3, 8, 19, 21] The domains are labelled as Enabling and Partnership, Providing General Information, Providing Specific Information, Coordinated and Comprehensive Care, and Respectful and Supportive Care. Each domain score, ranging from 0.0 to 7.0, is computed by averaging the ratings for the items of that domain. The "Not applicable" responses are treated as missing data and the questionnaires that have more than 50% missing and "not applicable" answers combined are discarded. In order to be able to calculate the mean of the scale at least two-thirds of valid responses have to be present for that domain items.

The Measure of Processes of Care for Service Providers (MPOC-SP) is a 27-item self-administered questionnaire. The items represent 4 domains, and the stem question and domain score calculation procedures are identical to MPOC-A. MPOC-SP has demonstrated good validity and reliability in previous testing in

paediatric settings.[19] However, no proper validation of MPOC-SP in adult health care has been undertaken.

The Client Satisfaction Questionnaire (CSQ) is an 8-item global satisfaction measure with reported psychometric properties (coefficient alpha 0.92, Pearson correlation of 0.56, p<0.01 for estimates of client satisfaction by health provider).[22] CSQ scores were shown to be moderately correlated with MPOC-A scores.[8]

Sample size: One of the goals of this study was to assess the factor structure of the MPOC-A and MPOC-SP questionnaires. The general rule of thumb for this procedure is to have a minimum of 5, and preferably 10, subjects per variable. MPOC-A has 34 items and MPOC-SP has 27 items so samples of at least 200 patients and 140 health care professionals, respectively, were planned.[23]

Statistical analysis was conducted with the Statistical Package for the Social Sciences (SPSS Version 20).[24] The range and the skewedness of responses were explored, including differences according to demographic characteristics, such as age and gender. The internal consistency was estimated using Cronbach's α coefficient. The factor analysis was performed where sample size permitted. Pearson product-moment correlation coefficients between the scales of the current measure and Global Satisfaction Scale were calculated to assess construct validity. The inter-rater reliability of MPOC-A was assessed with the Intraclass Correlation Coefficient (ICC).

Results

MPOC-SP(A)

A total of 384 valid responses were available for the analysis (Ontario 54 HCPs, Alberta 45, and US 285). The full range of available responses was used in the majority of questions (excepting Questions 3, 6, 13, and 22 in which the lowest score was not used). The skewedness and kurtosis values were all between -1 and 1 allowing use of parametric statistics for further analysis. The Internal Consistency varied from 0.67 to .88. Due to small number of items in the Communicating Specific Information domain, the split-half Spearman-Brown prediction formula was applied and the coefficient was 0.71. A summary of domain means, range of scores, and Internal Consistency is presented in Table 1. Person product-moment correlation coefficients between domains varied from 0.40 to 0.78.

Table 1: Descriptive statistics and internal consistency as assessed by Cronbach's coefficient alpha of MPOC-SP (A) domains.

Domain (number of items)	Mean (SD)	Min-Max	Internal consistency (Cronbach's α)
Showing Interpersonal Sensitivity (10)	5.1 (0.92)	2.4-7	0.88
Providing General Information (5)	4.1 (1.36)	1-7	0.88
Communicating Specific Information(3)	4.8 (1.17)	1.5-7	0.67*
Treating People Respectfully (9)	5.6 (0.78)	3.1-7	0.87

*Spearman Brown Coefficient 0.71.

Principal component analysis with Varimax rotation was performed to assess the multi-dimensional quality of the questionnaire. Both the Bartlett test of Sphericity and Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA=0.936) demonstrated that the data were appropriate for factor analysis. Four factors with eigenvalues ≥1 were extracted, and these accounted for 58% of variance. Four items, three in the original Showing Personal Sensitivity and one in the original Treating People Respectfully domains, had higher loadings on other domains. Specifically, Questions 11 and 21 had higher loadings (0.576 and 0.718

respectfully) on Treating People Respectfully domain, while Question 12 loaded more heavily on the Providing General Information domain. Question 13 from the original Treating People Respectfully domain had higher loading on Communicating Specific Information domain (0.542). The factor analysis was rerun excluding the four problematic items (N=23 items). Four factors with eigenvalues ≥1 were extracted, and these accounted for 60% of variance. The final loadings are presented in Table 2.

Table 2: Loadings of Factor analysis by domains.

Item #	**Domains with corresponding items** **In the past year, to what extent did you…**	**Factor Loading 27 items**	**Factor loadings 4 items removed**
	A: Showing Interpersonal Sensitivity		
1	suggest treatment/ management activities that fit with each patient's and family's needs and lifestyle?	.641	.644
2	offer patients and families positive feedback or encouragement (e.g., in carrying out a home program)?	.664	.666
3	take the time to establish rapport with patients and families?	.699	.699
4	discuss expectations for each patient with other service providers, to ensure consistency of thought and action?	.639	.659
5	tell patients and families about options for services or treatments for their condition (e.g., equipment, therapy)?	.652	.668
8	discuss/explore each patient's and family's feelings about having a condition (e.g., their worries about their health	.504	.510

	or function)?		
9	anticipate patients' and families' concerns by offering information even before they ask?	.501	.492
11	let patients and families choose when to receive information and the type of information they wanted?	.228*	Removed
12	help each family to secure a stable relationship with at least one service provider who works with the patient over a long period of time?	.371*	Removed
21	help patients and families to feel competent in managing their own care?	.355*	Removed
	B: Providing General Information		
23	promote family-to-family "connections" for social, informational or shared experiences?	.772	.777
24	provide support to help families cope with the impact of the chronic condition (e.g., informing patients and families of assistance programs, or counseling how to work with other service providers)?	.751	.759
25	provide advice on how to get information or to contact other patients (e.g., through a community's resource library, support groups, or the Internet)?	.857	.846
26	provide opportunities for the entire family to obtain information?	.701	.715
27	have general information available about different concerns (e.g., financial costs or assistance, respite care)?	.776	.778
	C: Communicating Specific Information		
14	tell patients about the results from tests and/or assessments?	.810	.786
15	provide patients with written information about their condition, progress, or treatment?	.707	.720

16	tell patients and families details about their services, such as the types, reasons for, and durations of treatment/ management?	.670	.703
	D: Treating People Respectfully		
6	accept patients and their family in a nonjudgmental way?	.600	.635
7	trust patients as the "experts" on themselves?	.591	.591
10	make sure patients and families had a chance to say what was important to them?	.577	.556
13	answer patients' and families' questions completely?	.384*	Removed
17	treat each patient and their family as an individual rather than as a "typical" patient?	.711	.723
18	treat patients as equals rather than just as a patient?	.720	.737
19	make sure patients and families had opportunities to explain their treatment goals and needs (e.g., for services or equipment)?	.548	.488
20	help patients and families feel like a partner in their own care?	.622	.585
22	treat patients and their families as people rather than as a "cases" (e.g., by not referring by diagnosis)?	.684	.700

*- items with larger loadings on other domains.

To test the hypothesis that domain responses will differ slightly between different projects a one-way ANOVA was performed. Leven's test supported homogeneity of variance across the samples. The results of the one-way ANOVA confirmed differences on three of four domains, with domain 1 (Showing Interpersonal Sensitivity) just above the significance level (p=0.053). The Tukey post hoc test

shown that there were small but significant differences across results from

Ontario, Alberta, and US (Table 3).

Table 3: Results of One Way ANOVA and Tukey post hoc test demonstrating site differences.

Domain	Location (I)	Location (J)	Mean Difference (I-J)	Std. Error	Sig.	95% CI	
						Lower Bound	Upper Bound
Showing Interpersonal Sensitivity	Ontario	US	.18	.14	.392	-.15	.51
	Alberta	Ontario	.15	.19	.71	-.30	.59
		US	.33	.15	.069	-.02	.67
Providing General Information	Ontario	US	.60*	.20	0.009	.12	1.07
	Alberta	Ontario	-.25	.27	.625	-.89	.39
		US	.35	.22	.252	-.17	.86
Communicating Specific Information	Ontario	US	-.11	.16	.753	-.49	.26
	Alberta	Ontario	.93*	.24	<.001	.37	1.5
		US	.82*	.19	.000	.38	1.3
Treating People Respectfully	Ontario	US	.11	.11	.626	-.16	37
	Alberta	Ontario	.26	.16	.216	-.11	.63
		US	.37*	.12	.009	0.08	.66

*. The mean difference is significant at the 0.05 level. CI-Confidence Interval

MPOC-A

A total of 61 valid MPOC-A questionnaires were completed by the patients and 16 by family members. More than half of patient responders were women (59%), following stroke episode (74%), with experience of multiple HCPs. The majority of family responders were spouses (mostly wives) with similar distribution of ages. The demographic characteristics of the sample are presented in Table 4.

Table 4: Demographic characteristics of the participants

Age, mean (min-max) in years		63.7 (19-85)
Gender, n (%)	Male	25 (41)
	Female	36 (59)
Main Condition, n (%)	Stroke	45 (74)
	Other	15 (24.6)
Length of Stay, n in days (min-max)		39.9 (14-140)
HCPs encountered, mean (min-max)		5 (3-7)
Family member, n (%)	Spouse	11(70), 2 husbands
	Child	2 (12.5)
	Parent	1 (6)
Family member age, mean (min-max) in years		60.3 (45-69)

The responses were analyzed to detect missing data patterns. Only one question (#33 …provide advice on how to contact other people with the same condition?)

had more than 20% missing responses (Not Applicable and missing combined). Analysis of missing data was performed by each domain and in cases where missing items did not exceed two-thirds of the questions, estimated scores for missing values (but not for 'Not applicable') were calculated by averaging scores of the domain for that respondent.

The skewedness and kurtosis values were all between -2 and 2, allowing use of parametric statistics for further analysis. Domain means varied from 4.03 to 5.78 for patients and 4.2 to 5.67 for family members, demonstrating similar trend for both subsamples. No statistically significant differences were detected in responses by age (one-way ANOVA) or gender (Independent t-test). Internal consistency varied between .82 and .90 for patients, and .87 and .95 for family. The summary of domain means, range of scores, and Internal Consistency is presented in Table 5.

Table 5: Descriptive statistics and internal consistency as assessed by Cronbach's coefficient alpha of MPOC-A domains

Domain Name (number of items)	Patient Responses (n=61)			Family Responses (n=16)		
	Mean (SD)	Min-Max	Cronbach's α	Mean (SD)	Min-Max	Cronbach's α
Enabling and Partnership (9)	5.51 (1.06)	2-7	.82	5.1 (1.1)	2.67-6.56	.92
Providing General	4.72 (1.74)	1-7	.85	4.25 (1.78)	1.8-7	.87

Information(5)						
Providing Specific Information(5)	4.03 (1.75)	1-7	.85	4.2 (1.77)	1.4-6.8	.91
Coordinated and Comprehensive Care (9)	5.78 (.99)	3.5-7	.89	5.58 (.85)	4.11-6.89	.94
Respectful and Supportive Care(6)	5.6 (.93)	3.8-7	.90	5.67 (.98)	3.83-7	.93
Global Satisfaction	27.87 (3.9)	16-32	.89	27.13 (4)	22-32	.89

Pearson correlation coefficients between the domains and global satisfaction measure varied from .32 to .67 for patients, and from .58 to .78 for family members (Table 6). Pearson correlation coefficients between domains varied from 0.52 to 0.84. Sufficient data were available for only 13 pairs (patients and their family members) for inter-rater reliability analysis. The ICC coefficients varied from 0.41 to 0.81 (Table 6).

Table 6: Pearson product-moment correlation coefficients of MPOC-A domain scores with client satisfaction scores

Domain	Pearson Coefficients (CI)		Inter-rater reliability (ICC) N=13
	Patient Global Satisfaction	**Family Global Satisfaction**	
Enabling and Partnership	.51 (.29-.68)	.65 (.15-.88)	.50
Providing General Information	.52 (.29-.69)	.62 (.16-.86)	.81
Providing Specific Information	.32 (.05-.54)	.58 (0.07-0.85)	.74
Coordinated and Comprehensive Care	.67 (.49-.79)	.78 (.44-.93)	.41
Respectful and Supportive Care	.65 (.47-.78)	.66 (.18-.89)	.56

Due to a limited sample size we were unable to complete the planned Factor Analysis and test-retest analysis.

Discussion

The purpose of this study was to initiate formal validation of the adapted measure of client-centredness of care for HCPs working with adult clients (MPOC-SP (A)), and to continue to explore the properties of the companion measure for patients and family members. The tools were well accepted by all

participants and a wide range of responses was provided. Similar to previous studies, the results of the Providing General and Specific Information domains were lower in both the HCPs and clients samples, identifying the well-known problem of providing timely and appropriate information.[3, 8, 25-28] Some clinicians, however, commented that the limitations of their scope of practice (i.e. therapist or nurse versus physician) often prevented them from communicating specifics related to the diagnosis or prognosis of the client. In addition, privacy and confidentiality laws require explicit patient consent for the information to be shared with the family. Hence, the Not Applicable option was more often used in these two domains.

Good to excellent internal consistency (0.71-0.88 for HCPs, 0.82-0.90 for patients, and 0.87-0.94 for family members), as well as moderate to good correlations between domains (0.40-0.78 for HCPs, and 0.52-0.84 for clients) supported internal reliability of the tools. Further, Exploratory Factor Analysis of the MPOC-SP (A) responses supported the multi-dimensionality of the questionnaire with four extracted factors, corresponding to MPOC-SP(A) domains, accounting for 58% of variance and with loadings varying from 0.501 to 0.857. However, we would recommend considering a shorter version of the MPOC-SP(A) containing 23 questions, excluding the problematic items (Questions 11, 12, 13, and 21). The properties of the shorter version will have to be examined in future studies.

As hypothesized, the MPOC-SP(A) was able to detect subtle differences among program participants in the study. Unfortunately, due to incomplete data, we were unable to test whether the responses also differed among different health care professionals. These differences could be expected since some disciplines (e.g. occupational therapist, social worker) have had client-centred care principles imbedded in their philosophy of care for some time and are introduced to these ideas during their studies.[29] Future studies should try to explore this idea more fully. This in turn could inform educators of future clinicians about specific areas that should be addressed during their schooling.

Similar to previous studies reporting on development and validation of MPOC,[8, 20] we used the Client Satisfaction Questionnaire, a well-known global satisfaction tool, as a criterion measure to assess construct validity of the MPOC-A. Moderate correlations between the MPOC-A domains and CSQ scores, with the exception of Providing Specific Information, supported that although measuring related constructs, the MPOC-A provides more specific and detailed information about quality of services than global satisfaction alone.

Interestingly, no differences by age and gender of clients were observed in the present studies. Previous studies reported that women and younger clients tended to report lower satisfaction scores with the services.[30-32] The relatively small sample in the present study might have prevented the detection of statistically significant difference.

It is important to discuss the challenges and consequently limitations that we have experienced during this study in hopes that this can assist others planning future studies. Following major illness patients and families represent a vulnerable population that is often not particularly interested in participating in research studies. In addition, following stroke there is often an issue of cognitive involvement that might prevent patients from being able to evaluate the quality of care. Although we had foreseen some of these difficulties, it was necessary to adjust our recruitment and data collection strategies along the way. Initially, eligible clients were identified by a charge nurse and asked for consent to participate in the study. After their discharge a package with questionnaires was mailed to their homes with a self-addressed, pre-paid envelope included for return. However, there were very few packages returned, and the decision was made to hire a research assistant (RA) to help with data collection. Toward the end of their stay on the unit the clients were still approached first by the nurse for consent, followed by a visit from the RA, who helped them to complete the questionnaires. However, this mostly limited the number of family members who agreed to complete the surveys to the ones who were present at the time of the RA visit. Although the packages for the families were left with the patients, they were seldom returned. There was a similar outcome with the repeated packages that were sent to clients' homes 2-4 weeks following the completion of the first survey, with only a small number of responses returned. This prevented us from being able to complete the test-retest analysis that was originally planned.

In addition, all charge nurses who were involved in recruitment commented that many patients were prevented from participating due to poor scores on cognitive assessment. In such cases it is possible that the opinion of the closely involved family member can be solicited as a proxy report for that patient. Although limited by the small sample, the results of this study demonstrated moderate to good agreement between patients and their family members (ICC of 0.41-0.81). These results were also supported in our previous work.[8] Similar results were demonstrated by Lovat et al.[25] In their study they directly adapted the MPOC-56 (the original paediatric version of MPOC containing 56 questions) to evaluate the perceptions of caregivers of stroke survivors of services provided by allied health care professionals. They reported strong face validity and internal consistency (Cronbach's α varying from 0.915 to 0.986).

In conclusion, in order to plan and deliver health services it is essential to understand the processes of care that are important from both clients' and HCPs' perspectives, especially in the context of chronic conditions. Exploring long-term relationships among patients, families, and HCPs with the help of MPOC-A and MPOC-SP (A) will not only assist with further development of the measures, but also improve our understanding of specific needs of clients who live with chronic illness and disability, and of their families. Both the MPOC-SP (A) and MPOC-A demonstrated promising psychometric properties in the adult rehabilitation settings. There were several limitations to the study, most prominent being limited sample size in the clients' section that prevented completion of

some of the planned analyses. Future larger studies should focus on exploring the validity and reliability of the measures in different health care settings.

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Chapter 5

Title of Paper: Exploring client-centred care experiences in in-patient rehabilitation settings.

Authors: Elena Bamm, Peter Rosenbaum, Seanne Wilkins, Paul Stratford, Nadilein Mahlberg.

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Abstract

Patient or Client-Centred Care has been widely accepted as an essential component of health care delivery in many countries. Few studies explore actual implementation of client-centred principles and clients' and health care providers' (HCPs) experiences with these approaches. Our objective was to explore current models of delivery of rehabilitation services from the perspectives of patients, families, and HCPs. We conducted semi-structured interviews with patients, families, and HCPs of one of four rehabilitation facilities in South-Central Ontario, Canada. *Being on common grounds/Working towards client set goals* was the main category identified by both clients and HCPs. Although successful partnerships were created, the majority of clients assumed a passive position. Clients needed more information about the rehabilitation progression and alternative treatment options. The results of the study suggest that we need to encourage and educate clients to become motivated, well-informed, proactive participants in their care.

Key words: client-centred care; quality of care; relationships, patient-provider; stroke, partnerships

Patient or client-centred care (CCC) has been widely accepted as an essential component of health care delivery in many countries. Thousands of articles have been published on the subject in the last decade. Similar to any developing subject, there are many names (e.g. person-, patient-, client-, family-centred care), and even more new definitions and conceptualizations of this idea (Abdelhadi & Drach-Zahavy, 2012; Bamm & Rosenbaum, 2008; Bechtel & Ness, 2010; Bertakis & Azari, 2011). Although they might differ slightly in how the concepts are operationalized, essentially all describe care "…*that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."*(National Research Council, 2001)

The preferences of patients and caregivers in different health care settings have also been explored. Consistently, the most important characteristics of client-centred care are described as information provision, good communication, accessibility, continuity, coordination, empowerment, and emotional support (Bechtel & Ness, 2010; Dancet et al., 2012). Several studies have also looked at the roles that clients would like to assume in the interaction with health care providers. The results differed between settings and countries. On one hand, people living with a chronic condition or caring for a person with a chronic condition were interested in developing partnerships with health care providers by participating in decision-making about their care (Bechtel & Ness, 2010).

Similarly, clients of infertility care clinics across Europe were interested in active participation (Dancet et al., 2012). On the other hand, Aro et al. (2012) reported that involvement in decision-making and involvement of family and friends were less important for patients of Estonian intensive care units (Aro, Pietilä, & Vehviläinen-Julkunen, 2012). Given these variations, different models of client/patient-centred care have been developed and empirically tested in different settings and disciplines (Abley, 2012; Rathert, Williams, McCaughey, & Ishqaidef, 2012).

Few studies explore actual implementation of client-centred principles and health care providers' experiences with these approaches (Bright, Boland, Rutherford, Kayes, & McPherson, 2012; Nieuwenhuijsen, 2009). In Canada patient/client-centred care is inherent to the health care system, being one of the main foci of every hospital and health care centre's mission statement (Goverment of Saskatchewan, 2013; Ontario Medical Association, 2010). Since the idea has been around for some time, it is a good time to stop and reflect on what is working and what still requires further attention.

The objective of this study was to explore current models of delivery of rehabilitation services from the perspectives of both patients and families (collectively the 'client') and health care professionals (HCP). To develop conceptualization of client-centred principles from stroke survivors and their caregivers' perspectives, we explored the following broad questions:

1. How do patients and families see their role in their interaction with health care professionals? Are they interested in assuming an active role?

2. How do clients perceive family involvement in rehabilitation?

3. What are clients' priorities for communication with HCPs, and for information?

To understand current experiences of HCPs with implementation of CCC principles, we explored the following issues:

1. How do health professionals define CCC and the "client" (patient only or family as a unit)?

2. What are some challenges (e.g., respecting wishes, taking preferences into account) when there are more than two parties involved, and what are the ways to deal with them?

3. Do HCPs feel supported and encourage by their superiors and colleagues when practicing client/family-centred care, and in what ways (available resources, incentives, education, etc.)?

4. What pros and cons do they perceive for themselves from practicing CCC?

In our work we have defined our concept as Client-Centred Care, where client stands for the patients and family (when involved). The broad topics for the present study were guided by the client and family-centred framework developed by the *CanChild* Centre for Childhood Disability Research (*CanChild* Centre for Childhood Disability Research, 2003). The core concepts of the framework are

Enabling and Partnership, Providing General Information, Providing Specific Information, Coordinated and Comprehensive Care, and Respectful and Supportive Care. The applicability of the framework for adult health care has been previously supported (Author, 2008; Dancet et al., 2012; Schoot, Proot, ter Meulen, & de Witte, 2005). The distinctiveness of this study involved interviewing both clients (patients and families) and health care providers of the in-patient rehabilitation units in which people were recovering after a stroke. This allowed for the input of all stakeholders to be considered when developing an understanding of processes of care as experienced from all sides of the relationship.

Methods

To explore processes of client-health care professional interaction in the rehabilitation settings, the Grounded Theory approach developed by Strauss and Corbin (1998) was adopted (Strauss & Corbin, 1998). The Grounded Theory approach was particularly suitable to answer the questions presented by this study for several reasons. First, the phenomenon under study is the process: the desired outcome of the study is developing a clear understanding of personal, organizational, and contextual factors and the interaction among them. Second, little is known about the current state of client-centredness in rehabilitation from either the clients' or clinicians' perspectives. The systematic examination of the topic and creation of the model will allow better understanding of the supports

and barriers to implementation of client-centred principles in adult rehabilitation (Strauss & Corbin, 1998).

We conducted semi-structured interviews over a 10-month period in 2011. We invited all patients and families receiving care for at least two weeks in one of four rehabilitation facilities in South-Central Ontario, Canada, to participate. Participants were excluded if they did not speak English or were diagnosed with severe cognitive impairment as assessed by the Montreal Cognitive Assessment (MoCA$\geq$19) or the Mini-Mental State Examination (MMSE$\geq$ 21) (outcome measures routinely used by stroke centres). In cases where no cognitive score was available, the decision about eligibility was left to the judgment of the clinical staff working with the patients.

Potential participants were identified and the study introduced by a health practitioner (nurse or social worker) from the patient's direct circle of care. The participants were selected based on the previously completed survey, the Measure of Processes of Care for Adults (MPOC-A), a measure of client-centredness of care adapted for adult health care settings (results reported elsewhere). To represent varied perspectives, interviewees were selected based on their varied perceptions of client-centredness as assessed by MPOC-A, ensuring variation across participants (the perspectives of people who rated the services as highly client-centred might differ substantially from those whose needs are not being met by their service providers). In addition, as the interviews progressed, we looked for clients of different ages and both genders, and clinicians from different

disciplines (theoretical sampling). Consenting participants were contacted by a research assistant to collect demographic and contact information. The interviews took place in a venue comfortable for participants. All but one were conducted by the first author in participants' homes (the exception was conducted at the public library) approximately 2-3 months after discharge. The interviews lasted 30-60 minutes.

All HCPs who have been practicing on one of the four rehabilitation units for at least three months (to ensure familiarity with the unit culture) were invited to participate. Lunch-and-learn sessions were presented at each site to inform the clinicians about the study and invite participation, following which information packages were left on the units. Interviews were conducted at the hospitals. Similar to clients, the selection of the HCPs for interviews was done based on their responses to the Measure of Processes of Care for Service Providers working with Adults (MPOC-SP(A)), a companion measure of client-centredness of care for clinicians.

Analysis and rigour

To help organize and analyze the data, the qualitative data analysis computer software package NVivo, version 9 was used (QSR International Pty Ltd, 2010). The interviews were transcribed and two researchers (EB and NM) carried out open coding independently and then compared their findings. Disagreements were resolved through extensive discussions.

We started the analysis with line-by-line reading of the transcripts and breaking the data into codes (open coding). Then the properties and dimensions of categories were further developed with every new interview, helping to relate the major categories to the sub-categories (axial coding). Constant comparison of the properties and dimensions of the emerging categories along with multiple viewpoints presented by patients, families, and HCPs helped us to maintain objectivity during analysis. The analytic thoughts and discoveries were recorded in the theoretic memos, which also helped with further development of each category. Diagrams helped to ensure clear relationships between and among the categories and identify categories that were poorly defined. When all categories were well defined and no new concepts or dimensions were emerging no further interviews were undertaken. Finally, the central categories were integrated to create the representation of the process or the model (selective coding) (Strauss & Corbin, c1998).

In addition to following grounded theory methods noted above, rigour was also ensured through a decision trail to track changes in codes and categories over the course of the project. Also ongoing discussions with the supervisory committee offered peer review opportunities. Reflexivity through journaling was used to highlight team and professional preconceptions and their impact on the process of analysis.

Ethical considerations. The protocol of the study was approved by McMaster University's Research Ethics Board and all participating sites' ethics committees.

Results

Eight patients and four family members from four rehabilitation units were interviewed. Patients ranged in age from 19 to 86, five were women, three of four family members were spouses (two women, one man) and one was the mother of the youngest participant. Participants described their experience along the continuum of care-related experiences from the actual event (stroke) to the discharge home from rehabilitation facility (Figure 1). Fifteen HCPs from four hospitals participated in the interviews. Several disciplines were represented: five physiotherapists, four occupational therapists, three social workers, two nurses, and one physician were interviewed.

Insert Figure 1 here

We focused our interviews on experiences related to the intake to rehabilitation, and actual rehabilitation. Five major categories were extracted and are discussed below. The categories are supported by anonymized quotes from interviews with patients (P), family members (F), and HCPs.

Part A: Patient and Family Experiences

Category I: Working Towards Goals set by the Client

This main category is in fact a combination of several threads. Participants described the importance of *working towards client set goals* (goals set jointly by the client and the therapists). We defined *compliance* as a patient's and family's

acceptance of treatment without them being interested in voicing an opinion (i.e. passive attitude). We also were interested in exploring whether the clients felt on equal ground with the hospital staff in making decisions – *position of power;* and how they interacted with the staff during therapy or any situation when confused or angry. Did they make themselves heard – *speaking up?*

Working towards client set goal. Regardless of age, all participants reflected on the importance of working towards goals that were meaningful and important for the client. Most clients were asked at the beginning of their stay what they would like to achieve, and then all the work was done to accomplish that: "I really liked the system there because one of the first things they asked was "What do you want to accomplish?" And then they did things to suit that. I really, really liked that." (P3)

Several clients also highlighted the importance of being involved in setting the goal, and understanding the steps, for improving their compliance:

We talked about what my goals were and we worked towards them… It was very much a joint - I don't know what the point is if the other person is not going to do what you ask them to do. If you're not going to do the exercises. They always explained why they were doing stuff, which was important for me, and for me to be successful I had to agree to what they wanted me to do and why they wanted me to do it. (P10)

Compliance and position of power. Although all patients and family members felt comfortable asking questions, the majority did not consider intervening in day-to-day decisions. One couple stated:

> … if he had wanted to ask questions, I think that would have been okay. Certainly I felt that the doctor was kind of open to, you know, questions and things. You just basically were in there with a problem and you were just complying with what was being said to do and working to get out, basically. (F 21)

However, they were also not interested in being an active participant – everything worked well for them. They felt that they came to the hospital to get professional care for the problem and they had to abide by the rules. Based on this couple's beliefs they did not expect anything different and were happy to follow instructions. They also could not think about what they would have done differently. It seems that as long as the plan did not clash with clients' beliefs they would not interfere, although they had an impression that they would be able to challenge the staff should they feel strongly about something. This idea was confirmed in several more interviews: "I just feel they [HCP] are there and they know what is, you know, best for you." (P 7)

Speaking up. Some clients did not raise their voice for fear of being called non-compliant or difficult. The older clients did not want to 'offend" anybody by speaking their mind and only did so when it was really important:

> That's the way I approach life. I don't speak up unless it's really important. I want people to know that when I speak up, I really mean it. It seems to me that some people are always complaining and always saying things, you know, and the other people tune out. (P 3)

At the same time they also felt that people who did complain and "fuss" were getting more attention. It felt that they had to be more "aggressive" in order to get the services in a timely manner. Here is a segment from a patient's husband to illustrate this point:

> It's almost like you have to be a veteran of hospital procedure or a veteran patient before you know what the routine is, because then you can start speaking up. Otherwise, we really didn't want to be a bother. …that was the impression I got. Now maybe that wasn't the reality but that was the impression that we got, that you have to be more aggressive in a hospital setting when really they should be taking care of you and you shouldn't have to worry about those things…. It's like the squeaky wheel gets all the oil. If you're good and you do what you're told, sometimes it just seems that you get less attention. *(F3)*

On the other hand one of the younger patients felt more confident about voicing his wishes and expectations; he wanted to be involved in decisions about therapies, alternative treatment providers, and overall plans of action. However,

he felt that he was being perceived as "whiny" and a "complainer". It also seems

that having a stroke at a younger age was associated with more concerns and less

clear answers from the medical staff, which also increased clients' anxiety. The

goals of younger clients were somewhat different, including returning to work,

driving, and family life, and some felt that they were wasting their time on

another CT scan instead of having an extra therapy session.

Category II: Support

As the patient and the family were going through very difficult times, they needed

all the support that was available from within the family unit but also from the

staff, extended family, friends, and family doctor.

Family. Family involvement in care and decision-making improved both patients'

and families' experiences of rehabilitation. Especially for patients whose speech

was affected (aphasia) it was very important to have somebody to voice their

questions and concerns: "My husband [caregiver]. Oh yes. He was very good at

asking lots and lots and lots of questions. He was asking the questions … he

thought he knew I wanted answers to." (P10)

This incredible support comes through during the interviews with two

participants affected with aphasia: in each case the family member encouraged the

participant to take the time and answer the questions, at the same time trying to

guess where they were going and offer some choices, but never talking over them.

One of the participants commented that being in a somewhat unstable and

confused state she was happy to have her husband on her side to help her

understand and follow what was going on. Family was also providing additional care and therapy:

> And then the walking in the hall – of course, our son, he had a lot to do with it, too. They showed him what to do…. And he used to do the therapy. So he would work his arm and work his leg. At one time that leg wouldn't move. I think between my son and the therapist, that's when we started to see the movement coming back. (F29)

Family members also reflected that being present for most of the time during the rehabilitation contributed to the positive experience that they all had with the hospital stay. They also commented on always being welcome to be there, invited to the therapy sessions and social events. Being present during the day, they were able to ask all their questions and did not require any special meetings with the staff:

> I found – I know some people have complained because they don't get answers and this and that and everything else. I think that ties in with their overall involvement. How do you get answers if you are not really there, if you're not involved, if you don't ask the questions? (F28)

Health care professionals. Clinicians' attitudes also helped to shape the experience for the clients. Having a positive attitude, being caring, outgoing, enthusiastic, committed, knowledgeable and approachable were repeatedly named

as very important personal attributes of the clinicians. For the most part the experiences were very positive, with therapists and nurses creating positive and supportive environment. However, based on her experience one participant wanted to highlight the importance of the staff focusing on clients' abilities versus what they cannot do. Although this was her only negative encounter with the therapists, she wanted it to be heard:

> I thought that [the therapist] was detrimental to my recovery. She was so negative. My very first time I met her, she sat in that chair and I was sitting there and she spent an hour talking about all the things that I could not do. My first day home from a hospital. Couldn't ride a bike. You can't run. You can't do this. You can't do that. It was because I was feeling so good about my recovery, she just couldn't – I don't know. Every time she came, it was so focused on what I couldn't do instead of what I could do. (P10)

Participants reflected that impatient, angry, and frustrated clinicians were detrimental to clients' self-esteem and recovery. One participant described her overall experience as very positive, with 95% of nurses creating positive experience: "The nursing staff there was fantastic. I have no complaints about any of them. They were good. They were kind. They were very caring" (P 7), but there were several – she called them "attack nurses" – whose bad mood affected the whole atmosphere of the unit. They also tended to 'blame' the clients for

unclear or conflicting recommendations provided by other members of the staff (doctors, therapists, other nurses). This client (P7) also reflected that it made her very miserable to watch other patients being 'bullied' by these nurses. Similar experiences were reported by all the participants. On the other hand it did not require much to brighten the day:

And there's different voices that you can use. So if you come in with a smile in your voice, it starts everybody's day out because nobody feels well. Nobody really wants to get up and go [laughs]. So to have somebody to come in with a smile on their face like that is nice, you know, or in their voice"(P7)

The therapists were repeatedly described as having a good attitude, believing in clients, and often advocating for their best interests. They were always accessible, ready to answer any questions or concern. This also continued on after the clients were discharged. They felt they could call the therapists for advice any time. Listening to clients was especially highlighted as a very important attribute of good quality care.

Family Doctor. More than half of participants would have liked to see their family doctor as part of the hospital team. They felt that having the doctor involved would not only provide additional support and information source, but also improve continuity of care after discharge. One participant felt that her doctor did not have all of the information about her condition and progress, and it affected

her care, especially given the complications that were mostly resolved in the hospital, but still required follow up. Other participants described often not knowing what questions to ask at the time. They believed that family doctors would have been able to explain things better and describe what was going to happen next.

Category III: Communication

All participants described the importance of good communication among all the partners: between the units of the hospital, between the staff members, between staff and clients, and also between patient and family.

HCPs and clients. For the most part there was good communication when the clients were transferred from unit to unit or between the staff of the rehabilitation ward:

> Even when she went from inpatient to outpatient. Granted, they always do their own initial testing, but they knew what they were getting and where she was coming from and where she was heading and everything. So no. That communication was there. There wasn't a gap or anything.(F 28)

However, several participants found it very frustrating and worrisome that when something was not done properly or recommendations were not recorded, the clinicians turned to the patients with their questions (i.e. why is the walker the wrong height, why are you taking certain medications, why is your urine a certain colour, etc.):

I got a walker. … And then on the Monday when the physios were in, they said, "Well why is it like this?" "This is the way it was given to me". I found that frustrating too. They would always ask – and this wasn't just in the rehab. This was everywhere. They would ask me questions. …And I found that very frustrating because I couldn't answer these questions, and then it started me worrying because if they didn't know then you know maybe something was wrong. It was everywhere.(P 3)

Different personalities tend to voice their concerns differently. In one instance, the patient was walking on a broken foot because the staff was not attentive to his quiet complaints. On another occasion the patient and her husband had repeatedly requested to be seen by a doctor to address the other chronic conditions that she was managing. Clients felt that more often the staff was focused on the immediate problem (i.e. stroke), ignoring the overall package of issues that the client brought with him or her.

Navigating the new system was very challenging and it was important for the clients to have a person to whom they could always turn with questions and concerns. It was not necessarily a formal caseworker, but rather any clinician who had a trustful relationship and was helpful and willing to guide the client. Many continued relying on their caseworker long after being discharged from the hospital: "…when there are changes when you are not well, you need somebody there to lead you through. To help you realize the different changes."(P7)

Among HCPs. Another frequently mentioned issue was the communication between the therapists and the nursing staff about patient progress. Several expressed that many functional achievements could have been reinforced had the nurses supported the clients in doing things the same way as they were done during therapy sessions.

Patient and family. Interestingly, the communication between the patients and the families was also not always successful. Some had memory or communication problems, while others were just confused. The spouse of one of the participants remembers:

> No I would ask him, when he would say, "Oh the doctor was in today" I would say, "Well what did they say?" and he would give me a couple of things and I would say, "Well did you ask him about this and did you" and of course he forgot quite a bit. (F29)

Category IV: Information

Not surprisingly the issue of information was identified as one of the important attributes of good quality care. The staff (mainly nurses, therapists, and social workers) was described as being the main source of information during the hospital stay. Following discharge, support groups, friends, and family also played an important part in educating the clients about treatment options and supports available in the community. Clients also described that having written information (pamphlets, handouts, and brochures) was helpful; however, it could

not replace the one-on-one information provided by the clinicians. Hence, the majority of clients who were admitted to the rehabilitation unit on Friday complained about not getting enough personal information until after the weekend (because most hospitals do not have regular therapy sessions during the weekends).

All participants agreed that when a direct question was asked, clear and detailed information was provided. However, many felt overwhelmed by their condition, and did not know what questions to ask at the moment. After the fact they thought that clinicians, having the experience, could have foreseen what information would be useful for the clients in their particular situation: "If I asked specific questions, I was always given the answer if they could, you know? That was just fine. Things weren't forthcoming, I think." (P3) "…the information was only provided if I asked." (P5)

Timeliness of the information was mentioned repeatedly by the participants. They felt that the majority of information was concentrated around transition periods (intake and discharge), and they would have liked to have the information spread out over their stay. Participants were well aware that it was impossible for the clinicians to give them specific timelines of their recovery. However, having at least tentative ranges based on previous experiences would have been greatly appreciated. It would also have made planning ahead easier: "Yeah, well I would have liked to have known more or been told more there,

because really a lot of the time we didn't know what was going to happen next."
(F29)

Another suggestion was to provide written materials about the rehabilitation unit prior to transfer, when the client is still on the acute ward. This would give the clients more time to learn about new rules and routines, and make the transition less stressful:

> I got pamphlets, but as I said, three days after I got to rehab. It would have even been nice if they'd given it to me before when they decided I was going to go. When I was still on surgery but I was going to go down to rehab. I would have read it all and known what was going on. (P3)

Clients would also have liked to know more about alternative, affordable or private treatment options both during their stay at rehabilitation and after discharge. It was especially important for clients with a specific problem that was more pronounced than others (i.e. speech impairment, physical limitations) and who wanted to supplement the amount of treatment provided by the hospital: "…they didn't really give me a choice about other options available. I'm not sure if there are other options available to me.' (P30)
Overall, the majority of participants felt that they were well equipped, both physically and with information prior to discharge.

Category V: Hospital Experiences

Positive features. The overall hospital experiences were also mentioned by all the participants as important attributes in shaping their satisfaction with their stay. All participants reflected on the helpfulness and kindliness of the auxiliary staff (kitchen and cleaning staff, and other services) and nurses and therapists: "Cleaning staff. They always came in with a smile on their face, so that was nice." (P7)

Surprisingly, over half of the participants found meals and especially the way they were provided in a common area as one of the best experiences: "Meals honestly are one of the high points of the day [laughs]." (P5) They also commented on the organization of therapy sessions and the helpfulness of having the schedule written on the notice board. This allowed the clients to plan their day and also organize visits from family and friends. Some rehabilitation units also encouraged their clients to dress in their home clothes. Many participants found it very uplifting:

"I liked the fact that you got dressed every day. You didn't feel you were sick of hospital gowns [laughs]." (P5)

Clients also commented on the variety of social activities organized for the patients and family members. The next quote was seconded by most participants:

> They had things for them to do, you know. They had outings and they had the barbeque every so often. You know. And they have beautiful grounds there. I mean, it was really not a bad place to be if you had to be somewhere like that. (F21)

Weekend passes were also mentioned by several clients as an important event. It provided an anchor for both the patient and family on the progress and special needs, and highlighted the areas that needed to be addressed before final discharge.

Negative features. There were several areas in which clients would like to see changes. Probably one of the most frequently mentioned was *being admitted on the weekend* (Friday). Participants felt that they were just left there to fend for themselves until the Monday when the therapy resumed. This brought up another point of *worrying and uncertainty* that many participants experienced near transition times (i.e. from unit to unit, going home) and which was increased by inadequate support when the transition happened before the weekend:

> The one thing I really didn't like was the fact I was moved to that [rehab] floor on a Friday afternoon and it was such a deadly weekend, even though I had visitors for myself but there was nothing going on the weekend. It honestly was depressing. It was depressing. The second weekend it was okay because I knew what to expect but that first weekend, it was very depressing. (P5)

Most participants also raised the problem of the shortage of nursing staff. They felt that there were not enough nurses to address all the needs of the patients, they were stressed and overworked which sometimes resulted in being

brusque, impatient, and insensitive. The majority of patients had limited mobility and required assistance even with minor tasks:

> I still think it all boils down to having enough staff so that they are not rushed off their feet, that they can deal with people in a kindly and timely way… But there were still times that really all you just needed was somebody to help you for two minutes, for your personal comfort. And if that had been looked after, it would have made it easier to get better, to get your spirits up, to make you well. (P7)

It is important to note that the overall experiences were very much coloured by the expectations and life situation of the clients. The experiences could vary from excellent to very poor almost regardless of the interventions. One of the younger patients was anxious to get back to work, and did not want to accept the consequences of stroke:

> I didn't want to be there. I did not want to be there. It was a critical point to my life and the stroke happened at the wrong time and I did not want to be there, so I was constantly complaining about wanting to leave. So I think that discoloured my whole perception of the whole experience, I guess. (P30)

Part B: Health Care Professionals' Experiences

Category I: Being on Common Ground

Clients and clinicians having similar goals and understandings of the outcomes have been mentioned as important aspects of health care professional/client interaction at the beginning of all interviews. Building a good rapport and working together on a goal not only improves the day-to-day experiences of both clinicians and clients, but also advances clients' outcomes. It is closely related to the clinicians' definition of CCC. On one hand they define CCC as working to attain clients' goals. On the other hand, the clinicians are facing a dilemma of matching a client's wishes and the reality of what can be attained based on their expertise and experience in rehabilitation. Following are extracts from two interviews: "We can't get them motivated to participate in therapy unless we are working on something that they want." (HCP 9)

Clinicians described stroke as a life-changing experience, with clients going through the steps of grieving and acceptance, and different challenges for both the patient and the family at different stages of rehabilitation. Often it is their first experience with a major illness that adds tremendous emotional, social, and financial burdens. These can be especially difficult for younger clients who have different family roles and are still working. The clients go through learning and adjusting processes to take control over what is going to happen next. They might present as confused, impractical, or depressed:

There are always challenges and different ones at different points in time. And depending also on the diagnosis. At the beginning, a lot of the times people are either too tired or too shocked or too, you know, afraid and

they don't really agree with being here. They don't really want to do anything." (HCP 31)

Clinicians described having different strategies that help them to get everybody on the same page. In general, it is important to create a supportive environment with open and honest communication, focusing on the achievements and not on negative aspects. *Education* and *information* for both the patient and the family were mentioned by all the participants as the main strategies to help them develop a clear understanding of their condition and prognosis. Other tactics included *problem solving* – breaking the long-term goal into smaller, manageable short-term goals that still work towards the client's ultimate goal (explaining this to the client), letting the client try the activity and discuss the results, involving the family in goal setting and discussions, and working as a team to maintain consistency:

> And so it's all a form of education ultimately but try to take the patient together with their family and me to problem solve, you know, can we attain this goal? And maybe making that long-term goal or more of a short-term goal of like let's change it and let's get your ability to sit unsupported for a little bit before we work on standing and then walking. (HCP30)

Clinicians also highlighted the importance of understanding the story of each client (their beliefs and preferences, specific life circumstances, and support system), walking them through the process, while giving them time to get used to their situation and the new environment:

> They are coming into this maybe for the first time and we've walked how many patients through it with maybe a similar diagnosis but their story is kind of a little bit different. I feel that it's important to understand that and I kind of walk them through. I'm more of a facilitator. (HCP45)

Several other points that were discussed included letting the patient go home for the weekend. Weekend passes provide great educational experiences for the patient and family. Making a list of functions to achieve and crossing out whatever has been achieved can be very illustrative of the client's progress. Often there are differences in perspectives and experiences of the patient and the family with the weekend passes, especially if the family has not been involved in day-to-day care. The patient is often happy and eager to be home, finding it exciting rather than challenging, while the family can be anxious and unsure whether they will be able to provide safe and appropriate care:

> …the weekend or day passes, when some patients feel ready to go back home and families are afraid. So we have to balance that. Personally, I try to bring the caregiver [into the hospital] to work with the patient, transfer

the patient, do some of the therapy the week before they go so both parties

feel confident… (HCP 29)

Category II: Partners in Care

Without necessarily naming it as such, all clinicians described the importance of

the client's active participation in all the processes of rehabilitation. Clinicians

would like to work in partnerships with both the patients and families where there

is mutual respect, trust, honesty, and on-going communication: "So being able to

have that mutual conversation so we can kind of grow together and have that

relationship together." (HCP 30)

Clients assuming an active role. Clients also have to ask questions, and question

the process; this not only keeps the therapist up to date, but also helps clients to

direct their own care. Clients are not only the experts on their previous conditions,

but also on what they need in order to cope and return to their life. They need to

understand what is going on and provide the clinicians with information about

what their needs and goals are. Clinicians highlighted the importance of clients

taking charge early in their recovery, feeling that this will make it easier for them

to take care of themselves after they leave the hospital: "…we do say to them,

'This is your therapy so without you we wouldn't be here. You are actually the

most important member of our team'". (HCP 52)

Unfortunately many older clients take a passive role, wanting the medical

professionals to make all the decisions: "A lot of times, and in the older

generations, there is almost this, you know, separation where they feel 'I'm the patient and you are the health care professional'. Working collaboratively is almost foreign to them." (HCP 9)

Some clinicians believe that it might be more personality and culture related. Others suggested that poor health literacy prevents clients from active participation, and being informed will empower the client and encourage control and participation: "I think it's a problem, poor general knowledge for everybody in society. They should teach it more in school." (HPC 5)

However, making or not making medical decisions does not mean that clients do not have preferences on how their life should be, and it is important to respect that.

Family involvement. All participants also talked about the importance of family involvement from the very beginning of rehabilitation. Given the constraints of stroke, family often is taking front stage, being a substitute decision-maker, advocate, main supporter, and caregiver. The outcomes of rehabilitation often depend on family readiness (physical, mental, and emotional) to provide support:

> I find the patients that do the best are the ones who have active family member involvement all the way through… we can show them exercises that they can follow through with, and they do so much better because instead of just the half hour of physio one-on-one, they get extra therapy with their loved one. (HCP 25)

It is beneficial for the family to be present for therapy sessions to see the progress and learn how to assist the patient with exercises and day-to-day activities. Family also acts as a cheerleader for a patient's successes, and becomes an active participant of the caring team. This not only gives them confidence and decreases stress, but also improves family dynamics:

> I feel that they feel more secure, the family members, more confident with their skills, and like I said they feel like they have an active role in the rehab of that loved one. So I find it brings them closer together. (HCP 25)

HCPs' roles. The clinicians also described the multiple roles that they take on apart from their actual profession. They often act as advocates for clients' best interests, educators, communicators between the client and the rest of the team, providing support both physical and emotional, ensuring continuity of care and sometimes just being a friendly face: *"*An advocate for patient's goals and what they want to achieve. It's also my role to both, I guess, support socially, emotionally, spiritually a patient and also their family member." (HCP 20)

At least half of the participants supported the idea of involving family physicians in the rehabilitation process to improve continuity of care: "I think it's nicer if the [family physicians] who deal with them the most and know them are involved in their care. Maybe that would lessen some anxiety." (HCP 2) However, realistically, they do not see family physicians being more involved due to attending privileges and time constraints. They also described a summary report

being sent with each client upon discharge and were confident that the doctors are well informed and should they have any questions or concerns it would be their responsibility to contact the in-patient rehabilitation team. The latter in fact almost never happens.

Organizational support. The context of practice was also described as important in supporting the developing model of care. All participants described their hospitals encouraging the clients and clinicians to work together in partnership. Updating hospital mission statements, educational sessions for clinicians, posters, and clients' education are just some of the strategies used. However, there is still a need for more practical education about actual implementation of CCC principles:

> I think people get [CCC] in theory. I just don't think we all do a very good job of implementing it – like from everyone across the board versus me in physio and her in OT and him in SLP or whatever it is. (HCP 30)

Category III: Definition of CCC and Client

We were interested in exploring how the health care professionals from different disciplines define CCC and whether this definition is in line with other definitions used in the literature.

The clinicians seemed to have a very clear understanding of CCC. All participants put the client in the centre of care, highlighting the importance of working towards client-set goals. One of the most comprehensive definitions is presented below:

Client-centred care would be care that is supporting and promoting the best interests of the clients, such that they are getting services that are tailored to their specific needs and that are going to best enhance, from a stroke care perspective, their ability to recover and reach their full potential. Also,… that's respecting the dignity of the client, having their wishes be known, that they are an active participant in their care, that they have some direction around how their care is managed and what they want to do and what their goals are. Things like that. So that they are sort of an active participant in the health care process. That's my understanding. (HCP20)

The majority also described the importance of all team members, including auxiliary services (kitchen and cleaning staff, technical support, etc.), supporting the client and creating a positive environment.

All participants defined the client as the patient and whoever else that the patient identifies as the next of kin. They also highlighted the importance of involving the family in care to improve outcomes for both the patient and the family, if the patient has given permission to contact them:

It is absolutely the patient and the family, or whoever they want to be involved. I always ask them when they are doing their planning if there is anybody they want me to contact to give the information. If they don't, then I deal just directly with the client. (HCP 41)

One of the formal strategies to keep the family informed are the family meetings
conducted with some of the clients, involving all therapists participating in
rehabilitation.

In general, all participants considered CCC to be a preferable way for all
the parties involved to practice. Engaging in partnership with the clients led to
improved job satisfaction, motivation, and client outcomes:

> So being able to do it and having the opportunity to do it here I think has
> been really beneficial for me. To enjoy coming in to work and to enjoy
> working with people. Patients who have a good sense of what they want to
> work on makes my job a lot easier… (HCP 46)

Partnerships in care also resulted in better organized and efficient care, decreasing
the load and the stress on the staff. Some commented on CCC being time
consuming, but described it as time well spent to ensure that engaged and
educated clients will be ready for discharge with less effort and stress:

> Well the benefits are that if a patient is involved in their goal setting, then
> they are more likely to work towards that goal. You know, I think that
> client-centred care or teamed client-centred care makes for smoother
> discharges. It makes for less wasting time. It's more organized. It's more
> timely, because if people are disjointed and don't know what the actual

goal is, then you can have the same people working on the different

things. (HCP9)

This was also the way that clinicians would like to be treated themselves, should

they need health care services. The only drawback clinicians described with

practicing CCC was in cases when the clients had unrealistic goals that they

insisted on pursuing or on the contrary did not want to participate in

rehabilitation: "I can't think of any cons unless what the person wants is

unattainable and they would not accept that." (HCP10)

Participants also described that with CCC, clients feel empowered, have

more control over what is happening with them, and consequentially there is

better adherence and outcomes, and overall more satisfying experiences: "Give

them control, as much as possible, and that helps them with their self confidence

and, you know, their perseverance. Again, they become committed to their rehab

and an active participant." (HCP25)

Category IV: Practising CCC

After reflection all participants spoke about already practising CCC, although

there is room for improvement in minor issues:

> I feel that we are practising it, though. When I am sitting around a table
>
> and we started talking about what we needed to change or when we did a
>
> gap analysis, I felt like in my opinion there wasn't a big gap. I felt like we

were already demonstrating a lot of those qualities but I think we just

needed to reinforce it or just bring it kind of to the forefront. (HCP 45)

Some disciplines (e.g. occupational therapists and social workers) believed CCC

to be embedded in their philosophy of care; others described the idea being

around for a long time, but recently emerging as the main general philosophy:

I think this is right in line with what we should have been doing or what

we've been trying to do all along. I think finally it's just been actually

written out. I think if anything, it's helped people who have been in an old

way of thinking, that we have the same goals with every client. It's helped

them to problem solve again and realize that everybody has different goals

[for] being here. (HCP 41)

Three participants described how having a personal experience of a family

member admitted with a serious illness changed their priorities in practice. Even

being more health literate than the general population, they felt overwhelmed by

the amount of information and the emotional load that they received. They

understood better what the clients are going through and are trying to advise the

clients on some of the strategies they have found useful:

And from a personal experience, when my husband was hospitalized, I

realized that when hospital staff talks to us, the information they gave us,

for us it was very emotionally loaded. So even though they kept giving us

very basic language and they told us the information a few times, we had difficulty recalling that information because we were emotionally reacting to it." (HCP 10)

Strategies. Several successful strategies to improve CCC have been introduced in different hospitals: writing a family note (a summary that is given to the family) at the family meeting, appointing a contact person/therapy leader for each client, improving continuity and coordination of care through interdisciplinary collaborations, having the same staff working with the client, providing written materials (binder or stroke passport – a booklet including all the information pertaining to the patient's rehabilitation: i.e. goals and progress, important information regarding procedures, assistance, discharge, etc.), creating flexible environments and educational sessions for patients and families, and organizing discharge:

> So one team member is a primary contact for each patient. So that patient and the family has one, you know, person that they can contact to get information. And having, like I said, that primary contact role is huge because it helps people figure out who to call if there's problems. It's more stable. It's more 'Okay, if I have a problem I know there's one number that I can call'. And that's for the patient and the family. (HCP33)

Most clinicians commented that although there is more information available today from the Internet and other media, it is not always accurate:

> [The] Internet has opened up a whole knowledge base. It's not always accurate so we have to try to correct that as much as possible… I think it's great to have these various resources available, just so long as it's good information that they are getting, right? Because not all of these websites are reliable. (HCP 25)

Hence the main source of information for clients and their families remains one-on-one education with clinicians. They stressed the importance of providing written information and having it available online for the family to explore: "There's lots of information in talking to them. There's probably not enough printed information. Yeah. We could do better with that." (HCP 5)

Discharge planning. Discharge can be a challenging time for the clients and providing education and coordinating services and supports in the community are the key for stress-free experiences. Participants commented that having a designated discharge planner improves the process of transition for the clients and decreases the load on the therapists. Having a community care representative participating in planning also improves the coordination: "Our CCAC [community care access centre] home care manager here, she works through CCAC but she is here. She is the bridge for the communication. She is excellent." (HCP 45)

Most clinicians felt that the clients are well equipped both with information and technical support when they leave the hospital; however, they were not sure about what is happening in the community: "…as far as resources though, I find they are well prepared, quite well prepared. Like I said, giving home exercise programs, equipment here." (HCP 25)

Interestingly, clinicians were unanimous on the personal qualities that are important for clinicians. Being caring, compassionate, patient, a good communicator, a team player, up-to-date, fun, resourceful, a good listener, and respectful were described by all participants as must-have attributes to provide good care.

Category V: Barriers to Good Quality Care

In order to describe the barriers, we first asked clinicians if they could name the important attributes of good quality care. The qualities most often described by the majority of participants included individualized care, continuity of care, open and honest communication among all the partners, active listening, educating/empowering the client, availability of the staff, being respectful, being team-based, having care provided by qualified clinicians, being compassionate, and timely provision of services.

All participants described that being short staffed and having to combine several responsibilities (i.e. primary contact clinician organizing discharge) do not allow them to perform to the best of their abilities and add stress to the staff. Many felt that there was too much demand on their time: "I feel sometimes that

client-centred care needs to be supported by having the appropriate amount of staff. Having the ability for a person to be able to do the productivity within a stress-free environment." (HCP 45)

Understaffing also results in staff having to prioritize to deal with the problematic cases, and not providing enough support and education to the clients who are "coping well". Having enough time with each client was also described by all as a barrier to CCC. The clinicians also wished for more flexibility in the clients' length of stay, and felt that not having to transfer the clients to a different rehabilitation facility would have eased the stress of the adjustment for an already vulnerable population.

Another issue was problems with communication. Clinicians described not having good communication strategies for families who are not present during the day:

> I think that families who are here during the day get way better information and way more knowledge than people who are here at night, right? Because you have access to the entire team when you are here during the day. I think we could benefit from a communication tool or a way of updating the family of what their loved one is up to, because I don't think we do that very well. (HCP 30)

The communication between different sites or hospitals is often fragmented and not timely, with the staff receiving partial notes, and clients not knowing about the

transfer ahead of time. Some hospitals implemented a universal computerized charting system that allows all health care professionals from the hospital to get updates on clients' conditions. Several participants also commented on poor communication within the unit, more specifically between therapists and nursing staff resulting in progress during therapy not being utilized and reinforced in the day-to-day function.

Discussion

The aim of the study was to explore current client-centred processes of care from clients' and clinicians' perspectives using in-patient rehabilitation units as our settings. Unlike previous studies that reported some discrepancies in clients' and clinicians' experiences, in the current study there were clear parallels between the identified categories that allowed creation of a uniform model (Figure 2) to describe processes of care (Berglund, Westin, Svanstrom, & Sundler, 2012; McCance, Slater, & McCormack, 2009; Rosewilliam, Roskell, & Pandyan, 2011; Tutton, Seers, & Langstaff, 2008).

Insert Figure 2 here

The central category from both clients' and HCPs' perspective was the importance of the whole team having mutual goals and understanding of the outcomes: 'being on common ground' runs as the main thread throughout all the interviews. Both clients and HCPs described successful partnerships in goal

setting; however, similar to other studies the participation of the clients in other decisions, including day-to day decisions about the amount and type of therapy, length of stay, and conditions of discharge, varied significantly based on their age and assertiveness. Older clients tended to assume a passive role, rarely voicing their opinions and preferences (Chung, Lawrence, Curlin, Arora, & Meltzer, 2012; Moreau et al., 2012), whereas younger clients faced additional challenges due to unclear diagnoses, and due to the multiple roles they were fulfilling in their pre-stroke lives. Although clinicians were striving to create a flexible environment, there still seemed to be set routines and procedures in rehabilitation processes. The amount of therapy could not always be adjusted to specific needs of the client. It was often limited by the understaffing of different disciplines. In addition, there were few options available to focus the treatment on specific therapy (i.e. speech language pathology or physiotherapy) for clients with severe limitations that would affect their post-discharge life. As stroke is increasingly affecting younger people (Kissela et al., 2012), the processes will have to be adjusted to better address unique needs and expectations of younger clients.

Any critical illness is a stressful, life-changing event for the entire family. It is also new ground for the clients where they might feel powerless, depressed, and unsure about any decisions. To help clients get some control over their situation, clinicians employed different strategies, including education and information provision, joint problem-solving, weekend passes, and focusing on achievements. Several studies in different settings described that client education

and information provision helped in setting more realistic goals for rehabilitation, and also improved outcomes for both the patient and the family (Foster et al., 2012; Hunt, Moore, & Sherriff, 2012; Kergoat et al., 2012; Leach, Cornwell, Fleming, & Haines, 2010; Levack, Siegert, Dean, & McPherson, 2009). In their report on patients' experiences on an experimental stroke unit, Lewinter and Mikkelsen (1995) described that changing the environment during weekend visits at home was having a therapeutic effect on their recovery (Lewinter & Mikkelsen, 1995).

To create productive partnerships, all participants highlighted the importance of teamwork. All clinicians described the patient and family as central members of the rehabilitation team. However, they would have liked the clients to be more pro-active in seeking information, asking questions and participating in decision-making. Most clients were happy with their role during their rehabilitation. Although they felt that they were listened to, and were free to ask questions, they did not perceive themselves capable of making medical decisions. The above ideas were also described by previous studies with stroke survivors and general patients (Chung et al., 2012; Ellis-Hill et al., 2009). Similar to other studies, early family involvement was found to benefit all the team members' experiences and outcomes (Foster et al., 2012; Levack et al., 2009; Mitchell & Chaboyer, 2010; Pellerin, Rochette, & Racine, 2011; Tutton et al., 2008). Clinicians were described as fulfilling multiple roles, advocating for clients' best interests, educating, and providing support. Positive attitudes of HCPs' were

extremely important in creating pleasant experiences. Inclusion of family physicians into the rehabilitation team was seen as beneficial, however it is not practical given the political constraints regarding hospital privileges. In the study by Wachters-Kaufman and colleagues (2005), nearly half of the stroke survivors and their caregivers would prefer their general practitioners to be their main source of information, due to long-term trusting relationships and follow up care that they provide. However, the therapists were found to provide most information (Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005).

Both the clients and HCPs agreed that efficient communication among all the team members and provision of timely and forthcoming information required further improvement. Importantly, these two main domains of CCC have been found deficient by previous studies (Arnold, Coran, & Hagen, 2012; Peoples, Satink, & Steultjens, 2011; Sinfield, Baker, Agarwal, & Tarrant, 2008; VisserMeily, van Heugten, Post, Schepers, & Lindeman, Mar 2005; Wachters-Kaufmann et al., 2005). Peoples et al (2011) conducted a systematic review of qualitative studies that explored stroke survivors' experiences of rehabilitation. They highlighted the importance of sufficient information for improving partnerships in care, and lack of information resulting in patients' assuming a passive role.

The main barriers to implementation of CCC identified by all participants were poor health literacy, time, understaffing, and organizational culture. Poor health literacy affects clients' ability to participate actively in their care by

preventing them from asking questions and making decisions. According to the Canadian Council on Learning, 60% of Canadians have poor health literacy (Canadian Council on Learning, 2007). Considering clients' literacy and educating them accordingly is essential if active partnership in care is desired (Levasseur & Carrier, 2010).

With no exception, participants described CCC as requiring more time than medically-focused care. This idea is indeed supported by the literature (Bright et al., 2012; Dilley & Geboy, 2010; Hunt et al., 2012; Leach et al., 2010; Saha & Beach, 2011). However, all agreed that it was time well spent. It allowed timely education for both the patient and family, increased clients' participation, and consequently ownership over their condition, and resulted in improved outcomes. As stated in Bright et al.: "…you do not have time **not** to do it." ((Bright et al., 2012, p 1001).

Understaffing can directly affect time available for each client, and indirectly increase stress levels and burnout of clinicians, resulting in decrease in empathy and client-centred communication (Bombeke et al., 2010; Passalacqua & Segrin, 2012). Organizational culture also has significant effects on implementation of CCC. Similar to previous studies, clinicians described the need for education, on-going feedback, and a general organizational atmosphere that is supportive of client-centred behaviours. In turn, HCPs also reported increased job satisfaction and motivation, and better understanding of their professional identity

(Dilley & Geboy, 2010; Kjörnsberg, Karlsson, Babra, & Wadensten, 2010; Perry, 2009; Rozenblum et al., 2012).

Finally, we would also like to highlight several minor, but no less important, points that were identified by the clients from different hospitals. Positive attitudes and helpfulness of the auxiliary staff (technical support, janitors, kitchen staff, etc.) made it easier to bear the long-term stay at the rehabilitation unit. Being dressed in regular clothes decreased the feelings of depression and sickness that hospital gowns often bring to people. On the contrary, being admitted on the weekend (or on Friday) left clients to adjust to the new environment without sufficient support and information from the therapists.

Some of the limitations of the current study include the relatively small number of participants. However, we felt that we gained sufficient depth and breadth in the qualitative interviews, and no new categories were emerging at the time we concluded interviewing. The study was conducted in in-patients rehabilitation units in Canada and caution must be exercised when applying the results in different health care settings and countries. Many of identified categories, however, were supported by international literature, and we feel that the results might be of high interest to any health care institution that has adopted, or plans to adopt, CCC as their philosophy of care.

Conclusions and Implications

The results of the current work suggest that clinicians have a clear understanding of the principles of CCC and are working in partnerships with the clients to achieve their goals.

Regardless of age, all participants reflected on the importance of working towards goals that were meaningful and important for the client. However, some clients tend to have passive attitudes to day-to-day decisions and their preferences should be respected and supported. Clients rely on a support group that includes family, friends, staff, and family physician. Efficient communication among all the parties is paramount. We need to encourage and educate clients to become motivated, well-informed, proactive participants in their care. Health education should begin as early as the school years in order to empower clients to participate in planning and decision-making about their care.

Several practical ideas that should be considered include:

- Provide the information as early as possible, i.e. prior to transfer to rehabilitation, written information can be provided about the new unit's processes and schedules.

- Avoid Friday admissions to allow clients to adjust to the unit and to acquire exercise routine they will be able to practice on their own.

- Studies suggest that although CCC requires more time, it improves outcomes and might result in decreased length of hospitalization.

- Adequate staffing can ensure better quality of care and improve clinicians' job satisfaction and well-being.

    In summary, it is important for clinicians to create a supportive and positive environment to improve the health care experience of rehabilitation, and provide timely and comprehensive information.

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Figure. 1. Continuum of hospitalization experiences following an acute event.

Figure. 2. Theoretical model of processes of care.
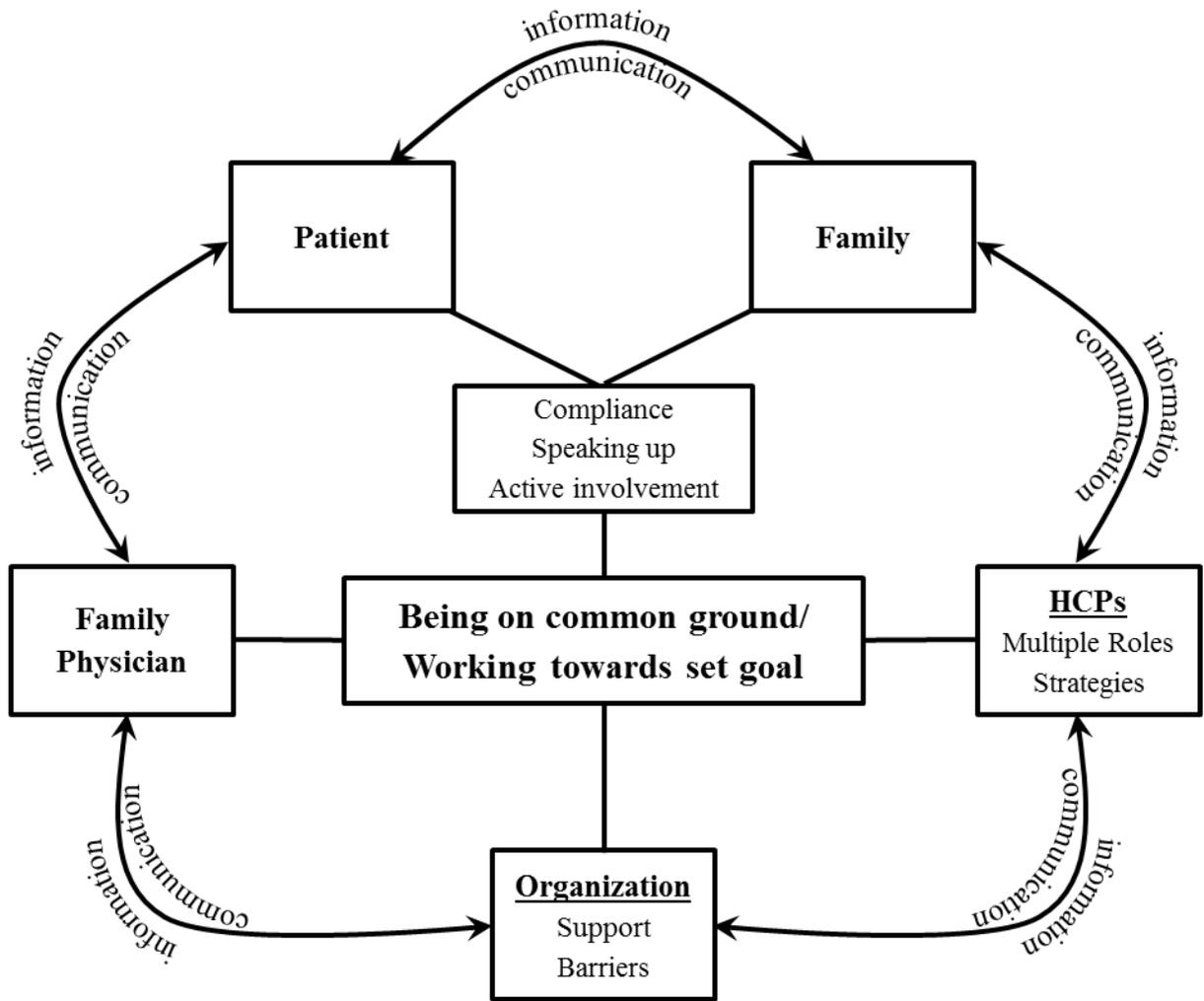
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Chapter 6: Discussion

Introduction

A lot has changed in the last decade in the way the health care is provided. Patients and families have graduated from being passive recipients of services to being consumers, and more recently, to equal partners with health care providers (Giuliano, Giuliano, Bloniasz, Quirk, & Wood, 2000; Haas, 1992; Litchfield & MacDougall, 2002; Morris, Payne, & Lambert, 2007a). Although many organizations have claimed for some time to be providing client and family-centred care (CCC), research has repeatedly demonstrated that this was often not the case. Clients were reluctant to assume more active roles, while HCPs were not clear what elements and skills constituted actual CCC. CCC in adult health care had to be conceptualized, and sound outcome measures were needed that would allow evaluation of services and serve as reflection tools for HCPs to assist with quality improvement (Attree, 2001; Lanza, 2006; Morris, Payne, & Lambert, 2007b; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005).

The overall purpose of my thesis work was to further our conceptualization of the principles of CCC in adult health care by (i) adapting outcome measures that could help to capture clients' and HCPs' experiences, and (ii) creating a model of client-centred interactions in in-patient rehabilitation settings. This summary chapter presents an overview of the results of my narrative review, validation study, and the mixed methods explorations that are presented in two manuscripts, the first looking at performance of the MPOC-A and MPOC-

SP(A) in rehabilitation settings, and the second presenting the results of the qualitative study.

Overview of paper results

The purpose of the narrative review was to provide an overview of the development and evolution of the client and family-centred theory as an underlying conceptual foundation for contemporary health care services (Bamm & Rosenbaum, 2008). The results of the review demonstrated that the majority of published work came from the pediatric field. However, in a few studies from adult care, patients, families and clinicians described concepts similar to those reported in pediatrics that they considered important for CCC. They also described similar challenges faced by clients and clinicians in engaging in partnership. Clients were not necessarily ready to assume an active role in relationships, often referring to clinicians as the 'experts'. Clinicians were divided in their understanding of CCC: some claimed always to have practiced it, while others were not interested in changing the paternalistic relationships with the clients; the majority was still not sure how to introduce the changes and create partnerships. In addition, to be able to assess the implementation of new principles, the study identified a need for valid and reliable measures of CCC for adult health care settings, and studies that explored actual implementation of these concepts in a variety of clinical settings (Bamm & Rosenbaum, 2008). The article continues to be commonly cited today. In 2011 it was among the Top 25 articles

of the SciVerse ScienceDirect Archives of Physical Medicine and Rehabilitation Hottest Articles (July-September) list.

The purpose of the validation study was to assess the psychometric properties of the adapted version of the Measure of Processes of Care for Adults (MPOC-A) (Bamm, Rosenbaum, & Stratford, 2010). Patients (176) who had undergone elective hip or knee replacement surgery and family members (81) completed the questionnaires. The results demonstrated high internal consistency of the sub-scales, with Cronbach's alpha varying between 0.81 to 0.93 for the patients and from 0.88 to 0.96 for family members. The domains of MPOC-A were moderately correlated with the Global Satisfaction Questionnaire for both patients and family members, supporting construct validity of the new tool. High to excellent agreement of test-retest scores supported stability of the measure over time. Moderate to good agreement between patients and family members (Intraclass Correlation Coefficients varying from 0.50 to 0.74) suggested that the proxy reports could be solicited in cases where patients are unable to complete the questionnaires. Overall the measure demonstrated strong psychometric properties in an in-patient orthopedic surgery unit. However, we recognized that larger studies in different health care settings (with longer-lasting partnerships between clients and clinicians) were needed to continue to explore the validity of the adapted tool.

The objective of the subsequent study was to complete adaptation and field testing of the Measures of Processes of Care for Adults (MPOC-A) and

initiate validation of an adapted companion measure for service providers working with adults (MPOC-A(SP)) (Bamm, Rosenbaum, Wilkins, & Stratford, Submitted September 2013). Patients, families, and HCPs of four in-patient rehabilitation facilities were invited to participate in the two-part study. The first component involved completing the questionnaires; the second part consisted of semi-structured interviews with interested participants. In addition, data from two other studies, one in Alberta (of which I was co-investigator) and another in the United States, were combined for the HCPs. Sixty-one patients, 16 family members, and 384 health care providers (Ontario 54 HCPs, Alberta 45, and US 285) completed the questionnaires. Good to excellent internal consistency (0.82-0.90 for patients, 0.87-0.94 for family members, and 0.71-0.88 for HCPs), as well as moderate to good correlations between domains (0.40-0.78 for HCPs, and 0.52-0.84 for clients) supported internal reliability of the tools. Results of exploratory factor analysis of MPOC-SP (A) supported the original multi-dimensional structure of the tool, and suggested that a shorter version of questionnaire might be more useful.

In conclusion, both the MPOC-A and MPOC-SP (A) demonstrated good psychometric properties in in-patient rehabilitation settings. However, future studies should consider exploring the performance of shorter versions of the measures in variety of health care settings.

The objective of the qualitative study was to explore the experiences of current models of delivery of rehabilitation services from the perspectives of

patients, families, and HCPs (Bamm, Rosenbaum, Wilkins, Stratford, &

Mahlberg, submitted September 2013). Eight patients, four family members, and

15 HCPs participated in the interviews. Being on common grounds/working

toward client-identified goals was the main category identified by both clients and

HCPs. All participants repeatedly highlighted the importance of good

communication among all the parties (patients, families, HCPs, community

services, etc.). In addition, ongoing information flow among all involved in the

care experience was also necessary. Although successful partnerships were

created, the majority of clients still assumed a passive position. The study

provided several practical suggestions on how the experience can be improved for

everybody. These included provision of written information prior to transfer from

unit/hospital to rehabilitation unit, avoidance of Friday admissions, and ensuring

sufficient staffing to decrease HCPs' burnout and allow creation of supportive and

positive environments for all persons involved.

Benefits of collecting quantitative and qualitative data

When exploring complex subject matter, such as processes of human

interaction, it is often impossible to rely on only one method of inquiry.

Quantitative data can help clinicians to gain an overall feeling of the field. Such

data allow easy and relatively quick identification of problematic areas, and the

baseline outcomes can be re-measured once the problems have been addressed. In

our research, using both quantitative and qualitative methods also allowed us to

select participants for the ensuing qualitative study based on their reported

experiences on the MPOC-A and MPOC-SP(A). The framework behind the outcome measures also helped with development of the interview guide for the qualitative study (*CanChild* Centre for Childhood Disability Research, 2003; Law et al., 2005).

In turn, the results of the qualitative study not only illustrated the current model of health care delivery in rehabilitation, but also provided validation of the initial framework and supported multi-dimensionality of the outcome measures. It also provided an opportunity for clients and HCPs to elaborate on the issues raised by the survey, and to reflect on other positive and negative experiences, as well as practical strategies that were used to achieve successful partnerships.

Implications of thesis work

Theoretical implications

As a field is developing it is always challenging to fully visualize the conceptualizations of the phenomena. At what point do we stop and say that there has been enough theorizing, and it is time to move on to practical implementation and evaluation of the outcomes? The narrative review provided an important overview of the CCC in adult health care today and outlined some key directions on which future studies should focus. It presented several broad definitions of the phenomenon, and outlined comprehensive frameworks that can be used to guide research and clinical initiatives. The review also helped to identify areas where more research was needed in order to promote implementation of CCC principles into practice.

Outcome measures

The service delivery format and principles have undergone dramatic changes in the last several decades. According to Global Programme on Evidence for Health Policy of World Health Organization "the concept of performance in any health system is centred around three fundamental goals: improving health, enhancing responsiveness to the expectations of the population, and assuring fairness of financial contribution. Responsiveness includes two major components: (a) respect for persons (including dignity, confidentiality and autonomy of individuals and families to decide about their own health); and (b) client orientation (including prompt attention, access to social support networks during care, quality of basic amenities and choice of provider)" (Murray & Frenk, 2000, p. 720-21). To improve health care services researchers, clinicians, and stakeholders need reliable measures that will make possible simple, valid and effective information gathering about the experiences of the services from patients' and families' perspectives. The pediatric versions of MPOC-A and MPOC-SP(A) have been shown to be valid, reliable, user friendly and to provide informative outcomes of client-centredness (Cunningham & Rosenbaum, in press; Dyke, Buttigieg, Blackmore, & Ghose, 2006; King, Rosenbaum, & King, 1996). Studies included in this thesis supported psychometric properties of the tools adapted for adult health care settings. It appears that MPOC-SP (A) is a useful measure insofar as it encourages self-reflection and allows identification of areas

in need of improvement. The characteristics of the tools that support their advantages will be discussed next.

   Administration. In the reality of today's health care services it is important for clinicians that the outcomes they collect are easily administered. The MPOC measures were developed as self-administered tools that clients can complete on their own or with the help of family and friends. It takes about 20 minutes to complete the MPOC-A, and 10-15 minutes to complete the MPOC-SP(A). The questionnaires targeted a grade 8 reading level and are user-friendly. Currently, only a paper and pencil form for the clients has been used. For clinicians the paper and pencil as well as on-line versions were used in the studies and seemed to be functioning similarly. It appears that older clients (the group that participated in both studies presented in this thesis) still prefer the paper version of the tool. However, it is not clear what the preferences of the clinicians are as this was beyond the scope of reported studies and will have to be examined in the future work.

   Scoring and Interpretation. Another advantage of the MPOC tools is the ease of scoring. The mean scores for the domains are calculated with no weighting involved. To be able to calculate the mean of the scale at least two-thirds of valid responses for that domain's items have to be available. If more than 25% of responders stated that certain behaviours occur "to a small extent" (domain average ≤ 4.0), the issues identified by the specific domain might warrant a closer look and possible intervention at the level of the program or service.

Moreover, item-by-item analysis of the scores can provide information on what specific behaviours should be improved or adjusted.

Processes of care

After a stroke, significant changes of everyday life and uncertainty in the face of the future place additional strain on stroke survivors' and caregivers' psychological well-being. Given functional limitations and reliance on family support to attend rehabilitation or follow-up sessions, even geographical proximity of the medical services becomes an important issue in satisfactory care. Moreover, patients often require additional time to ask questions, discuss issues of specific importance, and just talk about the meaning and implications of stroke for them. Several publications raised the importance of physical accessibility and availability, and continuity of the services for stroke survivors and their families (Eaves, 2006; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Morris et al., 2007a; Thomas & Parry, 1996; Zwygart-Stauffacher, Lindquist, & Savik, 2000).

One of the greatest problems pointed out by the participants in the current studies was staff shortages and limited time dedicated to each patient. One of the patients in the Thomas and Parry study (1996) characterized hospital care today as being "fast and furious". He reported a decrease in the amount of time nurses spent in conversation with patients, and frequent neglect of specific needs and conditions. Zwygart-Stauffacher et al. (2000), supported by Morris et al. (2007), identified problems in continuity of care and its negative influence on

informational and psychological satisfaction of patients and caregivers. In fact nearly 60% of caregivers did not perceive there was continuity and consistency in survivors' care. This issue can be addressed by designating at least one service provider who will follow the family over time and will be aware of all changes and adjustments that are required as the health and functional status of the patient evolves (Morris et al., 2007a; Zwygart-Stauffacher et al., 2000). This practice has been found to be very efficient in decreasing emotional stress, and improving treatment coordination and consequently satisfaction (VisserMeily, van Heugten, Post, Schepers, & Lindeman, 2005).

Thomas and Parry (1996) presented a model of post-stroke care as consisting of 3 key elements: formal care (primary and secondary health care and social service care), informal care (family, friends, voluntary groups), and self-care. They suggested that in order to provide good quality care, all parts of this "package" have to be coordinated with each other and within the group (Thomas & Parry, 1996). A qualitative study conducted later by the same authors found very poor in-hospital staff communication as well as staff-patient-caregiver communication. These findings were supported by more recent publications (Morris et al., 2007a; Zwygart-Stauffacher et al., 2000).

With increasing knowledge and acceptance of the CCC model of care, it was important to explore the current implementation of client-centred principles in adult health care. The qualitative study explored how the clinicians interpret CCC, what strategies they are using to promote partnerships, and how clients see

themselves in the interaction with HCPs. Although some findings were in line with previously demonstrated ideas (e.g., importance of good communication between all involved in care, the need of the patients and families for timely and specific information, etc.), there were several important issues that have been uncovered: it was encouraging to learn about successful partnerships between clients and HCPs, strategies that HCPs employed to improve clients' experiences, creative inter-professional teams and good coordination between different members of the team. Unlike some previous studies, the clients in my current study felt that they were the focus of care and equal members of the team and that the priorities of the clients matched closely the priorities reported by HCPs (Morris et al., 2007a). The study also provided some practical advice on how the experiences can be improved for both the clients and HSPs and directions for future studies.

Limitations of the studies

While conducting the narrative review we have endeavoured to cover all available literature (both academic and grey). However, the more stringent scoping review framework developed by Arksey and O'Malley (2005) might have produced more comprehensive results.

Conducting research in clinical settings can be challenging, especially when attempting to measure such a complex and multi-dimensional concept as CCC. When recruiting for the two validation studies we had significant challenges in reaching the desired number of participants. Hence some of the planned

analyses (e.g., factor analysis to confirm the multi-dimensionality of the MPOC-A) could not be completed because of limited sample size. In the validation study the questionnaires were sent to all patients who had undergone hip or knee replacement surgery in a specified time frame. It can be argued then that the self-selective nature of the sample can introduce bias into results. However, since the focus of the research was on examining the psychometric properties of the measure rather than the evaluation of specific hospital programs, we believe that as long as the participants shared similar experiences, the selection method did not constitute a problem.

We have also encountered some problems with the best timing of administration of the questionnaires. In the first study the questionnaires were mailed between 3 and 6 months following discharge from the program. Some would argue that recall bias could have been introduced. However, returning to the original argument, because the focus was on the tool rather than a specific program evaluation, administering the questionnaires at 6 months ensured that all treatment was complete and allowed assessment of the test-retest reliability without intervening experiences. In the subsequent study with stroke survivors we initially tried to follow the previous recruitment strategy and send the questionnaires 6-8 weeks following discharge from rehabilitation. However, the response rate was extremely low, and the recruitment strategy was adapted to start collecting data just prior to discharge with the help of research assistants.

An additional limitation of the second study sample was inclusion of only patients with mild to no cognitive impairment. In a stroke population cognitive involvement is a frequent concern and it will be important to assess whether, in cases where there is severe cognitive impairment will that prevent the patients from sharing their experiences, the proxy report provided by a family member could be obtained with the help of MPOC-A. Unfortunately the very small number of family members participating in the study limited the interpretability and generalizability of the results. However, cautiously, the results still suggest that the experiences reported by families are in line with those reported by patients.

Since only an English version of the MPOC-A is available today, the two validation projects were limited to participants who can read and write in English at a minimum Grade 8 level. In the qualitative studies in addition to language constraints, the results should be considered as pertinent to Canadian in-patient rehabilitation settings. However, the underlying principles of CCC that were highlighted in the current study were also reported in previous international studies. The current study also provides some important practical considerations that might be of interest to organizations with a similar model of care outside of Canada.

Future Directions

Despite extensive work conducted during this program of research, these studies are only a first step in validation of the adapted MPOC-A and MPOC-

SP(A). Reliability of the tool is dependent on the population and settings where the research is conducted. Hence the performance of the tools will have to be further tested with clients and HCPs managing other conditions and in different health care settings (i.e., community, chronic disease management, home care, etc.).

In the past few years we have received several inquiries from researchers and clinicians to obtain permission to translate the tools to other languages. Formal 'cultural' translation and validation studies are needed to ensure that the tools are performing as expected in other languages and cultural contexts.

Over the years as the original MPOC and MPOC-SP have been developed, shorter, more user-friendly versions of the tools have become available (i.e., MPOC-20 versus the original MPOC-56) (King, Rosenbaum, & King, 2004; Klassen et al., 2009; Siebes et al., 2007). The results of two validation studies presented in this thesis suggest that shorter versions of MPOC-A and MPOC-SP (A) might have as good or better psychometric properties. The performance of those shorter versions will have to be examined in future studies. In addition different modes of administration (i.e., on-line, electronic versions, and verbal administration) will have to be evaluated.

Recently, CCC has become a 'buzz' word when describing the quality of health care services. It appears that clinicians have a better understanding of the theoretical framework underlying CCC. However, there is a need for studies that will explore new strategies for the implementation of the principles and education

of clients to become more proactive and involved in their care. Future studies can develop and evaluate specific programs or initiatives that propose to improve partnerships and clients' experiences with their care.

Conclusions

This dissertation has presented an overview of the historical development of a CCC framework. The review identified areas that require further investigation and guided the subsequent studies. The MPOC-A has been shown to be a valid and reliable measure in orthopedics and in-patient neurological rehabilitation settings, and can assist with clinical program evaluation and data collection for research purposes. The MPOC-SP(A) has also demonstrated strong performance and apart from evaluating CCC of the program, can be used by clinicians as a self-reflection tool to improve their understanding of CCC principles, and subsequently quality of their service. The qualitative study provided a window into current practices of CCC from the perspectives of both clients and HCPs by developing a theoretical model of the processes of care. It also provided a list of recommendations to help improve these experiences for clients and HCPs.

Overall, the results of this program of work should help in facilitating communication between families and health professionals, and provide future directions on how planning and evaluation of long-term health care can be improved.

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Appendix A: MPOC-A

Measure of Processes of Care for Adults (MPOC-A)

In this questionnaire, we would like you to think about experiences you have had with health care providers **over the past year**. With these experiences in mind, indicate to what extent the event or situation has happened by circling a response using the scale from 7 (To a Great Extent) to 1 (Never).

The following is an <u>example</u> of the kinds of questions you will be asked.

This example also shows what your answer could mean.

TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES…	Indicate <u>how much</u> each event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
1. …provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (To a Great Extent), it means that people who give you questionnaires regularly provide very clear instructions about what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.

Once again, we are interested in your personal thoughts. We would like you to complete this questionnaire if possible.

Please note that there are questions on <u>both sides</u> of some pages.

DURING YOUR RECENT HEALTH-CARE EXPERIENCES… TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	Indicate <u>how much</u> this event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
1. …help you to feel competent in managing your own care?	7	6	5	4	3	2	1	0
2. …make sure you have a chance to say what is important to you?	7	6	5	4	3	2	1	0
3. …provide you with written information on what you are doing in therapy?	7	6	5	4	3	2	1	0
4. …trust you as the person who knows yourself best?	7	6	5	4	3	2	1	0
5. …provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0
6. …make sure that your health history is known to all persons working with you so that information is carried across services and service providers?	7	6	5	4	3	2	1	0

DURING YOUR RECENT HEALTH-CARE EXPERIENCES… TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	Indicate how much this event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
7. …let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
8. …tell you about the options for treatments or services?	7	6	5	4	3	2	1	0
9. …look at the needs of your 'whole' self (e.g. at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
10. …offer you positive feedback and encouragement?	7	6	5	4	3	2	1	0
11. …make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
12. …are polite and friendly to you and your family?	7	6	5	4	3	2	1	0

DURING YOUR RECENT HEALTH-CARE EXPERIENCES… TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	Indicate how much this event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
13. …fully explain treatment choices to you?	7	6	5	4	3	2	1	0
14. …provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
15. …appear aware of your needs as your health changes?	7	6	5	4	3	2	1	0
16. …provide enough time for you to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
17. …display honesty about your condition and how it may affect your life?	7	6	5	4	3	2	1	0
18. …plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0

DURING YOUR RECENT HEALTH-CARE EXPERIENCES… TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	Indicate how much this event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
19. …explain things to you in a way that you understand?	7	6	5	4	3	2	1	0
20. …provide opportunities for your entire family to obtain information?	7	6	5	4	3	2	1	0
21. …treat you as an equal rather than just as the patient?	7	6	5	4	3	2	1	0
22. …give you information that is consistent from person to person?	7	6	5	4	3	2	1	0
23. …make themselves available to you as a resource (e.g. emotional support, advocacy, information)?	7	6	5	4	3	2	1	0
24. …suggest therapy/treatment plans that fit with your needs and lifestyle?	7	6	5	4	3	2	1	0

DURING YOUR RECENT HEALTH-CARE EXPERIENCES… TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	Indicate <u>how much</u> this event or situation happens to you							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
25. … provide opportunities for your family to participate in decisions about your care?	7	6	5	4	3	2	1	0
26. …treat you as an individual rather than as a 'typical' patient?	7	6	5	4	3	2	1	0
27. …provide you with written information about your progress?	7	6	5	4	3	2	1	0
28. …have information available about your condition (e.g. its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
29. …provide you with written information about your medications (i.e. purpose, side effects, risks)?	7	6	5	4	3	2	1	0
30. …tell you about the results from tests/assessments?	7	6	5	4	3	2	1	0

DURING YOUR RECENT HEALTH-CARE EXPERIENCES…	Indicate how much this event or situation happens to you							
TO WHAT EXTENT DO **HEALTH CARE PROVIDERS** WHO WORK WITH YOU…	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
31. …have information available to you in various forms such as a booklet, video?	7	6	5	4	3	2	1	0
32. …give you information about the types of services offered at the health care facility or in your community?	7	6	5	4	3	2	1	0
33. …provide advice on how to contact other people with the same condition?	7	6	5	4	3	2	1	0
34. …provide opportunities for your family to receive information about your progress?	7	6	5	4	3	2	1	0

Appendix B: MPOC-SP (A)

MPOC-SP(A)

A Measure of Processes of Care

for Service Providers for Adults

IMPORTANT INSTRUCTIONS:

1. We would like you to describe your **"actual"** behaviour, rather than what you feel would be "ideal" service. We recognize that professionals may be unable to display behaviour to the extent they might wish, due to caseload size, policies, and other constraining factors. Please be assured that your **confidential** responses will not be viewed as a judgment of you or how you provide services.

2. Please recognize that just because a behaviour is addressed by this measure it DOES NOT mean that it is necessarily an important behaviour for all professions or to all professionals. Thus, do not feel that selecting a low number is equivalent to giving yourself a poor evaluation.

3. We would like you to think about **your experiences** as a service provider in adult rehabilitation settings, and their families, **over the past year**. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own **without discussing it with anyone**.

IN THE PAST YEAR, TO WHAT EXTENT DID YOU...	TO A VERY GREAT EXTENT	TO A GREAT EXTENT	TO A FAIRLY GREAT EXTENT	TO A MODERATE EXTENT	TO A SMALL EXTENT	TO A VERY SMALL EXTENT	NOT AT ALL	NOT APPLICABLE
1....suggest treatment/ management activities that fit with each patient's and family's needs and lifestyle?	7	6	5	4	3	2	1	0
2....offer patients and families positive feedback or encouragement (e.g., in carrying out a home program)?	7	6	5	4	3	2	1	0
3....take the time to establish rapport with patients and families?	7	6	5	4	3	2	1	0
4....discuss expectations for each patient with other service providers, to ensure consistency of thought and action?	7	6	5	4	3	2	1	0
5....tell patients and families about options for services or treatments for their condition (e.g., equipment, therapy)?	7	6	5	4	3	2	1	0
6....accept patients and their family in a nonjudgmental way?	7	6	5	4	3	2	1	0
7....trust patients as the "experts" on themselves?	7	6	5	4	3	2	1	0
8. ...discuss/explore each patient's and family's feelings about having a condition (e.g., their worries about their health or function)?	7	6	5	4	3	2	1	0

9. ...anticipate patients' and families' concerns by offering information even before they ask?	7	6	5	4	3	2	1	0
10. ...make sure patients and families had a chance to say what was important to them?	7	6	5	4	3	2	1	0
11. ...let patients and families choose when to receive information and the type of information they wanted?	7	6	5	4	3	2	1	0
12. ...help each family to secure a stable relationship with at least one service provider who works with the patient over a long period of time?	7	6	5	4	3	2	1	0
13. ...answer patients' and families' questions completely?	7	6	5	4	3	2	1	0
14. ...tell patients about the results from tests and/or assessments?	7	6	5	4	3	2	1	0
15. ...provide patients with written information about their condition, progress, or treatment?	7	6	5	4	3	2	1	0
16. ...tell patients and families details about their services, such as the types, reasons for, and durations of treatment/ management?	7	6	5	4	3	2	1	0
17. ...treat each patient and their family as an individual rather than as a "typical" patient?	7	6	5	4	3	2	1	0
18. ...treat patients as equals rather than just as a patient?	7	6	5	4	3	2	1	0

19. ...make sure patients and families had opportunities to explain their treatment goals and needs (e.g., for services or equipment)?	7	6	5	4	3	2	1	0
20. ...help patients and families feel like a partner in their own care?	7	6	5	4	3	2	1	0
21. ... help patients and families to feel competent in managing their own care?	7	6	5	4	3	2	1	0
22. ...treat patients and their families as people rather than as a "cases" (e.g., by not referring by diagnosis)?	7	6	5	4	3	2	1	0

THE NEXT SET OF QUESTIONS ASKS "TO WHAT EXTENT DID YOU (OR YOUR ORGANIZATION)...". BY "ORGANIZATION" WE MEAN THE FACILITY OR AGENCY FROM OR THROUGH WHICH YOU PROVIDE SERVICES. IF YOU DO NOT WORK AT AN "ORGANIZATION", PLEASE ANSWER FOR YOUR PROGRAMME, TEAM, OR YOURSELF.

IN THE PAST YEAR, TO WHAT EXTENT DID YOU (OR YOUR ORGANIZATION)...	TO A VERY GREAT EXTENT	TO A GREAT EXTENT	TO A FAIRLY GREAT EXTENT	TO A MODERATE EXTENT	TO A SMALL EXTENT	TO A VERY SMALL EXTENT	NOT AT ALL	NOT APPLICABLE
23. ...promote family-to-family "connections" for social, informational or shared experiences?	7	6	5	4	3	2	1	0
24. ...provide support to help families cope with the impact of the chronic condition (e.g., informing patients and families of assistance programs, or counseling how to work with other service providers)?	7	6	5	4	3	2	1	0

25. ...provide advice on how to get information or to contact other patients (e.g., through a community's resource library, support groups, or the Internet)?	7	6	5	4	3	2	1	0
26. ...provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
27. ...have general information available about different concerns (e.g., financial costs or assistance, respite care)?	7	6	5	4	3	2	1	0

Appendix C: McMaster University and HHS Research Ethics Approval

RESEARCH ETHICS BOARD

Hamilton Health Sciences ce, 293 Wellington St. N., Suite 102., Hamilton, ON L8L 8E7

Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8378

November 2, 2009

PROJECT NUMBER: **09-265**

PROJECT TITLE: Exploring Family-Centered Issues in Adult
                                Rehabilitation Settings: Health Care

                                Professionals', Patients', and Families

                                Experiences.

PRINCIPAL INVESTIGATOR: Professor Peter Rosenbaum

This will acknowledge receipt of your letter dated October 14, 2009 enclosing the revised consent forms and outstanding application signatures. These issues were raised by the Research Ethics Board at their meeting held on June 16, 2009. Based on this additional information, we wish to advise your study has been given *final* approval from the full REB.   The submission, Protocol #1 dated May 20, 2009, Information Letter and Consent for Patients and Families dated October 2009. Information Letter and Consent form for Health Care Professionals dated October 2009, Dear Patient and Families Consent for Interview dated October 2009, Dear Patients and Families Letter dated October 7, 2009, Dear Health Care Professional Letter dated October 7, 2009, Telephone Script for Research Assistant to Arrange an Interview with the Health Professional, Telephone Script for Research Assistant to Arrange

an Interview with the Patient and Family Member, Qualitative, Semi-Structured Interview guide for Interviewing Health Care Professionals, Qualitative, Semi-Structured Interview guide for Interviewing Patients and their Significant Other, the General Information Form for Patients, General Information Form for Family Member, General Information form for Health Professionals, Measure of Processes of Care for Adults (MPOC-A), Client Satisfaction Questionnaire (CSQ-8), and the MPOC-SP)(A) questionnaire, was found to be acceptable on both ethical and scientific grounds. ***Please note*** attached you will find the Information Sheet with the REB approval affixed; all consent forms and recruitment materials used in this study must be copies of the attached materials.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the REB meeting on June 16, 2009. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or information sheet must be approved by the Research Ethics Board.

The Hamilton Health Sciences/McMaster Health Sciences Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations.

Investigators in the Project should be aware that they are responsible for ensuring that a complete consent form is inserted in the patient's health record. In the case of invasive or otherwise risky research, the investigator might consider the advisability of keeping personal copies.

A condition of approval is that the physician most responsible for the care of the patient is informed that the patient has agreed to enter the study.

PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON
ALL FUTURE CORRESPONDENCE

Sincerely,

Jack Holland, MD, FRCP, FRCP (C)

Chair, Research Ethics Board

Appendix D: Grand River Hospital Research Ethics Approval

May 14, 2010   **Administrative Review**

School of Rehabilitation Science

Faculty of Health Sciences

1400 Main Street West-IAHS 402

Hamilton, Ontario, Canada L8S 1C7

Dear Dr. Rosenbaum and Elena Bamm

RE: Exploring Family-Centred Issues in Adult Rehabilitation Settings: Health care professionals', patients', and families' experiences.

Principal Investigator: Elena Bamm

Study application dated: February 18, 2020

Study identification number: RC2010-18

Thank you for your application requesting approval of the above-referenced study. The study was reviewed by the Grand River Hospital Research Committee for financial and resource impacts to Grand River Hospital staff and departments, and is granted approval.

Approval is granted to conduct the research project in accordance with the above-referenced protocol with the following responsibilities of the investigator:

a) Submission of any changes in the protocol that impact the finances and/or resources of the departments involved to the Grand River Hospital Committee;

b) Submission of a final report outlining study results and recommendations to the Grand River Hospital Research Committee within three months of completion of the study.

Please find attached the related signatures for administrative approval. Also included, below, is a study tracking sheet with key dates related to submission and approvals.

NOTE: The study identification number RC2010-18 has been assigned to your study. Please use this number on all future correspondence.

Yours truly,

Kerri Bennett

Chair, Grand River Hospital Research Committee

Director, Quality and Research

cc Michael Coughlin, Chair, Tri-Hospital Research Ethics Board

Grand River Hospital

Investigator Tracking Sheet

This is a tracking sheet for your own use. There is space to record the dates for submission/receipt of the following items. Please use the check box to indicate when an item is complete.

Grand River Hospital Research Committee

Application submission to committee: 18/02/2010

Presentation of study at meeting: 02/03/2010

☒ Approval letter: 10/03/2010

Research Ethics Board

Application submission to committee: 13/01/2010

Presentation of study at meeting: 03/02/2010

Approval letter: 11/02/2010

☒ Copy of approval letter sent to Research Committee: 02/03/2010

Research Data Agreement with Grand River Hospital

Draft submitted to Research Committee: 07/04/2010

Approval (from Privacy office): 20/04/2010

☒ Copy of signed contract agreement sent to Research Department: 07/04/2010

Risk Management contract agreement with Grand River Hospital (if applicable)

Draft submitted to Research Committee: dd/mm/yyyy

Approval (from Risk Management office): dd/mm/yyyy

☐ Copy of signed contract agreement sent to Research Department: dd/mm/yyyy

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Research Department

☒ Email notification from Research Department that study is ready to proceed: 14/05/2010

☐ Study final report sent to GRH Research Department: dd/mm/yyyy

Appendix E: Hotel Dieu Shaver Hospital Research Ethics Approval

Hotel Dieu Shaver

100 YEARS OF CARING

HEALTH AND REHABILITATION CENTRE

January 22, 2010

Ms. Elena Bamm
School of Rehabilitation Science
McMaster University

Re: *"Exploring Family-Centred Issues in Adult Rehabilitation Settings: Health care
        professionals', patients', and families' experiences"*

Dear Ms. Bamm:

Thank you for your presentation to the Hotel Dieu Shaver Research Ethics Board on Thursday,
January 21, 2010. I am pleased to let you know that the Research Ethics Board approves the
proposed research, *"Exploring Family-Centred Issues in Adult Rehabilitation Settings: Health
care professionals', patients', and families' experiences"*.

Best wishes with your study and we look forward to learning of your results upon completion.

Yours truly

Dr. J. Luce
Chair
Research Ethics Board

Hotel Dieu Shaver Health and Rehabilitation Centre 541 Glenridge Avenue, St.Catharines, ON L2T 4C2 **T** 905-685-1381
WWW.HOTELDIEUSHAVER.ORG
The Religious Hospitallers of St.Joseph of the Hotel Dieu of St.Catharines